

ABSTRACT BOOK



BRIDGING CARE: FROM RESEARCH TO CLINICAL PRACTICE

7th Maruzza International Congress
on Paediatric Palliative Care

Rome, 21st – 23rd October 2026



Auditorium Antonianum
Viale Manzoni 1

SPECIAL THANKS TO



WITH THE PATRONAGE OF



Scientific Committee

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Anna Garchakova, Director of the Public Association "Charitable Children's Hospice", Minsk, Belarus; member of St. Jude, member of ICPCN, member of IAHPC

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Scientific Programme

WEDNESDAY

21st OCTOBER 2026

- 17.30 – 19.30 **Opening ceremony**
- **Welcomes:** Manfredi Lefebvre D'Ovidio, Costanza Lefebvre D'Ovidio, Franca Benini, Ann Goldman, Daniel Garros, Ulrika Kreicbergs
 - **Keynote Lecture:** *Paediatric Palliative Care Research: Emerging Evidence and Recent Studies* -Julie Hauer
 - **Vittorio Ventafridda Award**
 - **Keynote Lecture:** *Key Developments in Paediatric Palliative Care Practice over the Past Five Years* - Stefan J. Friedrichsdorf
 - **Young Researchers Award 2026** Presented by the Vlček Family Foundation
 - **Keynote Lecture:** *Has Life Really Changed for the Patient and Family? Which Aspects Need More Attention and Implementation? A Patient/Family Experience* -Filippo Arnaudo, Federica e Matteo Zandali

THURSDAY

22nd OCTOBER 2026

- 08.30 - 09.00 **Plenary: Gaining insights**
Managing Uncertainty - Brian S. Carter
- 09.00 - 10.30 **Plenary session 1: From Research to Clinical Practice: Symptom Management**
Moderators: Mercedes Bernadà, Joanne Wolfe
- *Neuroirritability: Diagnosis and Management* - Harold Siden
 - *Sleep Disturbances* - Judith Owens
 - *Rare Symptoms That Are Difficult to Manage* – Stefan J. Friedrichsdorf
- 10.30 - 10.45 **Vlček Family Foundation Young Researcher Award-1st prize**
Toward Improved Access: Lessons from Four Decades of Paediatric Palliative Care in Canada - Liana Bailey
- 11.15 - 12.15 **Oral Abstract presentation session**
- Working session 1: Essential Clinical Care A**
Moderators: Brian S. Carter, Daniel Garros
- *Parents' Experiences of Perinatal Palliative Care after Prenatal Diagnosis of Severe Fetal Conditions* – Paola Camponovo
 - *Conceptualizing Quality of Life for Children with Medical Complexity and Neurological Impairment* Andrea Johnson
 - *Introducing the 'Cassandra complex' in PPC: a Pilot Study on Clinician-Family Prognostic Discordance* Jordi Royo
 - *BEACON: Developing a Breakthrough Pain Assessment Questionnaire for Children and Young People* Christina Liossi
- Working session 2: Psychosocial Well-being A**
Moderators: Justin N. Baker, Ulrika Kreicbergs
- *Nurses' Growth in Pediatric Palliative Care: An Interpretative Phenomenological Analysis* – Micha Massaad
 - *Rising from the Ashes: Religious Narratives of Hope among Bereaved Parents* – Alexandra Superdock
 - *Caring for Siblings Amidst a Family Life Marked by Child Loss to Cancer* – Eva De Clercq
 - *What is in Your Suitcase? From Sibling Invisibility to Recognition in Pediatric Palliative Care* - Marta Scignaro
- Working session 3: Miscellaneous A**
Moderators: Veronica Dussel, Anna Garchakova
- *Expanding Horizons in Pediatric Advance Care Planning: A Faculty Development Approach* -Julie Brunetta
 - *Is Telemedicine Fit for Pediatric Palliative Care? A Systematic Review* – Chiara Daicampi

- *Pulse Check: Assessing Pediatric Palliative Care Integration in the Cardiac Intensive Care Unit* - Andrea Cuvillo
- *Who Cares for the Carers? Ethical Dilemmas of Responsibility and Self-Care During Clustered Crisis* - Gražina Kokešová Kleinová

13.30 - 15.00

Plenary session 2: *What Counts as Paediatric Palliative Care? Defining the Field for the Next Generation*

(Young Professionals Session)

Moderators: Joe El Khoury, Sidhart Vemuri

- *Expanding the Scope: From Standards to Global Practice* - Megan Doherty
- *Rethinking "Palliative": Ethical Complexity and the Concept of Harm* - Richard Hain
- *Interprofessionalism and Power: Who Defines Palliative Care?* - Nicholas Purol

16.15 - 17.15

Oral Abstract presentation session**Working session 4: Ethics and Human Rights**

Moderators: Joe El Khoury, Nicholas Purol, Sidhart Vemuri

- *Te Whare Kaiao - Empowering Families to Care for their Child with Palliative Care Needs* - Tess Moeke-Maxwell/Gemma Aburn
- *Earlier Access and Evolving Referral Patterns in a Hospital-Based Paediatric Palliative Care Service* - Ané Büchner
- *Considerations and Challenges in Physician Decision-Making for Advanced Pediatric Cancer in LMICs* - Marta Salek
- *Maintaining School Routines: A Holistic Approach to Pediatric Palliative Care* - Monique Albuquerque Ferreira

Working session 5: Organizational Aspects A

Moderators: Veronica Dussel, Julie Hauer

- *Catalysing Change: A Regional Leadership Initiative Creating System-Level Change in Southeast Asia* - Megan Doherty
- *Adolescents' Perspectives of Complex Chronic and Palliative Care across Home and Healthcare Settings* - Eddy Carolina Pedraza Salcedo
- *Quality Indicators and Core Outcome Sets in Pediatric Palliative Care: A Systematic Review* - Robin Fierst van Wijnandsbergen
- *Prioritizing Complexity: A Structured Referral System for Case Discussions in PPC Team* - Federico Pellegatta

Working session 6: Psychosocial Well-being B

Moderators: Nur Elçin Boyacıoğlu, Michelle A. Meiring

- *"Closing the Circle": Postmortem Interview after a Child's Death in Pediatric Palliative Care* - Carlotta Ghironi
- *Family Talk Intervention Improves Communication and Psychosocial Health in Pediatric Palliative Care* - Kerstin Ivéus
- *Spiritual Themes and Meaning-Making in Pediatric Palliative Care: A Retrospective Chaplaincy Study* - Lidia Zloh
- *From Global Quality Indicators Research to Local Improvement in Pediatric Oncology End-of-life Care* - Rima Saad Rassam

17.15 - 18.15

Focus Sessions*Beyond 'Dimensions': Building an Existential Understanding of Suffering in PPC* - Daniel Toro-Pérez*AI and New Technologies in PPC: Use in Daily Practice* - Diana Ferro*Models of training/training opportunities in PPC* - Megan Doherty

**FRIDAY
23rd OCTOBER 2026**

- 08.30 - 09.00 **Plenary: Gaining insights**
Social Mourning/Digital Spaces – Alejandro Nespral
- 09.00 - 10.30 **Plenary 3: From Research to Clinical Practice: End of Life Care**
Moderators: Stefan J. Friedrichsdorf, Anthony R. Herbert
 - *Palliative Sedation* - Joanne Wolfe
 - *Aggressive Treatments and Parental Choice* - Michelle Koh
 - *Managing Last Hours of Life at Home* - Emily Harrop
- 10.30 - 10.45 **Book Presentation** - *Childness and the Myth of the Unfinished Human* - Richard Hain
- 11.15 - 12.15 **Oral Abstract presentation session**
Working session 7: Psychosocial Well-being C
Moderators: Ann Goldman, Michelle A. Meiring
 - *Developing a Transferable Group Intervention Model in Paediatric Palliative Care* – Emília Comas Carbonell
 - *Pain Management in Children with SNI does not always improve Caregiver Well-being: Results of an RCT* – Gail Andrews
 - *Dignity Therapy in Pediatric Palliative Care: Development of a By Proxy Protocol* - Ana Raquel Sapeta
 - *Reducing Psychological Harm Following the Death of a Child Through Trauma-Informed Bereavement Care* - Crystal Luk-Worrall
Working session 8: Organizational Aspects B
Moderators: Anna Garchakova, Joana Mendes
 - *Pediatric Palliative Care Referral at DNR Designation Reduces Hospital Resource Use in LMICs Country* – Anwar Al-Nassan
 - *French National Guidelines for Pediatric Palliative Care Pathways* – Ashley Ridley
 - *Mapping Stakeholder Perspectives on Home Monitoring in Paediatric Complex and Palliative Care* Ana Paula Giordano
 - *Exploring Values, Goals and Preferences in Paediatric Care: A Content Analysis of ACP Conversations* – Leonie la Rondelle
Working session 9: Miscellaneous B
Moderators: Daniel Garros, Alejandro Nespral
 - *Integrated Palliative Care in Italian Pediatric Oncology Centres: Current Practice and Unmet Needs* - Lucia De Zen
 - *Fathers' Experiences of Caring for a Child with a Progressive Life-Limiting Condition* – Marianne Sjuls
 - *Bereavement Groups in Paediatric Palliative Care: Parents' Experiences in Denmark* – Malene Beck
 - *Ethical Attitudes Among Pediatric Palliative Care Professionals in Spain* – Iñigo de Noriega Echevarría
- 13.30 - 14.30 **Oral Abstract presentation session**
Working session 10: Essential Clinical Care B
Moderators: Mercedes Bernadà, Julie Hauer
 - *Bridging SICIP Adult and Pediatric Palliative Core Curricula: Developing a Transition Age Care Model* – Iacopo Bellani
 - *When Parents and Pediatricians Disagree: Clinicians' Experiences in Pediatric Palliative Care* Ragnhild A. Fretland
 - *The Grey Zone in Neonatal Life-and-Death Decision-Making: A Scoping Review* – Lisa Willems
 - *A National Centre of Research Excellence in Paediatric Palliative Care* – Anthony R. Herbert
Working session 11: Education/Training in Children's Palliative Care
Moderators: Julia Downing, Justin N. Baker
 - *Between Empathy and Exhaustion: Examining Healthcare Providers' Comfort with Pediatric Death Work* – Andrea Cuvillo
 - *Impact of Simulation Training on Self-Efficacy in Paediatric Palliative Care* – Sarah Sogeler
 - *When the "Parent" is AI: Co-Producing Simulation for Serious Illness Communication Training* - Naomi Goloff
 - *Bereaved Parents as Co-Educators: Lessons from a Pilot Training Programme* – Martin Loucka

Working session 12: Organizational Aspects C

Moderators: Ann Goldman, Anna Garchakova

- *A children's Palliative Care Assistant: Data-Driven Decisions through LLM Integration* – Laura Dale-Harris
- *Shared Emergency Pathways for Children Receiving Pediatric Palliative Care* – Martina Di Schiena
- *Building an Integrated Pediatric Palliative Care Service at a Teaching Hospital: A 5 Year Journey* -Krithika Rao
- *Supporting Referral Decisions via Virtual Consultation for Children with Incurable Cancer in Wartime* – Alexandra Müller

15.30 - 17.00

Plenary 4: Home and Community- Based Care

Moderators: Brian S. Carter, Emily Harrop

- *Sustainable Models of Care* -Joana Mendes
- *Providing Support for the Family* -Veronica Dussel
- *The Challenges of Developing Compassionate Communities in PPC* -Justin N. Baker

17.00 - 17.30

Closing Ceremony*Conclusions*

POSTERS

MONITOR A

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103	<i>Improving Anticholinergic Antihistamine Prescribing for Children Attending a Children's Hospice</i>	Sozan Abdelrahman
175	<i>A Remote Palliative Care Project for Children with Oncological/Hematological Diseases in Russia.</i>	Natalia Klipinina
206	<i>What's in a Name? Parents' Perceptions of Pediatric Palliative Care in Pediatric Haemato-Oncology</i>	Marta Adavastro
70	<i>Family Remote Music Therapy for Cognitively-Impaired Children with Medical Complexity</i>	Terrah Akard
76	<i>From Voices to Vision: A Family-Informed Model for the Future of Paediatric Palliative Care</i>	Tala Al- Dabbous
122	<i>Translation & Multi-Site Validation of ACCPED from Italy to English</i>	Nidhal Al Harrasi
233	<i>Comparative Abstract: Development of Palliative Care in Ireland and Oman</i>	Nidhal Al Harrasi
45	<i>Physician Attitudes on Early Pediatric Palliative Care in Eastern Mediterranean Oncology: ADAPT</i>	Anwar Al- Nassan
43	<i>Intravenous Ketamine for Refractory Cancer Pain in 433 Patients: Real-World Study from Middle East</i>	Anwar Al- Nassan
51	<i>Pediatric Palliative Care at a National Cancer Center: A 10-Year Service Evolution</i>	Anwar Al- Nassan
112	<i>Schooling, Identity and Meaning-Making in Children and Adolescents with Cancer</i>	Monique Albuquerque Ferreira
64	<i>Symptom Management Planning in Paediatric Palliative Care: A Systematic Review</i>	Haiqah Amjad
29	<i>Evaluation of an Online Educational Programme in PPC for Professionals in Norway</i>	Monica Andresen
227	<i>Treating the Child, Trusting the Parent: Parent-Reported Benefit of Gabapentin for Pain in Children</i>	Gail Andrews
84	<i>Tiny Frames, Complex Stories: Musculoskeletal Pain and Psychosocial Factors in MOPD Type 2</i>	Helen Armstrong
264	<i>Diagnostic Groups and Outcomes in Children Referred to Specialized Pediatric Palliative Care Team</i>	Karin Bäckdahl
251	<i>From Lab Inception to Clinical Impact: Building a Research Strategy in Pediatric Palliative Care</i>	Justin N. Baker
208	<i>Clinicians' Training Needs in Transition-Age Palliative Care: An Italian Delphi Study</i>	Iacopo Bellani
6	<i>Clinical Obstinacy and Unreasonable Persistence in Paediatric Care: Theory and Practice</i>	Cristina Beltrami
88	<i>The "Quiet Box" – Memory Making in the Neonatal Intensive Care Unit (NICU)</i>	Yael Ben Gal
106	<i>Bringing Paediatric Palliative Care Closer to Home: A Family-Centred Community Model</i>	Laura Berrill
129	<i>Trust in Pediatric Oncologists Among Parents of Children with Poor Prognosis Cancer</i>	Alexa Bobelis
312	<i>Point-Of-Care Ultrasound In Pediatric Palliative Care: A Look at the Present and Future</i>	Marco Bolognani
183	<i>Communication about Values and Goals of Care: A Systematic Review of Educational Strategies</i>	Julie Brunetta
134	<i>Can I Die from this Disease? End-of-life Communication Patterns in Pediatric Advance Care Panning</i>	Julie Brunetta
184	<i>From Training to Implementation: Knowledge Transfer in Pediatric Advance Care Planning</i>	Julie Brunetta
269	<i>A Multidisciplinary Champion Model for Paediatric Palliative Care Capacity Building</i>	Ané Büchner
298	<i>Validation of an AI-Based Early Detection System for Pediatric Palliative Care Needs in Denmark</i>	Alexandra Bungum
41	<i>Pediatric Autonomy vs. Children's Agency: What is the Difference and How Does It Matter?</i>	Sydney Campbell
242	<i>Moral Distress as a Barrier to Perinatal Palliative Care: A Literature Review</i>	Oriana Capelli
229	<i>Care, Culture, Complexity: Cultural Humility and Ethics of Care In Home-Based PPC</i>	Anna Capogreco

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287	<i>After Death Reflections: Reflective practice on a National Scale</i>	Alison Cashell
289	<i>Formalising Community Care for Children at End of Life - Implementation of HSE Guidance</i>	Alison Cashell
194	<i>Complex Clinical Decision-Making in Pediatric Cardiology and Palliative Care: A Case Report</i>	Igor Catalano
166	<i>French Translation and Cultural Adaptation of a Pain-Assessment Scale for Newborns</i>	Louise Charrie
121	<i>Rethinking Space in Pediatric Palliative Care: Adapting Hospital Rooms for End of Life Care</i>	Louise Charrie
94	<i>From Complexity to Competence: High-Fidelity Simulation Training in Paediatric Palliative Care</i>	Silvia Ciprés Roig
53	<i>The Incidence of Mucopolipidosis II (I-Cell Disease) in Ireland: A Retrospective Chart Review</i>	Jonathan Clarke
249	<i>End-of-Life Practices at Pediatric Intensive Care Units in Brazil: A Nationwide Survey</i>	Cintia Tavares Cruz
22	<i>Pediatric Withdrawal of Life-Sustaining Technologies in the Intensive Care Unit</i>	Andrea Cuvillo
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140	<i>Palliative Sedation in Children Cared for by Pediatric Palliative Care Teams: Multicentric Study</i>	Iñigo de Noriega Echevarría
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259	<i>Trisomy 18 in Clinical Practice: Perspectives of Healthcare Professionals and Parents</i>	Lucia De Zen
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225	<i>REACH Nurses: Strengthening the Global Children's Palliative Care Workforce Through Online Education</i>	Megan Doherty
40	<i>Development and Pilot Testing of a Structured Perinatal Palliative Care Program</i>	Laure Dombrecht
50	<i>Validation of a Dutch PaPaS Scale: Mixed-Methods Study with Professionals, Parents and Adolescents</i>	Laure Dombrecht
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160	<i>A Pilot Feasibility Randomized Controlled Trial for Children with Severe Neurologic Impairment</i>	Veronica Dussel
247	<i>Management of Intractable Cancer Pain in Adolescents and Young Adults Using an Intrathecal Pain Pump</i>	Thomas Eichholz
257	<i>Hope4Kids Work Package 6: Developing International Guidelines for Oncological Paediatric Palliative Care</i>	Linda Fasterius
26	<i>From Cloud to Butterfly: Narrative Meaning-Making and Continuing Bonds in Paediatric Palliative Care</i>	Monique Ferreira
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11	<i>Healthcare Providers' Attitudes Towards Advanced Care Planning in Children with Medical Complexity</i>	Riza Flores
81	<i>Pre-Connection Information Behaviors in Grief Support: Web Analysis of the Grief Support Project</i>	Ayaka Fujita
71	<i>How Do Oncologists Communicate About Prognostic Uncertainty? A Scoping Review of the Literature</i>	Stephanie Gehle
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201	<i>A Child's Voice Across Cultures: Advance Care Planning in Pediatric Palliative Care</i>	Carlotta Ghironi
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87	<i>Short Lives, Lasting Stories: Documentary Film as a Narrative-Based Educational Intervention in PPC</i>	Naomi Goloff
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111	<i>Paediatric Palliative Care and Society: Space to Learn, Time to Change.</i>	Naomi Heller
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161	<i>Evolving Use of Methadone in Pediatric Palliative Oncology: A 12-Year Case Series</i>	Dave Lysecki
322	<i>"Life-changing": A Mixed-Methods Study of In-Home Massage Therapy for Children with Serious Illness</i>	Dave Lysecki
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101	<i>Transition to Adult Services for Young People with Life Limiting Conditions: Role of Primary Care</i>	Josefine Magnusson
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10	<i>Domiciliary Cornea Ablation After Home-Based End of Life In a Patient with Adrenoleukodystrophy</i>	Maria Celina Malzone
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267	<i>Beyond Diagnosis: Identifying Palliative Care Needs in Children with Medical Complexity</i>	Linda Maynard
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MONITOR E

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Managing the Last Hours of Life at Home

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Home-based caregiving at the end of life is a common preference, but the meanings attached to it vary across cultural contexts; South Asian families may view caring for a child at home as moral and relational obligation, whereas White British families have reported a desire to preserve normality at home, maintain parental identity, and to keep the child within familiar surroundings. Where these needs are not understood it may delay engagement with palliative care services. NICE examined how we might understand when a child is approaching the end of their life, in order to support shared decision making (by looking at variables such as breathing pattern, level of awareness & peripheral perfusion), the rate of observed changes is also important. NICE additionally described what we should consider before a rapid transfer home for EoLC including any intended changes to treatment & when they should happen; specific care plans, support for the family after the child or young person dies; and identifying the professionals who will help with the practical and administrative arrangements after the death. This can be best achieved by regions developing rapid transfer processes specific to the needs of their population and setting. Whilst UK national guidance consistently advocates for access 24/7 to advice from a consultant in paediatric palliative care (at least by phone); local nursing available face to face and daytime availability of visits from the specialist palliative care team, evidence from statutory death reviews identifies significant gaps and inequalities in practice.

Symptoms are best managed at home by considering environmental and non-pharmacological measures early and always using specialist guidelines or formularies for prescribing, such as the APPM Formulary (2027 edition). The child & family should be involved actively in choices relating to routes of administration and dose ranges. Aiming to stay a step ahead with anticipatory prescribing is important to ensure a smooth supply of essential medications. The sparse landscape of evidence in the pharmacology of paediatric end of life care prescribing occasionally requires the taking of carefully weighed risks, in the best interest of the child and family. Risks must be mitigated as much as is practicable, and must be taken in pursuit of a morally desirable outcome.

The cost of offering home based end of life care requires complex modelling and will differ widely between settings. Cochrane have advocated that, in the case of adult patients with cancer, care at home reduces symptom burden and should be advocated. NICE conducted pharmacoeconomic modelling for paediatric home based end of life care, during the production of national guidance. This concluded that rapid transfer home for withdrawal of life-sustaining treatment constituted a welfare gain for the child and family, which may be cost neutral if it is felt to save more than 2.5 days of intensive care treatment (acknowledging a high degree of uncertainty). It was felt possible to configure 'real world' 24/7 home care that might be at least cost-neutral, but this was felt to depend significantly on the volume of patients, and the nature of the region covered.

Case studies used in the presentation illustrate the importance of family choice, and demonstrate that families find teamwork, good communication and positive relationships to be most important. Harnessing this feedback and noting the guidance from NICE, it seems that we are 'stronger when we work together'. The mindful creation of managed clinical networks that meet the needs of their own local populations, is the most effective and realistic way for us to deliver end of life care at home for dying children.

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Sustainable Models of Care

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Background and aims: Sustainability in pediatric palliative care concerns the capacity of health systems to provide continuous, equitable and family-centred care across settings and prolonged illness trajectories. This presentation identifies key elements of sustainable pediatric palliative care, focusing on integrated community and home-based care, multiprofessional collaboration, nursing, technology and system resilience.

Methods: A narrative and critical synthesis of recent international evidence, professional recommendations and policy frameworks

Results: Sustainable home-based pediatric palliative care requires more than transferring interventions from hospital to home. It depends on coordinated networks involving specialist teams, paediatricians, nurses, primary care and psychosocial professionals, with children and families as active partners. Early integration, shared goals, clear responsibilities, anticipatory planning and continuity across organisational boundaries are essential. Digital health, teleconsultation and remote symptom assessment may strengthen access and continuity, but should complement rather than replace relational care. Nurses are central through care coordination, advanced communication, shared decision-making, advocacy, anticipatory planning, family support and leadership. Sustainable provision also requires a prepared workforce, 24-hour professional support, access to medicines and technologies, respite and bereavement care, appropriate financing and resilient community services.

Conclusions: Sustainability should not be measured by how much care is transferred to families, but by whether children can safely receive the care they need, where they prefer, without increasing inequity, caregiver burden or avoidable risk. The home becomes sustainable only when responsibility is shared by a prepared, connected and accountable system around the child and family.

The Challenges of Developing Compassionate Communities in Pediatric Palliative Care: From Fragmented Services to Integrated Ecosystems

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Children with serious and life-limiting illnesses and their families require compassionate, coordinated care that transcends institutional boundaries and extends into their homes and communities. Yet pediatric palliative care remains fragmented across healthcare systems, with substantial barriers related to access, workforce capacity, reimbursement, geographic disparities, and continuity of care. Families frequently bear the burden of navigating these disconnected services, particularly during transitions between hospital, home, hospice, and community-based settings. Developing truly compassionate communities requires moving beyond traditional models of institutional care toward integrated, sustainable ecosystems that place children and families at the center.

This presentation will explore the challenges and opportunities associated with building compassionate communities in pediatric palliative care, drawing upon emerging experiences from the Northern California Pediatric Palliative Care Collaborative and the Bay Area Pediatric Palliative Care Co-Lab. These initiatives bring together academic medical centers, community-based organizations, pediatric hospice providers, and other stakeholders to develop innovative approaches to care coordination, shared expertise, workforce development, and sustainable reimbursement. Through collaborative design and implementation, participating organizations are exploring practical models for improving hospital-to-home transitions, respite care, end-of-life support, and access to specialized pediatric services.

Central to this approach is the concept of a Pediatric Palliative Care Ecosystem, grounded in seven interconnected principles: choice, continuity, competence, connection, capacity, coordination, and compassion. Rather than expecting families to navigate fragmented systems, this framework challenges organizations to function as a coordinated community of care, sharing responsibility for quality of life across the continuum of serious illness.

Aligned with the Congress theme, Bridging Care: From Research to Clinical Practice, this presentation will examine how collaborative partnerships, implementation science, and community-driven innovation can translate evidence into sustainable clinical practice. Particular attention will be given to the importance of trust, interdisciplinary collaboration, family engagement, and collective advocacy in overcoming structural barriers.

Ultimately, compassionate communities are not defined simply by the services they provide, but by how children and families experience care. Building these communities requires a shared commitment to ensuring that every child and family, regardless of diagnosis, geography, or resources, has access to compassionate, coordinated care that promotes dignity, relieves suffering, and advances quality of life for all.

Childness and the Myth of the Unfinished Human

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What we mean by 'person' is the starting point for ethics. All too often ethicists have restricted that meaning to a handful of cognitive capabilities that they suggest must characterise the ideal person; typically rationality, autonomy, and awareness of the future. To those who do possess them (like, say, ethicists), they are important, and there is no doubt that, when present, they often contribute to personal value. Everyday experience, however, is that their connection to individual flourishing is unreliable. It is not true that everyone flourishes who possesses those capabilities. Nor, crucially, does it follow that those who lack them cannot flourish, or that they are the *only* possible contributors to personal value. The privilege some bioethical theories give to them is little more than an expression of the authors' own personal preference. Unchallenged, it introduces an inherent bias that means such theories, when used as a basis for medical ethics, will inevitably fail to recognise some patients' personal value.

Children are particularly vulnerable to that ethical bias, because the defining cognitive characteristics of childness are largely antithetical to those of adulthood. The child, especially as a baby, demonstrates relationality rather than rationality; dependence on others rather than autonomy; and enjoyment of existence in the present moment rather than awareness of what might happen in the future. Ethical theories (at least, those that express the value of moral action solely in terms of outcome) accordingly have to evaluate a child's flourishing by reference to adulthood, appealing to the value of the potential adult the child might become, or to the adult-like traits the child already demonstrates, or to the rationally-held preferences of the adults around the child. Yet no-one who has cared for babies and children is in any doubt that they themselves are capable of flourishing. Indeed, when we talk about someone being 'deprived of their childhood' we are referencing a golden time that everyone should expect to enjoy before the vicissitudes of adult life. Given the opportunity to do so, babies and children exuberantly enjoy their existence despite lacking the characteristics of adulthood. One day they will become adults and will flourish as adults; in the meantime, they are already flourishing as babies and children. They are not 'works in progress' but already persons in their own right.

The lesson that babies and children should teach bioethics is that the range of ways in which individuals can flourish is extremely wide, and that the range of cognitive traits that can facilitate that flourishing is correspondingly extensive, mapping only very poorly onto traditional adult-normative ideas of what can confer value on a person. That has implications not only for the way modern utilitarian bioethics should evaluate babies and children, but also for the way we should value the existence of any patient who flourishes without being able to demonstrate the traditional *desiderata* of personhood.

Beyond 'Dimensions': A Relational and Existential Approach to Suffering in Pediatric Palliative Care

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Suffering is a central yet conceptually complex construct in pediatric palliative care (PPC). Although it is commonly described as a multidimensional phenomenon—including physical, psychological, social, and spiritual domains—this framework may be insufficient to capture its full clinical meaning. As described by Cassell (1982, 2010), suffering cannot be reduced to symptoms alone but is intrinsically linked to the perceived threat to the integrity of the person.

This focus session proposes an integrative framework that moves beyond traditional dimensional models toward a relational and existential understanding of suffering in PPC. Building on three complementary perspectives identified in the literature—person-centered definitions, multidimensional models, and relational-existential formulations—this approach addresses key limitations in current conceptualizations. Person-centered frameworks emphasize meaning, identity, and subjective experience (Cassell, 1982). Multidimensional models organize suffering across domains but may fragment the experience. Relational and existential approaches extend the understanding of suffering beyond the individual child, incorporating family dynamics, developmental processes, communication, and future orientation as core elements shaping the experience.

Drawing on stress and coping theory (Lazarus & Folkman, 1984), ecological models (Bronfenbrenner, 1979), developmental perspectives (Piaget, 1972), and pediatric medical traumatic stress models (Kazak et al., 2006), suffering is conceptualized as a subjective, dynamic, developmental, and relational process. Within this perspective, particular attention is given to the role of protective factors and sources of strength, which contribute to sustaining wellbeing even in the context of serious illness. In this sense, the framework incorporates the concept of Double Awareness (Rodin & Zimmermann, 2008), which describes how patients can simultaneously engage with narratives of life—hope, meaning, relationships—and narratives of death—awareness of illness progression and mortality. Adaptation is understood as the dynamic balance between these two narratives, rather than the dominance of one over the other, allowing individuals to maintain psychological equilibrium in the face of uncertainty and threat. The session is grounded in qualitative research using grounded theory methodology, which identifies key interacting factors influencing this balance, including illness-related threats, intrinsic processes such as coping and emotional regulation, extrinsic conditions such as social support and quality of care, and systemic family dynamics. These results will be used as a basis to structure reflection and discussion throughout the session.

In addition, empirical findings from previous studies (Toro-Pérez et al., 2023; Toro-Pérez et al., 2024) highlight consistent differences in the perception of suffering and wellbeing depending on the evaluator. Children and adolescents tend to report higher levels of wellbeing than parents and professionals. These differences are not considered measurement errors but meaningful clinical information, reflecting differences in interpretative processes, adaptive coping strategies such as optimism, and protective communication dynamics. This supports the understanding of suffering as a “shared but different” experience and highlights the importance of integrating multiple perspectives in assessment and clinical decision-making (family voice). The session will be structured around a clinical case and will include an interactive component using small group discussion. Participants will be invited to reflect on how suffering is assessed in practice, identify key sources of complexity, and explore how integrative frameworks can inform more person-centered and relational approaches to care.

By bridging theoretical models, empirical research, and clinical experience, this session aims to advance understanding of suffering in PPC and to support clinicians in addressing its complexity in everyday practice.

Plenary session 1: From Research to Clinical Practice: Symptom Management Sleep Disturbances

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Background and aims: Sleep disturbances are an often overlooked feature of children's challenges in PPC settings. Adequate sleep has the potential to improve immune function, metabolic health, mental health and cognitive function, reduce pain and fatigue, and improve overall functioning and quality of life for both children and their caregivers. Common sleep disturbances in these children that can potentially be ameliorated include chronic insomnia, circadian rhythm disorders and hypersomnia resulting from a myriad of causes. This presentation outlines what PPC providers and families need to know about the potential impact of sleep disturbances on children and families in palliative care settings, the most common sleep issues and etiologic factors and outlines an expert consensus approach to management of sleep concerns.

Methods: A Delphi consensus process through which an international group of experts (Pediatric Sleep and Palliative Care Group) provided recommendations for defining and managing sleep problems in children and adolescents needing palliative care. A two-round Delphi approach was used to develop recommendations in the areas of Definition, Assessment/Monitoring, and Treatment of sleep problems in PPC. After selecting a panel of 72 worldwide experts, consensus (defined as $\geq 75\%$ agreement) was reached through an online survey.

Results: At the end of the two voting sessions, a total of 53 consensus recommendations were adopted. The Definition recommendations include emphasis on the multi-factorial etiology, frequent presence of multiple sleep problems, the contributions of nighttime medical and nursing procedures and postural issues, and bi-directional relationships between sleep and factors such as pain and medications. Assessment and re-assessment as needed of sleep concerns using appropriate tools are underscored as "gold standard" care in PPC. Recommended Treatment modalities emphasize a multidisciplinary approach that includes behavioral interventions, optimization of the sleeping environment, pharmacologic management, complementary and alternative therapies and consultation with pediatric sleep specialists. The need to assess and manage sleep concerns in caregivers is emphasized throughout.

Conclusions: Sleep is an important component of well-being in PPC. Education of PPC providers is critical to improving care of these children and families. Additional research is needed to define other risk factors, develop population-specific assessment tools, examine the experiences of caregivers, providers and children regarding sleep concerns, develop tailored evidence-based therapeutic interventions and inform sleep health policies in PPC settings.

Social Mourning/Digital Spaces

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Background and aims: Paediatric palliative care (PPC) has traditionally been delivered in hospital and home settings. The public health approach to palliative care and the compassionate communities model propose extending its principles beyond the health system, recognising the community as an active agent in end-of-life care and bereavement (1). This presentation aims to describe a trajectory that, starting from clinical practice in PPC, led to educational, community and digital initiatives, and to reflect on the links between community palliative care and its social dimension.

Methods: In response to requests from teachers in the city of Bariloche (Río Negro, Argentina) who lacked tools to address death and grief at school, the Ideas Paliativas en Acción Foundation (IPA), a non-governmental organisation founded in 2014 to promote and disseminate palliative care, developed the Grief in Schools project, whose central proposal is to include death and grief as educational topics. The project has a preventive line, based on training workshops, and a postventive line, offering guidance to institutions after a death in the school community (2). Coordinated by PPC specialists, the project showed that core themes of PPC could reach other settings.

In September 2024, Cultura Paliativa (CUPA) was launched: an education and outreach platform combining editorial content, a podcast and a virtual campus offering training courses, as well as a space for sharing perspectives, reflections and narratives. In 2026, CUPA conducted the First Ibero-American Survey on Digital Consumption related to Palliative Care (3).

Results: Regarding death and grief in the school context, a study of 734 education professionals showed that 84.6% had never received specific training on grief, and 82.6% considered such training highly important (4). Between 2014 and 2026, Grief in Schools reached more than 150 educational institutions (from preschool to university) through more than 100 workshops aimed mainly at teachers, but also at students and families, training more than 1,500 people in Argentina and Uruguay. At the community's request, the Grief in Companies project emerged and has already supported more than 10 companies in Bariloche in situations of loss. More than 500 people, including health professionals, teachers, families and members of the public, have taken CUPA courses, and more than 180 people have taken part as course lecturers or as authors of articles, interviews and columns. In the survey (n=181; 17 countries), 80% considered that digital platforms contribute significantly to disseminating palliative care, and 84% and 85% valued scientific rigour and a human tone, respectively. While 52% had used artificial intelligence (AI) to seek information, 89% mainly trust identified health professionals. Half of respondents also produce palliative care content, although only 17% do so frequently.

Conclusions: PPC has dynamic boundaries: its broad field of action includes outreach to the communities where its projects take place and the development of languages capable of reaching wider audiences, both scientific and community-based. Schools and workplaces can become spaces of care that embrace core principles of palliative care: the subject of death, accompaniment of suffering and approaches to grief. Community palliative care is thus not limited to providing care in the community, but also involves building the community's own capacity to care. Digital environments and AI can sustain education, continuous reflection and dissemination in palliative care, without replacing the human presence that care requires (5). Integrating PPC into social, educational and digital spaces extends its reach beyond the health system and contributes to building a palliative culture, in which fragility, loss and care become a responsibility shared by the community.

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Palliative Sedation

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Background and Aims: What do we do when a seriously ill child is suffering and our best efforts to relieve that suffering are no longer enough? Palliative sedation may offer an important last option yet determining when and how to use sedation can be among the most challenging decisions in pediatric palliative care. The pediatric evidence base remains limited, with substantial variability across countries and care settings in definitions, indications, medications, and reported prevalence. This variability also highlights an important distinction between intensified symptom management with medications that may cause sedation and the intentional reduction of consciousness to relieve otherwise refractory suffering.

This presentation will review the current evidence and translate it into a practical approach to clinical care.

Methods and Results: Topics will include determining when symptoms are truly refractory, clarifying goals of care and preferences regarding awareness, engaging children and families in decision-making, proportionately titrating medications, and reassessing comfort. Particular attention will be given to intent, proportionality, and communication with families.

Conclusion: Available evidence suggests that when children have access to expert interdisciplinary palliative care and symptom management, the need for true palliative sedation is rare—but essential when suffering cannot otherwise be relieved.

Neuroirritability: Diagnosis and Management

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Background and Aims: A large number of children cared for in pediatric palliative care programs are non-verbal /poorly communicative due to brain disorders from a wide variety of etiologies. With global functional impairments the term Severe Neurological Impairment (SNI) has been used. The causes include hypoxia-ischemia, structural brain dysgenesis, and wide-variety of gene-driven functional disorders, both the classical metabolic and newly understood conditions. It is well-established that "pain" is the most severe and most frequently reported concerns of parents/caregivers for these children. Not all of the behaviours we observe, however, are due to common nociceptive-inflammatory pain. Pain-like or otherwise known as distress behaviours, can have many causes. These include neuropathic, nociplastic pain, children's context and environment. In this presentation emerging concepts regarding other sources of distress behaviour, described as neuroirritability will be discussed.

Method: I will review a recent international Delphi consensus project involving 66 experts from 16 countries on the nature of neuroirritability in children with SNI. I will also describe follow-up work on consensus with a working group, and new projects being conducted in my research group to delineate underlying sources of distress behaviour.

Results: A total of 55 statements were endorsed during the 2 voting sessions that span a description of the core features, and recommendations for assessment, diagnosis and ongoing care. Questions remain as to whether or not it is inherent to abnormal neurological function, an expression resulting from the child's contextual environment, and how it overlaps with the newly described nociplastic pain modality.

Conclusions: This presentation is targeted towards a richer understanding with more precise language of the concept of neuroirritability. In addition, avenues being pursued for the next phases of research will be described.

Providing Support for the Family: Listening to the Evidence — and to Parent

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Background and aims: Pediatric palliative care (PPC) is, by definition, family-centered: a child's serious illness is experienced and managed primarily within the family system, most of the time at home and in the community. Yet what it takes to support a family well, beyond managing the child's symptoms, remains underspecified in everyday practice. This talk will synthesize evidence to help close that gap, aiming to translate current knowledge into concrete implications for clinical practice.

Methods: I will combine three sources of evidence: (i) a structured literature search of scoping/systematic reviews on family experience and support in PPC from the last five years, which yielded 41 systematic and scoping reviews and four book chapters; (ii) a review of our own group's research with families of children with advanced illness; and (iii) a qualitative analysis of open-ended responses to a 2024 satisfaction survey of 167 families cared for by a PPC service in Uruguay.

Results: Taking all the evidence together, it seems apparent that family support needs converge on a small number of recurring, actionable themes. Families want to be known as a whole family, not reduced to their child's diagnosis; they want continuity, so they are not required to retell their story to a new clinician each time; parents want to continue to be parents and be taught to care for their child, not only have things done for them; and they consistently rate clear, honest communication, especially about options near the end of life, as central to feeling prepared and in control. This includes discussing and planning where their child dies, which our own work links to more home deaths and fewer hospital admissions. Equally consistent across the evidence is who is still underserved by current models of support: fathers, whose experience is distinctly under-studied; families facing financial hardship or marginalization, who carry disproportionate burden, including the burden of taking part in research itself, even though altruism, wanting to help other families, is what draws most parents to participate; and families outside major urban centers, who report little access to palliative care. Most of the evidence is drawn from pediatric oncology; a few reviews address cystic fibrosis or perinatal conditions, but families facing other serious illnesses, such as severe neurologic impairment or genetic and metabolic conditions are largely absent from this literature. Evidence on what helps, bereavement support, legacy-making, and communication-focused interventions, is growing but still uneven. Throughout, competent clinical care and relational, human care are not substitutes for one another: families value both and value them together.

Conclusions: Our results point to a specific, teachable model of family support that should include: (i) empowering families as partners rather than passive recipients; (ii) providing competent symptom management; (iii) delivering care that is relationship-based, consistently available, genuinely coordinated, and explicitly attentive to underserved groups. Two tasks lie ahead: generating new evidence—particularly on interventions and for groups and settings still underrepresented, such as fathers, non-oncology populations, and under-resourced settings—and translating existing evidence into routine practice, particularly in home and community settings.

Holding Hope: Parental Choice, Treatment Burden and Paediatric Palliative Care

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For parents confronted with a child's life-limiting illness, the imperative to pursue every possible treatment can be powerful. Advances in oncological experimental therapies and access to treatment internationally have increased the options available to families. However, the availability of another treatment does not mean that treatment will benefit the child. When prognosis is poor and the probability of meaningful response is small, clinicians and parents face difficult questions about how far treatment should continue, where the limits of parental choice lie and the role of palliative care in supporting the child and family.

This presentation uses the case of a six-year-old child with diffuse intrinsic pontine glioma (DIPG) whose parents rigourous researched potential therapy options and sought treatment internationally following this devastating diagnosis. Their determination to give their child every possible chance led to successive treatment decisions as her disease progressed. Her clinical course provides a framework for exploring the tension between parental hope and advocacy, professional responsibility, treatment proportionality and the interests of the child.

Paediatric palliative care has a particular role within this uncertainty. It does not require parents to relinquish disease-directed treatment or accept that further treatment should cease. Instead, palliative care can accompany the child and family throughout treatment: managing symptoms and treatment burden, helping families understand an evolving clinical situation, exploring what parents hope treatment might achieve, and ensuring that the child's comfort, function and quality of life remain visible within complex decision-making. Palliative care can provide a space in which these hopes are heard while preparing families for different possible outcomes. As disease progresses, its role includes helping clinicians and families repeatedly reassess whether the potential benefits of further treatment remain proportionate to the burdens experienced by the child.

The case will explore how palliative care can support parental choice without becoming either an advocate for continued treatment or the service tasked with persuading parents to stop. Through symptom management, anticipatory planning, communication and attention to the child's experience, palliative care can help preserve meaningful choices even as therapeutic possibilities narrow.

Ultimately, decisions about aggressive treatment require more than determining whether another intervention can be offered. They require continuing attention to what treatment can realistically achieve, what it asks of the child, and whether those burdens remain justified by the possibility of benefit. Through one family's experience of DIPG, this presentation will examine how paediatric palliative care can hold together parental hope and choice, professional responsibility and the interests of the child when treatment decisions become increasingly difficult.

Toward Improved Access: Lessons from Four Decades of Paediatric Palliative Care in Canada

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Background and aims: Over the past four decades, paediatric palliative care (PPC) in Canada has expanded considerably, yet significant inequities in access remain. Infants, children, and youth continue to be underserved, and specialist PPC services remain unevenly distributed across the country. To help inform health service planning and delivery (future), this study aimed to describe the evolution (past) and current state (present) of PPC in Canada.

Methods: A qualitative descriptive study was conducted using surveys, document analysis, and semi-structured interviews with representatives from all 17 specialized PPC programs in Canada, including hospital-based, hospice-based, and combined programs. Data were analyzed thematically using Braun and Clarke's reflexive thematic analysis framework.

Results: Participants traced the origins of many programs to grassroots efforts led by clinicians, families, and communities who recognized that children were dying without adequate support. At present, despite important growth, participants spoke of persisting challenges, including the chronic burden of defining and justifying PPC, the fragility of programs due to funding precarity, and the unique challenges of caring for children and families across a vast geography. Looking forward, participants emphasized education and national collaboration as essential to building capacity and strengthening care delivery nationally.

Conclusion: While specialized PPC programs have grown over the past 40 years, access remains uneven and many programs continue to face significant structural challenges. Participants' accounts from this study suggest that the commitment, collaboration, and community-driven action that gave rise to PPC in Canada may also provide the foundation for its next chapter: one focused on building capacity, strengthening connections, and advancing more equitable access across the country.

Parents' Experiences of Perinatal Palliative Care after Prenatal Diagnosis of Severe Fetal Conditions

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Background and aims: To explore parents' experiences of Perinatal Palliative Care (PnPC) following prenatal diagnosis of life-limiting (LL) or life-threatening (LT) fetal conditions.

Methods: A single-center observational study was conducted at San Gerardo Hospital (Monza, Italy), where a structured multidisciplinary PnPC program has been available since 2016. The study included all couples enrolled in the program between 2016 and 2025 after choosing to continue a pregnancy with an LL or LT fetal condition. Parents' experiences were assessed through an anonymous questionnaire including closed- and open-ended questions. Quantitative data were analyzed descriptively, while qualitative responses underwent thematic analysis using a descriptive phenomenological approach.

Results: Among 136 couples receiving a prenatal diagnosis of an LL or LT fetal condition, 33 (24%) chose a PnPC pathway. The most frequent diagnosis was trisomy 18 (47%). Overall fetal mortality was 64%, while 36% of infants were born alive; however, most died during the neonatal period and only one survived beyond 1 year. Forty-five parents from 31 couples completed the survey (73%). Counseling, information, professional empathy and support were highly rated (>4/5 on a 5-point Likert scale). Personal values and ethical or religious beliefs were the main factors influencing decision-making. Qualitative analysis identified five themes: diagnosis as a disruptive event, mutual support, the importance of meeting the baby, care organization, and healthcare professionals' attitudes. Overall, 79% rated their experience highly (≥8/10), 82% would make the same decision again, 88% would recommend the pathway to other families, and 76% reported a positive impact on their current emotional well-being.

Conclusions: PnPC was highly valued by participating families and associated with positive parental experiences. These results support integrating PnPC into maternal-fetal medicine services.

Shared Emergency Pathways for Children Receiving Pediatric Palliative Care

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Background and aims: Children receiving pediatric palliative care (PPC) often have complex clinical conditions, technological dependence, and individualized care goals requiring emergency management consistent with advance care planning and treatment proportionality. However, out-of-hospital emergency services often have limited access to information on baseline condition, escalation planning, technological supports, and preferred referral pathways. This study aimed to describe the development of a shared pathway and a structured communication tool between a community-based PPC service and the territorial emergency medical system.

Methods: A collaboration between PPC professionals and the territorial emergency medical system was developed through multidisciplinary meetings involving physicians, nurses, and emergency dispatch professionals. A structured “special-patient notification” form was co-designed on emergency dispatch operational needs.

Results The shared pathway enabled early recognition of PPC patients within the emergency dispatch system and facilitated coordinated responses tailored to individualized care goals. The notification tool included diagnosis, baseline condition, technological supports, home emergency medications, caregiver contacts, home accessibility information, preferred referral hospital, 24/7 PPC contacts, and documentation of shared care planning signed by families. Specific sections addressed escalation planning, symptom-oriented management, ventilatory support, and proportionality of resuscitation interventions.

Conclusions Shared emergency pathways and structured communication tools may improve continuity, coordination, and proportionality of emergency interventions for children receiving PPC. Integrating advance care planning into territorial emergency systems is a feasible strategy to support individualized and family-centered emergency management in community settings.

Conceptualizing Quality of Life for Children with Medical Complexity and Neurological Impairment

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Background and Aims: Children with medical complexity (CMC) and neurological impairment (NI) often live with life-limiting medical conditions and receive care from paediatric palliative care (PPC) programs. Enhancing quality of life (QoL) is a primary goal of their care however QoL for this population has been poorly explored. Because many CMC+NI are unable to verbally express their needs and preferences, their perspectives on their QoL are rarely the focus of research. To address this gap, we developed a conceptual framework of QoL for CMC+NI grounded in parents' perceptions of their child's lived experiences of QoL and what their child would consider meaningful to their QoL.

Methods: We conducted a qualitative study informed by Interpretive Description methodology with bereaved and non-bereaved parents of CMC+NI. Semi-structured interviews were completed with parents who were asked questions specifically focused on their child's experiences of their QoL and what they believed their child would identify as important to their QoL. Data were analyzed using reflexive thematic analysis to identify and develop concepts of QoL meaningful to CMC+NI.

Results: Data were collected from parents of 13 CMC+NI, including six bereaved and seven non-bereaved parents. The ages of participants' children ranged in age from 2 months to 15 years and all were dependent on caregivers for activities of daily living. Analysis of the data identified four key concepts of QoL for CMC and NI: 1) **Physical wellbeing**; 2) **Meaningful time**; 3) **Being known**; and 4) **Inclusion**. Together with two contextual factors, 1) **Parental wellbeing**; and 2) **Homecare nursing support**, these concepts informed our conceptual framework of QoL for CMC+NI.

Conclusion: QoL developed from the direct experiences of CMC+NI differs from how QoL is traditionally considered and measured for this group of children. Our conceptual framework offers a child-centred approach to understanding QoL for CMC+NI within PPC practice and research.

Introducing the '*Cassandra complex*' in PPC: A Pilot Study on Clinician-Family Prognostic Discordance

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Background: In paediatric palliative care (PPC), paediatricians often communicate poor prognosis information that families cannot believe or integrate, generating a sustained discrepancy linked to distress and clinical consequences. We introduce the '*Cassandra complex*' (clinical construct, not a diagnosis), evoking the Greek myth of the prophetess condemned to be disbelieved, metaphor used in health sciences but not in PPC. We assessed its frequency, impact and correlates.

Methods: Cross-sectional anonymous online survey; snowball sampling via PPC network (Nov–Dec 2025; n=18). Participation was voluntary with informed consent. An ad hoc questionnaire assessed frequency items and agreement items (1–5), global distress (0–10 VAS), and clinical-decision modification. Descriptive statistics, Spearman correlations, Mann-Whitney U.

Results: Mean age 44.2±11.3 years; 61.1% women; 88.9% PPC specialists. 72.2% reported anticipating outcomes the family could not accept; 66.7% reported this discrepancy persisting beyond the first conversation. Mean distress when disbelieved was 6.3±2.0 (median 7; range 3–10). 55.6% modified clinical decisions due to family non-acceptance, with higher distress (7.3 vs 5.1; p=0.027). All adapted communication to perceived family denial. Impact: 66.7% reported erosion of clinician-family trust; 55.6% endorsed burnout and 55.6% moral distress. Distress correlates: professional loneliness (rho=0.60; p=0.008), self-doubt (rho=0.66; p=0.003) and perceived burnout (rho=0.50; p=0.034). Protective factors: interdisciplinary team (94.4%) and communication training (83.3%).

Conclusions: The '*Cassandra complex*' may name a recognisable pattern of prognostic discordance with professional and clinical impact in PPC. Conceptualising it could offer a clinical and educational tool supporting professionals and improving care. Limitations: pilot study; ad hoc, non-validated single-item measures. Larger samples and validated instruments are needed.

Funding: None.

BEACON: Developing a Breakthrough Pain Assessment Questionnaire for Children and Young People

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Background and aims: Breakthrough pain (BTP) is a common and distressing symptom in children and young people (CYP) with life-limiting and life-threatening conditions, yet remains under-recognized and inadequately assessed. No validated, standardized instrument currently exists for assessing BTP in paediatric populations. The BEACON multicentre study aims to develop a reliable, valid, and multidimensional Breakthrough Pain Assessment Questionnaire (BTPAQ) for CYP aged 3 months to 25 years across hospice, hospital, and community settings.

Methods: Questionnaire development followed a sequential mixed-methods design in accordance with COSMIN guidelines. Methods included systematic reviews, qualitative interviews with CYP, parents, and healthcare professionals (HCPs); an international Delphi survey; an expert item-generation workshop; cognitive testing with CYP, parents, and HCPs; patient and public involvement and engagement activities; and an independent linguistic review.

Results: Two versions of the BTPAQ were developed: a self-report questionnaire for CYP able to report their own pain and a proxy-report questionnaire for parents and HCPs caring for pre-verbal, non-verbal, or cognitively impaired patients. The questionnaires were refined through iterative stakeholder feedback and cognitive testing to ensure content relevance, comprehensiveness, and acceptability. Psychometric validation is currently underway to evaluate measurement properties, including content and construct validity, internal consistency, test-retest reliability, responsiveness, and feasibility.

Conclusions: The BTPAQ addresses a significant gap in paediatric palliative care by providing the first standardized questionnaire specifically designed to assess BTP in CYP with life-limiting and life-threatening conditions. Ongoing psychometric testing will establish its suitability for clinical practice and research, with the potential to improve BTP recognition, assessment, and management.

Nurses' Growth in Pediatric Palliative Care: An Interpretative Phenomenological Analysis

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Pediatric palliative care (PPC) is emotionally and existentially demanding, yet research often emphasises distress and burnout among nurses. However, this focus offers a partial insight into their experiences, overlooking how nurses make sense of their work in ways that shape identity, meaning, and professional development. Aim: To explore how nurses experience personal and professional growth through their work in PPC, including the internal and external factors that shape this development and its perceived impact on their clinical practice and personal lives.

An interpretative phenomenological approach (IPA) is used. Twenty-one PPC nurses from 11 countries were recruited through purposive and snowball sampling across diverse care settings. In-depth semi-structured interviews were audio-recorded, transcribed verbatim, and pseudonymised. Data were analysed using IPA to develop themes.

Preliminary findings suggest that nurses experience growth in PPC as a dynamic and multidimensional process. It unfolds through relational engagement with children, families, and multidisciplinary teams. It is further supported by reflective practice, openness, and the development of holistic, meaning-oriented approaches within supportive, often less hierarchical environments. This process is reflected in the deepening of relational capacities such as listening and presence, and engagement in advocacy and practice addressing patient needs. It is shaped by internal factors, including pre-existing values, and external influences such as team support, meaningful relations and organisational contexts that enable or constrain practice.

Growth emerges as a central and multidimensional aspect of nurses' experience in PPC, representing a meaningful dimension of practice that may support engagement and well-being. Supporting relational, reflective, and organisational conditions may have important implications for workforce development and retention.

Rising from the Ashes: Religious Narratives of Hope Among Bereaved Parents

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Background: Religious beliefs, practices, and communities often shape how parents of children dying from cancer construct and sustain hope, yet the role of religion in reframing hope during bereavement is understudied. To address this gap, we aimed to characterize religious narratives in bereaved parent reflections on hope.

Methods: In this photo-elicitation interview study at a U.S. pediatric cancer center, parents whose child died on hospice 6-24 months prior shared up to five photos representing 'hope during hospice' in a semi-structured interview. Reflexive thematic analysis generated a theme describing how parents see hope through the lens of their beliefs and values. A narrative sub-analysis further examined religious narrative arcs, including story elements such as change, constancy, meaning, and agency. For this analysis, 'religion' encompassed beliefs, practices, values, sacred texts, sacred objects, and faith communities.

Results: 20 parents from Protestant, Catholic, Hindu, and non-religious backgrounds shared photos. Many photos depicted sacred imagery or spiritually meaningful moments. Religious content appeared in 19/20 interviews, typically integrated into the broader narrative. Religious reflection was especially prominent when parents described their child's death and the family's grief. Four narrative themes were generated: 1) Reframing Miracles, 2) Disrupted Faith, 3) Hope Beyond Death, and 4) Restored Gratitude for Life. The child's spirituality was central as a source of meaning and peace. Stories depicted parents striving to hold onto hope while also accepting that hope transformed in ways beyond their control or understanding.

Conclusion: Religious narratives illuminate how bereaved parents construct coherence, meaning, and agency following loss. Deepening our understanding of how parents narrate faith and hope can guide clinicians in responding to spiritual coping, honoring evolving hopes, and supporting families before and after a child dies.

Caring for Siblings Amidst a Family Life Marked by Child Loss to Cancer

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Background and aims: The loss of a sibling is one of the most painful bereavement experiences. Existing research highlights the importance of viewing sibling loss in a family context as parents' responses to grief interact with and influence the grieving process of surviving siblings and vice versa. Although less optimal parenting may expose bereaved siblings to a greater psychosocial risk, little research has focused on the parenting experiences and support needs of bereaved parents. In light of this research gap, this study aimed to examine the experiences of bereaved parents when parenting a bereaved sibling following the loss of a child to cancer.

Methods: This study forms part of a larger mixed-methods study on bereavement care for parents of children with cancer. For this secondary analysis, we interviewed 19 bereaved parents who together had 25 surviving siblings. Reflexive thematic analysis was used to analyze the data.

Results: Many parents recognized that their grief could have a negative impact on their surviving children. They expressed uncertainty and sometimes regret about their changed approach to parenting. They sought support from healthcare professionals and schools, but encountered barriers, particularly the grief illiteracy of teachers. Parents recognized sibling grief as a lifelong process. To help their children cope, they continued parenting both their deceased child and their surviving children. Finally, our findings underscore the challenges faced by both parents and surviving siblings in continuing family building - whether through pregnancy, adoption, or foster care - after the death of a child from cancer.

Conclusions: Healthcare professionals can support parents by sharing insights into the parenting experiences of other bereaved families. They should also consider how siblings' grief responses change over time. There is a need for more grief-sensitive educational environments.

What Is in Your Suitcase? From Sibling Invisibility to Recognition in Pediatric Palliative Care

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Background and aims: Siblings of children receiving pediatric palliative care (PPC) frequently experience emotional burden, relational changes, and role disruption, while remaining insufficiently recognized within care pathways. The lack of structured assessment tools and intervention models contributes to their invisibility. This study aimed to describe a sibling support model developed within a PPC service to promote emotional expression and developmental support.

Methods: A multidisciplinary team developed a structured sibling support pathway based on five domains: developmental parenting, sibling identity, sibling-patient relationship, emotional processing, and ecosystemic resilience resources. The intervention integrated Creative Connection and developmental bibliotherapy through play-based, narrative, and exploratory activities. Counseling sessions to support parental communication and networking activities with educational agencies were also included. The pathway was primarily led by educators with multidisciplinary team involvement and concluded with the creation of an artistic memory box.

Results: The pathway was implemented in 71 families involving 89 siblings aged 2–19 years. Among participating families, 82% had a child with a life-threatening condition and 8% with a life-limiting condition. Overall, 44% of interventions were conducted exclusively in hospice, 43% began in hospice and continued at home, and 13% were delivered exclusively at home. The model enabled dedicated spaces for emotional expression, narrative meaning-making, and recognition of siblings' relational experiences throughout the illness trajectory.

Conclusions: Recognizing siblings' experiences within PPC represents an ethical and clinical responsibility of the multidisciplinary team. Structured sibling-focused interventions may promote family-centered care by supporting emotional expression, developmental needs, and continuity of relationships across illness and bereavement trajectories.

Expanding Horizons in Pediatric Advance Care Planning: A Faculty Development Approach

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Background: Implementation of pediatric advance care planning (ACP) depends on dedicated healthcare providers (HCPs), with limited education and lack of time as barriers. A faculty development program (FDP) was developed to support HCPs in ACP implementation through education. This study examines how the FDP program influences ACP implementation by HCPs in their clinical context through education.

Methods: HCPs working in pediatric palliative care completed the IMPACT ACP training in 2024 and subsequently participated in a 2-year FDP. The program, designed by a multidisciplinary team, consisted of six face-to-face meetings and aimed to improve participants' knowledge, attitudes, and skills related to ACP education, as well as to develop an individual implementation plan. Participants' needs for the FDP were collected through the surveys and integrated throughout the program. Participants completed pre- and post-training surveys using 5-point Likert scales to evaluate knowledge, attitudes, and skills related to ACP education. Results are presented descriptively.

Results: A total of 29 HCPs participated in the FDP, including nurses (n=19) and doctors (n=10), from primary (n=12), secondary (n=3), and tertiary care (n=14). The curriculum integrated reported participants' needs regarding intercultural communication, working with parents as educators, didactic principles, and attention to HCPs' emotions in palliative care. At baseline, 31% of the participants reported feeling skilled to educate ACP ((fully) agree), 50% at 12 months, and 68% at 16 months. The percentage of participants educating ACP to others increased from 31% before to 42% during the first year of the program.

Conclusions: Pediatric HCPs engaging in the FDP seem to experience improved skills in delivering and implementing ACP education into their clinical practice. Further implementation may be strengthened by targeted support for individual HCPs to implement ACP into routine care.

Is Telemedicine fit for Pediatric Palliative Care? A Systematic Review

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Background: Telemedicine may improve access to pediatric palliative care (PPC), especially for children receiving home-based care or living far from specialist services. This review synthesised evidence on telemedicine in PPC and populations with medical complexity.

Methods: A PRISMA-guided systematic review was registered in PROSPERO (CRD420251275237). PubMed/MEDLINE, CINAHL, PsycINFO, Scopus and Embase were searched for English-language primary studies published from 2005 to 2025. Two reviewers screened records, extracted data, and assessed quality with Joanna Briggs Institute tools.

Results: Of 2,630 records, 1,515 unique records were screened, 163 full texts assessed, and 27 studies included. Most were from high-resource settings and used observational, feasibility, pilot or case-series designs. Quality was high in 13 studies, moderate in 13 and low in one. Telemedicine was feasible and acceptable, with high caregiver satisfaction and perceived safety, although technical and caregiver-related difficulties occurred. Evidence suggested improved or maintained access and continuity, including lower emergency department use, readmissions or hospitalisations, increased team contact, reduced travel burden, and home-based care. It enabled symptom discussion, medication review, care planning, detection of selected problems and escalation. Emotional support and coordination were maintained, although sensitive discussions may be fragile online. Economic evidence was limited.

Conclusions: Telemedicine appears well-suited to several PPC components, especially access, continuity, monitoring, and coordination, but it is not a universal substitute for in-person care. Hybrid models should individualise use by clinical acuity, family preferences, digital access and relational complexity.

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Pulse Check: Assessing Pediatric Palliative Care Integration in the Cardiac Intensive Care Unit

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Background: Congenital heart disease affects approximately 1% of all newborns, the majority of whom require care in a cardiac intensive care unit (CICU). Pediatric palliative care (PPC) can offer families facing a complex life-limiting and often life-threatening illness, psychosocial support, assistance to ensure goal-concordant care and aid in symptom management. Despite this, PPC is infrequently utilized in this space.

Methods: Semi-structured qualitative interviews were conducted with interdisciplinary healthcare providers in the CICU across 5 major cardiac centers in the USA. Interviews were designed to understand perceptions, barriers and facilitators to PPC integration in the CICU.

Results: 30 interviews have been completed to date representing physicians, surgeons, nurse practitioners, nurses, social work, respiratory, child life, music therapy, and psychology. Despite most participants defining PPC as "holistic, goal-concordant care that promotes quality of life", PPC is still predominately consulted for end-of-life support. Participants identified ideal triggers for PPC consultation to include diagnosis-specific factors (i.e. single ventricle physiology and heart transplant), medical-related factors like poor prognosis or no surgical options and psychosocial elements (i.e. adolescents). Common barriers to PPC integration involved misperception of PPC by both providers and families, lack of PPC resources, and perceived dichotomy of goals between medical teams. Increasing PPC education and fostering PPC champions within the CICU team were suggestions for improved collaboration.

Conclusions: Early PPC may benefit patients, families and healthcare providers caring for children in the CICU. Education on PPC principles and standardization of PPC referral practices can promote improved collaboration between PPC and the CICU.

Who Cares for the Carers? Ethical Dilemmas of Responsibility and Self-Care during Clustered Crisis

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Background: Pediatric palliative care (PPC) teams, due to their small size and intense relational nature, are especially vulnerable to the impact of personal crises among team members. PPC professionals often embody an ethical paradox: their role requires deep personal engagement and “being there for others.” However, less is known about the ethical legitimacy of withdrawing from care during personal crises, particularly for team leaders. Our hospital PPC team experienced a clustered crisis involving all physicians within a short period, including anticipatory grief, neonatal intensive care needs, reproductive loss, and planned absence.

Methods: A qualitative exploratory study was conducted 10 months after the crisis using semi-structured interviews. Participants included physicians who personally experienced the crises as well as other team members including nurse, social worker, psychologist, chaplain, crisis intervention specialist, and external consultant. Interview questions were developed based on existing professional literature on PPC ethics and relational care. Data were analysed using thematic analysis.

Results: The team described a strong culture of psychological safety, where stepping back from clinical duties during personal crises was seen as ethically justified. Yet, significant ethical dilemmas emerged, especially the paradox of care: balancing obligation to patients with healthcare professionals’ right to vulnerability. At leadership level, the team leader’s dual role in fostering safety while feeling irreplaceable constrained her own access to support, creating ethical asymmetry. This complex interplay highlights the ethical paradox in PPC leadership: when and how to withdraw ethically while maintaining continuity.

Conclusions: This study reveals that PPC team crises require explicit ethical reflection on relational responsibility and vulnerability. Leadership roles carry unique moral weight, often limiting self-care despite a supportive team culture.

Te Whare Kaiao - Empowering Families to Care for their Child with Palliative Care Needs

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Findings from a New Zealand study exploring attitudes and knowledge of clinicians caring for children with palliative care needs, highlighted the need for an indigenous informed paediatric palliative care (PPC) framework to guide clinicians and strengthen holistic care. Clinicians in the study also identified the need for resources to empower Indigenous families in caring for their child, recognising the importance of culture and spirituality. Our aim was to design and produce an Indigenous informed framework for PPC to support clinical care delivery and empower families to access PPC support and consider cultural and spiritual preferences for their child's care.

Method: Kaupapa Māori (Indigenous research methods) were used to bring an Indigenous group together to lead the development of a culturally robust framework. The first meeting was carried out at a Māori meeting house with four elders, a Māori healer, and a grandmother with lived experience of PPC. A PPC academic and a Māori researcher consulted the group across all stages of the framework's development. A graphic artist worked in partnership with the team to develop the framework into images and resources for families.

Result: Participants favoured the concept of a 'living' symbolic framework to highlight the holistic and cultural palliative care needs of children and families. '*Te Whare Kaiao*' (*breathing life into the house*) was conceptualised as a useful resource; the concept was adapted from the popular 'Whare Tapa Whā' health framework. *Te Whare Kaiao* enables information about the holistic needs of children and families to be acknowledged and supported by the images depicted in *Te Whare Kaiao*.

Conclusion: In collaboration with participants and a graphic artist, we designed and published *Te Whare Kaiao* electronically and as a printable document for families to explore the needs of their child. This resource is currently being used by families caring for a child, and in a national family experiences study.

Earlier Access and Evolving Referral Patterns in a Hospital-Based Paediatric Palliative Care Service

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Background and aims: Hospital-based paediatric palliative care (PPC) services are increasingly being established in low-resource settings; however, little is known about how referral patterns evolve as these services mature. This study describes the characteristics of the first 401 referrals to a hospital-based PPC service and examines changes in referral patterns and timing during the early stages of service development.

Methods: A retrospective review was conducted of the first 401 children referred to a hospital-based PPC service over 17 months. Data collected included diagnosis, referral source, referral date and date of death where applicable. Referral patterns and referral-to-death intervals were compared between the first 200 and the second 201 referrals.

Results: Among 401 referrals, 105 (26.2%) were oncology patients and 296 (73.8%) had non-malignant conditions. Referrals originated from multiple specialties, most commonly haematology/oncology (21.0%), neonatology (16.2%), critical care (14.7%) and neurosurgery (13.7%). Children had diverse diagnoses, including cancer (26.7%), central nervous system disorders (21.4%), cardiovascular conditions (11.5%) and perinatal conditions (6.0%). Compared with the first cohort, haematology/oncology referrals decreased from 26.5% to 15.4%, while referrals from neonatal, neurosurgical, cardiology and surgical services increased. Of the total cohort, 145 children (36.2%) had died. Median time from referral to death increased from 34 days among the first cohort to 79 days among the second cohort.

Conclusions: During early service development, referrals broadened beyond oncology reflected increasing integration of PPC across multiple specialties. The increase in median referral-to-death interval suggests earlier integration of PPC into patient care as the service matured. These findings highlight how hospital-based PPC services may grow into integrated services supporting children with a wide range of life-limiting conditions.

Considerations and Challenges in Physician Decision-Making for Advanced Pediatric Cancer in LMICs

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Background: Physicians in low- and middle-income countries (LMICs) face complex decision-making for children presenting with advanced cancer, including consideration of non-curative therapy. In this qualitative study, we explored factors influencing decision-making and challenges encountered.

Methods: Semi-structured interviews were conducted with 36 physicians caring for children with cancer across all world regions and diverse resource settings. Interviews were conducted in English, audio-recorded, and transcribed. Inductive content analysis identified multi-level factors influencing decision-making, organized using the Consolidated Framework for Implementation Research, while thematic analysis characterized challenges.

Results: Most participants were female (n=24; 67%) and practiced at centers treating >100 new pediatric cancer cases annually (n=26; 72%), primarily in lower-middle-income countries (n=20; 55%). 72 factors influencing decision-making were identified across multiple levels, including individual (e.g., family preferences), hospital (e.g., available treatments), health system (e.g., care access), community (e.g., foundation support), and country (e.g., policies) levels, as well as disease-related factors (e.g., stage). A subset modified decision-making, including shifts from curative to non-curative intent (e.g., treatment affordability). Challenges included system constraints (e.g., lack of home-based palliative care), complex, unsupported decision-making (e.g., uncertainty, lack of guidance), and resultant impacts (e.g., differential care, burnout).

Conclusions: Decision-making for these children is shaped by multi-level factors beyond clinical considerations, including health system, socio-economic, and policy contexts. Addressing challenges to improve outcomes will require context-specific strategies, including decision support and integrated palliative care, that incorporates the perspectives of children and families.

Maintaining School Routines: A Holistic Approach to Pediatric Palliative Care

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Background: Pediatric palliative care (PPC) seeks to preserve identity and quality of life. For children with life-limiting conditions, education is a human right and a source of belonging and social connection. This study aimed to demonstrate how Educational Services for Hospitalized Children and Adolescents (ESHCA) contribute to maintaining school routines and preserving human dignity and quality of life during hospitalization.

Methods: This retrospective descriptive study cross-referenced records from 2021 to 2024 from a pediatric oncology palliative care service that included an ESHCA. A total of 250 children were identified in the records; however, only children older than five years were included in this study (n=160). ESHCA was conducted by teachers, offering individualized support in both inpatient and outpatient settings. These educators participated in multidisciplinary planning meetings and evaluated each clinical case of children in PPC. Enrollment in ESHCA and the return to regular school were analyzed.

Results: Of the 160 children, 105 (65.62%) participated in the ESHCA program, with 79 (75.24%) studying in an inpatient setting, while 26 (24.76%) studied in an outpatient setting. Only 24 (22.85%) of the children returned to regular school at some point during treatment, while 81 (77.15%) remained exclusively in the ESHCA. Additionally, 17 (16.2%) of the children attended more than 40 classes, including during the final stages of life.

Conclusions: Studying while hospitalized is an essential part of the holistic approach to PPC. Beyond academic outcomes, ESHCA preserves identity, dignity, and continuity of life, while also serving as a bridge between comprehensive healthcare and social inclusion. In summary, this study suggests that ESHCA should be considered a fundamental component of comprehensive care.

Catalysing Change: A Regional Leadership Initiative Creating System-Level Change in Southeast Asia

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Background & Aims: Access to children's palliative care (CPC) remains extremely limited across Southeast Asia. Expanding access requires more than clinical expertise; it requires leaders who can drive service development, build capacity, influence policy, and foster collaboration across borders. To address this gap, a leadership continuum model was developed, with a foundational CPC Leadership Program followed by Catalyst Lab, an advanced leadership initiative to support scaling-up impact nationally. This abstract describes the implementation and outcomes of this initiative.

Methods: The Leadership Continuum combines progressive stages of leadership development. Phase 1 includes in-person workshops, virtual learning sessions, individualized mentorship, and a leadership change project. Phase 2, the Catalyst Lab, is a 2-year advanced program focused on strategic leadership, policy influence, and regional collaboration. Program outcomes were assessed through project reports, participant reflections, and knowledge translation outputs.

Results: Forty participants from seven countries completed the foundational (Phase 1) leadership program and implementing individual leadership change projects. These initiatives trained more than 2,400 healthcare providers and enhanced care for 300,000 children and families. Projects included new CPC services, training, and advocacy initiatives. Knowledge dissemination included presentations, podcasts, and articles. The Catalyst Lab in 2026 with 8 teams (19 participants), focuses on expanding successful initiatives to regional and national levels.

Conclusions: A Leadership Continuum model provides a structured pathway for developing and sustaining CPC leaders in settings with limited CPC services. By linking foundational leadership training with advanced team-based support, the model links progression from local to national health systems change, a framework for strengthening leadership capacity globally.

Adolescents' Perspectives of Complex Chronic and Palliative Care across Home and Healthcare Settings

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Comprehensive care for children and adolescents with complex chronic conditions (CCC) and palliative care (PC) needs is a priority. Home-based monitoring is associated with improved quality of life, early identification of clinical changes, and greater confidence in home care. Despite increasing implementation of paediatric home-care models, little is known about adolescents' perspectives.

Aim: To explore adolescents' perspectives on communication and coordination priorities in home-based care between specialised and primary care, to inform the development of a future home-based tele-monitoring model.

Methods: This qualitative study analyses data from two focus groups with Spanish adolescents with CCC and PC needs, conducted within the HOME-C2P2 project. A co-design "care-mapping" approach was used to explore and improve care pathways across settings. Data were analysed using rapid qualitative and reflexive thematic analyses. Ethical approval was obtained.

Results: Participants (n=8, aged 12-21) described perspectives along a continuum of care negotiation, with normalization and disruption in their lives, experiences with care information, and autonomy. Age and clinical condition seem to influence their perspectives. Five interconnected themes were identified: (1) autonomy as a gradual and relational process, (2) ambivalent engagement with information, (3) home as a key site of care and safety, (4) communication and trust as core components of care, and (5) varied positioning towards healthcare settings between adaptation and critique.

Conclusions: Adolescents' perspectives on home care are dynamic and relational, highlighting the need for flexible, adolescent-centred models that promote autonomy, responsive communication, and integrated care across settings. These findings suggest the importance of supporting adolescents in actively developing a user-centred telehealth/telemonitoring home-based model, strengthening their role in care.

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Prioritizing Complexity: A Structured Referral System for Case Discussions in PPC Team

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Background and aims: Pediatric palliative care (PPC) teams frequently manage complex clinical, ethical, and organizational situations requiring multidisciplinary reflection. This project aimed to develop a structured referral system to support prioritization, agenda planning, and focused multidisciplinary discussion within a community-based PPC service.

Methods: In 2026, a digital referral system based on the SBAR framework (Situation, Background, Assessment, Recommendation) was implemented for weekly multidisciplinary meetings involving professionals across home care and hospice settings. All team members can submit cases through a standardized electronic form accessible at any time. The tool collects concise clinical and contextual information, indicators of complexity, technological supports, family situations, active services, and care-planning issues. Professionals are invited to formulate a specific question, define the objective of the discussion, and assign one of three priority levels: high-priority cases (requiring discussion within the same week), medium-priority cases (scheduled for subsequent meetings), and low-priority cases (suitable for deferred discussion). All submitted contributions are reviewed to generate a structured agenda.

Results: The tool standardizes access to multidisciplinary discussion by requiring explicit formulation of discussion goals and priorities. This promotes focused use of meeting time and facilitates shared clinical reasoning. The model also encourages professionals to transform clinical concerns into clear questions, supporting more structured multidisciplinary reflection. Evaluation of the new working method (tool, user perception, organizational impact) is currently underway.

Conclusions: Structured referral systems may improve multidisciplinary case discussions by supporting prioritization, reflective practice, and more effective use of collective expertise within PPC teams.

Quality Indicators and Core Outcome Sets in Pediatric Palliative Care: A Systematic Review

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Background: Despite increasing recognition of the importance of quality measurement in pediatric palliative care (PPC), existing quality indicators remain fragmented, disease-specific, and often focused on end-of-life care, limiting their use for evaluating and improving PPC across the full disease trajectory. The aim of this study is to identify existing prioritized indicators and core outcome sets, providing a comprehensive overview of current knowledge.

Method: A systematic literature search was conducted in PubMed/MEDLINE (searched on 6 January 2026) and the COMET database (searched on 29 January 2026) to identify studies reporting prioritized quality indicators (process, structure and outcome indicators) and core outcome sets for PPC. PPC was defined as the care for children with a life-limiting or life-threatening diagnosis between 28 days and 21 years of age at the time of receiving care, irrespective of time since diagnosis. In addition we checked reference lists of relevant articles and asked experts in the field. Study selection was performed by two independent reviewers; data extraction was done by one reviewer and checked by another.

Results: We included 8 studies describing 149 quality indicators (129 process indicators, 14 outcome indicators and 6 structure indicators) and 15 core outcomes. The indicators covered the following domains: multidisciplinary team, physical and psychosocial aspects of care, communication, end-of-life care, bereavement support, and other.

Conclusion: No comprehensive, standardized framework for measuring PPC quality across the disease trajectory currently exists. This review identifies important gaps in existing quality measurement and provides the evidence base for developing an international core outcome set and accompanying quality indicators to support evaluation and improvement of PPC in clinical practice.

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Family Talk Intervention Improves Communication and Psychosocial Health in Pediatric Palliative Care

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Background: Families with a child with a life-limiting or life-threatening condition face psychosocial challenges where communication is central for coping. However, evidence-based family interventions to support communication remain limited.

Aim: To evaluate the manual-based, Family Talk Intervention (FTI), regarding psychosocial outcomes and underlying processes of change in clinical care.

Methods: This mixed-methods trial included families with a life-limiting or life-threatening condition. Quantitative data were collected using a pre-post design (n = 105; 29 families) to assess changes in family communication and psychosocial health, analyzed with linear mixed models. Qualitative data were obtained through semi-structured interviews (n = 40; 13 families) and analyzed using Interpretive Description.

Results: FTI significantly improved family communication (p = 0.049 post-intervention; p = 0.005 at 6-month follow-up), family satisfaction (p = 0.014; p < 0.001), and anxiety (p < 0.001 at both time-points). Parental skills improved at 6-month follow-up (p = 0.035). Children's mental health problems decreased post-intervention (p = 0.034), with no sustained effect at 6 months. No significant changes were observed in resilience. Interviews showed that changes were driven by a central process "breaking the silence". Family conversations enabled sharing of unspoken worries, made children's perspectives part of family knowledge and facilitated dialogue about illness-related uncertainty, death, and mutual understanding.

Conclusion: The findings suggest that FTI strengthens family communication and psychosocial health. By facilitating open communication and making children's perspectives shared within the family, FTI helps break silence around illness related uncertainty. Integrating structured family-centered interventions supporting psychosocial health, including communication, into clinical care may support families in coping with illness-related stress and existential concerns.

Spiritual Themes and Meaning-Making in Pediatric Palliative Care: A Retrospective Chaplaincy Study

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Background: Spiritual care is a core component of pediatric palliative care (PPC), yet families' spiritual experiences and meaning-making remain insufficiently described. This study aimed to identify recurring spiritual themes, existential concerns, and coping processes expressed by families of children receiving PPC.

Methods: A retrospective qualitative study was conducted using anonymized chaplaincy clinical notes from routine PPC encounters recorded between June 2024 and May 2026. The analysis included documentation related to 63 pediatric patients and 81 family members. Data were analyzed using inductive thematic analysis to identify patterns related to spirituality, suffering, hope, relational identity, and meaning-making. Ethical requirements for retrospective analysis of de-identified data were followed.

Results: Analysis identified recurring themes of hope amid prognostic uncertainty, meaning-making, relational identity, and spiritual coping. Families sought continuity in the child's life and identity while navigating serious illness. Spiritual needs extended beyond religious practice and included presence, compassionate listening, emotional validation, and existential reflection. A notable theme involved beliefs that the child had "chosen" the parents before birth, reinforcing meaning, parental identity, and resilience. For some families, religious beliefs and rituals functioned as coping resources. Cultural and spiritual backgrounds influenced communication about suffering, decision-making, and preparation for end-of-life care.

Conclusions: Families receiving PPC experience complex spiritual needs closely linked to meaning-making and relational coping. Chaplaincy documentation provides valuable insight into spiritual experiences that may remain underrecognized within interdisciplinary care. Integrating structured spiritual assessment and chaplaincy perspectives into PPC may strengthen holistic family-centered support.

Funding: No external funding.

"Closing the circle": Postmortem Interview after a Child's Death in Pediatric Palliative Care

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Background and aims: Bereavement support is central to pediatric palliative care (PPC). This work describes the implementation and perceived impact of a structured post-mortem interview offered by a PPC service in Lombardy, Italy, to parents after their child's death. The aim was to assess whether this follow-up could support meaning-making, reduce abandonment, monitor grief and improve care.

Methods: A bereavement management procedure was shared with the multidisciplinary team. Parents were contacted by the psychologist 1–2 months after death and, if they accepted, the interview was scheduled within two months. Before each meeting, the team held a debriefing. The interview was led by the psychologist, physician and nurse involved near death, included a retrospective phase (illness trajectory and unresolved doubts), and a prospective phase (family reorganization, parental resilience, siblings' adjustment). Data were derived from textual analysis of clinical summaries collected between 1 Oct 2022 and 31 Mar 2026. Participation was voluntary, and descriptive statistics were used.

Results: During the observation period, 85 children died and 17 interviews were conducted (20%). Although many parents expressed gratitude for the care received, most did not feel able to attend soon after death. The interviews appeared to reduce feelings of abandonment, clarify doubts that might consolidate into guilt, support early identification of complicated grief, and increase attention to siblings' adjustment. For professionals, they provided feedback to improve care, helped process unresolved issues, and supported compassion satisfaction while helping prevent compassion fatigue.

Conclusions: The postmortem interview may bridge the end of care and bereavement support. Its main limitation is low uptake, reflecting the emotional burden of early bereavement. Nevertheless, structured post-death follow-up can promote individualized family support, improve PPC practices, and sustain care teams.

From Global Quality Indicators Research to Local Improvement in Pediatric Oncology End-of-life Care

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Background and aims: Children with cancer in limited-resource settings experience inequities in access to high-quality End-of-life (EOL) care, due to lack of relevant indicators and multi-system barriers. The Pediatric Oncology Tool for End-of-Life Care Treatment (ProTECT) is a global research initiative that generated 64 relevant quality indicators, an assessment tool, and a follow-up approach for promoting an institution's capacity to deliver EOL care in childhood cancer. This multicenter project reports local progress in EOL practice improvement after engagement in ProTECT.

Methods: We designed quarterly follow-ups with 13 pilot sites from 13 countries starting August 2025. Each site, represented by a physician, a nurse and an interprofessional team member, received an electronic survey to complete collectively. The survey combines 18 mixed-method items addressing the stages of project implementation, completion status, milestones, number of impacted patients, scientific products, and insights on challenges faced. Data was analyzed using descriptive statistics and thematic analysis as appropriate.

Results: Across follow-up rounds, 9 sites reported progress on 24 projects initiated across several EOL domains. Projects covered integration of specialized pediatric palliative care (PPC) services, improvements in physical and psychosocial symptom management, ethics consultations, PPC education, and bereavement support. To date, 9 projects are halfway to the goal and 10 fully completed, benefiting more than 1300 patients/families and producing 7 scholarly activities. Qualitative findings revealed that staff shortage, turnover, and lack of funds and experience challenge projects' sustainability.

Conclusions: Over time, ProTECT turned science into practice improvement with potential amplification of clinical impact and dissemination. Intentional and steady follow-up maintains momentum and supports ongoing local progress toward quality EOL care in childhood cancer worldwide.

Developing a Transferable Group Intervention Model in Paediatric Palliative Care

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Background: Despite more than 8 years of experience delivering group interventions in paediatric palliative care (PPC), transferable models remain scarce, limiting implementation and evaluation.

Aim: To develop a group intervention model for children, adolescents and families receiving PPC and complex chronic care.

Methods: A multiphase qualitative study was conducted through a clinical-academic partnership between a specialised PPC service and a university faculty of psychology (2024–2026)

Phase 1: review of 49 publications on group psychotherapy and psychosocial PPC

Phase 2: observation of 30 group sessions involving children, adolescents, siblings and parents, plus a multidisciplinary focus group

Phase 3: expert supervision and consensus-building involving 11 therapists and 3 external supervisors

Phase 4: co-creation of the intervention model with 13 multidisciplinary professionals

Results: Phase 1 identified the model's conceptual foundations: systemic and ecological approaches, Yalom's therapeutic factors, group developmental processes, paediatric suffering frameworks and the concept of Double Awareness

Phase 2 identified five implementation domains: heterogeneity, group development, setting, intervention structure and integration into clinical care

Phase 3 generated consensus regarding objectives, therapist roles and intervention processes

Phase 4 produced a model defining target populations, inclusion criteria, objectives, intervention phases and evaluation. Core components include psychologist-led groups and PPC nursing co-therapists, small groups, sessions every 3–4 weeks, face-to-face or online formats, a psychologist observer providing feedback to participants and therapists, and evaluation using therapeutic factors and structured feedback

Conclusions: This study transformed more than 8 years of clinical experience into a transferable and evaluable group intervention model. The framework offers a practical implementation tool and a foundation for future effectiveness studies

Pain Management in Children with SNI Does not Always Improve Caregiver Well-being: Results of an RCT

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Background and Aims: Children with life-limiting and severe neurological impairment (SNI) represent a profoundly vulnerable population, often living with complex medical needs and significantly shortened life expectancy. In addition, they may experience pain and irritability of unknown origin (PIUO), requiring round-the-clock care. Families assume the majority of responsibility for managing their child's medical needs, which may impact caregiver sleep and well-being. Understanding how care teams can support these families is crucial. The present study examines whether improving a child's PIUO is related to change across multiple domains of caregiver well-being.

Method: In a randomized control trial, 72 children with SNI and their caregivers were enrolled across 4 tertiary care centres in Canada. The waitlist-control intervention included a history and physical, diagnostic screens, and nursing support. At study end, children's pain outcomes were classified as: Resolved, Identified, or Not Resolved or Identified. Two children died during the study period. Caregivers completed the PROMIS-57 Profile v2.0 survey assessing fatigue, physical function, sleep disturbance, anxiety, depression, pain interference, and social functioning at 3 time points. Linear mixed models were fitted to examine change in well-being against time and study outcome.

Results: Caregivers reported higher levels of fatigue, sleep disturbance, anxiety, depression, and pain interference relative to the general population. Resolving or identifying a child's PIUO was not associated with significant changes across most measures.

Conclusion: Caregivers experienced higher care burden regardless of their child's PIUO outcome. Although diagnostic clarity may offer some relief for families of children with PIUO, it is insufficient to meaningfully improve overall caregiver well-being. These findings underscore a need for dedicated, home-based supports for families of children with SNI to address caregiver well-being.

Dignity Therapy in Pediatric Palliative Care: Development of a By Proxy Protocol

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Background: Dignity Therapy (DT) is an evidence-based psychotherapeutic intervention designed to preserve meaning, identity and legacy in people facing life-limiting illness. While well established in adult palliative care, its application in paediatric palliative care (PPC), particularly for children unable to communicate, remains underdeveloped. This study aimed to develop and validate a DT *by Proxy* protocol adapted to the Portuguese PPC context.

Methods: A multi-stage iterative development process was undertaken, including literature review, specialised training in DT, consultation with PPC teams and development of a preliminary protocol. Content validation was conducted through a modified two-round Delphi process involving a multidisciplinary expert panel. The revised protocol subsequently underwent qualitative validation with family caregivers to assess clarity, acceptability and clinical relevance. Feedback from professionals and families informed the final version of the protocol.

Results: The final protocol comprises 14 questions organised into eight thematic domains, preserving the core principles of DT while incorporating relational, developmental and legacy-oriented dimensions relevant to paediatric care and proxy narration. Expert and family contributions improved conceptual clarity, emotional accessibility and clinical applicability, resulting in a culturally adapted and clinically meaningful intervention for children unable to communicate within paediatric palliative care.

Conclusions: This study resulted in the co-construction of a novel dignity-conserving intervention for paediatric palliative care. The protocol demonstrated preliminary content validity, acceptability and clinical relevance, supporting future feasibility and implementation studies. By facilitating meaning-making, memory preservation and continuity of bonds, it may contribute to addressing the psychosocial and existential needs of children with life-limiting conditions and their families.

Reducing Psychological Harm Following the Death of a Child Through Trauma-Informed Bereavement Care

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Background: The death of a child is the most devastating experience a parent can endure and is associated with significantly increased rates of mental ill health, including anxiety, depression and post-traumatic stress disorder (PTSD). Maternal suicide rates are reported to be four times higher following a child death. Despite the known psychological impact, bereavement services across Europe remain inconsistent, with limited access to coordinated, trauma-informed care and evidence-based therapeutic interventions tailored to families' needs. This work aimed to identify how to deliver quality, trauma-informed bereavement care when a child dies.

Method: An opt-out referral model enabled 600 families automatic access to hospice-based bereavement support. Families completed routine clinical screening using validated mental health assessment tools (VATs). Over 700 responses were analysed to inform personalised care pathways, while anonymised data was examined for service evaluation and programme development.

Results: Extremely high levels of psychological distress were identified. 82% of parents screened positive for PTSD and 10% disclosed active suicidal ideation. Findings challenged assumptions around timing of support, with greater trauma severity observed among parents presenting later for care, highlighting potential harm associated with delayed intervention. Post-treatment outcomes demonstrated marked clinical improvement, with PTSD prevalence reducing from 96% to 22%. Findings have driven the development of a national collaborative focused on embedding evidence-informed models of care.

Conclusion: A population-based, automatic referral approach combined with routine use of VATs informed a framework for quality bereavement care, enabling early identification of clinical risk, and timely, trauma-informed interventions. Wider adoption across Europe has the potential to improve outcomes for bereaved families, significantly reducing avoidable psychological suffering.

Pediatric Palliative Care Referral at DNR Designation Reduces Hospital Resource Use in LMIC Country

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Background: A widely held assumption in global pediatric palliative care (PPC) is that families in Muslim-majority and LMIC settings will resist do-not-resuscitate (DNR) designation, limiting opportunities for early palliative integration. We report the experience of a regional tertiary cancer center in the Middle East where structured, culturally adapted goals-of-care conversations anchor an automatic PPC referral model: DNR designation triggers immediate transfer of primary care responsibility to the PPC team. We aimed to characterize DNR uptake and to quantify the impact of this pathway on acute hospital utilization and place of death.

Methods: Retrospective cohort study of all pediatric oncology patients (<18 years) who died between January 2017 and December 2024 with documented DNR orders. Hospital admissions, emergency room (ER) visits, intensive care unit (ICU) admissions, inpatient days, home-care visits, and place of death were extracted from institutional records and compared in the 30 days before versus 30 days after PPC referral, using Wilcoxon signed-rank and paired t-tests ($p < 0.05$). Ethical approval was obtained.

Results: 804 children (median age 7.8 years), 92.6% had active DNR orders, with a median DNR-to-death interval of 0.8 months — challenging assumptions about cultural resistance. Post-referral admissions fell by 52% ($p < 0.001$), ER visits by 48% ($p < 0.001$), and inpatient days by 41% ($p = 0.007$). ICU admissions dropped from 18 to zero ($p < 0.001$). Home-care visits rose more than tenfold (3 to 34/month, $p < 0.001$), yet only 13% of children died at home.

Conclusions: Culturally adapted goals-of-care communication can achieve very high DNR uptake in a Muslim-majority LMIC, enabling an automatic PPC pathway that eliminates ICU use at end of life and shifts care into the home. The gap between home contact and home death points not to family preference but to under-resourced community infrastructure — a priority for policy and investment in similar settings.

French National Guidelines for Pediatric Palliative Care Pathways

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Background: Pediatric palliative care (PPC) has developed considerably in the 21st century. Today, PPC teams experience an increasing number of referrals for complex patients that require strong multidisciplinary collaboration to meet the needs of these families. The French Society for Pediatric Palliative Care and the French National Health Authority drafted national evidence-based guidelines to define PPC pathways within the context of French healthcare.

Methods: A systematic search of Embase, MEDLINE, published international PPC guidelines, and gray literature was conducted in Jan-Feb 2025. Nearly 200 publications on PPC, primarily from the past decade, were selected according to methodological quality criteria with a focus on reviews, meta-analyses and guidelines. Documents were drafted by a 28-member interdisciplinary working group and reviewed by a 54-member expert panel. Final documents will be made available online in open access on Oct 8, 2026 (www.has-sante.fr).

Results: The following documents were produced: evidence-based rationale, pathway guide, critical points in the care pathway and management strategies, care pathway vignettes, and supplementary materials. The main documents follow a six-step outline: 1) Diagnosis or recognition of a life-limiting/life-threatening condition (LL/LTC); 2) Living with a LL/LTC; 3) Living with disease progression and deterioration; 4) End of life care; 5) Care after death, and 6) Bereavement support. For each step, evidence-based and practice-based guidelines are provided to support professionals working in general or specialized PPC across diverse care settings.

Conclusions: These guidelines offer a national, evidence-based framework to structure PPC pathways, promote multidisciplinary collaboration, and improve quality of care across diverse healthcare settings in France. We will present an overview of the guidelines, their implementation within the French healthcare context, and their relevance and applicability to the international community.

Mapping Stakeholder Perspectives on Home Monitoring in Paediatric Complex and Palliative Care

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Background and Aims: Rising demand for Paediatric and Palliative Care underscores the need for overarching paediatric home-care models. Digital tools can enhance home-care reach, but these should reflect user needs to be effective and sustain engagement. Telehealth models that can serve heterogeneous patient populations remain under evaluated. The HOME-C2P2 project examines end-user needs across two European systems with different health care systems and digital readiness levels. The study aims to map communication touchpoints across home-care phases and identify stakeholder needs among paediatric patients with palliative care needs and/or chronic complex conditions, their caregivers, and healthcare professionals, examining barriers to home-monitoring integration and co-designing requirements for a refined model.

Methods: Multisite qualitative study run in Denmark and Spain. Data were collected via adapted Metro-Mapping focus groups, and care-mapping drawing sessions. Analysis combined thematic and rapid notes-based analysis. Ethical approvals were obtained locally.

Results: Data collected from patients aged 12-21, caregivers, and healthcare professionals across hospital and primary care settings (Spain: 33 participants; Denmark: 15 participants). Analysis identified convergent requirement domains such as shared care plans, structured discharge protocols, caregiver training, proactive monitoring, embedded escalation pathways, and structured transition to adult care. Families in both systems see themselves as the primary source of shared information between healthcare professionals. Site-specific requirements reflect structural differences in each national healthcare system.

Conclusions: This study sheds light into cross-national stakeholder needs, serving as a foundational framework for a home-care telehealth model used in different health care systems. Findings will inform a telemonitoring pilot-study.

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Exploring Values, Goals and Preferences in Paediatric Care: A Content Analysis of ACP Conversations

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Aim: Paediatric advance care planning (ACP) aims to align future care with the values, goals and preferences of children and families. Little is known about how HCPs explore parents' and children's values, goals and preferences and respond to these expressions in actual ACP conversations. This study aimed to gain insight into how this process unfolds in practice.

Methods: Audio-recorded paediatric ACP conversations, conducted according to the IMPACT method for ACP conversations, were qualitatively analysed using QUAGOL and a combined deductive-inductive coding approach.

Results: 13 ACP conversations were analysed, involving 11 HCPs and 21 parents across hospice (n=3), home (n=4) and hospital care (n=6) settings. Values, goals and preferences often emerged implicitly through parents' descriptions of daily-life positive and negative experiences, self-reflection and identity-related narratives, however, were rarely explicitly expressed. Summarising values, goals and preferences and translating them into concrete care goals and actions by or with HCPs often remained limited. HCPs' communication styles varied considerably. Conversations with clear ACP introductions, open-ended questions and mutual understanding of perspectives more often resulted in the formulation of identifiable goals of care and actions. The use of a summary at the end of the ACP conversation helped clarify child and families' values, for both parents and HCPs, which formed the basis for subsequent goals and actions. Not helping, e.g., was not introducing clearly the goal of ACP.

Conclusion: ACP conversations enable parents and HCPs to discuss their values and preferences, but these insights are not yet routinely summarised and translated into concrete plans for future care. Clear conversational structure and HCP guidance appear important in articulating values and goals. These findings may help improve HCP training and support, in order child and family values are clearly reflected in person-centred care.

Integrated Palliative Care in Italian Pediatric Oncology Centres: Current Practice and Unmet Needs

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Background/aims: Early integration between Pediatric Palliative Care (PPC) and Pediatric Oncology (PO) is recommended to improve quality of life for children with cancer and their families. Despite increasing recognition of its value, the organization and implementation of integrated PPC models remain heterogeneous. This study aimed to describe current PPC practices within Italian PO centres and identify unmet needs and barriers to integration.

Methods: A structured national survey was conducted among HCPs participating in the Italian Association of Pediatric Hematology and Oncology (AIEOP) Working Group on PPC. The questionnaire explored service organization, symptom management, referral practices, communication processes, and perceived barriers to PPC integration.

Results: 52 professionals from 34 of 48 PO centres (71%). Symptom management emerged as the most challenging area, particularly for non-pain symptoms and psychological distress. Organizational heterogeneity was evident: some centres lacked dedicated PPC professionals, while others relied on internal, external, or mixed PPC models. Home-based PPC services were available in most centres, although integration with PO teams was variably perceived. The most frequently reported needs included earlier referral to PPC (35%), insufficient PPC staffing (29%), lack of professional training in PPC (15%), barriers to communication between HCPs (15%), and difficulties in family acceptance of PPC involvement (6%). Participants also identified educational priorities including communication, ACP, cultural diversity, bereavement care, symptom control, and ethical decision-making.

Conclusions: Although integration between PPC and PO is increasingly established in Italy, significant variability persists across centres. Earlier referral pathways, dedicated training programs, and stronger collaboration between PO and PPC teams may support more equitable access to integrated PPC for children with cancer and their families.

Fathers' Experiences of Caring for a Child with a Progressive Life-Limiting Condition

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Background: Fathers remain underrepresented in PPC research, particularly in non-oncological settings. Despite their essential caregiving role, fathers often report grieving privately, balancing multiple responsibilities, and feeling overlooked by healthcare professionals. As PPC emphasizes holistic family-centred care, a deeper understanding of fathers' experiences is needed to provide equitable support for the entire family.

Aim: To explore fathers' in-depth experiences of caring for a child with a progressive life-limiting condition.

Methods: The presentation draws on findings from a qualitative systematic review and metasynthesis, and qualitative interviews with 13 fathers of children with progressive life-limiting conditions. The studies explored fathers' experiences related to diagnosis, everyday caregiving, and healthcare and welfare services. All data were analysed using a phenomenological hermeneutical approach.

Results: Fathers' experiences were shaped across multiple levels. *Individually*, fathers described anticipatory grief, uncertainty, role conflict, and the need to establish a "new normal." In *healthcare encounters*, many felt marginalized or treated as secondary caregivers, while proactive professionals who recognized their expertise were highly valued. *Organizationally*, fragmented and poorly coordinated services placed major advocacy and coordination burdens on families. *Societally*, traditional gender norms contributed to fathers' invisibility in healthcare and research.

Conclusion: The findings indicate a need to strengthen a holistic family-centred approach in paediatric palliative care, in which fathers' roles and needs are made more visible. This requires greater recognition of fathers as equal caregivers with distinct emotional and practical needs as well as father-inclusive communication, improved service coordination, and increased awareness of structural and societal barriers such as gendered assumptions to better support fathers.

Bereavement Groups in Paediatric Palliative Care: Parents' Experiences in Denmark

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Background: Follow-up after the death of a child is part of specialised paediatric palliative care. In regional Danish services, structured bereavement groups are offered to parents. Empirical knowledge remains limited, however, regarding what it is like to take part in such groups and how they should be organised in a Scandinavian healthcare setting.

Aim: To explore what it is like for parents to participate in hospital-initiated bereavement groups and to identify themes of relevance for their organisation and facilitation.

Methods: A qualitative study was conducted in a regional hospital-based bereavement programme in Denmark. Parents who had lost a child and completed a group course were invited to participate in individual or focus group interviews. Data were analysed using thematic analysis informed by a phenomenologically oriented approach. Ethical approval was obtained according to national regulations.

Results: Three themes were identified. First, the group offered a sense of belonging, as parents met others who had also lost a child. Second, it provided a space for sharing and carrying memories, allowing the child's life to remain present in conversation. Third, participation supported ongoing attempts to make sense of the loss, as past events were revisited in light of present life. Skilled facilitation, stable participation, and sufficient time were important conditions.

Conclusions: Bereavement groups within regional paediatric palliative care may provide shared settings in which loss can be spoken of, remembered, and gradually integrated. The findings inform the continued development of bereavement support in Scandinavian contexts.

Ethical Attitudes among Pediatric Palliative Care Professionals in Spain

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Background/context/aims: Pediatric palliative care (PPC) involves ethically complex decisions under clinical uncertainty and limited evidence. This study aimed to describe the attitudes of PPC professionals in Spain toward frequent ethical conflicts.

Methods: Descriptive cross-sectional study using an anonymous online questionnaire based on 15 fictional clinical scenarios and 71 statements rated on a 0–4 Likert scale. The questionnaire was reviewed through a Delphi process by six experts in ethics and PPC. Scenarios were grouped into five domains: information and mature minors, best interests of the child, proportionality of interventions, comprehensive care, and emerging ethical scenarios. High consensus was defined as $\geq 75\%$ agreement or disagreement.

Results: Sixty professionals completed the survey; 63.3% were women, 68.3% pediatricians, and 65.0% worked exclusively in PPC. Overall, 28/71 statements (39.4%) reached high consensus. Professionals favoured intermediate courses of action, comprehensive interdisciplinary care, and open communication with patients and families. Statements limiting information or communication were largely rejected, as were invasive or disproportionate interventions with low perceived benefit. Consensus was highest in the comprehensive care domain and lowest in the best interests of the child domain. In 16/71 statements (22.5%), no response category reached 50%, particularly regarding referral to clinical ethics committees and emerging scenarios such as euthanasia or controlled donation after circulatory death.

Conclusions: PPC professionals in Spain show strong agreement on prioritising communication, proportionality, comprehensive care, and prudent intermediate pathways. Greater disagreement in clinically uncertain scenarios highlights the need for targeted ethics training, deliberative support, and further research on decision-making in complex PPC.

Bridging SICIP Adult and Pediatric Palliative Core Curricula: Developing a Transition Age Care Model

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Background and Aims: The increasing survival of children with life-limiting and life-threatening conditions requires continuity between Pediatric Palliative Care (PPC) and Adult Palliative Care (APC). However, no dedicated expertise currently exists for Transition. The study compared the Italian Society of Palliative Care (SICIP) *Core Curricula* for physicians and nurses in adult and pediatric settings to identify similarities, gaps, and educational needs, useful for developing a specific *Core Curriculum* for Transition Palliative Care.

Methods: A comparative qualitative analysis of the SICIP *Core Curricula* in APC and PPC was conducted. Competencies were categorized into clinical, communicative, organizational, and ethical-relational areas. Data were also integrated with a review of international literature on Transition Palliative Care.

Results: Shared competencies identified in all *Curricula* included symptom management, communication skills, ethical decision-making, teamwork, and family support. Pediatric *Curricula* showed emphasis on development, family-centered care, long-term trajectories, and multidisciplinary; adult *Curricula* focused more on autonomy, advance care planning, and end-of-life. Transition-related skills were underrepresented in both *Curricula*, especially adolescent autonomy support, congenital rare disease management in adulthood, transition planning, and healthcare networks.

Conclusions: Current SICIP *Core Curricula* provide a solid foundation for Palliative Care education but address insufficiently adolescent and young adult needs. A Transitional Care *Curriculum* may improve interdisciplinary collaboration and person-centered assistance. Limitations include the qualitative analysis and lack of clinical validation.

When Parents and Pediatricians Disagree: Clinicians' Experiences in Pediatric Palliative Care

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Background and aims: Disagreements between parents and clinicians may arise in pediatric palliative care (PPC). While previous research has focused on how pediatricians navigate complex treatment decisions, less is known of how they experience and manage disagreements with parents in such illness trajectories. Our objective was therefore to explore pediatricians' experiences of parent-clinician disagreements in PPC, including their frequency, perceived causes, management strategies, and impact on physicians

Methods: We conducted a cross-sectional survey among pediatricians at a tertiary care hospital. A nine-item questionnaire assessed experiences with disagreements in clinical trajectories that ended with the child's death.

Results: A total of 87 pediatricians participated. A large majority of respondents (71%) had experienced disagreements with parents in PPC. The most common perceived source of disagreement was limitation of life-sustaining treatment, including timing of extubation (n = 60). Pediatricians identified time for repeated conversations, involvement of psychosocial professionals, and communication training as key strategies for managing situations better. Disagreements were associated with emotional impacts on physicians, including rumination and discomfort, but also positive learning experiences. Almost all respondents expressed a desire to participate in communication training.

Conclusion: Disagreements between pediatricians and parents in PPC are common and arise primarily around complex treatment decisions. Organizational structures providing pediatricians with adequate time for decision-making conversations with parents, communication training, and strengthened interdisciplinary collaboration may prevent and better manage disagreements. The emotional impact on clinicians, combined with a strong interest in training, calls for targeted educational initiatives to promote PPC communication.

The Grey Zone in Neonatal Life-and-Death Decision-making: A Scoping Review

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The grey zone in neonatal life-and-death decision-making refers to situations in which multiple ethically permissible approaches exist, ranging from life-sustaining treatment to comfort-focused care, guided by parental values and preferences. However, terminology and interpretations vary widely across the literature. This scoping review aims to systematically map definitions, criteria, key characteristics, factors, conceptual delineations, and frameworks regarding the grey zone in neonatal life-and-death decision-making.

The review followed the Joanna Briggs Institute methodology. PubMed, Cochrane, Embase, PsycINFO, and Web of Science were searched in September 2025 for studies published between 2001 and 2025 in Dutch, English, French, German, Italian and Spanish. Scientific articles exploring the grey zone in neonatal life-and-death decision-making were included.

A total of 22,586 records were identified; 442 underwent full-text review, and 212 were included. Publications comprised empirical studies, theoretical and ethical analyses, commentaries, clinical guidelines, policy documents, and case-based discussions. Populations included extremely preterm infants (22–26 weeks), newborns with severe congenital anomalies, acquired neurological injury with uncertain recovery, and other life-limiting diagnoses or uncertain prognoses. Grey zone terminology, both explicit and implicit, was categorised as ethical/philosophical, operational/clinical, and legal/policy. Decision-making frameworks, cultural or geographical contexts, and case-based illustrations were additionally mapped.

This scoping review comprehensively maps the conceptual landscape of the grey zone in neonatal life-and-death decision-making across 212 articles. Despite wide terminological variation, consistent themes emerge: the grey zone is characterised by clinical and prognostic uncertainty, a spectrum of ethically permissible treatment options, and a central role for parental values in shared decision-making.

A National Centre of Research Excellence in Paediatric Palliative Care

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Background and aims: The Australian Centre of Research Excellence (CRE) in Paediatric Palliative Care (PPC) is a national initiative aimed at improving quality of life for children with life-limiting conditions and their families. Funded through a national grant, it brings together clinicians, researchers and people with lived experience. The CRE aligns with Australia's Paediatric Palliative Care National Action Plan. The CRE aims to identify major evidence gaps, generate high-quality evidence, translate research into practice, and build research capacity through collaboration and consumer engagement.

Methods: In its first year, the CRE has focused on capacity building and establishing a coordinated national network. Priority research areas include identifying key research questions, developing pathways for priority populations, improving communication, and measuring outcomes. Two PhD candidates have commenced, contributing to the future PPC research workforce, and a national research agenda is now in place.

Results: Early achievements include two national workshops (academic writing; clinician-led research) and two webinars on consumer engagement. The network has grown to more than 700 clinicians, researchers and consumers. Research is progressing in stages in different children hospitals and universities around Australia including developing priorities for PPC Research. Additional projects include: developing a model of care for children with cancer; co-designing a culturally safe, community-led care pathway; two advance care planning projects; research on consumer preferences, historical analysis of PPC in Australia; and exploration of legacy-making for young people.

Conclusion: Early outcomes show the value of a coordinated, capacity-building approach. The CRE is establishing a sustainable, collaborative platform to drive impactful, inclusive research and improve care for children and families, contributing to global PPC advancement.

Between Empathy and Exhaustion: Examining Healthcare Providers' Comfort with Pediatric Death Work

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Background: Death work refers to any therapeutic or supportive work conducted by a healthcare professional surrounding death. While death, grief, and loss are inevitabilities of the human experience, there remains a noticeable gap in education and training for death work, and consequently, the effects of this work on healthcare professionals.

Methods: Through an anonymous electronic survey, we sought to assess multidisciplinary healthcare providers' perceived comfort in death work and to identify areas for improved education, skill development and support.

Results: 477 surveys were completed. Most participants were female (n=401, 84%), nurses (n=212, 44%), practicing in an intensive care setting (n=249, 52%), and had ≤ 10 years of experience (n=308, 65%). Almost all participants had experienced personal loss of a loved one (n=428, 90%). Many reported caring for ≥ 10 children/year with life-threatening illnesses (n=322, 68%) and a third of participants cared for 5-20 dying patients/year (n=163, 34%). When assessing comfort with death work, there was reported comfort in addressing physical symptoms and providing emotional support for patients/families at the end-of-life (EOL). Discomfort was noted in addressing questions from patients/families about death and dying. Polarized responses were notable for the statements: "My emotions should not be impacted by death work," and "I do not bring work-induced emotions into my life". Participants identified increased education, easier identification of resources to support EOL care and simulated training opportunities as top priorities for enhancing their skills in supporting death work.

Conclusions: Caring for children and their families at the EOL spans many disciplines and settings. Supporting healthcare professionals to confidently deliver EOL care and feel supported in their death work is a vital task to improve patient/family experience and promote resiliency among healthcare providers.

Impact of Simulation Training on Self-Efficacy in Paediatric Palliative Care

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Background and aims: Healthcare professionals (HCP) report feeling insufficiently prepared to care for paediatric palliative care (PPC) patients due to the infrequency and complexity of this area of practice. Simulation-based (SIM) training offers the opportunity to develop confidence, skills and knowledge by practicing scenarios in a safe and reflective environment without risking patient safety. However, there is limited use of validated assessment tools to measure the impact of this learning approach. The study aimed to evaluate whether a SIM training day improves attendee's self-efficacy.

Method: A one-day, medium fidelity SIM programme was delivered by a highly experienced specialist PPC team to a range of HCP working with children. Sessions included lectures, small group discussions and interactive scenarios using actors and manikins. The scenarios covered communication, symptom management, end-of-life care and dying. Attendees completed a modified Paediatric Palliative Care Questionnaire (PPCQ) pre and post training.

Results: A total of 24 nurses/other HCP and 12 doctors completed pre and post training questionnaires. Self-efficacy scores significantly improved post sessions ($z = 4.769$, $p < 0.001$). Statistically significant improvements were observed across 21 out of 23 self-efficacy questions (p -value range < 0.001 - 0.046). Course evaluation scores were high, all participants reported the training was useful, relevant to their clinical practice and would recommend it to others.

Conclusion: HCP often have limited exposure and experience in PPC which can affect their confidence in delivering care and inhibit meaningful communication. SIM training is an effective and well-received approach to improve self-efficacy and develop key competencies in this field. This highlights the value of embedding specialist SIM training into education programmes and continued professional development to support practitioners in delivering high quality care.

This study received no funding

When the “Parent” Is AI: Co-Producing Simulation for Serious Illness Communication Training

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Background: Serious illness communication (SIC) skills are foundational to good pediatric care. Clinicians' responses to emotion, hopes, worries, and values influence the patient and family experience of medical care and shape how easily they can participate in care decisions. Trainees often lack opportunities to practice these complex relational skills, and artificial-intelligence (AI)-supported simulated conversations can fill this gap. Because this inherently involves interacting with caregivers, creating a credible "AI parent" actor is the crucial first step for these simulations.

Methods: This project brought together clinicians, a bereaved parent partner, interprofessional learners, educational and computer scientists, and AI industry experts (Linarite AI) to co-produce an AI parent actor (AI parent) for SIC skills practice. Through team-based iterations, we generated and evaluated sample dialogues, creating a rubric to assess the AI-parent functions and dynamic responsiveness to learner statements.

Results: Early iterations identified recurring problems, such as generic AI responses. The process clarified that a core design requirement was not generic realism, but contingent emotional responsiveness based on learner communication choices. We improved the model by training it to recognize common learner mistakes and skilled alternatives. Stakeholder engagement grounded the AI parent in pediatric serious illness care, bereaved parent experience, clinical expertise, and learner needs.

Conclusion: This work provides the foundation for an AI-parent-supported SIC training platform in pediatrics. Next steps are to refine the scenarios, incorporate AI coach feedback, and pilot the platform with learners. This technology has the potential to fill a critical gap in pediatric training and ultimately strengthen communication that enables family participation, shared decision-making, and goal-concordant care.

Bereaved Parents as Co-Educators: Lessons from a Pilot Training Programme

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Background and aims: Basic paediatric palliative care education is increasingly available, including international programmes such as EPEC and ICPCN. Less is known about how professionals can continue their development after foundational training, particularly through reflective learning grounded in families' lived experience.

Methods: The presentation will report on two pilot three-day courses for 40 multidisciplinary professionals, including physicians, nurses, psychologists and social workers. It is an advanced participatory educational programme that involves bereaved parents as co-educators and aims to create a community of practice. The content follows family trajectories from diagnosis, through decision-making, to end of life and bereavement. Morning sessions use parent narratives and facilitated reflection; afternoon sessions translate themes into practical tools through workshops. Evaluation includes participant feedback, facilitator field notes, and debriefing interviews with 7 bereaved parent co-educators.

Results: The presentation will summarise feasibility and acceptability, perceived learning mechanisms, and early feedback on how authentic family narratives influence reflection, communication, interprofessional learning and practice change. It will also describe how parent co-educators experience the role as an opportunity to honour their child's memory, contribute to better care for other families, and articulate feedback to health and social care systems.

Conclusions: This pilot will offer a transferable model for advanced paediatric palliative care education complementing the topics and methods typically taught in foundational courses. It provides evidence that meaningful partnership with bereaved parents can deepen professional learning while requiring careful preparation, facilitation and ethical safeguards.

A Children's Palliative Care Assistant: Data-Driven Decisions through LLM Integration

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Background and Aims: Data-driven decision-making in children's palliative care (CPC) demands tools that are accessible, evidence-grounded, and adapted to the realities of global service delivery. We developed a comprehensive self-assessment tool co-created with CPC providers across 20+ countries to support teams in collecting and acting on service data. We subsequently integrated an AI assistant to enhance accessibility and augment provider decision-making through citation-grounded responses.

Methods: The tool was integrated into a Retrieval-Augmented Generation (RAG)-enabled AI environment using a grounded large language model (LLM) approach. The tool's 10 focus areas, evidence-informed resources, case studies, and 100 metrics served as primary source material, together constituting a practitioner-informed self assessment resource for global CPC. Guided prompts were developed to support first-time users and optimise engagement.

Results: Users receive comprehensive, citation-backed responses generated in real-time. The RAG framework substantially reduces hallucination risk by grounding outputs in validated CPC-specific resources, ensuring clinical and administrative recommendations remain evidence-aligned. The assistant supports engagement in 80+ languages, reducing accessibility barriers for global audiences, including practitioners in low-resource settings where specialist CPC guidance is scarce.

Conclusions: Integrating generative AI into a practitioner-developed CPC tool marks a shift from static resource libraries to interactive, scalable clinical support. Grounding LLMs in specialised CPC information enables rapid, evidence-based decision-making at scale, with direct implications for care quality and equity across diverse global contexts.

Building an Integrated Pediatric Palliative Care Service at a Teaching Hospital: A 5 year journey

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Background: Children with serious illnesses in low- and middle-income countries (LMIC) often have unmet palliative care needs due to delayed referrals, limited specialist services, inadequate symptom management, and fragmented psychosocial support. In India, pediatric palliative care (PPC) remains limited, especially outside major cities.

Aim: To describe the development and growth of an integrated PPC model within a tertiary university teaching hospital and its impact on service utilization and capacity building.

Methods: A consultation-liaison PPC service was established in December 2019, initially with pediatric oncology, later expanded to other pediatric subspecialties. A dedicated PPC consultant conducted needs assessments, participated in multidisciplinary rounds, and promoted early identification of children requiring specialist palliative care. Initiated capacity building within teams, thereby referral and care pathways were developed. Service growth was assessed using inpatient referral and outpatient data from January 2021 to December 2025.

Results: The service showed sustained growth. Inpatient referrals increased from 10 in January 2021 to 220 in December 2025, while outpatient visits rose from 56 to 286 during the same period. The multidisciplinary team expanded to include a physician, nurse, psychologist, and academic/research support staff. Key achievements included participation in global leadership and training initiatives and securing competitive research funding to evaluate the embedded PPC model in pediatric oncology.

Conclusion: Establishing the region's first integrated PPC service within a tertiary teaching hospital demonstrated that embedding PPC into pediatric subspecialty services is feasible and sustainable in a resource-constrained setting. The program strengthened institutional capacity through education, research, and international collaborations. This model may provide a scalable framework for similar settings in LMIC.

Supporting Referral Decisions via Virtual Consultation for Children with Incurable Cancer in Wartime

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Background: Following the February 2022 invasion of Ukraine, disruptions in care for children with cancer prompted international evacuation to maintain continuity of care. Families of children with incurable cancer pursued evacuation, resulting in unintended consequences, including false hope, family separation, and complex repatriation after death. In response, a virtual consultation pathway was implemented in January 2024 to support evacuation decisions.

Methods: This retrospective study analyzed evacuation registry (02/2022–05/2026) and clinical consultation data (01/2024–05/2026). During consultations, suspected incurable cases were reviewed by an international oncology expert panel; standardized written assessments outlining prognosis, benefit-burden considerations, and palliative care recommendations were provided to families and treating teams. Registry data analyses were descriptive; use of anonymized data was IRB-approved.

Results: Before consultation pathway implementation, 665 patients were evacuated, including 33 (4.96%) with suspected incurable disease: 19 high-grade glioma (57.6%), 5 alveolar rhabdomyosarcoma (15.2%), 3 ATRT (9.1%), 2 DSRCT (6.1%), and 4 others (12.0%). Following implementation, 42 patients with suspected incurable disease received clinical consultation; 39 (92.9%) ultimately remained in Ukraine. Communication of treatment expectations through the written assessment was central to decision-making. Three families left Ukraine to seek external confirmation of incurability.

Conclusion: A structured, virtual consultation pathway reduced uncertainty and supported complex decision-making in a humanitarian crisis, promoting goal-concordant, comfort-focused care while minimizing non-beneficial evacuation. Confirming incurability was the principal enabler, as referrals were frequently motivated by hope of cure; remaining in Ukraine was feasible because palliative care remained accessible despite the war. Limitation: descriptive design.

Improving Anticholinergic Antihistamine Prescribing for Children Attending a Children's Hospice

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Background and Aims: Anticholinergic burden (ACB) in adults is associated with increased adverse drug reactions and mortality. Evidence in children is limited but a study in neurologically impaired children associated high ACB scores (≥ 3) with increased parent-reported side effects.

Antihistamines were identified as medications where an alternative with a lower anticholinergic burden is readily available.

We aimed to determine whether there is potential for improved prescribing of anticholinergic antihistamines by identifying:

1. how many children are on antihistamines
2. extent of anticholinergic antihistamine prescribing and ACB score
3. whether indications for antihistamine are documented in Drug chart or electronic health records (EHR).
4. any patients who might benefit from switch to an alternative antihistamine with lower ACB score

Methods: All drug charts for children attending the hospice for respite were manually reviewed. Data was recorded in Excel. ACB scores were calculated using acbcalc.com.

Drug charts and EHR were checked for indications. If indications were unclear, parents/carers were contacted.

Results: 16% (50/306) of children were on one or more antihistamines. 6% (18/306) were prescribed a 1st generation antihistamine with an ACB score ≥ 3 .

Of these 18, 7/18 (41%) indications were not documented. After clarification 7/18 (41%) were for sleep/sedation, 2/18 (11%) anti-emetic. 1/18 excluded from switch for clinical reasons. 8/18 (59%) could potentially benefit from a switch to a 2nd generation antihistamine. Overall ACB scores for regular medicines ranged from 0-15. High-scoring medications included Glycopyrronium Bromide, Amitriptylline, Hyoscine Butylbromide, Hyoscine Hydrobromide.

Conclusion: Eight children identified who could potentially benefit from switching from chlorphenamine to a lower ACB antihistamine. . Re-audit is planned.

Further work needed to improve documentation of indications and identify other opportunities to reduce high ACB.

A Remote Palliative Care Project for Children with Oncological/Hematological Diseases in Russia

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Background, Context, and Objectives: Palliative care for children with oncological/hematological diseases is developing unevenly across Russian regions. Since 2015, the interdisciplinary remote project "Quality of Life" of the Podari Zhizn Foundation has been helping to provide patients and their families with systematic, qualified medical, social, legal, and psychological support that is lacking locally.

Methods: The project supports approximately 100 children and adolescents with oncological/hematological diseases at the palliative stage annually. Medical and nursing consultations with parents and local services are essential to monitor the child's condition and manage symptoms. A separate achievement has been the use of targeted therapy (especially for children with sarcomas). Social assistance includes targeted financial support, equipment, medications, consumables, nutritional food, and transportation. Psychological support is offered individually and in groups during treatment and the grieving process. Legal consultations help ensure that families receive the maximum amount of state assistance. A Memorial Day is held annually for 60-70 families after the loss of children.

Results: Comprehensive support improves the quality and life expectancy of children with oncological/hematological diseases from 1-4 months to 10-12 months. Children spend most of their lives at home, not in hospitals; they are included in their usual social environment, learning, developing, and traveling. Families highly value the work and support of the multidisciplinary team throughout the palliative stage and after the child's death.

Conclusions: The foundation's remote palliative care service allows for the timely identification of missing components of local palliative care and targeted supplementation of medical, social, psychological, and other support components. As a result, the quality and duration of life of children with oncological/hematological diseases is improved.

What's in a Name? Parents' Perceptions of Pediatric Palliative Care in Pediatric Haemato-Oncology

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Background and aims: Early integration of Pediatric Palliative Care (PPC) is recommended. However, PPC is often associated with end-of-life, limiting its acceptance among families. While parental attitudes toward PPC have been explored, the impact of terminology on parents' perceptions remains poorly investigated. This study aimed to evaluate if the term "Pediatric Palliative Care" influences parents' emotions, perceptions, acceptance of early PPC involvement.

Methods: An exploratory survey was conducted among parents of children with onco-hematological diseases. Two anonymous questionnaires describing the same service were administered. Questionnaire A (QA): "support service for the child's and family's Quality of Life (QoL)"; Questionnaire B (QB) explicitly used the term "Pediatric Palliative Care". Both described symptom care, QoL enhancement, psychological and family support. Data regarding usefulness, timing of involvement, information needs, emotional associations were collected.

Results: 30 parents completed the survey (QA: n=15; QB: n=15). Perceived usefulness was high in both: all respondents in QA rated the service as "very useful" vs 66.7% in QB. Parents exposed to QA associated the service with help (11/15), support (11/15), hope (8/15), protection (6/15), comfort (6/15). Parents exposed to QB associated PPC not only with support (9/15), but also with sadness (8/15), death (8/15), fear (6/15), disease worsening (5/15). Early involvement (diagnosis) was preferred by 93.3% of parents in QA vs 53.3% in QB.

Conclusions: Parents recognized the value of a service focused on symptom management, QoL, family support. The explicit use of the term "Pediatric Palliative Care" evoked stronger associations with death, sadness, disease worsening and was associated with lower acceptance of early involvement. These findings suggest that terminology may influence families' perceptions and highlight the importance of communication strategies for earlier integration of PCC.

Family Remote Music Therapy for Cognitively-Impaired Children with Medical Complexity

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Background and aims: Music-based interventions can improve psychological and physical outcomes, yet gaps exist for cognitively-impaired children with medical complexity (CMC). Specific aims were to determine the feasibility and preliminary efficacy of a music therapy intervention, RemoteMT, for cognitively-impaired CMC and parents. We hypothesized that RemoteMT would be feasible and improve child psychological distress and physical symptoms, parent psychological distress, and family environment.

Methods: We used a 1-group pre/post-test design. Participants included cognitively-impaired CMC aged 5-17 who had received a palliative/complex care consult and parents. Dyads completed RemoteMT via Zoom (4 sessions over 4 weeks). A board-certified music therapist guided dyads through a songwriting process, creating a music video for the family by incorporating lyrics; musical accompaniment; photographs/video of child and family; and audio-recordings (verbalizations, respirations) of the child. Parents completed measures at baseline (T1) and 6-weeks post-baseline (T2). Wilcoxon Signed Ranks Tests were used to assess changes in the outcome measures scores from T1 to T2.

Results: All parents (N=17) completed T1 baseline measures; 10 completed T2. Fifty-one music therapy intervention sessions were completed. Results demonstrated strong signals for increased family cohesion ($p = 0.095$; $d = +0.53$); decreased child physical stress ($p = 0.027$; $d = -1.48$); and decreased parent sleep disturbance ($p = 0.105$; $d = -0.75$). Parents ($n=10$, 100%) reported the intervention helped themselves, their child, and family.

Conclusions: This innovative study determined feasibility and acceptability of RemoteMT for cognitively-impaired CMC and their families. Results show positive signals for clinical benefit to the children, their parents, and their families.

From Voices to Vision: A Family-Informed Model for the Future of Paediatric Palliative Care

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Background: Families remain the most authoritative voices in shaping paediatric palliative care. While interdisciplinary, family-centred models are increasingly advocated, evidence directly linking structured team-based care to measurable family satisfaction remains limited, a gap this study set out to address by systematically capturing lived experience across all dimensions of hospice care.

Methods: A digital satisfaction survey was administered across 60 families at a PPC hospice. The validated 28-item instrument comprised 23 Likert-scale items (1–5) and 5 open-ended questions, covering: admission, environment, staff communication, clinical and nursing care, home care, psychosocial and spiritual support, meals, and access to specialist services.

Results: Satisfaction was consistently high across all domains. Environmental scores were near-perfect (suite cleanliness: 4.94/5; overall amenities: 5/5), with unanimous agreement on privacy, comfort, and accessibility. Communication was rated excellent, with 100% of families affirming empathetic, respectful interactions. Clinical care — including symptom management, received universal satisfaction. Cultural sensitivity and sibling support were highlighted as meaningful. Meals averaged 4.69/5. Notably, 100% of families valued access to dual keyworkers (medical and psychosocial), underscoring the perceived benefit of coordinated, specialist-led care.

Conclusions: These findings offer direct, family-derived evidence that an advanced interdisciplinary model translates into an overwhelmingly positive care experience. The dual keyworker framework and integrated specialist access emerged as structural pillars of continuity and holistic support. This work contributes actionable insights toward bridging the research-to-practice gap, helping translate evidence into models that meaningfully honour the dignity, culture, and autonomy of children and families facing life-limiting illness.

Translation & Multi-Site Validation of ACCPED from Italy to English

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Background: Few tools exist to assess the palliative care needs of children with serious illnesses. One such tool is the Pediatric Complex Care Needs Assessment scale (ACCAPED), developed by a group of pediatric palliative care experts in Italy. It evaluates care complexity across 11 clinical domains to categorize palliative care needs into three levels: low, moderate, and high.

Aim: This study aimed to translate and validate the Pediatric Complex Care Needs Assessment scale (ACCAPED) from Italian into English.

Design: The methodology included (1) translation, (2) expert panel validation, (3) end-user validation, (4) expert panel review, and (5) multi-site validation with a sample of children with various conditions and needs from Saudi Arabia, Kuwait, and Oman (N = 199).

Results: During the translation and validation process, optimization strategies were employed to improve the scale's psychometric properties, including adjusting the weighting of the clinical needs domain, modifying the complexity category thresholds, adding three items, and removing 16 items, thereby enhancing the scale's construct validity. Using a regression model, factors such as mobilization, pain, instability, and skin integrity were identified as significant influences on expert judgments of patient complexity. Like the original, the translated English version contains 11 domains.

Conclusion: The English Modified-ACCAPED scale appears to be a practical tool for screening for palliative care needs in children with potentially life-limiting conditions and for guiding them early in their disease trajectory toward appropriate resources. However, future research is recommended to strengthen its psychometric properties. <https://link.springer.com/article/10.1186/s12904-026-02031-1>

Comparative Abstract: Development of Palliative Care in Ireland and Oman.

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Background: Palliative care has evolved as a cornerstone of compassionate healthcare, focusing on relief from pain and suffering while enhancing the quality of life for patients and families. This abstract compares the development of palliative care systems in Ireland and Oman, two countries at distinct stages of evolution — one representing a mature policy-driven model and the other an emerging, rapidly developing framework.

Aim: This study compares and analyze policy development, system integration, and service access in both countries. Identify workforce and education strategies supporting palliative care growth.

Results: Ireland's approach demonstrates complete policy integration, sustainable funding, and quality monitoring at all healthcare levels. Ireland has a long-established palliative care, progressing from early hospices in the 1870s to a fully structured national programme. Key achievements include institutionalized governance under the National Clinical Programme, funding growth from €54 million (2004) to €155 million (2024) with 25% workforce increase planned by 2029 with interdisciplinary training.

Oman's palliative care journey began in the 2010s, led by the Oman Cancer Association (OCA) and the Ministry of Health (MOH). The Royal Hospital established the nation's first specialized service, and subsequent partnerships with the Cicely Saunders Institute and King's College London have advanced capacity building. Key milestones include, over 180 nurses trained; a Leadership & Research Course launched in 2016 and public awareness campaigns and seminars (2018–2019).

Conclusion: Ireland illustrates a model of systemic maturity anchored in strong policy, research, and national equity. Oman, while at an earlier stage, demonstrates rapid foundational progress through education, advocacy, and strategic partnerships. Both nations underline that the success of palliative care relies on policy commitment, intersectoral collaboration, and sustained community engagement.

Physician Attitudes on Early Pediatric Palliative Care in Eastern Mediterranean Oncology: ADAPT

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Background: The World Health Organization (WHO) designates early integration of pediatric palliative care (PPC) as an ethical and clinical imperative in the care of children with cancer. However, implementation across the Eastern Mediterranean Region (EMR) remains variable and poorly characterized.

Aim: To evaluate physicians' perceptions of ideal versus actual timing of PPC integration and to identify barriers to early integration across EMR pediatric oncology programs.

Methods: We conducted a cross-sectional, WHO-aligned adaptation of the ADAPT (Assessing Doctors' Attitudes on Palliative Treatment) survey among physicians caring for children with cancer across 19 EMR countries. Descriptive statistics summarized timing and barriers; the McNemar test compared ideal versus actual timing responses.

Results: Among 458 respondents, 59% were pediatric hematology/oncology specialists and 62% were female. While 51% endorsed PPC involvement at diagnosis for high-risk patients and 47% for all patients, only 27% and 16%, respectively, reported this occurring in practice ($p \leq 0.001$). PPC was most commonly initiated when no curative options remained (69%) or at end of life (52%). Major barriers included lack of trained PPC personnel (88%), absence of national policy (87%), limited access to PPC services (83%), lack of home-based services (85%), and limited physician knowledge (87%).

Conclusion: Physicians across the EMR strongly support earlier PPC integration; however, systemic, workforce, and policy barriers delay referrals until advanced disease stages. Targeted workforce development, policy integration, and expansion of home-based services are essential to achieving diagnosis-concurrent PPC across the region.

Intravenous Ketamine for Refractory Cancer Pain in 433 Patients: Real-World Study from Middle East

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Background: Ketamine is used as an adjunct analgesic for cancer pain refractory to opioids, but evidence remains limited. Published data come predominantly from small series in high-income settings, with few reports from the Middle East and few studies including both adults and children.

Methods: Retrospective study of all patients who received intravenous ketamine infusions for pain at King Hussein Cancer Center (KHCC), Jordan, between February 2018 and April 2026. Pain scores, concomitant medications, and hemodynamic parameters were extracted from structured electronic health record data. Pain mechanism, clinical response, and adverse events were extracted from clinical notes using a large language model pipeline, with independent manual validation of a 10% random sample by two investigators (AA, EK). The primary outcome was change in peak pain score (maximum in 72 hours pre-ketamine vs. minimum in 24 hours post-initiation), a metric chosen to reflect the clinical goal of suppressing breakthrough pain peaks.

Results: 433 patients received IV ketamine (median age 23 years; 183 [42%] pediatric; 72% deceased at follow-up). Pain was predominantly nociceptive (53%) or mixed (22%). Among 141 patients with paired pain scores, median peak pain decreased from 7 to 0 ($p < 0.001$; effect size $r = 0.73$). Among patients with clinically significant baseline pain ($\geq 3/10$), 80% achieved a ≥ 2 -point reduction. Adverse events, likely underreported in this retrospective design, were documented in 25 patients (5.8%), most commonly hallucinations and agitation. Hemodynamic parameters remained clinically stable.

Conclusions: In the largest single-center series reported to date, adjunctive IV ketamine was associated with reduced pain scores in cancer patients with refractory pain, including children. These real-world data support ketamine as a feasible adjunct in the palliative setting, though prospective controlled studies are needed to quantify its independent contribution.

Pediatric Palliative Care at a National Cancer Center: A 10-Year Service Evolution

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Background: Structured pediatric palliative care (PPC) services remain limited across the Middle East. This study describes the 10-year evolution of a PPC program at a national cancer center in a middle-income country, examining service volume, DNR utilization, time from DNR documentation to death, and place of death between 2015 and 2024–2025.

Methods: Descriptive analysis of a prospectively maintained PPC registry (2015–2025). Variables included palliative consultations by care setting (inpatient floor, outpatient clinic, PICU, emergency room, home), new DNR orders per year, interval from DNR documentation to death (2025 cohort with complete records), and place of death. No patient-identifying data are reported.

Results: In 2015, the team provided 414 palliative consultations (309 clinic, 105 floor), 50 home visits (exclusively for DNR patients), and 81 new DNR orders, with 59 deaths. By 2024–2025, inpatient consultations reached 195–238 annually and outpatient contacts exceeded 1,141 per year. Home visits grew to 168 visits for 46 patients, a 3.4-fold increase from 2015. New DNR orders were 109 (2024) and 103 (2025). Among 79 DNR patients in 2025 with complete records, the median time from DNR to death was 16 days (range 0–540); 27% died within 7 days, 61% within 30 days, and 22% survived beyond 90 days. Place of death shifted over the decade: floor deaths declined from 74% (2024) to 63% (2025); home deaths rose from 7% to 11%; ICU deaths increased from 7% to 16%.

Conclusions: This PPC program demonstrated sustained growth over 10 years, with meaningful expansion of home-based support. The short median DNR-to-death interval and predominance of in-hospital deaths indicate that formal end-of-life planning remains concentrated in the final days of life. Earlier palliative integration may extend the window for goals-of-care discussions and support higher rates of home death for children with life-limiting illness.

Schooling, Identity and Meaning-Making in Children and Adolescents with Cancer

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Background: Paediatric palliative care promotes quality of life, participation, dignity and meaning throughout serious illness. In paediatric oncology, schooling is often discussed as a way of maintaining educational continuity and social participation. Its contribution to identity preservation, however, remains underexplored.

Methods: This study presents a secondary analysis of a systematic review conducted according to PRISMA guidelines. The review included 126 peer-reviewed studies published between 2015 and 2025 addressing schooling, identity and childhood, adolescent and young adult cancer. Findings were revisited through a paediatric palliative care lens, focusing on identity, belonging, continuity, participation and recognition.

Results: Schooling emerged as more than a curricular activity. Across studies, it supported social bonds, future perspectives, student identity and continuity during treatment. Research on school reintegration, hospital education and psychosocial adjustment highlighted belonging, recognition and participation. While few studies explicitly referred to palliative care, many described practices consistent with its principles, including identity preservation, meaningful roles and social inclusion. Children and adolescents with cancer were often portrayed in universal terms, with limited attention to race, ethnicity, gender and sexuality.

Conclusions: Schooling can be viewed as an overlooked dimension of paediatric palliative care. Beyond educational continuity, it helps preserve identity, belonging and social participation. Closer dialogue between education, paediatric oncology and palliative care may strengthen more holistic approaches to care.

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Symptom Management Planning in Paediatric Palliative Care: A Systematic Review

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Background and aims: Children with life-limiting and life-threatening conditions carry a substantial symptom burden across physical, psychological, and spiritual domains. Despite this, no internationally agreed framework for symptom management planning in paediatric palliative care currently exists. This review aimed to identify and synthesise evidence for existing models, stakeholder needs, and gaps across any care setting and diagnostic group.

Methods: MEDLINE and PubMed were searched from January 1990 to May 2026 per PRISMA 2020 guidelines and prospectively registered on PROSPERO (CRD420261397099). Two independent reviewers screened 479 records. Narrative synthesis was conducted per SWiM guidelines with quality assessment using the Mixed Methods Appraisal Tool.

Results: 151 studies spanning 32 years were included. Six themes were identified: existing models and frameworks; patient needs; parent and carer needs; professional needs; system needs and service delivery; and gaps and barriers. Condition-specific guidelines exist but no universally applicable standard for symptom management planning was found. Symptom burden was consistently high and frequently undertreated across diagnostic groups. Parents ranked symptom management above all other domains of care in every preference study. Professional training deficits were documented across all settings and countries. System fragmentation, late specialist referral, and inadequate out-of-hours support have remained stable barriers across three decades.

Conclusions: No agreed definition of a "symptom management plan" currently exists in the paediatric palliative care literature. This gap in standardisation is experienced by children, parents, professionals, and healthcare systems across all diagnostic groups and settings. Its consistency across 32 years and diverse populations makes the case for action hard to ignore. An international survey of current practice and formal consensus work are the necessary next steps.

Evaluation of an Online Educational Programme in PPC for Professionals in Norway

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International standards in paediatric palliative care PPC describe three levels of care. Level 2 General PPC is particularly relevant for professionals working with children with life-limiting or life-threatening conditions and their families in community and home-based services. However, structured education at this level remains limited. This study aimed to develop and evaluate a Norwegian online educational programme to strengthen competence, confidence, and reflective practice among Level 2 providers, including professionals without formal PPC training.

An educational programme based on national and international PPC standards was developed. It included: (1) five digital e-learning modules covering PPC principles, interdisciplinary collaboration, holistic care of the child, support to family members, and caregiver support; (2) three facilitated group reflection sessions; and (3) a written reflection assignment. The programme was developed by an interdisciplinary team in collaboration with patient organisations and public and private stakeholders in PPC. Programme evaluation included participant feedback on relevance, confidence, and applicability to practice.

In 2025, ten groups involving 81 professionals from municipal and specialist services completed the programme. Participants rated the content as highly relevant to clinical practice and reported increased understanding of PPC principles, holistic child and family care, interdisciplinary collaboration, and the importance of caregiver support. The combination of e-learning and facilitated reflection was highlighted as particularly valuable for strengthening confidence and translating knowledge into practice.

Combining e-learning with structured reflection appears to strengthen competence and practical application among Level 2 PPC providers. The programme's accessibility, interdisciplinary approach, and free availability help address an important gap in competence development within community-based PPC services.

Treating the Child, Trusting the Parent: Parent-Reported Benefit of Gabapentin for Pain in Children

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Background and Aims: Children with severe neurological impairment (SNI) often experience medical complexity that leads to a shortened lifespan. They exhibit pain behaviours without an identifiable nociceptive-inflammatory cause. Adjuvant uses of gabapentin have included safely relieving chronic complex pain in children. This N-of-1 trial aims to explore the individual efficacy of gabapentin in decreasing non-nociceptive pain behaviour in children with SNI within a pediatric palliative program.

Methods: A single double-blind, randomized placebo-controlled cross-over (N-of-1) design was used to evaluate effectiveness. Children 0.5-18 years old who had SNI and were assessed for non-nociceptive pain were eligible. Each child received gabapentin for 25 days following a titration schedule up to a maximum dose (60mg/kg/day if <15kg or 45mg/kg/day if ≥15kg) or to clinical effect. On the other cycle they received fully matched placebo. Pain was measured using the Non-Communicating Children's Pain Checklist-Revised (NCCPC-R).

Results: 4 families completed the study. The average baseline NCCPC-R score was 24.25 (range 9-33). Pain scores were lower in treatment than placebo periods in 2 children, equivalent in 1 child, and lower in placebo in 1 child. Only 1 family continued with gabapentin, and reported the trial was highly effective in alleviating pain. Three families discontinued gabapentin with reports of worse or unchanged pain, or uncertainty about whether the drug resulted in decreased pain instead of other factors during the study period.

Conclusions: The efficacy of gabapentin in managing complex pain may be specific to the clinical characteristics of each child. Personalized evidence alone is seemingly insufficient to determine whether families perceive benefit. Further research can seek optimal dosage and pharmacodynamics of gabapentin and explore why parents choose medications for their child to provide a more comfortable childhood for families navigating SNI.

Tiny Frames, Complex Stories: Musculoskeletal Pain and Psychosocial Factors in MOPD Type 2

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Background and Aims: Microcephalic Osteodysplastic Primordial Dwarfism type 2 (MOPD II) is a rare, life-limiting condition with literature focused on vascular complications and limited guidance on musculoskeletal pain. This study aimed to identify effective pain management in a child with persistent severe pain. Although initially presumed neuropathic, a multifactorial aetiology was explored, incorporating musculoskeletal, psychosocial and existential contributors within a paediatric palliative framework.

Methods: Prospective single-case observational study across hospital and hospice settings. Literature review found no evidence on non-vascular pain in MOPD II. Pain assessment used self-reported scores, clinical observation and response to sequential pharmacological therapies. MRI brain/spine and hip/knee radiographs were performed. Data were collected through clinical review and caregiver reporting. Analysis was descriptive; anonymised reporting standards were followed.

Results: Pain was consistently rated 4–5/5 despite no objective distress. Examination showed right hip internal rotation and toe walking; MRI was non-contributory. Paracetamol, ibuprofen, gabapentin, morphine and clonidine showed no benefit. Hospice review localised pain to the hip/knee, suggesting mechanical origin. Imaging showed coxa valga, femoral head uncovering and early physeal fusion. Naproxen produced partial improvement with intermittent pain-free periods. Psychosocial factors, including caregiver burden, adherence challenges, housing constraints and existential stress, influenced pain expression.

Conclusions: Findings support a musculoskeletal origin, with poor response to neuropathic agents and better response to NSAIDs, highlighting risk of misclassification. The case demonstrates how psychosocial and existential stress in life-limiting illness shapes pain experience, reinforcing a biopsychosocial model central to paediatric palliative care. Limits single case. Advise try NSAIDs first line.

Diagnostic Groups and Outcomes in Children Referred to Specialized Pediatric Palliative Care Team

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Background and aim: Children with life-threatening and life-limiting conditions are entitled to specialized pediatric palliative care integrated with ongoing treatment. To improve identification, coordination, and support, the SOL Teamet (Symptom Relief and Quality of Life Team, "The SUN Team") was established at Astrid Lindgren Children's Hospital in August 2023. Differences in disease trajectories and care needs between diagnostic groups make it important to understand the population referred to specialized pediatric palliative care services.

Methods: All children referred to the SOL Team between August 2023 and December 2025 were included. Patients were categorized into neurological diseases, oncological diseases, or other conditions. Data on diagnosis, mortality, follow-up status, and reasons for discontinuation of contact were analyzed descriptively.

Results: A total of 64 children were referred during the study period. Neurological diseases were the largest group (n42), followed by oncological diseases (n17) and other conditions (n5). Thirty children died during follow-up. Among these, 17 had neurological diseases, 12 had oncological diseases, and one had a pulmonary disease. Of the 34 surviving children, 22 remained under active follow-up, while 12 were no longer followed. Reasons included transition to adult healthcare (n2), no further need for specialized palliative care (n7), or family choice to discontinue contact (n3).

Conclusions: Children referred to specialized pediatric palliative care shows differences between the two main diagnostic groups. Neurological diseases were the most common indication for referral and were associated with prolonged involvement, sometimes extending into adult care. In contrast, oncological diseases accounted for a larger share of deaths. These findings emphasize the need for flexible and sustainable pediatric palliative care models adapted to differing disease trajectories, long-term care needs and end-of-life care.

From Lab Inception to Clinical Impact: Building a Research Strategy in Pediatric Palliative Care

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Background: Despite growing recognition of palliative care as a core component of the right to health, the evidence base remains fragmented and research–practice gaps persist. We established an interdisciplinary pediatric palliative care research lab, creating a unique opportunity to build a research and capacity-building program from the ground up. We aimed to design and implement a strategic plan to guide the Lab's growth over the next 10 years.

Methods: We led a structured strategic planning process to define the Lab's priorities using evidence mapping, environmental scans, and extensive stakeholder engagement. In parallel, we established guiding principles, defined core outcomes of interest, and identified priority regions.

Results: The strategy addresses a critical dual need in our field: we will generate new high-quality evidence and build research capacity across diverse settings. We identified five research focus areas: evidence-driven models of care; communication and decision-making; ethical, legal, and social considerations; whole-family wellbeing; and workforce development. Our work is guided by core principles, including authentic patient/family engagement, scientific rigor, trust-based partnerships, prioritizing unheard voices, and a focus on implementation. Initial work spans the US, Sub-Saharan Africa, and the Asia-Pacific region, with plans for global expansion. We then launched a coordinated portfolio of studies aligned with the strategy's priorities. Current projects include developing a new end-of-life referral tool, addressing parent information needs and intervention research (including a national meaning-centered grief therapy trial), alongside collaborative projects in Rwanda, Kenya, Ethiopia, Papua New Guinea and India.

Conclusions: We describe a strategic approach to building a research lab that integrates knowledge generation and capacity building, offering a practical model for strengthening pediatric palliative care research globally.

Clinicians' Training Needs in Transition-Age Palliative Care: An Italian Delphi Study

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Background–Context–Aims: Improved survival of children with life-limiting or life-threatening conditions increased the number of adolescents requiring transition to adult healthcare services. Continuity of care, stronger integration between pediatric and adult settings, and specific competencies are required to start Transition Palliative Care. The study aimed to provide the educational basics of physicians and nurses caring for patients in transition age and recommendations for training development.

Methods: An anonymous multicenter two-round Delphi survey was conducted, involving experienced physicians and nurses who work in hospitals, hospices, and community services. A questionnaire was developed from the comparative analysis of the Italian Society of Palliative Care *Core Curricula* in pediatric and adult settings, integrated with a review of the international literature on Transition Care. The accepted level of consensus was defined as a percentage of $\geq 90\%$ on a 7-point Likert scale (scores of 6–7).

Results: Sixty experts were invited; 35 completed round I and 21 round II. A progressive convergence was observed, with an increased consensus from 57.8% to 60.5% and a decreased non-consensus from 18.4% to 15.7%. High agreement was reached on key competencies, including chronic conditions management (91.4–95.2%) and persistent paediatric diseases in adulthood (74.3–100%). Communication and continuity of care achieved near-unanimous consensus. Ethical and decision-making skills showed strong agreement, while transition timing did not. Lastly transition was supported as guided by clinical maturity rather than chronological age (94.3–85.7%).

Conclusions: The study evidenced the importance of dedicated skills for Transition Palliative Care. Continuous education, multidisciplinary supervision, and shared clinical experiences may improve the quality of care for adolescents and young adult patients. Limitations include limited sample size and predominance of Italian experts.

Clinical Obstinacy and Unreasonable Persistence in Paediatric Care: Theory and Practice

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Background: clinical obstinacy is the initiation of treatments presumed to be ineffective or their continuation after they have become ineffective; it occurs in complex situations and is more dramatic in paediatrics: because the patient is not autonomous, it is more difficult to objectively assess pain and suffering, and the evaluation of the overall benefit of invasive treatments is left to the doctors and parents, who are responsible for pursuing the best interests of the child. In practice, however, parents almost always want to prolong their child's life, while doctors often continue treatment for fear of being accused of actively interrupting life-sustaining treatment. The combination of these two errors detracts from the goal of achieving the best possible well-being for the child.

Methods: literature review, 2020 motion by the Italian government's National Bioethics Committee (CNB), 2023 independent review by the Nuffield Council on Bioethics on disagreements between families and healthcare teams.

We examined the bioethical profiles in 6 cases that gained notoriety in the media for episodes of excessive treatment: Ashley (USA, 2007), Davide (Italy, 2008) and 4 British cases: Charlie (2016), Alfie (2018), Tafida (2019) and Indi (2023).

Finally, we analysed bioethical profiles of 4 cases from our personal caseload; the most controversial is a 13-years-old boy suffering from severe progressive incurable congenital multisystemic condition, whose parents refused palliative kidney transplantation in order to give him a life that may be slightly shorter but of higher quality.

Results: aggressive treatment in paediatrics is widely practised due to the dynamics described above.

Conclusions: the development of paediatric palliative care (PPC) is essential to prevent this: there is a serious lack of paediatric hospices and home PPC in most Italian regions: the CNB published an opinion stating in 2025 that these shortcomings constitute a national emergency for Italy.

The “Quiet Box” – Memory Making in the Neonatal Intensive Care Unit (NICU)

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Background: The death of babies in the NICU is traumatic, certainly for parents but also for the medical team. Team members strive to provide appropriate emotional response to newly bereaved families. The Quiet Box is a memory making tool that can offer such support.

Memory preservation is a psychological, social and cultural concept that acknowledges the existence of the newborn and legitimizes the parents' grief. It allows for creation of tangible and symbolic memories that will accompany the family through their grief journey.

Methods: The "Quiet Box" project was established as a collaboration between the pediatric palliative care and neonatal teams. The box, which is given to parents before they leave the NICU after a child's death, contains the baby's personal items (pacifier, cloth, toys), name-card, ankle identification bracelets, and a hand/foot print freshly made. Lastly, a letter of condolence from the medical and nursing teams is included. The box was designed for ease of assembly, and a cadre of nurses was recruited to serve as facilitators, with one on site at all times. At the time of death, families are approached about the Quiet Box, which is provided upon their permission.

Results: Starting June 2025, seventeen families from diverse cultural and ethnic backgrounds were approached, of them 14 agreed to receive the box. Recipients of the Quiet Box expressed positive reactions, and staff members expressed feelings of meaningfulness by the act of offering the memory preservation tool.

Conclusion: The Quiet Box project provides a therapeutic tool that fosters the creation of positive and meaningful memories for grieving families, by preserving the dignity and memory of a person whose presence was all too transient in this world. Moreover, it holds value for the treating team as a way to continue to support families even after the death of their child. In the future, we will generate data to assess the impact of this special tool on this unique population.

Bringing Paediatric Palliative Care Closer to Home: A Family-Centred Community Model

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Background: Death & dying happen in communities. Families may struggle to access children's hospice & palliative care because of distance, travel, culture & socioeconomic barriers. Professionals outside specialist services often lack knowledge & confidence in paediatric palliative care (PPC). We piloted an inclusive community-based PPC clinic to improve local knowledge & equitable, coordinated access for children, young people (CYP) and families.

Method: Three quarterly clinic days were held. Ten CYP & families were invited; 8 attended, (1 cancellation; 1 did not attend). Reasons for attendance included introduction to PPC or hospice, advance care planning, symptom advice and transition to adult services support. Clinic team included specialist PPC, hospice, community & acute paediatrics, community nursing, transition teams & social care.

Results: Feedback was collected from 3 families by telephone questionnaire & 7 professionals via MSForms. Families understood the purpose of the clinic, felt their goals were met, & valued having the right professionals present. They felt listened to & not rushed, & suggested access to a play specialist so CYP could be supported separately while parents focused on discussion. Professionals valued access to specialist PPC, the multidisciplinary format & learning opportunities. They felt the clinic supported family engagement with PPC & improved family wellbeing following the clinic. Professionals wanted clinics more often, clearer pre-clinic written information & time for case-based learning.

Conclusion: This pilot clinic format in-reaching into the community improves access to specialist PPC & hospice support & reduces barriers such as distance & cost of travel for families. Further work is needed to engage communities facing cultural & religious barriers, refine the model, & define clinical outcomes & patient experience measures using family & professional feedback. We are also working with families to improve feedback methods.

Trust in Pediatric Oncologists Among Parents of Children with Poor Prognosis Cancer

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Background: Trust describes a caregiver's belief that their physician is competent, honest, and committed to their child's wellbeing. It is foundational to therapeutic relationships in pediatric oncology. Oncologists often worry bad news will erode trust, yet empirical data is limited. This analysis aimed to examine parental trust at key timepoints in the illness trajectory of advanced pediatric cancer.

Methods: This analysis examined a longitudinal study in which disease reevaluation conversations between oncologists and caregivers of children with poor prognosis cancer were audio-recorded over 24 months or until the child's death. Parents completed a modified Pediatric Trust in Physician Scale (Pedi-TiPS; 11-items, 5-point Likert; scored 0-100) at baseline and after cancer progression. Analyses included descriptive statistics, interval change, and item-level variance. A case series examined encounters among parents with low trust scores or substantial changes in trust over time.

Results: 46 parents completed baseline Pedi-TiPS inventories; scores skewed toward high trust (median 91, range 32-100). Trust scores did not appear to differ by the type of news (good or bad) parents had just received. 16 parents completed follow-up Pedi-TiPS after cancer progression; scores remained high (median 87, range 52-100). Median interval change was -1 (-11 to +27). Greatest variance was observed for the item about seeking a second opinion. Items related to care and compassion consistently reflected high trust. A case series of 6 parents (12 encounters) highlighted communication practices—including cultural humility, patience, and early prognostic disclosure—may foster trust.

Conclusion: Parental trust in pediatric oncologists remained high and relatively stable, even after receiving bad news. These findings may reassure physicians that sharing bad news does not erode trust. Instead, honest, clear, and timely communication may help sustain, or even strengthen, trust over time.

Point-of-Care Ultrasound in Pediatric Palliative Care: A Look at the Present and Future

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Background and aims: The term POCUS (Point-Of-Care Ultrasound) describes the performance of a non-specialist ultrasound scan at the patient's bedside, as a complement and guide to clinical care. It represents a reliable, non-invasive tool, well-tolerated and accepted by patients, avoids ionizing radiation associated risks and can be performed at home. The speed and simplicity of application, the immediate and repeatable results (with good intra-operator concordance), and the rapid learning curve make POCUS a valuable ally in pediatric palliative care (PPC), but its application is still not uniform across the country, both in hospital settings and especially at home.

Methods and Results: Analysis of POCUS introduction in the clinical practice of our CPP team, which treats approximately 90 families, prioritizing home care.

Results: From March 2024 to June 2026 we performed 104 non-specialist bedside ultrasounds (average: 1/week), 96% of which were chest ultrasounds (diagnosis and monitoring of bronchiolitis, pneumonia, pleural effusions, pulmonary bronchodysplasia, congenital chylothorax, congenital diaphragmatic hernia) and 4 % were bladder ultrasounds and placement of vascular access. This approach has made it possible to avoid hospitalization and manage diagnosis and treatment at home, to the benefit of children and their families.

Conclusions: POCUS is a reliable, cost-effective, practical, and well-accepted tool for pediatric patients and caregivers to aid in the diagnosis, monitoring, and management of numerous issues and procedures. It offers undeniable advantages in terms of comfort and quality of care, particularly for patients in PPCs. It can be used both at home and in hospital and/or hospice settings. This practice should be implemented in terms of frequency and scope, with a concerted effort to train and maintain skills, so that quality of care translates into quality of life, the primary goal of PPCs.

Communication about Values and Goals of Care: A Systematic Review of Educational Strategies

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Background: Aligning care and treatment with the values, goals, and preferences of children with life-limiting conditions (LLC) and their families is key in pediatric palliative care. Communication skills among healthcare providers (HCPs) are considered vital yet are not always perceived as optimal. Although education in advance care planning may improve communication skills, it is not yet structurally embedded in medical curricula. This review aims to examine the components and effectiveness of educational strategies that support communication about values, goals and preferences of children with LLC and their families.

Methods: A systematic search was conducted in the databases PubMed, Embase and CINAHL. Studies, published up to May 2024, describing educational strategies in communicating values, goals and preferences were selected through machine learning 'ASReview'. Components and effectiveness of educational strategies were extracted and analysed using narrative synthesis.

Results: 44 studies were included. Educational programs were mostly face to face and mainly involved providing theoretical knowledge and practicing skills through simulated role-play in parent communication. Specific instructions to discover child- and family values, goals and preferences were limited, with none of the studies explicitly defined what values entail. Listening skills were underemphasized. Evaluation of educational programs relied mainly on self-assessment surveys of knowledge, attitude, and skills, and generally did not assess outcomes in clinical practice.

Conclusions: Education strategies for communicating values, goals, and preferences often explore children's and families' perspectives on a superficial level, with limited attention for exploring values and goals of care. Educational programs should adopt a more child-centred approach that incorporates simulated children and emphasizes listening skills, enabling children and families to articulate their values and goals.

Can I Die from This Disease? End-of-Life Communication Patterns in Pediatric Advance Care Planning

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Background: Discussing the child's end of life (EOL) and EOL preferences is a component of advance care planning and involves exploration of perspectives with children with life-limiting conditions (LLC) and their families to ensure care aligns with what matters most to them. However, healthcare providers (HCPs) may hesitate to discuss the child's EOL due to the sensitive nature of the topic. This study analyses phrasing and EOL communication patterns to explore how this topic is discussed.

Methods: An inductive qualitative analysis of EOL dialogues was performed on the transcripts of audio-recorded ACP conversations with children with LLC, and/or their parents, and their HCP.

Results: Twenty-five ACP conversations between children with LLC (n=5), parents (n=41) and HCPs (n=18) were audio recorded. The child's EOL was addressed in 143 separate EOL dialogues across 24 ACP conversations. Observed initiations to start an EOL dialogue were explicit or implicit EOL-related questions or statements. Responses were categorized as an ongoing explicit or implicit EOL dialogue, a brief acknowledgment, or no response to the topic. In general, explicit initiations (n=85) resulted primarily in explicit EOL dialogues (n=61) whereas implicit initiations (n=58) led to implicit EOL dialogues in about half of the dialogues (n=27). Explicit expressions initiated by HCPs (n=37) or children (n=5) were responded to in most cases in an explicit manner (respectively n=32 and n=4), whereas in 18 dialogues explicit expressions by parents (n=43) were not explicitly responded to.

Conclusion: Explicit EOL initiations tend to start dialogues in which the child's EOL is discussed explicitly, whereas implicit EOL initiations more often lead to implicit EOL dialogues. Insight into EOL communication patterns within the context of ACP can support HCPs in selecting verbal strategies to discuss EOL in a manner that suits the communication preferences of children and their families.

From Training to Implementation: Knowledge Transfer in Pediatric Advance Care Planning

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Background: Advance care planning (ACP) aims to align future medical care with values, goals and preferences of children and their families. Although ACP is valued by stakeholders, its implementation requires specific communication skills, for which healthcare providers (HCPs) report a need for training. This study evaluates ACP knowledge transfer from training to clinical practice.

Methods: 121 HCPs participated in the IMPACT ACP training and were invited to complete baseline and one-month post-training surveys. Knowledge transfer was evaluated through an open-ended question in both surveys by comparing the descriptions of ACP to the internationally accepted ACP definition (Rietjens et al., 2017). Introductions of ACP in audio-recorded ACP conversations conducted by trained HCPs were compared to the international ACP definition to explore how HCPs worded the concept of ACP to parents.

Results: Baseline and post-training surveys were completed by 119 and 93 HCPs, respectively; participants were mainly nurses (n=59) and doctors (n=56) from primary (n=34), secondary (n=31), and tertiary care (n=52). 13 ACP conversations involving 21 parents were recorded. After the training, the definition of ACP was described more thoroughly, while "values" were only described explicitly to a limited extent pre- and post-training. ACP introductions focused on communicating goals and preferences for future care and treatment; underlying values were framed as what matters most to children and families. Notably, documentation and sharing of ACP outcomes were rarely addressed in ACP definitions, but more prominently addressed in introductions to parents.

Conclusions: After the training, HCPs named more aspects of ACP in their definitions. The main goal of ACP to explore underlying values to define goals and preferences, was not consistently reflected in clinical practice. Future training should further support HCPs in translating ACP knowledge into explicit ACP introductions to parents.

A Multidisciplinary Champion Model for Paediatric Palliative Care Capacity Building

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Background and aims: Specialised paediatric palliative care (PPC) services remain scarce in many low- and middle-income countries. To strengthen capacity within existing services, a one-day multidisciplinary PPC workshop was developed for healthcare professionals caring for children with complex neurodisability and other life-limiting conditions. This study evaluated its impact on participant confidence and intended practice change.

Methods: Healthcare professionals attended a one-day Introduction to PPC workshop comprising symptom management, communication skills, family support and referral pathways. Participants completed pre- and post-workshop questionnaires assessing confidence across seven PPC domains using a 5-point scale. Open-ended questions explored challenges in caring for children with complex conditions and intended changes to practice.

Results: Forty-eight healthcare professionals (HCP) attended; 42 completed pre-workshop and 44 post-workshop questionnaires. Participants included occupational therapists, physiotherapists, dietitians and other allied HCPs. Confidence improved across all domains. The largest increases were observed in assessing pain in non-verbal children (2.76–4.20), conducting difficult conversations (2.76–4.14) and identifying children who may benefit from PPC (3.31–4.66). Before training, participants identified caregiver distress, communication challenges and supporting families as the most difficult aspects of care. After training, participants most frequently reported intentions to listen more actively, improve caregiver support and communicate more effectively.

Conclusions: A short multidisciplinary PPC workshop improved self-reported confidence and stimulated intended practice change among HCPs caring for children with special needs. Training local champions may represent a feasible, scalable strategy for expanding PPC capacity where specialist services are scarce, and may help integration of palliative care into routine care.

Validation of an AI-Based Early Detection System for Pediatric Palliative Care Needs in Denmark

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Early identification of children with pediatric palliative care (PPC) needs is essential for timely symptom management, coordinated care, and improved quality of life. However, identification remains challenging, particularly for children with non-oncological and rare diseases because of heterogeneous and unpredictable disease trajectories. Existing screening tools are often time-consuming or limited to short-term mortality prediction. Furthermore, none currently enables large-scale, real-time pediatric screening using artificial intelligence (AI) and electronic health record (EHR) data. To address this gap, the PALLIAKID Early Detection System (EDS), an AI-based algorithm, was developed to identify children and adolescents with PPC needs using routinely collected EHR data.

The aim is to validate the PALLIAKID EDS using retrospective Danish cohort data and evaluate its ability to identify children with PPC needs before clinician referral.

The EDS will be evaluated using our Capital Region Danish PPC cohort. This retrospective cohort study will include approximately 200 children and adolescents aged 0–18 years who were referred to the Capital Region PPC team between 2016 and 2025. EDS performance will be assessed retrospectively at three and six months before clinician referral. Sensitivity will be calculated from the numbers of true-positive and false-negative cases.

It is hypothesized that the EDS will correctly identify at least 90% of children already referred to the PPC service and will identify more than 60% of patients three to six months before referral to the PPC service. The EDS will be run in September and preliminary results will be presented at the Maruzza Conference in 2026.

This study aims to provide the first validation of an AI-based tool for the early identification of PPC needs. If validated, the PALLIAKID EDS may support earlier identification of children with unmet PPC needs and facilitate more equitable and timely access to specialized PPC services.

Pediatric Autonomy vs. Children's Agency: What Is the Difference and How Does It Matter?

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Background & Aims: In children's palliative and end of life (PEOL) care, autonomy and agency are often used to justify whether and how a child or youth ('young person') is integrated as a partner in their care. Yet, robust insight into and opportunities for child and youth engagement in PEOL care and policy remain marginal to date; further, little is known about how autonomy and agency are interpreted, defined, and mobilized to facilitate or hinder young people's engagement.

We undertook a review of the literature to examine how these concepts are used and constructed in children's PEOL care and policy research. This presentation shares our findings and invites dialogue on implications for healthcare teams and researchers.

Methods: Our team, inclusive of two youth co-researchers, conducted a narrative review, drawing on a comprehensive search strategy using four electronic databases. After screening, we retained 52 articles for analysis. Analysis was informed by Childhood Ethics as a theoretical frame.

Results: Findings reveal tensions in how autonomy is applied in children's PEOL research, while agency has more recently been introduced to centre a young person's social position. Though both terms describe where, when, and how young people 'fit' into decisions about their care, the terms were often conflated.

Through a Childhood Ethics lens, distinction between autonomy and agency has important implications for young people's engagement in their own care. We can imagine the shift towards respecting, protecting, and upholding young people's agency (vs. autonomy) offers opportunity to better support young people's authentic engagement to advance quality care and effective policy.

Conclusions: This review highlights key considerations for how autonomy and agency are defined and mobilized in PEOL research. Our presentation aims to prompt critical reflection on their applicability for interdisciplinary healthcare teams and explore areas where further training may be beneficial.

Moral Distress as a Barrier to Perinatal Palliative Care: A Literature Review

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Background and aims: Perinatal Palliative Care (PnPC) supports fetuses and newborns with life-limiting conditions and their families through complex clinical and ethical decision-making. Despite increasing recognition of its importance, access to PnPC remains limited in many settings. Among the factors influencing implementation, Moral Distress (MD) has emerged as a potentially significant but underexplored challenge for healthcare professionals. This study aimed to analyze the role of MD among nurses involved in PnPC and identify factors associated with its development.

Methods: A narrative literature review was conducted on Moral Distress in pediatric and perinatal palliative care settings. Studies exploring professional experiences, organizational factors, and ethical challenges associated with MD were analyzed.

Results: The literature revealed considerable variability in the reported prevalence of MD among nurses working with critically ill neonates and children. Organizational factors associated with increased MD included staffing shortages, high clinical workload, limited access to specialized palliative care services, and lack of shared protocols. Situations involving end-of-life decision-making, uncertainty regarding goals of care, and difficult communication with families were consistently identified as emotionally challenging. Individual factors also influenced vulnerability to MD, while spirituality, personal beliefs, and supportive team environments emerged as potential protective elements.

Conclusions: Moral Distress may represent a relevant barrier to the development and delivery of Perinatal Palliative Care. Addressing organizational determinants, strengthening professional support systems, and promoting ethics-informed education may contribute to staff wellbeing and facilitate wider implementation of PnPC services.

Care, Culture, Complexity: Cultural Humility and Ethics of Care in Home-based PPC

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Background and aims: Home-based paediatric palliative care (PPC) entwines clinical and cultural dimensions. In families of diverse origin, stigma operates as a symbolic frame for illness and as lived isolation, amplified by institutional microaggressions. This study describes the intercultural case-mix of a community-based PPC service and a model integrating cultural mediation with nurses and social workers within a cultural humility framework.

Methods: Retrospective study in a community-based PPC service (04/25–03/26), with longitudinal and cross-sectional analyses. Ethical frame: autonomy, relational non-maleficence, culturally situated beneficence, justice of care, via cultural humility. Subgroup: migratory-background or non-Italian patients aged 1–20 with oncological or complex chronic life-limiting conditions. The cultural mediator was integrated across all phases of care as facilitator of narrative exploration.

Results: Of 114 patients, 74 remained at 31/03/26. Migratory background: 28% (n=32; 18 nationalities, mainly Eastern Europe, Egypt, Pakistan); 64% Italian-born 'second-generation' profiles. Clinical: 78% complex chronic, 22% oncological and 14 deaths (12%), 19 discharges (17%). Diverse religious traditions emerged (mainly Islamic and Christian); stigma recurred in family narratives. No inequalities in access or outcomes were observed in the subgroup. Structured integration of the cultural mediator ensured communicative alignment and continuity.

Conclusions: In high-migration urban contexts, trans-multiculturality is a defining feature of home-based PPC, requiring care models beyond migration-emergency frames. Stigma is a dimension of suffering rather than a barrier. The absence of inequalities suggests provisional substantive equity, to be confirmed prospectively. Cultural humility offers an adequate ethical posture, welcoming narratives and beliefs without reducing them. Structured cultural-mediator integration emerges as essential clinical competence.

An Intra-Hospital Paediatric Palliative Care Support Team in Oncology: A Four-Year Analysis

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Background/Aims: The complexity of paediatric oncological disease requires a multidisciplinary approach. When facing a life-threatening or life-limiting illness, an Intra-Hospital Paediatric Palliative Care Support Team (IHPPCST) provides adequate symptom control and quality of life. This study describes the activity of an IHPPCST at a paediatric oncology reference centre, highlighting the nursing role in case management and community liaison.

Methods: Descriptive analysis of assistential activity from 2022 to 2025, focusing on diagnoses, referral reasons and follow-up data. The team comprises physicians, nurses, social worker, nutritionist, early childhood educator, teacher, psychologist, and spiritual care provider.

Results: 65 children were referred over four years. Progressive disease was the main referral reason (2022: n=18; 2023: n=8; 2024: n=14; 2025: n=15). CNS tumours, haematological malignancies and solid tumours were the predominant diagnostic groups. A 45% increase in shared care cases was recorded. In 2025, 59% of children who died were accompanied by the IHPPCST. Community liaison ensured symptom control, reduced emergency visits, and supported death in the family's preferred setting.

Conclusions: The IHPPCST is essential for promoting symptom control and dignity in paediatric oncological care, enabling evidence-based and family-centred practice, reduction of emergency episodes, caregiver empowerment, real-time sharing of individual care plans, and bereavement support. Nurses play a central role in care coordination, ensuring a holistic and humanised approach centred on the individual needs of the child, adolescent and family throughout the entire illness trajectory.

After Death Reflections: Reflective Practice on a National Scale

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After Death Reflections (ADR), formally known as After Action Reflections, were initially introduced in a tertiary centre following the death of a child in hospital. It was part of a Quality Improvement initiative introduced to the hospital group as part of a research project, with the aim to support professionals caring for children at end of life (EOL). ADRs are now being used all over the country following the death of each child in the community.

The purpose of an ADR is to allow those providing EOL care from primary, secondary and tertiary care to meet (remotely) following the death of a child in their care, and discuss the case under three headings - What went well, What was challenging and What would we do differently next time. This non-debrief forum allows for open reflections of the individual case, and proposes ways to make changes for future cases. A bespoke Facilitation Skills workshop for the Clinical Nurse Coordinator for Children with Life Limiting Conditions (CNC CLLC) group was completed in May 2024, to ensure they, the professionals facilitating the ADRs in the community, have the skills required. This training was provided by HSE Leadership, Learning and Talent Management department.

The national roll out of After Death Reflections following the death of a child in the community is well underway, and was recently added as a Key Performance Indicator (KPI) for the HSE National Office of Palliative Care. These KPIs will be used in line with the National Palliative Care Policy to improve services for those receiving and delivering palliative care.

The feedback from CNC CLLCs regarding both attending and facilitating ADRs is largely positive, with the benefits of ADRs for future cases being noted. Anecdotally, other service users comment on their usefulness.

Formalising Community Care for Children at End of Life - Implementation of HSE Guidance

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In 2020, the Health Service Executive (HSE) published the Clinical governance and operational arrangements for supporting a model of care for children with life limiting conditions towards the end of life in the community in Ireland. This framework formalises established practices by ensuring that every child requiring end-of-life care outside the hospital setting is supported by a designed core multidisciplinary team.

The core team consists of:

- 1) a named paediatrician
- 2) the local community specialist palliative care team (utilising established expertise in end-of-life care)
- 3) the child's General Practitioner (GP)
- 4) an aligned Clinical Nurse Coordinator

Ireland does not maintain regionally based specialist paediatric palliative care teams due to the geographical spread. In lieu of this, the community specialist palliative care teams (CSPCT) deliver end-of-life care locally in collaboration with the core team identified above, supported by the clinical governance and operational policy.

We sought to identify if the structures implemented had helped identification of cases and consequently increased caseload numbers. Secondly, we sought to identify whether the shift from "long established practice" to "defined governance" of this same practice, had changed the location of death tendencies across the group of children in the caseload.

The location of deaths of the children known to the CNC CLLC service in a specific geographical area attached to a tertiary paediatric hospital were reviewed using routinely collected data from 2019 (pre policy) and 2025 (post policy).

The formalisation of the practice ensures that children and their families are offered the option to be cared for at home if that is their preferred place for end of life care, in line with national policy.

Complex Clinical Decision-Making in Pediatric Cardiology and Palliative Care: A Case Report

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Background and aims: Severe neonatal cardiomyopathies raise complex ethical and clinical challenges, particularly when heart transplantation is the only potentially curative option. In infants, limited donor availability, high waiting-list mortality, uncertain prognosis, and risks associated with invasive support complicate decisions on treatment proportionality and the child's best interests. Pediatric palliative care (PPC) may support shared decision-making in this context.

Methods: A single-case study combined with a narrative literature review was conducted. Literature on neonatal cardiomyopathy, pediatric heart transplantation, and treatment proportionality was reviewed.

Results: T was a 2-month-old infant with a prenatal suspicion of congenital heart disease and a postnatal diagnosis of non-compaction cardiomyopathy associated with a PKP2 mutation and multiple ventricular septal defects. After admission to the NICU, the child initially remained stable but progressively required intravenous diuretics and inotropic therapy, with unsuccessful weaning attempts. Given the uncertain prognosis and potential candidacy for heart transplantation, a PPC consultation was requested to support complex decision-making. PPC involvement facilitated discussions on the proportionality of treatment, balancing survival-oriented interventions with QoL, avoidable suffering, and the child's opportunity to experience meaningful family relationships beyond an exclusively intensive care environment. The palliative care team acted as an ethical and relational facilitator, promoting shared goals of care centered on the child's best interests.

Conclusions: Early PPC involvement may enhance ethical reflection, interdisciplinary collaboration, and shared decision-making in complex pediatric cardiology cases characterized by uncertainty. Building a shared ethical climate requires the intentional integration of PPC competencies to support transparent and proportionate clinical decisions.

French Translation and Cultural Adaptation of a Pain-Assessment Scale for Newborns

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Background: Assessing pain in hospitalized newborn remains a challenge. In France, few tools are available, each with their own scoring thresholds, populations (full-term, preterm), and pain types (procedural, acute, or prolonged). However, none are applicable for assessing prolonged pain and sedation in preterm and full-term newborn, regardless of their ventilated status.

Objective: The aim was to obtain a cross-cultural adaptation of the COMFORTneo scale into French and to evaluate the adapted scale.

Methods: The process followed five steps: (1) translation, (2) backtranslation, (3) review by an expert committee, whose members completed a four-point Likert scale to calculate the content validity index (CVI) of each item, (4) pretest with 50 NICU healthcare professionals who completed a five-point Likert scale for CVI calculation, and (5) committee appraisal.

Results: No significant difficulties were encountered during the process, whether it be the back-translation step, the committee review or the pretest. Members of the expert committee were satisfied with their involvement and the global process. The global CVI for the French version was 0.99, with one item with a CVI >0.78, and the others with a CVI of 1.

Conclusion: The COMFORTneo scale was properly adapted into French, with the experimental version achieving semantic, idiomatic, experimental, and conceptual equivalence with a good CVI. Further validation of the psychometric properties of the French COMFORTneo is planned in a larger study.

Rethinking Space in Pediatric Palliative Care: Adapting Hospital Rooms for End of Life Care

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Background: Pediatric palliative care (PPC) in France is provided almost exclusively in the acute hospital setting or at home, as specialized structures such as hospices or PPC inpatient units do not yet exist. However, the current architecture of standard hospital rooms does not offer optimal comfort for families at end of life. In 2025 our PPC team oversaw the remodeling of two hospital rooms in cardiology and neurology to meet these families' needs.

Methods: A team of health care professionals, architects and artists met to discuss the unique needs of these families (space to welcome family members, comfortable bed for parents, desk space, storage space, appealing artwork) as well as the staff (compact and multipurpose furniture that could be moved between rooms depending on where it is most needed). A mobile furniture unit was conceived by the team that included: pull-out bed for two, convertible table, built-in fridge, shelves, and additional storage space. The units were designed with a beach or castle theme. A generous philanthropic donation covered all manufacturing costs.

Results: Feedback from families and healthcare professionals has been highly positive. The artwork, comfortable furnishings, and functional workspace create a more homelike environment, helping families feel more at ease, while staff appreciate the unit's adaptability in supporting family-centred care. During the poster session, we will present our custom-designed units with detailed photographs.

Conclusion: Rethinking hospital room design for end-of-life care is an important step toward creating a safe, comfortable, and culturally responsive environment for patients, families, and caregivers. Adaptable to virtually any hospital room, these units may be of interest to hospital-based PPC teams.

From Complexity to Competence: High-Fidelity Simulation Training in Paediatric Palliative Care

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Background: Paediatric palliative care (PPC) healthcare professionals require advanced clinical, communication and relational skills. However, opportunities to practice complex situations in a safe learning environment remain limited. Simulation-based education may help bridge the gap between theory and clinical practice.

Aim: To develop and explore the feasibility, acceptability and perceived clinical applicability of a high-fidelity simulation-based training program in PPC.

Methods: Phase 1: A multidisciplinary expert panel of six PPC professionals identified priority clinical situations, competency needs and learning objectives.

Phase 2: Feasibility was explored through delivery and participation indicators, while acceptability and perceived applicability were measured using a post-course 5-point Likert scale.

Results: Phase 1: Five core competencies were identified: complex communication, interdisciplinary decision-making, symptom management, end-of-life care, and psychosocial complexity. The intervention consisted of an 8-hour face-to-face course adapted from the Boston Children's Hospital simulation model. Participants completed prior PPC and communication training.

Phase 2: The programme was delivered in three editions involving 27 professionals: paediatricians (n=11), nurses (n=10), psychologists (n=3), social workers (n=2) and one spiritual care provider (n=1). Scenarios addressed referral, psychosocial complexity, symptom control, acute deterioration, care coordination, end-of-life communication, palliative sedation, and home/telephone-based care. Mean scores were 5.0/5 for perceived acceptability and 4.9/5 for applicability.

Conclusions: An expert-informed simulation program was feasible, highly acceptable and perceived as applicable to clinical practice. This educational model represents a promising strategy to translate key PPC competencies into clinical care and supports future research on competency development, behavioral change and long-term clinical impact.

The Incidence of Mucopolysaccharidosis II (I-Cell Disease) in Ireland: A Retrospective Chart Review

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Background and Aims: Mucopolysaccharidosis II (ML II), or I-Cell disease, is a rare autosomal recessive lysosomal storage disorder characterised by early-onset multisystem involvement and high infant mortality. This study evaluates the incidence and clinical characteristics of ML II in Ireland over a 25-year period, with emphasis on implications for early diagnosis and palliative care.

Methods: A retrospective review of clinical records was conducted from 1998 to 2023 across Paediatric Metabolic services in Ireland. Demographic, clinical, and molecular data were extracted and analysed, including ethnicity, consanguinity, presenting features, genetic variants, feeding support, and age and cause of death. Incidence was estimated using national live birth data.

Results: Thirty-four cases of ML II were identified, corresponding to an estimated incidence of 1 in 47,000 live births. Of these, 82.4% (n=28) were from the Irish Traveller community. Consanguinity was documented in 70.6% (n=24) of cases. The GNPTAB c.3503_3504del mutation was the most prevalent pathogenic variant, observed in over half of genotyped cases. The median age at presentation was birth. Common presenting features included dysmorphism, failure to thrive, and congenital heart disease. The median age at death was 1.7 years; most patients died in early childhood, typically from cardiac failure, respiratory infections, or progressive multisystem deterioration. Palliative care involvement was inconsistently documented despite the predictably poor prognosis.

Conclusions: ML II is significantly more prevalent in Ireland than the <1 in 1,000,000 figure cited by Orphanet, with particularly high incidence among the Irish Traveller population. This reflects the influence of consanguinity in a small, endogamous population. Findings support the need for targeted carrier screening, culturally sensitive community education, and development of structured palliative care pathways tailored to the disease's clinical trajectory.

End-of-Life Practices at Pediatric Intensive Care Units in Brazil: A Nationwide Survey

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Background: Data on end-of-life (EOL) care practices and professional preparedness in Brazilian pediatric intensive care units (PICUs) are scarce.

Objective: To describe EOL practices and healthcare professionals' preparedness in Brazilian PICUs.

Methods: National cross-sectional anonymous survey of healthcare professionals working in PICUs across all five regions of Brazil.

Results: A total of 716 professionals participated (61% physicians); 83% were female and 64% had children. Pediatric palliative Care (PPC) services were available in 65.2% of institutions, with marked regional disparities. PPC availability was associated with higher perceived EOL care quality (OR 3.3; 95% CI 2.37–4.59) and greater confidence initiating palliative sedation (OR 1.56; 95% CI 1.03–2.37). Most respondents (83.3%) agreed with withdrawal or limitation of life-sustaining therapies following family agreement, and 73.7% considered palliative extubation acceptable. Professionals younger than 35 years were more likely to feel unprepared for EOL care (OR 1.82; 95% CI 1.28–2.58), while having children was associated with greater confidence (OR 1.75; 95% CI 1.26–2.44). Confidence appeared more strongly associated with age and professional experience than with formal PPC training. Respondents from Northern Brazil were less likely to agree with or feel confident performing palliative extubation (OR 0.33; 95% CI 0.20–0.50). Formal emotional support following patient deaths was absent in 54.3% of institutions.

Conclusions: Despite important advances in pediatric palliative care over recent decades, substantial disparities in PPC availability and gaps in EOL/PC training, institutional support, and emotional resources persist in Brazilian PICUs. Access to PPC and clinician characteristics (role, age, and parenthood) were key determinants of confidence and practice. Structured education, clear institutional policies, and multidisciplinary support are needed to improve EOL care nationwide.

Pediatric Withdrawal of Life-Sustaining Technologies in the Intensive Care Unit

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Background: Approximately 40,000 children die within the United States each year, with a majority of those occurring in an intensive care unit (ICU) and following the withdrawal of life-sustaining technologies (WOLST). Much of the literature focuses on provider and caregiver perceptions related to WOLST, however gaps remain in understanding who these patients requiring WOLST are and their needs from a symptom management standpoint.

Methods: A retrospective chart review was completed at a single-quaternary children's hospital of all children undergoing WOLST in an ICU setting over a 3-year period. Demographics, disease characteristics, and end-of-life characteristics, including medication use 24-hours prior to death were collected.

Results: 348 patient deaths were reviewed, of which 205 were due to WOLST. Patients were mainly male (n=123, 60%) and of Caucasian decent (n=89, 43%) with most patients undergoing WOLST in the PICU (n=106, 52%) followed by the NICU (n=58, 28%) and CVICU (n= 41, 20%). Mean age at death was 4.7 years, and the most common underlying diagnoses were cardiac in origin (n=65, 32%), congenital/genetic disorders (n=39, 19%) and neurologic disorders (n=35, 17%). 75% (n=155) of patients had palliative care (PC) involvement, with the top reasons for consultation including goals of care (n=72, 35%), illness understanding (n=57, 28%), shared medical decision making (n=48, 23%) and communication support (n=44, 22%). All patients received an opioid and a benzodiazepine within 24 hours prior to death, and over half of patients (n=124, 61%) received a sedative medication including dexmedetomidine, ketamine, phenobarbital and propofol.

Conclusions: Pediatric patients undergoing WOLST in an ICU may require extensive symptom management support as evidenced by the high frequency of sedative use during the last 24 hours of life. Further exploration into PC involvement and symptom management may promote a "quality death" for these patients and their families.

What Technology Looks Like in Children's Palliative Care: A "Day in the Life"

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Background and Aims: Technology shapes children's palliative care in ways that remain poorly understood globally. This study explored technology use across the care journey, and examined whether a "day in the life" format could make qualitative findings more accessible.

Methods: Over six months, interviews and written responses were collected from 9 families, 10 clinicians, and 3 technologists across seven countries through children's palliative care networks. Consent procedures including participant information and follow-up support. Findings were synthesised into a representative "day in the life" narrative, drawing on anonymised family and clinician experiences. AI support (Claude, Anthropic) was used to draft, structure and refine public-facing prose under editorial oversight. Authors retained responsibility for research design, quote selection, factual content and final editorial decisions.

Results: Nineteen insights were identified across care delivery, communication and psychosocial support. Priorities included information sharing between families and providers, medical device support, symptom tracking, home monitoring, assistive technology, and medication support. The "day in the life" narrative brought findings together through composite family and clinician perspectives, showing where technology supported access, coordination, confidence, and connection, and where it was limited or inappropriate. Concerns included unequal access, digital literacy, cultural acceptability, sensitive conversations, and potential detriment to end of life care.

Conclusions: This study identifies practical opportunities for technology in children's palliative care while showing that equity, culture, and relational care shape what is appropriate. Limitations include a small sample, no interviews with children, and limited contextual representation. AI-supported composite storytelling may offer a rigorous and accessible approach to qualitative knowledge translation.

Digital Technology in Children's Palliative Care: An Open-access Library for Global Practitioners

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Background and Aims: Children's palliative care (CPC) remains inequitably distributed globally, with digital technologies offering underutilised potential to extend reach. A fragmented landscape of tools, limited practitioner awareness, and scarce peer-reviewed evidence impede systematic adoption. We aimed to

(1) characterise current digital technologies in CPC and

(2) develop an open-access, practitioner-oriented library to support identification, comparison, and uptake of relevant solutions across diverse health system contexts.

Methods: A rapid landscape scan synthesised available evidence on digital tools across four domains: telehealth, symptom monitoring, clinician support, and caregiver support. Findings were structured into a publicly accessible library with tools categorised by function, target users, deployment stage, and context of use, designed to enable ongoing practitioner contribution and iterative refinement.

Results: A diverse array of solutions was identified, including AI-enabled symptom trackers, remote training modules for non-specialist providers, and play-based interventions. Most tools remain siloed or poorly adapted for low-bandwidth settings. Key barriers include limited interoperability, variable data privacy standards, and insufficient implementation funding. Where deployed effectively, digital tools reduced caregiver isolation, enhanced symptom monitoring, and supported continuity of care across settings.

Conclusions: Digital innovation in CPC holds significant promise but is constrained by structural fragmentation and under-documentation. The open-access library offers a global practitioner resource to identify, compare, and integrate effective digital solutions, with an architecture designed for shared learning and iterative improvement across diverse health systems.

Patient Safety in Pediatric Palliative Care: A Scoping Review

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Background/context/aims: Children receiving pediatric palliative care (PPC) are highly vulnerable to safety incidents. However, patient safety is rarely addressed as an explicit domain in PPC. This scoping review aimed to map the available evidence on patient safety in PPC and identify priority areas for clinical practice, service organization and future research.

Methods: Scoping review based on PubMed/MEDLINE, Embase and CINAHL, supplemented by grey literature from relevant organizations. Publications from 2000 onwards in English or Spanish were eligible if they addressed patient safety, adverse events, medication safety, communication, coordination, safety culture or safety-related interventions in PPC.

Results: A total of 1504 records were identified. After removing duplicates, 1392 records were screened; 119 full texts were assessed and 33 publications were included. Evidence was heterogeneous and mainly descriptive, qualitative or consensus-based, with few analytical or intervention studies. Six safety domains emerged: general frameworks, medication safety, transitions and coordination, procedures and medical devices, infection prevention and multidrug-resistant organisms, and safety culture/error management. Medication safety was the most developed domain, particularly regarding polypharmacy, off-label prescribing, drug manipulation and caregiver-administered treatment at home. Other recurrent concerns included hospital-home transitions, communication failures, home procedures, device-related risks, infection prevention and the need to involve caregivers as active safety partners.

Conclusions: Patient safety in PPC is an emerging but underdeveloped field. Current literature describes risks more clearly than solutions. Future work should move from problem identification to evaluation of structured interventions, including medication safety bundles, proactive risk analysis, standardized home-care procedures, caregiver training and safety culture initiatives.

Palliative Sedation in Children Cared for by Pediatric Palliative Care Teams: Multicentric Study

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Background & aims: Palliative sedation is a key intervention for refractory suffering at the end of life, but pediatric evidence is scarce and practice may vary across services. This study aimed to describe its frequency, indications, decision-making process and associated factors in children cared for by pediatric palliative care (PPC) teams in Spain after implementing and standardized national protocol.

Methods: Multicenter observational prospective study including children who died while being followed by PPC teams between April 2024 and March 2025. Participating centers were recruited through the national PPC society. Demographic and clinical variables, place of death, team characteristics and sedation-related data were collected. Descriptive, bivariate and exploratory multivariable logistic regression analyses were performed.

Results: Twenty-three centers provided data on 221 patients. Overall, 43.3% received palliative sedation. Median age at death was 7.2 years (IQR 1.9–14.4) and 55.2% were male. Cancer was the main underlying disease in 47.5%; neurological comorbidity was present in 63.1%. Median follow-up was 4.5 months (IQR 1.1–20.1). The main indication was refractory symptoms (91.7%), most commonly dyspnea (44.7%); 35.1% had more than one refractory symptom. Sedation was usually continuous (91.8%). Midazolam was used first-line in 95.8% and as first or second drug in 99.0%. The PPC team and family participated in decision-making in 93.8% of cases, and this was documented in 81.4%. In the final model, cancer, hospital death and lack of 24-hour care were associated with palliative sedation.

Conclusions: Palliative sedation was frequent among children dying under PPC care and was mainly used for refractory symptoms, especially dyspnea. The findings suggest consistent use of midazolam, relevant family involvement and a possible influence of organizational factors such as 24-hour care.

Beyond Age-based Transfer: A Flexible Framework for Transition in Paediatric Palliative Care

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Background and aims: Advances in medicine and life-sustaining technologies have increased survival among children with life-limiting/threatening conditions, resulting in more adolescents and young adults requiring palliative care. According to the Italian PalliPed study, approximately 16% of children receiving PPC are older than 16 years, highlighting the need for structured transition pathways. Transition is particularly challenging for patients with high clinical complexity, caregiver dependence and social vulnerability. For some young people, transition to adult services may be inappropriate or unfeasible. This project aimed to develop a structured and transferable framework to support transition from paediatric to adult services.

Methods: A multidisciplinary working group developed a shared framework. Evidence, pathways and organizational practices were reviewed to identify key elements supporting continuity of care, family involvement and integration of health and social services.

Results: The framework describes a transition process beginning in early adolescence, including early identification of eligible patients, multidimensional assessment, individualized planning and progressive involvement of adult services. A key feature is a period of shared care between paediatric and adult teams, ensuring continuity of clinical, relational and organizational support. The model recognizes a subgroup of patients for whom transition may require prolonged shared care or alternative arrangements. Patient and caregiver preparedness, family engagement and access to social resources were key factors in outcomes.

Conclusions: Transition in PPC is a flexible, person-centred process rather than an age-based transfer. Multidisciplinary collaboration, psychosocial support and integration of social care resources are essential to reduce fragmentation of care and support young people with complex needs and their families. Special attention is needed for patients outside standard pathways.

Trisomy 18 in Clinical Practice: Perspectives of Healthcare Professionals and Parents

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Background: Trisomy 18 is the second most common trisomy syndrome. Historically, it was considered a condition incompatible with life. Nonetheless, survival rates have increased, leading to significant changes in management guidelines and prompting a re-evaluation of both prenatal and postnatal care. Communicating with parents, sometimes even prenatally, is challenging and requires adequate training. Moreover, healthcare professionals' (HCPs) values and beliefs may influence communication, parental understanding, and subsequent decision-making.

Methods: This descriptive study involved doctors and nurses working in neonatal departments and parents of children affected by trisomy 18. They were asked to complete an anonymous questionnaire developed *ad hoc* by a multidisciplinary team: HCPs were asked on the management of these cases, while parents on their personal experience with the healthcare system.

Results: Of the 180 HCPs who responded, 155 had cared for at least one newborn with trisomy 18. Diagnosis communication was extremely heterogeneous in terms of professionals involved. 41% did not feel adequately prepared to manage such communication. 23% agreed with the definition of trisomy 18 as a condition incompatible with life. Discharge planning and home care were also highly heterogeneous, particularly regarding the availability and involvement of palliative care services. 25 parents responded to the questionnaire. 72% felt that the diagnosis of trisomy 18 was inadequately communicated by HCPs. A palliative care team had been introduced in 28% of cases, and an advance care plan had been developed in 24% of cases.

Conclusions: Trisomy 18 can no longer be considered a condition incompatible with life, but this change has not yet been fully embraced and applied uniformly by HCPs. Communication with is still a critical area which must be improved, as stated in a recent study conducted by our team.

Hope4Kids WP8: Landscape of Palliative Care Education and Training Programs in Pediatric Oncology

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Background/aims: Pediatric palliative care (PPC) is a key component of comprehensive care for children affected by cancer. Training healthcare professionals (HCPs) in PPC is essential to strengthen collaboration between pediatric oncology (PO) and PPC teams, improve serious illness care competencies, and enhance the quality of care provided to patients and families. Within the European Joint Action **HOPE4Kids** (Holistic Oncological Palliative Care for Europe's kids), co-founded by the EU, Work Package (WP) 8 aims to develop a freely accessible PPC education and training program for PO HCPS across Europe.

Methods: A systematic literature review was conducted in PubMed, Web of Science, Embase, and Scopus from database inception to October 2025. Studies were included if they focused on pediatric oncology, palliative care and described an educational or training intervention. Studies not reporting actual training activities or not specific to oncology were excluded.

Results: Of 2,100 records identified, 46 studies met the inclusion criteria. Among them, 21 involved HCPs, 10 focused on nurses and 15 for fellows. Training formats were highly heterogeneous and included online courses, small-group learning, conferences, workshops, videoconferences, simulations, bedside teaching, co-management of clinical cases, debriefing sessions, lectures, and faculty-led educational activities.

The main educational topics were PPC principles, pain assessment and treatment, end-of-life care, parent bereavement, communication skills, quality of life, psychosocial and spiritual care, advance care planning, ethical issues, integration of PPC with other specialties,

Conclusion: Educational initiatives in PPC within PO are diverse and increasing in number. Significant variability exists in training content and delivery methods. This overview will serve to define the topics covered, identify existing gaps, and guide the WP8-HOPE4Kids project.

REACH Nurses: Strengthening the Global Children's Palliative Care Workforce Through Online Education

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Background: More than 96% of children requiring palliative care live in low- and middle-income countries (LMICs), where access to children's palliative care (CPC) education remains limited. Nurses are central to the delivery of CPC but often have limited opportunities for training, mentorship and professional networking. Resources, Education and Awareness in Children's Palliative Care for Health Providers (REACH) Nurses was developed to address this gap, with the Project ECHO model. This implementation study describes the program and its outcomes.

Methods: A descriptive mixed-methods evaluation was conducted among participants. The program included 8 weekly sessions with didactic teaching, case presentations and discussion, reflecting ECHO's "All Teach, All Learn" approach. Sessions were facilitated by nurses and focused on foundational nursing competencies in CPC (Table 1). Data collected included participant demographics, knowledge, attitudes, self-efficacy, and program evaluation.

Results: Three cohorts of REACH Nurses were conducted (Oct 2025-May 2026), with 742 nurses from 51 countries participating. Beyond simply delivering training, the program facilitated global knowledge exchange, peer learning, and mentorship, supported the development of a global community of practice for nurses. Post-course knowledge assessments showed significant improvements in CPC knowledge, while program evaluations had high acceptability and relevance to clinical practice.

Conclusions: REACH Nurses demonstrates a feasible and scalable virtual, nurse-led training model for strengthening the global CPC nursing workforce. Beyond education, the program fostered mentorship, professional networks, and communities of practice which are critical for practice change.

Table 1.

Session # Session Topic

1 Foundations in CPC

2 Pain in CPC

3 Holistic and Specialized CPC

4 Symptom Management

5 Communication and Family Support

6 End of Life Care in CPC

7 Grief and Bereavement Support

8 Ethical Considerations in CPC

Development and Pilot Testing of a Structured Perinatal Palliative Care Program

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Background: Perinatal palliative care (PPC) supports families facing life-limiting fetal or neonatal diagnoses. Despite international recommendations, rigorously developed and evaluated PPC programs remain scarce, resulting in fragmented care across professionals, wards, and care phases. This study aimed to develop and pilot test a structured, evidence-based PPC program supporting families and healthcare providers from diagnosis through bereavement. Funded by FWO.

Methods: A PPC intervention was developed through co-creation with healthcare professionals and bereaved parents. Participatory workshops resulted in a prototype with 5 core components: a dedicated PPC team with a case manager, formal PPC training, a structured PPC pathway, proactive psychological support for families and staff, and team debriefings. A pre-post pilot study assessed feasibility in two hospitals, including prenatal and neonatal cases.

Results: Barriers include delayed recognition of palliative needs and a high burden of inviting parents to participate, particularly in neonatal settings. Continuity of care remained challenging despite case managers due to time constraints to take up the role. Psychological support for parents was often not timely due to staff shortages.

PPC trajectories differ from adults as death was not always the endpoint, some children transitioned out of PPC or into long-term follow-up. The program increased informal staff discussions and awareness of care goals. Structured documentation of trajectories improved ward transfers when consistently applied. Psychological support for professionals was valued variably. Case managers reported enhanced feelings of professional closure.

Discussion: Found facilitators and barriers can inform targeted refinement of existing PPC programs. Findings highlight the need to strengthen continuity of care through clearly defined and assigned roles and protected time for coordination. The program can now be adapted towards large-scale evaluation.

Validation of a Dutch PaPaS Scale: Mixed-Methods Study with Professionals, Parents and Adolescents

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Introduction: Globally an estimated 21 million children could benefit from pediatric palliative care (PPC) yet access remains unstructured. The Paediatric Palliative Screening Scale (PaPaS) supports early identification of PPC needs, yet needs linguistic and cultural validation to ensure applicability. This study aimed to translate and psychometrically validate a Flemish version.

Methods: A multi-phase validation study was conducted in Flanders (Belgium).

- Phase 1: forward-backward translation and expert Delphi study with healthcare professionals (n=17) to establish face and content validity.
- Phase 2: reliability and predictive validity evaluated through a retrospective chart review (n=150).
- Phase 3 (ongoing): Delphi study with parents (n=5) and adolescents (n=5) receiving PPC to assess relevance and acceptability of the items from a service user perspective.

Results: The expert validation showed strong content validity (S-CVI=0.98) and good test-retest reliability (ICC=0.88), with moderate inter-rater reliability. Predictive validity analyses showed a significantly higher likelihood of PPC initiation for higher PaPaS scores. During validation only minor adaptations were required primarily focusing on clarity and contextual relevance. These included refinement of wording to improve clinical interpretability, adjustments in response options, and the addition of an introductory section to emphasize its subjective nature and guide useage over time. Data collection for parents and adolescents is ongoing, final results will be available at the conference.

Discussion: The Dutch version of the PaPaS scale is a reliable and clinically relevant tool to support healthcare professionals in identifying PPC needs. Local adaptation of internationally recognized screening scales is essential to improve equity in PPC access and enable meaningful cross-country comparisons. Ongoing validation with parents and adolescents will further strenghten validity by integrating lived experience.

A Retrospective Audit of Emergency Care Plans in an Irish Tertiary Paediatric Hospital

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Background and aims: An Emergency Care Plan (ECP) is a formalised document for patients with life-limiting illnesses, outlining agreed interventions in the event of a clinical deterioration. Clear documentation is essential. This audit evaluated the prevalence, quality, and accessibility of ECP documentation for patients known to the palliative care service in a tertiary hospital, using a Plan-Do-Study-Act (PDSA) framework.

Methods: A retrospective review of healthcare records was undertaken for all patients referred to the paediatric palliative team over a 12-month period (Plan/Do). Ethical approval was sought. Documentation practices were assessed against local institutional standards, which specify that ECPs should use an approved template, an alert should appear on the patient file, and the plan be disseminated to the emergency department, the ambulance service, and parents/caregivers (Study). Findings from the audit will inform focused education and system improvements (Act).

Results: 69 patient records were reviewed, of whom 26 had an ECP documented. 21 ECPs utilised the most up-to-date documentation template. 15 patients had an electronic ECP alert visible on their healthcare record. Regarding distribution of ECPs, copies were located in the emergency department for only 8 patients, while 21 had documented dissemination to the national ambulance service. Confirmation of parent/caregiver receipt was documented in 5 cases.

Conclusions: This audit highlights variability in the implementation and accessibility of ECPs within a tertiary hospital. Limitations of the audit include the small sample size and single centre design; additionally, patient caregivers were not contacted to confirm receipt of ECPs. Planned quality improvement initiatives including staff education, dissemination of audit findings, and measures to improve accessibility will occur in the hospital. Re-audit following intervention will assess for improvement in compliance with institutional standards.

Enabling Realistic Choice Through a National Paediatric Palliative Care Advisory Service

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Background: Access to specialist paediatric palliative care (PPC) expertise remains inequitable across Scotland, particularly in rural and smaller Health Boards. A national 24/7 Clinical Advisory Service (CAS) was established to provide specialist PPC support to professionals caring for children with life-limiting conditions who are deteriorating or approaching end of life. This evaluation examined the impact of the CAS on national access to specialist support and enabling realistic choice around preferred place of care and death.

Methods: A mixed-method service evaluation used routine CAS activity data, multidisciplinary team records, out-of-hours call data, patient outcomes and clinician feedback collected between November 2024 and October 2025.

Results: The CAS supported 56 children across 10 Scottish Health Boards through weekly national multidisciplinary review and 24/7 specialist advice. Children had high medical complexity, symptom burden and healthcare utilisation. During the evaluation period, 162 case discussions and over 260 out-of-hours consultations were undertaken. Forty-three children died. Preferred place of death was achieved in 91% (39/43) of cases, compared with 70% in the previous year. Hospital deaths reduced from 48% to 30%, while deaths at home increased from 29% to 40% and hospice deaths from 14% to 26%. Clinicians reported increased confidence, improved decision-making and greater ability to deliver care locally, particularly in areas without established specialist PPC teams.

Conclusions: A national PPC advisory model can extend equitable access to expertise and support local end-of-life care. Combining multidisciplinary review with 24/7 specialist advice enabled realistic family choice, increased achievement of preferred place of death and reduced hospital-based end-of-life care. This model offers a scalable approach to addressing geographical inequities in specialist PPC.

Funding: Children's Hospices Across Scotland (CHAS) and participating NHS Boards

Building National Capability in Children's Palliative Care: A Scottish Nurse Education Partnership

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Background: Delivering high-quality care for dying children requires confidence in communication, symptom management and end-of-life care. Opportunities to develop these skills can be limited, particularly for nurses working outside specialist paediatric palliative care services. Children's Hospices Across Scotland (CHAS) and NHS partners developed a national education programme to strengthen knowledge, confidence and competence in care around dying for senior children's nurses across Scotland.

Methods: A multidisciplinary faculty from CHAS and NHS Boards delivered a two-day foundation programme using teaching, case-based discussion, simulation and practical skills training. Content included goals of care, communication, treatment escalation planning, symptom management, confirmation of death, subcutaneous medication administration and professional wellbeing. Participants completed structured post-course evaluations.

Results: Participants reported high confidence following the programme. Mean scores demonstrated strong understanding of goals of care (4.8/5) and their influence on clinical decision-making (4.9/5). Confidence was reported in recognising transition towards end-of-life care (4.7/5), interpreting symptom management plans (4.7/5), understanding advance care planning documentation (4.6/5) and identifying when to seek specialist support (4.6/5). Practical skills sessions were highly valued. Feedback highlighted increased confidence in caring for dying children, the value of multidisciplinary learning and the importance of ongoing simulation and skills refreshment.

Conclusions: This national partnership successfully delivered a standardised paediatric palliative care education programme for senior children's nurses. Early evaluation suggests collaborative education can strengthen workforce capability, improve confidence in end-of-life care and support wider access to specialist paediatric palliative care knowledge across Scotland.

Strengthening Paediatric Palliative Care Capacity in Papua New Guinea

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Background and aims: Provision of childhood palliative care in low- and middle-income countries (LMICs) remains poor due to cultural beliefs, late diagnoses, limited healthcare infrastructure and shortage of trained personnel. Recognising the need for capacity building, a multidisciplinary team of Australian paediatric palliative specialists designed, and delivered, a structured programme to equip PNG healthcare workers with skills in paediatric palliative care.

Methods: Since 2024, an in-person training programme has been co-delivered with local experts. 192 paediatricians, nurses, allied health, and chaplains from 11 provinces have participated. The concept of paediatric palliative care and core topics including pain and symptom management, palliative care approaches and psychosocial support, sessions tailored to PNG's unique challenges and cultures. Effectiveness assessed through post-training surveys capturing session quality, perceived knowledge gains, and priority areas for future education and system strengthening.

Results: Survey responses identify high training satisfaction. Key challenges include cultural acceptance, medication access and appropriate opioid use, multidisciplinary workforce capacity and psychological burden on providers. Participants highlight systemic barriers to implementing learned strategies, including resource and institutional support limitations. Learnings have informed return visits to consolidate work in Port Moresby and deliver face2face education into four additional provinces. The development of culturally appropriate resources and ongoing zoom case-based discussions, learnings and debriefing sessions enhance the work.

Conclusions: This training represents steps toward improving palliative care provision in PNG. Future efforts will focus on developing sustainable programmes tailored to local needs, expanding multidisciplinary involvement, and reinforcing the need for integrating palliative care into paediatric services.

How Many Children Need Palliative Care? a Scoping Review of Systems that Use Administrative Data

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Background & aims: Multiple classification systems exist to estimate population-based pediatric palliative care (PPC) need, producing highly variable results. This creates uncertainty for service planning, resource allocation, and policy development. To understand this variability, we mapped classification systems that use administrative data and examined their conceptual models, coding approaches, and overlap.

Methods: Scoping review following JBI methodology (PRISMA-Sc-R). The review protocol was prospectively registered. Six databases, gray literature, and reference lists were searched through August 2025. Identified systems were organized according to their conceptual and genealogical relationships. Systems containing ICD-10 code lists were standardized to WHO-2019 four-digit format and compared using Jaccard similarity and containment indices, and visualized through diagnostic-specific radar plots.

Results: Twenty-five studies yielded 13 original systems and 12 adaptations, grouped into three families: Life-limiting/Life-threatening Conditions (LLC/LTC), Complex Chronic Conditions (CCC), and Serious Health-related Suffering (SHS). Ten systems were included in quantitative comparisons. Across systems, 8,268 ICD-10 codes were represented (66% of all codes), but only 732 (9%) showed high consensus (shared by ≥ 8 systems), predominantly neoplasms ($n=485$, 66%). Nearly 75% of codes were unique to a single system.

Within-family similarity was high; between-family containment patterns partially reflected expected conceptual and size-based relationships, with each family extending into distinct diagnostic domains reflecting their underlying framework.

Conclusions: Variation across classification systems may explain differences in estimates of PPC need. Understanding these differences is important for planning and policy decisions. Expanding a shared core code set to include relevant non-cancer conditions may ensure broader identification of children who may benefit from PPC.

A Pilot Feasibility Randomized Controlled Trial for Children with Severe Neurologic Impairment

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Background and aims: Children with severe neurologic impairment (SNI) often experience recurrent pain, irritability, and distress (PID) that is frequently under-recognized and under-treated. Specialized pediatric palliative care (SPPC) may improve PID assessment and management, yet clinical trials in this population are lacking. We evaluated the feasibility and acceptability of a SPPC intervention designed to address recurrent PID in children with SNI.

Methods: We conducted a single-center phase II pilot randomized controlled trial at a tertiary pediatric hospital. Children aged ≥ 1 year with SNI and moderate-to-severe recurrent PID, along with one parent caregiver, were randomized (2:1) to intervention or usual care. The intervention combined weekly parent-reported symptom monitoring, automated feedback to families and clinicians, and enhanced SPPC integration focused on recurrent PID. Primary outcomes included feasibility (recruitment, retention, intervention fidelity) and acceptability (parent quantitative and clinician qualitative assessment). Variability and preliminary effect sizes for child pain and symptom outcomes were explored.

Results: Thirty-six child-caregiver dyads were enrolled, including 24 assigned to the intervention. Prespecified feasibility targets were achieved, with 71% recruitment, 83% retention, and 78% overall survey completion rates. Parents rated study acceptability highly (mean 8.6/10). Clinicians reported the intervention was practical to implement and easily integrated into routine care. Exploratory analyses suggested improvement in selected child pain and discomfort measures, although substantial heterogeneity was observed.

Conclusions: A SPPC intervention combining parent-reported symptom monitoring, automated feedback, and enhanced clinical integration was feasible and acceptable for families of children with SNI and recurrent PID. Findings support a larger effectiveness trial to evaluate impact on child symptom burden and family outcomes.

Management of Intractable Cancer Pain in Adolescents and Young Adults using an Intrathecal Pain Pump

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Background: Pain is one of the most common and debilitating symptoms in children with terminal-stage cancer. Even with multimodal and combination drug therapy, achieving pain relief can be challenging. Side effects further impair patients. In such cases, intrathecal pain therapy might be an option, recommended in adults. Nevertheless, this therapy has rarely been used in pediatric palliative care.

Methods: We report retrospectively on the indications, outcomes, and challenges regarding two AYA patients with metastatic recurrences of solid tumors who were cared for by an outpatient pediatric palliative care and an anesthesiology pain management team and for whom an intrathecal pain pump (IPP) was implanted.

Results: Both patients suffered from severe and rapidly increasing pain with both nociceptive and neuropathic components, which was difficult to control. Treatment consisted of opioids, NSAIDs, ketamine, and various co-analgesics. The predominantly localized pain impaired the patients, who otherwise had an acceptable QoL. Using an implanted IPP, pain could be controlled far better, with fewer systemic side effects. Oral maintenance medication could be significantly reduced. The use of adjusted as-needed medication was essential. The filling and adjustment of the IPP could not be performed on an outpatient basis, as the palliative care team was not trained for this. As diseases progressed, treatment of other symptoms became necessary, i.e. additional opioids for respiratory distress.

Conclusions: The use of IPP's is feasible and can be helpful in certain children with cancer pain. Providers should be trained to fill and adjust the pumps on an outpatient basis in order to spare patients in the end-of-life phase the need for transfer to the hospital.

Hope4Kids Work Package 6: Developing International Guidelines for Oncological Paediatric Palliative Care

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Background & aims: Paediatric palliative care (PPC) aims to relieve suffering in children with life-threatening or life-limiting conditions and support their families. Despite improved survival in childhood cancer around 20% of children cannot be cured, highlighting the need for high-quality PPC. Inequalities in access to specialised PPC persist across Europe. The Joint Action Hope4Kids aims to support the development of evidence-based PPC across Europe. Within this initiative, Work Package 6 develops international guidelines on the following themes: advance care planning, shared-decision making, preloss and bereavement care, symptom management, psychosocial care, and models of care.

Methods: International multidisciplinary working groups, including PPC specialists, researchers, guideline methodologists and patient representatives, have been established for each theme. The development process includes guideline mapping, concordance/discordance analyses, identification of gaps, formulation of clinical questions, systematic literature review, GRADE appraisal of the evidence, formulation of conclusions of evidence, and development of recommendations informed by evidence, clinical expertise and patient/family values.

Results: Sixteen PPC guidelines were identified through a literature search and experts in the field. Eight guidelines were evidence-based and included in the mapping process. In each theme recommendations were assessed as concordant, discordant or unique to a single guideline. Moreover, gaps in recommendation areas have been identified. Together, these findings inform the next step in developing clinical questions and guide the subsequent steps of the guideline process.

Conclusions: Developing harmonized European guidelines is a complex process but necessary because of variations and inequalities in PPC and cultural and spiritual specificities across countries. These guidelines will support high quality, family-centred, and transferable PPC.

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From Cloud to Butterfly: Narrative Meaning-Making and Continuing Bonds in Paediatric Palliative Care

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Background: Children living with life-limiting conditions face challenges related not only to physical illness, but also to identity, belonging, hope, and the search for meaning. Narrative and artistic approaches may provide opportunities to explore these experiences through symbolic language, supporting emotional expression and the preservation of relationships throughout the illness journey.

Methods: A reflective experience report was conducted using an original children's literary narrative inspired by experiences commonly encountered in paediatric oncology and paediatric palliative care. The narrative was examined through concepts frequently discussed in this field, including meaning-making, hope, identity, and continuing bonds.

Results: The narrative follows a child who embarks on a journey toward healing after discovering a cloud within her body. Along this path, encounters with supportive companions, challenges, and transformations create opportunities for reflection on illness and personal growth. Thematic analysis identified five interconnected dimensions: (1) meaning-making in the face of uncertainty; (2) hope as a dynamic process rather than a fixed outcome; (3) reconstructing future perspectives and possibilities; (4) preservation of identity beyond illness; and (5) continuing bonds through symbolic representations of connection, memory, and presence. The child's transformation into a butterfly offers a metaphor through which change, legacy, and enduring relationships can be explored without reducing the experience to loss alone.

Conclusions: Children's literature may represent a valuable resource within paediatric palliative care, fostering communication about complex experiences while supporting hope, identity, and relational continuity. Narrative-based approaches may help children, families, and professionals engage with questions of meaning and belonging, contributing to more holistic and person-centred models of care. Funding: Self-funded.

Towards High-Quality Paediatric Palliative Care: from Perceived Quality to Measurable Indicators

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Background: Despite growing international recognition of paediatric palliative care (PPC), there is still limited consensus on how to define and measure high-quality PPC. Existing evaluations often fail to capture outcomes that matter most to children and families. A shared framework for quality measurement is needed to support quality improvement, benchmarking, and research. This study aims to improve PPC in the Netherlands with the development of a national set of process and structure indicators.

Methods: Based on a systematic literature review, the Dutch guideline for PPC, and expert consultation, a candidate list of process and structure indicators was developed. These will be prioritized using a Delphi study among Dutch healthcare professionals in PPC and patient representatives. To validate the process and structure indicators, an interactive workshop will be organized in the Netherlands with healthcare professionals, patient representatives, and parents with lived experience.

Results: The candidate indicator list consists of 66 indicators across 7 domains: (1) multidisciplinary care, (2) physical aspects, (3) psychosocial aspects, (4) spiritual aspects, (5) communication (6) end-of-life care, (7) bereavement.

Delphi rounds will run from July to September 2026. The first results can be presented at Maruzza International Congress on Paediatric Palliative Care. It is expected that a prioritized set includes 5 to 10 process and structure indicators.

Conclusions: Establishing and implementing quality indicators will facilitate consistent evaluation, benchmarking, and tracking of PPC quality over time. This will support the identification of improvement priorities and foster the ongoing advancement of PPC, thereby helping bridge the gap between research and clinical practice.

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A Qualitative Evidence Synthesis of Sleep Disruption in Parents of Life Limited or Complex Children

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Background and Aims: Parents caring for a child with a life-limiting condition (LLC) or complex healthcare needs (CHN) frequently experience significant sleep disruption due to the intensity and complexity of caregiving demands. There is limited research on how sleep disturbance impacts parents' physical, emotional and social wellbeing. This qualitative evidence synthesis aimed to consolidate existing evidence on parental sleep experiences, identify factors contributing to sleep disruption, explore its consequences and examine how recovery may occur, including the role of support.

Search Methods: A qualitative evidence synthesis was conducted and reported in accordance with ENTREQ guidance. A systematic search of three databases, CINAHL, Medline and PsycINFO, was undertaken for qualitative studies, with no time restrictions applied. Quality appraisal was conducted using the Critical Appraisal Skills Programme (CASP) checklist and data was analyzed thematically following Thomas and Harden's approach.

Results: Thirteen studies were included in the synthesis. Four themes emerged: Constant care demands and fear of switching off; no respite from psychological burden and role strain; parental consequences of sleep disruption; and the role of support in enabling sleep.

Conclusion: Parents of children with LLC or CHN experience persistent and significant sleep disruption from caregiving demands. The impact to affect wider family functioning, with physical, emotional and functional consequences. Sleep disruption is influenced by the availability and accessibility of support, which is often inconsistent, fragmented and difficult to access. This synthesis advances previous understanding by identifying a cyclical relationship between sleep deprivation and psychological distress, further disrupting sleep. This review highlights the need for professionals working in this field to help break this cycle by recognizing parental sleep as a vital component of caregiver wellbeing.

Paediatric Trainees' Experiences of Education and Training in Paediatric Palliative Care

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Background: Paediatric palliative care (PPC) is a developing subspecialty in Ireland, yet little is known about the training experiences of paediatric trainees. It is recommended that all healthcare professionals (HCPs) involved in the care of children living with a life-limiting condition (LLC) need to have an understanding of the core principals of PPC and to be able to adopt them appropriately.

Aim: The aims of this project were to identify paediatric trainees current experience of PPC and the education and training they have received to date and subsequently characterise the suggestions for further education within PPC at trainee level.

Methods: A mixed-methods survey with a pragmatic paradigm was distributed to all Irish paediatric trainees (n=259). Quantitative data were analysed using descriptive statistics and subgroup comparisons, while qualitative free-text responses underwent thematic analysis.

Results: Seventy-three responses were collected (response rate 28%, 73/259). Trainees reported routinely encountering children with LLCs but limited confidence in managing complex symptoms, particularly pain, psychological distress, and dystonia. Themes identified included communication challenges, knowledge deficits, management of emotions and baseline understanding of the role of PPC. Trainees education in PPC is minimal prior to commencing their training programmes. 100% of respondents expressed a need for further PPC training.

Discussion: This study demonstrates that paediatric trainees lack knowledge and confidence in managing patients with PPC needs. Respondents expressed a demand for enhanced education and training in PPC, especially in areas of symptom management and communication. Despite trainees reporting emotional challenges when managing these patients, they consistently deprioritised their self-care. Embedding PPC into the paediatric curriculum is essential to adequately prepare future paediatricians in this complex and sensitive area of practice.

A Narrative Review of Education and Training in Paediatric Palliative Care for Medical Professionals

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Background: Paediatric palliative care (PPC) is an evolving subspecialty that equips healthcare professionals (HCPs) with essential skills to support children with life-limiting conditions (LLCs) and their families. While the importance of PPC education is widely recognised, the extent and format of training for paediatric trainees remains unclear.

Aim: This narrative review aimed to analyse current literature on PPC education and training for medical professionals, identify barriers and effective teaching modalities, and highlight gaps to inform future research on paediatric trainees' experiences and learning needs.

Methods: Searches were conducted in PubMed and Academic Search Complete (2004–2024, English only) using key terms relating to “paediatric palliative care,” “education,” and “medical professionals.” Twenty-one relevant studies were included. Both qualitative and quantitative studies were analysed thematically.

Results: Three core themes were identified: general barriers to engagement with PPC, desire for further education in PPC and previously utilised teaching modalities. Key features within barriers to engagement included availability of specialist advice and support and baseline knowledge and experience. Areas for further education included communication, symptom management, treatment effects, and development of advanced care plans. Identified teaching modalities included simulation-based training, mentorship, narrative methods, and structured fellowship programmes.

Conclusions: The literature highlighted that PPC education is insufficient yet highly desired across healthcare disciplines. Current research provides limited information on paediatric trainees. This represents a critical gap, particularly in Ireland, where PPC training opportunities remain scarce. Addressing this gap through a mixed methods study of paediatric trainees' experiences could provide evidence to guide curriculum development and workforce planning.

Healthcare Providers' Attitudes Towards Advanced Care Planning in Children with Medical Complexity

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Background: Advance Care Planning (ACP) is integral to the care of children with medical complexity and life-limiting conditions, supporting communication, shared decision-making, and goal-concordant care. Understanding healthcare providers' (HCP) attitudes and readiness to engage in ACP is essential for strengthening paediatric palliative care practice.

Aim: To explore HCPs' knowledge, attitudes, and perceived barriers to engage in ACP in a local tertiary institution in Singapore

Methods: An online pilot survey was conducted to assess five domains: ACP knowledge and training, attitudes and beliefs towards ACP, perceived ability to communicate an ACP, perceived barriers to ACP creation, and caregiver-related perceptions towards ACP based on a validated questionnaire.

Results: 17 HCPs participated in the survey, comprising physicians (35%), nurses (29%), and medical social workers (35%), most with over 10 years of experience (53%) and prior exposure to ACP (59%). HCPs generally supported early ACP conversations and reported adequate foundational knowledge, though 12% felt uncertain using ACP tools. Barriers to ACP included prognostic uncertainty (59%), limited time (47%), and cultural or language difficulties (35%). HCPs felt denial of illness severity (100%), family-driven decision dynamics (59%), and fear of death (59%) were commonest hindrances to ACP. HCPs cited lack of confidence (94%) and insufficient training (53%) as key obstacles to ACP. HCPs felt ACP support tools (59%), support from subspecialty teams (59%) and clear institutional practices (53%) would help them engage more confidently in ACP.

Conclusion: The pilot survey demonstrated both readiness and barriers among paediatric providers engaging in ACP. Findings will guide survey refinement and inform service-wide ACP development efforts.

Pre-Connection Information Behaviors in Grief Support: Web Analysis of the Grief Support Project

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Background and aims: Online information may serve as an entry to grief support, but behaviors before consultation are often missed. This study examined how users reached, read, revisited, and checked support information.

Methods: Target pages were for bereaved children (/children), parents who lost a child (/parents), and grandparents who lost a grandchild (/grandparents). Preparatory behaviors were defined as online actions before explicit support use: reaching information, checking content/credibility, revisiting, downloading resources, and clicking support pathways. GA4 reports were analyzed for January 1, 2025-April 18, 2026; GA4 BigQuery Export, additional events, and Google Search Console were analyzed for April-May 2026. A privacy policy was posted and cookie/analytics consent was obtained; only anonymized aggregated data were analyzed.

Results: In the long-term period, 2,903 landing-page sessions were recorded; direct entry to the combined target pages accounted for 948 sessions (32.7%). The detailed period identified 282 sessions and 463 page views; direct entry to target pages accounted for 108 sessions (40.1% of identifiable landing sessions). Organic search accounted for 160 sessions (56.7%). Search Console showed 1,614 impressions and 79 clicks (CTR 4.89%); /children led with 42 clicks and 1,133 impressions. Of 282 sessions, 191 (67.7%) ended after one page; however, single-page sessions on /children and /parents averaged 83.9 and 154.2 seconds of engagement. Eighteen later-returning users averaged 3.50 sessions, 6.33 page views, and 350.7 seconds. There were 91 support-pathway clicks by 33 users, 26 downloads by 10 users, and 8 inquiry-form clicks by 5 users.

Conclusions: Users reached relevant pages through search, read them intensively, revisited, and checked resources or pathways. Evaluation should include search, direct entry, prolonged single-page reading, revisits, downloads, and pathway clicks, not only inquiries.

How Do Oncologists Communicate About Prognostic Uncertainty? A Scoping Review of the Literature

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Background and aims: As science advances towards improved cancer survival, there is increased hope and uncertainty about long-term outcomes for patients with cancer. Guidance for how oncologists should communicate about uncertain prognoses is limited, and best practices for how to study this topic are ill-defined. This review aimed to synthesize available evidence on how oncologists communicate prognostic uncertainty, how this communication impacts the patient/family, and how researchers define, assess, and improve prognostic communication in the context of uncertain outcomes.

Methods: We conducted a scoping review following PRISMA guidelines across the following databases: MEDLINE, Embase, Cumulative Index of Nursing and Allied Health, Web of Science, PsycINFO, Cochrane Library, and Social Sciences Full Text. We included original research on communication of prognostic uncertainty with patients with cancer, their caregivers, and/or clinicians as participants including any date, language, or age of participants. Data was extracted to a pre-defined template to synthesize study characteristics.

Results: 41 articles met inclusion criteria. Most studies (32/41, 78%) included adults. Data collection included interviews (15/41, 37%), recorded dialogue (14/41, 34%), surveys (5/41, 12%), and combined methods (7/41, 17%). Most studies used qualitative analysis. Seventeen studies (17/41, 41%) reported strategies (eg best case vs worst case) oncologists used to communicate uncertainty. Twenty-one studies (21/41, 51%) reported the impact of communication to the patient/family, including interpreting uncertainty as a source of hope, desire for guidance, honesty about uncertainty, and control of information exchange.

Conclusions: Very few studies tested communication interventions, though significant themes highlight approaches oncologists used to communicate uncertainty. Opportunities exist to expand research on approaches for the communication of uncertainty.

Supporting Advance Care Planning in Paediatric Palliative Care: The Co-IMPACT C3 Study Programme

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Background: Advance Care Planning (ACP) supports person-centered care in paediatric palliative care (PPC). While use of ACP in PPC is increasing in the Netherlands, its integration into practice remains unclear. The Co-IMPACT C3 study aims to describe the process of ACP and examine the relationship between ACP and family outcomes over time.

Methods: Co-IMPACT C3 is a quantitative observational study comprising two main studies and three complementary sub-studies. Healthcare providers (HCPs) caring for children 0-25 y.o. with life-limiting or life-threatening conditions and parents of children with such conditions are eligible.

1. HCP main study: measurements of ACP in PPC at baseline, six months and two years.
2. Sub-study: cost-analysis assessing time allocation and staff deployment for ACP in a sub-sample of HCPs.
3. Parent main study: repeated measures at baseline, six months and 1.5 year assessing ACP, quality of life (novel tool adapted from CPOS-2), integrated childcare (PREM) and patient-centered communication (PedCOM-8).
4. Sub-study: development and psychometric evaluation of the adapted CPOS-2 for the Dutch PPC context.
5. Scoping review: identification of challenges and strategies of parent recruitment within PPC research.

Results: Data collection is ongoing, with final results expected in 2027. To date, 119 HCPs (sub-study n=23) and 21 parents (sub-study n=47) have been recruited. Preliminary findings show active integration of ACP across participating centres, with at least 122 ACP conversations conducted by HCPs during the first six months of follow-up. Both parents and HCPs identified discussions about potential deterioration of the child's condition as among the most challenging aspects of ACP.

Conclusion: By combining HCP measurements, family outcomes, cost evaluation, instrument development, and recruitment strategies, the Co-IMPACT C3 study will generate evidence to support the integration, evaluation and sustainable implementation of ACP in PPC.

The Pediatric GoWish Together tool as a bridge to Advanced Care Planning

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Background and aims: Pediatric advance care planning (pACP), requires tools that support early, sensitive, family-centred conversations about values and goals of care. This study describes the *Pediatric GoWish Together* tool as preparation for pediatric Advanced Care Planning (pACP) conversations in neonatal pediatric palliative care.

Methods: A single-case clinical practice description was conducted in a pediatric hospice in Italy. Participants were parents of a 2-month-old infant with a severe genetic condition and high fragility, before first discharge home. Validated English-language cards were used with a Pakistani family with good English comprehension. The 45-minute session was led by the psychologist before multidisciplinary pACP meetings. Data included card choices, observations, follow-up interview, and pACP content. Analysis focused on values, meanings and effects on communication and decision-making.

Results: The tool enabled access gradual to complex topics and helped identify shared priorities and individual concerns. Shared themes included the parental relationship, caregiving capacity, financial worries, home discharge, technological support and religion; divergent emphases concerned caregiving-related fears, family autonomy, pACP documentation, care networks and cultural roots. These elements were reorganized around faith, family origins, quality of life, and stability. Clinically, the process clarified care references, family resources, and goals consistent with the child's condition and values. A wish for maximized intervention became more proportionate.

Conclusions: The *Pediatric GoWish Together* tool acted as a bridge toward emotionally and ethically complex conversations. Limitations include the single-case design, exploratory use, and language mediation through English. This case suggests that the tool may support pACP as a shared construction of clinically relevant meanings, improving clarity and family-centred decision-making.

A Child's Voice Across Cultures: Advance Care Planning in Pediatric Palliative Care

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Background and aims: Advance care planning (ACP) in pediatric palliative care (PPC) becomes particularly complex when prognostic uncertainty intersects with cultural differences and language barriers. This study aimed to describe the relational and communicative dynamics emerging during an intercultural ACP pathway.

Methods: A single-case study was conducted in a PPC service. Relevant literature on pediatric ACP (pACP), intercultural communication, child participation, and culturally sensitive decision-making was reviewed.

Results: The patient was a 12-year-old boy with advanced pulmonary fibrosis who arrived in Italy from East Africa for lung transplant assessment. When transplantation was no longer feasible, the team faced the challenge of communicating non-curability and redefining goals of care. The communicative process was complicated by linguistic and relational fragmentation: the child had a different first language from both parents. Although the mother lived with the child in Italy, she had experienced prolonged separation from him for several years before reunification. The father's involvement remained mediated through remote communication. The child explicitly requested to be directly involved in conversations about his condition and future care. Linguistic-cultural mediation proved essential not only for translation, but also for clarifying meanings, family roles, expectations, and emotional positioning within the decision-making process. Video calls and mediated conversations enabled the father's participation. Communication was gradual, direct, and tailored to developmental age and relational context, supporting dignity, trust, and shared understanding despite significant intercultural complexity.

Conclusions: This case highlights how intercultural pACP requires linguistic-cultural mediation and multiprofessional support to enable ethically and culturally meaningful shared decision-making in life-limiting illness.

Developing an Integrative Medicine Care Model for Palliative Patients in a Children's Hospital

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Background: Integrative medicine (IM) addresses physical, emotional and functional needs of children, and is well aligned with the goals of pediatric palliative care (PPC). Most reports about the use of IM for children arise from pediatric oncology and hematopoietic cell transplant units, demonstrating benefit for symptom relief and enhanced caregiver agency. We describe the development of a hospital-wide palliative-integrative care model at a tertiary children's hospital, offering inpatient IM services for children receiving palliative care.

Methods: The care model is based on the extensive experience of a long-standing integrative medicine program (IMP) within the pediatric oncology division. A collaboration between the PPC team and the IMP team created a framework for enhanced support for children with palliative care needs, of varied underlying diagnoses. Referrals are made by the PPC team, and care is administered by IM providers at the patient's bedside on all units, and is documented in the hospital's electronic medical record.

Results: Preliminary data from the first 6 months of collaboration show 51 patient referrals and 15–35 treatments per month. Patients were referred from all Intensive care units (NICU, PICU, PCICU), all general pediatric wards, and pediatric surgery. Bedside interventions include a variety of touch-based therapies, mind-body approaches, and parental guidance. Caregiver feedback suggests high satisfaction, with common requests for repeated visits. IMP providers reported an overall smooth transition to the treatment of new patient populations.

Conclusions: This model demonstrates the feasibility of a hospital-wide palliative-integrative framework within a tertiary children's hospital. We plan to start collecting prospective data regarding the efficacy of this program, and suggest that similar IMP programs can be instituted as a component of PPC in children's hospitals.

Funding is provided by a hospital affiliated non-profit foundation.

Short Lives, Lasting Stories: Documentary Film as a Narrative-Based Educational Intervention in PPC

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Background: Across pediatric palliative care (PPC), clinicians care for children with serious illness and their families amid uncertainty, suffering, and hope. This work requires more than disease-specific knowledge; it demands close listening, thoughtful communication, and relational understanding. Yet structured opportunities to learn these relational dimensions are scarce. Narrative-based education centred on lived experience can address this gap. Documentary storytelling offers a powerful medium, preserving voice, context, relationships, and meaning in ways traditional case-based teaching may not.

Methods: This study explores how clinicians and trainees narrate their experiences of how documentaries, paired with reflection, support their learning. *Short Lives, Lasting Stories* is a short-form documentary series centred on the life and care of a child with a serious illness. The educational intervention pairs an episode with facilitated discussion and written reflection, creating space to engage with stories, consider the relational dimensions of care, and reflect on how narrative may inform practice. Participants will view one episode, engage in a focus group, and complete a prompted written reflection. Caregivers featured in each episode will participate in separate interviews to inform interpretations of the films' educational and relational significance. Data will be analyzed using narrative inquiry.

Results: We anticipate participants will describe key shifts in understanding and perspective-taking.

Conclusion: This work positions documentary storytelling paired with reflection as a novel, relationally grounded educational strategy, but its primary focus is illuminating the internal experience of learning. By capturing how participants narrate their shifts in perspective, this study will reveal how engaging with the everyday realities of serious illness shapes meaning-making and deepens clinicians' understanding of attentiveness, humility, and compassion in practice.

Methadone for Complex Gastrointestinal Pain in Non-Oncological Pediatric Palliative Care

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Background and aims: Children with severe neurological impairment increasingly experience gastrointestinal (GI) symptoms, sometimes leading to nutritional failure. GI pain is poorly characterized and may involve both nociceptive and centrally mediated mechanisms (neuropathic pain, autonomic dysfunction). Guidelines suggest third-line antineuropathic agents under specialist supervision. Methadone, with mu-opioid agonism, NMDA receptor antagonism, and monoaminergic activity, may represent a valuable option. This study describes GI pain phenotypes and methadone response in PPC patients.

Methods: Retrospective study (2012-2025) of PPC patients with neurological impairment treated with methadone for moderate-to-severe pain with GI features. Pain phenotype and response were assessed by proxy.

Results: 15 patients with neurological conditions (mainly cerebral palsy) were included. Three phenotypes: visceral hyperalgesia (n=7), GI dystonia (n=5), feeding-related abdominal pain (n=3). Convergent features: pain on ingestion, nausea/vomiting, abdominal distension, autonomic signs (pallor, sweating, brady/tachycardia), and relief with feeding interruption. All patients had failed prior treatments (analgesics, adjuvants, prokinetics, opioids). Methadone was used as first-line opioid in 30%; route was enteral/oral in 12/15, intravenous in 3. Response rate: 86.7% (13 improved; 1 partial, 1 no response). Benefits included reduced abdominal and feeding-related pain, less irritability, fewer rescues and dystonic episodes, and improved sleep. 8 patients had no adverse events; 5 had mild self-resolving effects or required dose reduction; 1 needed antiemetic therapy. Baseline ECG was available in 6/15.

Conclusions: Methadone appears effective for complex GI pain in PPC patients with neurological impairment. Its multimodal mechanism offers a rationale where conventional therapy fails. Limitations: retrospective design, proxy assessment, small sample. Prospective studies are needed.

Low-dose Methadone for Mixed Pain and Dyspnea in Palliative Care: A Case Report of Cerebral Palsy

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Background and aims Patients with severe neurological impairment often experience a complex symptom burden, including refractory mixed pain and dyspnea, whose management is complicated by multifactorial etiology and comorbidities. Although evidence in pediatric palliative care (PPC) remains limited, methadone, with its multimodal pharmacological profile (including mu-opioid agonism, NMDA receptor antagonism, and monoaminergic activity), may represent a valuable option for refractory pain and, given its opioid effects, a rational choice for dyspnea management.

Methods Case report. An 18y patient with cerebral palsy, chronic malnutrition, multifactorial chronic pain, and restrictive lung disease secondary to neuromuscular scoliosis, presenting with recurrent nocturnal pain crises characterized by crying, distress, and suspected dyspnea. At first evaluation, the patient was receiving low-dose pregabalin, with acute episodes treated with ibuprofen, achieving only partial control. Previous trials with fentanyl, clonidine, and gabapentinoids were discontinued due to marked sedation even at minimal doses, impairing oral intake. The patient was admitted to pediatric hospice for symptom optimization.

Results Given poor tolerability to prior analgesics, methadone was cautiously introduced at 0.025 mg/kg every 12 hours orally. Bedtime paracetamol, hydrozine, melatonin, and non-pharmacological interventions (repositioning, airway secretion aspiration) were added to improve sleep quality and comfort. Treatment was well tolerated, with no adverse events. Significant improvement in pain control (with reduced number and duration of episodes), sleep, and respiratory comfort was observed. Caregivers reported improved comfort and easier care.

Conclusions This case highlights the potential role of low-dose methadone in managing refractory mixed pain and dyspnea in PPC patients with severe neurological impairment. Further studies are needed to define dosing, safety, and indications in this setting.

Methadone in Pediatric Palliative Care: A 14-Year Retrospective Descriptive Study

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Background and aims: Pain in pediatric palliative care (PPC) is often complex, chronic, and neuropathic. Methadone, a synthetic opioid with multimodal action (mu-opioid agonist, N-methyl-D-aspartate antagonist, serotonin-noradrenaline reuptake inhibitor), may benefit patients with refractory or neuropathic pain. Pediatric evidence remains limited. This study describes methadone use in a specialized PPC unit over 14 years, assessing efficacy, tolerability, and prescribing strategies.

Methods: Retrospective study of all patients receiving methadone for moderate-to-severe pain in a specialized PPC unit (2012-2025). Clinical features, indications, administration routes, rotation strategies, efficacy, and adverse events were analyzed. Pain was assessed using self-report or proxy measures.

Results: A total of 36 patients (age 0-23 years, median 11.5) were included; 80.5% in home care. Non-oncological diagnoses accounted for 60% of cases (mainly cerebral palsy) and advanced solid tumors for 40%. Pain was mixed in 86% of cases. Most patients (70%) were opioid-experienced (mainly morphine); rotation was driven by inefficacy or toxicity, with morphine-equivalent conversion ratios from 2:1 to 10:1. Methadone was started as a first-line opioid in 30% of cases. Daily doses ranged 0.2–197 mg; median treatment duration 46 days. Pain improved in 86.1% of patients: reduced intensity, fewer rescue doses, improved sleep and quality of life. Half of patients reported no adverse events; 6 had moderate-to-severe events. No deaths were attributable to methadone.

Conclusions: Methadone is an effective analgesic in PPC for complex and neuropathic pain, including in non-oncological patients, a population underrepresented in the literature. Its emerging use as first-line therapy supports earlier introduction in selected cases. Limitations include retrospective design and inconsistent use of pain assessment scales. Prospective and pharmacokinetic studies are needed to better define dosing in PPC.

Transfusion Management at End of Life in Pediatric Hospice: A Clinical-Ethical Case Report

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Background and aims: Transfusion support in advanced pediatric cancer reflects the tension between clinical appropriateness and ethical proportionality. Red cell transfusions provide limited, transient benefit at end of life; platelet use should focus on bleeding prevention and comfort rather than thresholds. Parents may struggle to distinguish disease-modifying from supportive care, perceiving treatment reduction as abandonment.

Methods: Case report. L., a 15-year-old Ukrainian girl with end-stage acute myeloid leukemia, transfusion-dependent, admitted to pediatric hospice for the last 45 days of life. Context: forced migration from a war zone, language barrier, social isolation, and parental resistance to therapeutic optimization. The case was analyzed from clinical, bioethical, and psychological perspectives using the Four Topics Approach within Italian Law 219/2017.

Results: Red cell transfusions, initially maintained, were progressively discontinued due to lack of effect on asthenia and dyspnea; platelet decisions shifted from thresholds-based to symptom-driven criteria. Parental requests reflected the need to counter deterioration and resist perceived abandonment. The team balanced clinical-ethical appropriateness, patient protection, and symbolic meaning, using transfusions as a bridge toward comfort-focused care. Collaboration with disease specialists reinforced clinical communication and trust. A modulated therapeutic inertia, respecting family readiness, preserved the relationship and enabled acceptance of sedoanalgesia in the critical phase.

Conclusions: Clinical appropriateness and ethical proportionality are dynamic and continuously renegotiated processes. Integrating between palliative care and disease-specific specialists is key to sustain coherent, continuous care. Therapeutic inertia can have relational value as active waiting, creating space for families to process dying at their own pace, without compromising the duty to relieve suffering.

Healthcare Workers' Perceptions of Neonatal Memory Boxes at an LMIC Tertiary Hospital

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Background: Memory-making interventions like memory boxes can comfort bereaved families after neonatal loss and support healthcare workers (HCWs). However, little is known in LMICs about HCW perceptions of its use, particularly in resource-constrained tertiary settings. This study explored HCW perceptions of using memory boxes in neonatal end-of-life care at an LMIC tertiary hospital. To address a lack of connection and personalised counselling, an in-hospital paediatric palliative care service introduced memory boxes for parents at their baby's death to serve as a treasured keepsake.

Methods: This mixed-methods study was conducted across three neonatal wards at a South African tertiary hospital. Anonymous data was collected via electronic and paper self-administered, semi-structured questionnaires. Quantitative data was analysed descriptively using percentages; qualitative responses were organised within a thematic framework.

Results: Out of 24 survey responses (mostly female), three were incomplete but included. Most respondents were registered nurses. Over 50% perceived memory-making as beneficial and were willing to incorporate it into routine practice. Key barriers were staff shortages, time constraints, and limited training, while enablers included the boxes' availability and their ability to provide family comfort and closure. Findings suggest broad support for memory-making despite practical challenges.

Conclusion: HCWs are generally willing to engage in memory-making, suggesting memory boxes are a meaningful, feasible way to strengthen family-centred neonatal end-of-life care. However, findings highlight a need for ongoing, skills-based training to support consistent implementation.

Mobile Units of Healthcare Clowns Empower Palliative Children and Youth in their Home Surroundings

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The World Health Organization frame it like this: *Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family.* But in order to interact with children and youth, it requires an adapted language different from the medical or educational. For thousands of years, art has developed an artistic language, asked questions, wondered about alleged truths and seen the world from new angles. The artistic language creates opportunities for children and youth to express themselves and experience mastery in facing the unknown. Art should not be considered as something extra, but as an or important contributor in pediatric palliative care. As healthcare clowns our main goal is to defend childrens perspective and identity in all circumstances. With our artistic tools we help to reduce anxiety, traumas and stress.

After working as healthcare clowns in hospitals for 25 years we established mobile units in 2018, to visit children and youth in their home surroundings. Our goal is to serve approximately 8500 children, who lives a pediatric palliative life in our country. The children are referred to our organization via local child palliative care teams, advanced home hospital, hospital wards or the families contact us directly.

We empower patients identity through playing, imagination and creating new ways to express themselves, also in end-of-life care. Together with the families we are creating memorable moments that are documented forever. Respectfully we take part in rituals and ceremonies related to the childs death. Our team also support siblings and the childs environment after the child passed away. All children should have the opportunity to play, even when their bodies are changing and we have to find new ways of communicating. Children´s identity should never be synonym with diagnosis, condition or medical treatment. We share our knowledge to a wide range of units, organizations and institutions.

Paediatric Palliative Care and Society: Space to Learn, Time to Change

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Background: In Paediatric Palliative Care (PPC), inequities (compounded by structural inequalities and poor understanding) may act as barriers to delivering holistic and inclusive care, and development of a responsive and cohesive workforce, with implications for staff and patient experiences.

In response to this, the Paediatric Palliative Care and Society (PPCaS) working group was established to foster reflection, learning and action on equity in PPC.

The group's first initiative has been development of a free educational webinar series.

Methods: The webinars featured clinicians, educators, and community voices exploring how personal, structural and global factors shape care.

Webinar topics included: Global PPC, Culturally Sensitive Bereavement Care, Trauma Informed Practice, Deaf Perspectives and Traveller Communities.

Anonymised feedback was collected from attendees after each webinar and this feedback informed ongoing development of PPCaS education and how best to meet the group's aims.

Results:

- Attendees represented a broad range of professional backgrounds: hospice, hospital, community and academic, with varied levels of experience (new – 10+years in PPC).
- >90% of respondents reported intention to apply insights from sessions in their clinical practice.
- >90% felt sessions challenged or refined aspects of their thinking about their practice.
- Qualitative feedback showed attendees valued the webinars for addressing an “unmet need” and facilitating shared learning.

Conclusions: The PPCaS working group was established to support collaborative and creative educational activity centred on equity and inclusion.

The webinar series was well received and prompted reflection on clinical practice across a diverse professional audience.

Initial findings suggest structured educational activities may promote more inclusive and responsive approaches to care.

Further work is required to evaluate longer-term impact, and to develop future educational initiatives expanding equity in PPC.

Finding Joy in Colors: Adolescent Reflections on Art Interventions during Cancer Treatments

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Background/Purpose: Receiving oncology treatments are stressful for adolescents with cancer. Supportive interventions are needed to help adolescents with cancer cope with oncology treatments in the hospital and clinic setting. Distraction techniques using art-making interventions have demonstrated reduced anxiety symptoms during oncology treatments in adult patients with cancer. A need for evidence exists about the impact of art-making interventions upon adolescents with cancer during oncology treatments. This study's purpose was to review shared perspectives by adolescents with cancer on the helpfulness/meaningfulness of participating in an art-making intervention during cancer treatments.

Methods: A pilot descriptive mixed-methods study design guided implementation and evaluation of an art-making intervention for adolescents (aged 11 to 18 years) receiving oncology treatments. Semi-structured post-intervention interviews were conducted approximately 6 weeks after each adolescent completed the art intervention. The adolescents' responses were analyzed using a thematic-analysis approach. Most of the adolescent participants chose to create an art-making color by number picture of a family pet or of a selected interest (e.g., vacation location, flowers, or sport activity).

Results: Twenty adolescent participants were recruited from within a major midwest pediatric-oncology hospital in the US. Interviewed adolescents included 8 boys and 12 girls aged 11 to 18 years with different types of cancer. The analyzed adolescent responses were grouped into the following theme categories: (1) Art Fostered an Effective Form of Distraction, (2) Perceived Benefits of Receiving an Art Intervention, and (3) Suggestions about Future Implementation of Art Interventions for Adolescents with Cancer.

Conclusions: Art-making interventions can provide an innovative, easy, inexpensive, and fun mechanism to foster positive distractions for adolescent patients during cancer treatments.

Development of a National Centre of Research Excellence for Paediatric Palliative Care in Australia

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Background and aims: The Australian Centre of Research Excellence (CRE) in Paediatric Palliative Care (PPC) is a national initiative aimed at improving quality of life for children with life-limiting conditions and their families. Funded through a national grant, it brings together clinicians, researchers and people with lived experience. The CRE aligns with Australia's Paediatric Palliative Care National Action Plan. The CRE aims to identify major evidence gaps, generate high-quality evidence, translate research into practice, and build research capacity through collaboration and consumer engagement.

Methods: In its first year, the CRE has focused on capacity building and establishing a coordinated national network. Priority research areas include identifying key research questions, developing pathways for priority populations, improving communication, and measuring outcomes. Two PhD candidates have commenced, contributing to the future PPC research workforce, and a national research agenda is now in place.

Results: Early achievements include two national workshops (academic writing; clinician-led research) and two webinars on consumer engagement. The network has grown to more than 700 clinicians, researchers and consumers. Research is progressing in stages in different children hospitals and universities around Australia. A James Lind Alliance Priority Setting Partnership is underway to identify key research questions. Additional projects include: developing a model of care for children with cancer; co-designing a culturally safe, community-led care pathway; two advance care planning projects; research on consumer preferences, historical analysis of PPC in Australia; and exploration of legacy-making.

Conclusion: Early outcomes show the value of a coordinated, capacity-building approach. The CRE is establishing a sustainable, collaborative platform to drive impactful, inclusive research and improve care for children and families, contributing to global PPC advancement.

Evaluation of the Paediatric Palliative Care Outreach Collaborative

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Background and Aims: The Electronic Paediatric Palliative Service (E-PPCS Program) is a telehealth program that supports patients living in regional, rural and remote locations of one state of Australia. Our aim was to evaluate the outreach provided by this clinic..

Methods: The RE-AIM Framework was used to evaluate the Reach, Effectiveness, Adoption, Implementation, and Maintenance of the E-PPCS Program.

Families living in regional, remote and very remote areas of Queensland and receiving paediatric palliative care telehealth outreach, and health professionals involved in telehealth consultations were eligible to participate in the evaluation. Participation for individuals receiving or participating telehealth outreach involves completion of surveys at various time points.

Results: This abstract will focus on Parent Survey Responses. To date 18 surveys have been completed (between September 2024 and March 2026). The children have a variety of diagnoses, and in all but 2 cases mothers completed the survey. Half of the patients (50%) had 10 or more appointments with the service.

Patient satisfaction was measured through the modified Fam-Care tool for paediatrics with most respondents being "very satisfied" or "satisfied" in response to the Fam-Care question. Respondents also were in strong agreement that Telehealth made PPC easier to access. Free text qualitative responses were also possible and included comments such as "This team has been super fast to respond to any concerns or make any referrals to other specialists".

Conclusions: It has taken time to collect completed surveys from families. Data suggests that families are satisfied with the care provided by Telehealth and appreciated its convenience, particularly in relation to travel.

Implementation of Family Talk Intervention: Organizational Context Shapes Palliative Care Practice

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Background and aims: The Family Talk Intervention is a psychosocial family-based intervention in six sessions to support families with children when a family member has palliative care needs. Effective implementation is essential to ensure that families are reached. One potentially important area for further investigation is the role of contextual factors and their influence on implementation processes. The purpose of this study was therefore to examine the organizational context and its association with the implementation of Family Talk Intervention among families in which a parent or child is severely ill with palliative care needs.

Methods: The study was part of a larger implementation-intervention hybrid project where Family Talk Intervention was implemented through a structured program in different clinical care contexts: children's hospital, specialized palliative care and adult cancer care. As a part of the implementation, healthcare social workers received education and training in Family Talk Intervention as well as support and facilitation. Two validated questionnaires were used to measure healthcare social workers' ratings of the organizational context and the implementation of Family Talk Intervention.

Results: Higher ratings on three organizational aspects, namely: informal exchanges between individuals working within the organization, social capital (active connections, trust, networking), and culture (the way we do things in the work organization) were significantly associated with feeling more familiar and trusting of Family Talk Intervention and of adequate resources to deliver the intervention.

Conclusions: Informal communication, supportive relationships, and a positive workplace culture can help make the implementation of family-based interventions like Family Talk Intervention more successful. These factors should be encouraged and strengthened during implementation to better support families with children who have palliative care needs.

When “Spirituality” Becomes a Barrier: Understanding Spiritual Needs in Adolescents and Young Adults

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Background: Spiritual care is a key component of pediatric palliative care, yet spirituality may be understood differently across cultures. During the Czech cultural adaptation of Voicing My CHOICES™ (VMC), an advance care planning guide for adolescents and young adults (AYAs), we explored how young people with cancer understand spirituality and spiritual needs.

Methods: Five AYAs aged 18–20 years participated in a focus group reviewing the spirituality section of the Czech VMC translation. Participants included one patient with progressive disease and four survivors in remission. Data were analyzed using thematic analysis.

Results: Participants consistently associated spirituality with religion, prayer, clergy, and church communities. Most initially considered the section irrelevant because they were not religious and therefore believed they had no spiritual needs.

After discussion, participants identified several non-religious concerns they considered important when facing serious illness: meaning in life, hope, death, legacy, relationships, being remembered, and questions about what happens after death. They emphasized that these topics remained relevant despite the absence of religious belief.

Participants recommended reframing spirituality using language better suited to the Czech context. Suggested concepts included inner reflections, care of the soul, philosophical reflection, meditation, and visits to meaningful places. Most participants stated that the word “spirituality” itself discouraged engagement with the topic.

Conclusions: In this predominantly secular cohort, spirituality was initially perceived as synonymous with religion, creating a barrier to engagement. Cultural adaptation suggested that existential and meaning-centered concerns remained highly relevant but required different language and framing. These findings highlight the importance of culturally sensitive approaches to spiritual care and advance care planning for seriously ill AYAs.

Building Perinatal Palliative Care Where Diagnosis Begins: The PeriVision Project

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Background: Perinatal palliative care (PnPC) remains underdeveloped in many healthcare systems. A 2024 review at University Hospital Motol, one of the largest perinatal centers in Czechia, revealed a gap between potential need and access to specialist palliative care.

Results: Between January and October 2024, 73 prenatal deaths (32 early losses, 34 later losses, 7 stillbirths) and 10 neonatal deaths were recorded, representing approximately 83 families with potential palliative care needs. In contrast, only five pregnant women received prenatal consultation from the pediatric palliative care (PPC) team.

PnPC is already well established in the neonatal intensive care unit (NICU), where NICU and PPC teams have collaborated successfully for years. The main unmet need therefore lies earlier in the care pathway, among pregnant women receiving a life-limiting fetal diagnosis.

These findings led to the launch of the four-year PeriVision project in October 2025. The project focuses on education, early identification, and multidisciplinary collaboration. During the first year, a PeriVision Group was established, bringing together professionals from obstetrics, neonatology, nursing, and supportive care. Education in perinatal and pediatric palliative care was initiated, two hospital-wide seminars introduced the project, and mentorship by an international expert was launched. Key referral points, including fetal cardiology, genetics, ultrasound, and MRI services, were identified as priority settings for staff education and early referral.

Conclusions: Our experience suggests that successful development of PnPC should begin where families first receive serious fetal diagnoses. Education of obstetric staff, local champions, and support at diagnostic referral points may facilitate earlier access to palliative care. This implementation model may be transferable to hospitals and countries where perinatal palliative care is still emerging.

From Education to Community: A National Pediatric Palliative Care ECHO Project

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Background: The number of healthcare professionals with expertise in pediatric palliative care (PPC) remains insufficient in the Czech Republic. Inspired by the Pediatric Palliative Care ECHO program developed by the University of Toronto and The Hospital for Sick Children (SickKids), University Hospital Motol launched the first Czech PPC ECHO program in 2023 under the auspices of the Pediatric Palliative Medicine Section of the Czech Pediatric Society.

Methods: We performed a descriptive analysis of program data collected between January 2023 and December 2025, including the number of sessions, live participants, and views of archived recordings. ECHO sessions consisted of expert teaching, case presentations, and multidisciplinary discussion.

Results: Sixteen webinars were delivered on topics including communication, advance care planning, symptom management, ethics, psychosocial support, and end-of-life care. A total of 531 healthcare professionals participated live, with annual attendance increasing from 102 participants in 2023 to 237 in 2025. Archived recordings generated 1,173 additional views.

Participants consistently identified discussion as the most valuable component of the program. Discussions enabled networking between hospital and community providers, strengthened interdisciplinary collaboration, and supported the development of a national community of practice. As the program evolved, more time was intentionally allocated to discussion, reflecting its importance for peer learning, relationship-building, and shared problem-solving.

Conclusions: The Czech PPC ECHO program proved to be a feasible and scalable educational model. Beyond knowledge transfer, it fostered professional networks and collaboration across care settings. Building a connected community of practice may be one of ECHO's most important contributions to improving care for children with life-limiting conditions and their families.

Parental Experiences in Caring for Children with Complex Chronic Conditions during Dehospitalization

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Background and aims: With the increase of children with Complex Chronic Conditions (CCC), the demand for care has an impact on the health and well-being of their families, which can cause stress, sleep deprivation and emotional difficulties for family members. The objective of the research is to evaluate the level of family difficulty regarding hospital discharge and home care, and to identify the feelings experienced by caregivers during the training and dehospitalization process.

Methods: This was a cross-sectional observational qualitative-quantitative study. Eligibility criteria: caregivers of children/adolescents under 18 years of age with CCC who were hospitalized between January-2018/October-2023 and required tracheostomy care and/or home mechanical ventilation. Exclusion criteria: patients with CCC who died, were rehospitalized, could not be contacted. The study was approved by the Research Ethics Committee. Data were collected through a demographic questionnaire and medical record. Statistical analyses: descriptive statistics and linear regression analyses, statistical significance = $p < 0.05$.

Results: The sample of 31 participants. Caregivers had a mean age of 36 years; 93% female, 49% single, 52% had a low socioeconomic status, 71% unemployed at the time of the study, and 84% had left their jobs to care for their children. The mean time dedicated to caregiving: 9 hours/day. Comparison between caregivers' total sleep time (median=5 hours) and the total time devoted to daytime care showed statistical significance ($p < 0.005$). 42% considered the dehospitalization process difficult. 67% reported negative feelings during the dehospitalization process and 33% were positive. Ambivalent feelings were identified in 12% of participants.

Conclusion: Caring for a child with CCC interferes with caregivers' total sleep time. The dehospitalization process is perceived as difficult and family members experience ambivalent feelings throughout the training and discharge process.

Assessment of Palliative Care Knowledge among Multiprofessional Residents

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Background and aims: Training in Pediatric Palliative Care (PPC) is essential to prepare healthcare professionals to provide appropriate care for children with life-threatening conditions. This study aimed to evaluate residents' knowledge of palliative care (PC) before and after their experience with the PPC team.

Methods: This is a qualitative-quantitative prospective study. Inclusion criteria: being a resident and participating of meetings with the PPC team at the university hospital. The study was approved by the Research Ethics Committee. Data were collected regarding personal and academic characteristics, previous experience and exposure to PC, self-assessment of preparedness to provide PC, level of knowledge in PC and the Bonn Palliative Care Knowledge Test. Statistical analyses: descriptive statistics, Chi-square test for paired measures, statistical significance set at $p < 0.05$.

Results: The sample of 20 participants. The mean age: 27 years; 85% female. 55% were pediatricians, 25% physiotherapists, 10% were medical geneticists and 10% social workers. Pre- versus post-experience data with the PPC team showed that 90% versus 55% did not consider themselves prepared to provide care for patients receiving PC. Regarding self-reported, before the experience, 57% rated their knowledge reasonable and 34% inadequate, whereas after the experience, 46% adequate and 37% reasonable. The mean Bonn test score increased from 17 to 19 points. Following their experience with the PPC team, 72% reported that their knowledge of PC had greatly increased. An association was found between the level of palliative care knowledge and the profession of medical geneticists, who demonstrated knowledge classified as appropriate ($\chi^2 = 205$, $p < 0.001$).

Conclusion: Participants' perception of their preparedness and knowledge in PC improved after their experience with the PPC team. Medical geneticists demonstrated an appropriate level of PC knowledge when compared with other professional groups.

Implementation of a Multiprofessional Teaching Outpatient Clinic for Pediatric Palliative Care

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Background and aims: Technological advances in healthcare have increased the survival of children with complex chronic conditions (CCC), expanding the need for early and longitudinal integration of pediatric palliative care (PPC). There is still a scarcity of structured services and studies that evaluate their care, educational, and organizational impacts. This study aims to describe the implementation of a Multiprofessional Teaching Outpatient Clinic for PPC in a university hospital.

Methods: This is a prospective and longitudinal study with a quantitative-qualitative approach. Children aged 0 to 12 years with CCC and an indication for PPC will be included. Data collection: standardized clinical instruments, scales of functionality, symptoms, parental stress, and quality of life, in addition to interviews with family members and portfolios of residents. The data will be analyzed using statistical methods and thematic content analysis.

Results: The implementation of the outpatient clinic began in March 2026, with a multiprofessional team: pediatricians, nursing, psychologist, physiotherapy, social work, and pharmacy. Pediatric residents participate in theoretical activities, outpatient care, and hospital visits. To date, eight children and their families have been assisted. With weekly appointments, it is expected to characterize the population's clinical profile and biopsychosocial symptoms, and evaluate indicators of structure, process, and outcome. Expected outcomes: better symptom control, reduction hospitalizations, strengthening of the care network, and development of ethical, communicational, and technical skills among residents.

Conclusions: The multiprofessional teaching outpatient clinic for PPC has the potential to improve care for children with CCC and their families, promoting humanized and individualized care. In addition, it may contribute to professional training and the production of evidence to support the expansion of PPC care in the health system.

Palliative Care in Lithuanian Neonatal Intensive Care Units: Nurses' Experiences

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Background and aims: Palliative care in Lithuania is still developing, with growing interest in its integration into healthcare. However, palliative care in Neonatal Intensive Care Units (NICU's) remains insufficiently defined. Since nurses play a key role in caring for critically ill newborns and supporting families, this study aimed to explore nurses' experiences in providing palliative care in the Lithuanian NICU's.

Methods: A qualitative study design was used, involving semi-structured interviews with 10 NICU nurses. Data were analyzed using qualitative content analysis.

Results: Four themes emerged from the interviews analysis: **(1)** palliative care in the NICU, encompassing the need for specialised care and principles of palliative care; **(2)** barriers to palliative care implementation, including organisational, environmental and ethical challenges; **(3)** living with death, reflecting nurses' experiences of neonatal loss and end-of-life care; and **(4)** family-centred care, highlighting communication difficulties, parental support needs and continuity of care concerns.

Conclusions: Palliative care was described as an essential component of NICU care for infants with life-limiting conditions, prioritizing symptom management, parental involvement, and shared decision-making, while focusing on relieving suffering and strengthening the parent-infant bond through meaningful moments and memory-making. However, its implementation is hindered by clinical uncertainty, limited guidance, and regulatory gaps. Nurses experience significant emotional challenges when caring for dying infants and their families in intensive care environment. The findings highlight the need for clearer guidelines, psychological support systems, and improved continuity of care, contributing to the ongoing development of neonatal palliative care in Lithuania.

What Matters Most? Parental Experiences of Specialist Paediatric Palliative Care

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Background: Understanding what families value in specialist paediatric palliative care (PPC) is essential for service development. Evaluations often focus on activity and outcomes, with less attention to what parents identify as most important. This study explored parental experiences of a hospital-based specialist PPC service.

Methods: Parental feedback collected between 2020 and 2025 within a specialist PPC service was analysed using thematic analysis. Responses were reviewed iteratively to identify recurring experiences, priorities and areas for service development.

Results: Five major themes were identified. Parents described the importance of compassionate, family-centred care that recognised the child as a person and supported the wider family. Families valued support that enabled them to live meaningfully, create memories and feel confident caring for their child. Continuity of clinicians and trusted relationships were central to positive experiences, reducing the need for families to repeatedly explain their child's condition and circumstances. Parents highlighted the role of specialist PPC in enabling care at home and supporting preferred place of care and death. Despite overwhelmingly positive feedback, families consistently identified the need for specialist advice outside standard working hours, particularly when caring for a seriously ill child at home.

Conclusions: Families value specialist PPC not only for symptom management, but for the relationships, continuity and confidence it provides. These findings highlight the importance of holistic family-centred care, continuity of clinicians and access to specialist support beyond traditional working hours. Future service development should prioritise sustainable models that preserve relational care while improving 24/7 access to specialist PPC advice.

Improving Healthcare Professionals' Knowledge and Confidence in ACP: An Interventional Study

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Background & Aim: Advance Care Planning(ACP) is an important component of pediatric palliative care(PPC) supporting communication about future care preferences and goals between healthcare professionals(HCP) patients and families. This study aimed to evaluate HCP knowledge of ACP and their confidence in conducting ACP conversations within a multidisciplinary team in a Danish pediatric hospice.

Methods: A pre-post intervention study was conducted at a pediatric hospice in Denmark. Thirteen HCP completed anonymous questionnaires immediately before and after an educational intervention consisting of an ACP presentation and role-play exercise. The study adhered to the Declaration of Helsinki. Informed consent was obtained; GDPR was not required. Data are analyzed with descriptive statistics and results are presented as raw numbers and percentages. Despite guaranteed anonymity the small sample size may have increased social desirability bias as participants might have felt identifiable.

Results: Confidence in conducting ACP conversations increased following the intervention. Before the session one participant(7.7%) strongly agreed that she felt confident conducting an ACP conversation compared with eight participants(61.5%) after the intervention. Knowledge was also improved: While nine participants(69.2%) agreed they knew the central elements of ACP before the intervention eleven participants(84.6%) strongly agreed that the presentation had increased their ACP knowledge.

Conclusions: The educational intervention was associated with increased self-reported confidence and knowledge regarding ACP. These findings suggest that targeted education and role-play may strengthen ACP competencies among pediatric hospice professionals even among those with prior knowledge of ACP. All the subjects in the study have had previous training in PPC prior to the intervention some up to ten years. A different level of experienced HCP and a larger sample size could have influenced the results.

Implementation of an Individualized Perinatal Palliative Care Plan

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Background: At Karolinska University Hospital, a small number of fetuses are diagnosed annually with life-limiting conditions, and some families continue the pregnancy. Early structured engagement is essential for coordinated perinatal palliative care and family-centered decision-making.

Aim: To describe the implementation and clinical experience of an individualized perinatal palliative care plan.

Methods: This clinical implementation study describes a five-year experience of an individualized perinatal palliative care pathway. Families met with a multidisciplinary team at the fetal medicine unit. In collaboration with parents, an individualized care plan was developed including birth preferences, cultural and religious considerations, neonatal and end-of-life care, memory-making, funeral arrangements when relevant, and bereavement support. The plan was documented in the maternal record and shared with involved healthcare providers.

Results: Around 5–6 families per year received a care plan. The plans documented parental wishes and improved communication and coordination between obstetric, neonatal, and palliative teams. Families received structured information about psychosocial and medical support services. The approach supported continuity of care, alignment with family preferences, and opportunities for memory-making and meaningful time with the child. Follow-up conversations after death provided bereavement support and reflection.

Conclusion: Implementation of an individualized perinatal palliative care plan is feasible and supports coordinated, family-centered care. It improves communication, ensures documentation of parental wishes, and supports continuity and bereavement care. It may also enhance families' sense of continuity, involvement, and security.

Developing National Guidelines for Paediatric Palliative Care services – The Singapore Experience

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Over two decades, paediatric palliative care (PPC) in Singapore grew organically out of specialist paediatric oncology and community hospice services.

In January 2024, a workgroup was commissioned by Ministry of Health, Singapore to produce national guidelines for PPC services that includes a self-assessment workbook.

Ten members from various sectors & practice disciplines met regularly over 14 months Feb 2024 to Apr 2025.

The approach taken and insights gained are shared here.

Methods: Work began with a search for international best practice guidelines in either English or Chinese. Collated material were analysed thematically to organise diverse findings into broad domains. Individual domain data were interrogated within small groups to formulate service standards. Next, meaningful yet feasible indicators were shortlisted by the entire group over several consensus-based meetings.

Culture, care context, and patients, parents & professionals perspectives underpinned final guidelines and indicators.

Results: The five key domains and 25 structural, process & outcome indicators:

Care of the Child: Holistic needs assessment & management; Processes for working & communicating across settings and disciplines

Care of the Family: Meeting family's needs; Effective communication

Care of the Provider: Team training; Ethics support

End of Life Care: Recognise, anticipate & manage symptoms; Memory making

Bereavement care: Grief & bereavement support

Full guidelines and workbook <https://www.singaporehospice.org.sg/e-library/resources/national-palliative-care-qi-programme-natpallqi/>

All 4 of Singapore's PPC services (hospital, hospice, homecare) successfully completed a first audit cycle (Jun-Aug 2025), confirming the indicators were relevant and feasible to audit.

Conclusions: These pragmatic yet aspirational guidelines reflect a collective national vision and commitment to quality care; while the accompanying workbook highlights areas of excellence and opportunities for improvement.

Suffering, Grief and Hope in the Context of the Dying of Children

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Over the years, I have come into contact with hundreds of seriously and terminally ill children and their families, and I have strived to find ways to help these children and their loved ones.

Sick children and their parents often confided in me in private, describing the difficulties they face—as well as the relief brought by things that, from an outsider's perspective, seem like small matters. The outside world's perception of these families' needs does not always align with how they themselves perceive their situation.

In my doctoral thesis, I therefore decided to closely examine the authentic testimonies of families and those who help them.

The aim of the research was to map the landscape in which the loss of a child occurs: I sought to identify sources of suffering and ways to potentially alleviate it, as well as sources of hope.

The research component of my work was conducted in the form of unstructured and semi-structured narrative interviews, specifically with parents and siblings of seriously ill children, with bereaved parents and siblings, with healthcare professionals, as well as with funeral service staff and crematorium operators. I knew all the respondents personally. Their authentic accounts provide deep insight into their personal experiences

The following themes emerged repeatedly:

- Ethical implications of informed consent
- The importance of the spiritual dimension—regardless of religious affiliation
- More space for play during illness.
- Contradictory approaches to pain
- The importance of bereaved parents' contact with their deceased child's body
- The importance of parents' active role in preparing and organizing the farewell (funeral)

Among the practical conclusions of my work are recommendations for best practices, which I would like to present in my submission.

Friendly Fire – Is Paediatric Palliative Care Always the Knight in Shining Armour?

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The topic of death and dying has become rather trendy in the past couple of years – and paediatric palliative care is no exception.

Too much inappropriate attention, however, may be equally detrimental as avoiding the topic.

There is a growing number of studies focusing on paediatric palliative care from medical, nursing, psychological, social and spiritual perspectives. The research is of mixed quality and doesn't necessarily identify real problems and result in better understanding of what the families need and in better care for them.

Multidisciplinary palliative teams are being formed, consultants in ethics involved, casuistries shared – and as each subject has to justify its own existence to maintain funding, the „body of evidence“ keeps swelling. And, in the process, the kids and their families are being both helped and exploited, both quoted and unheard, both pampered and disempowered.

German linguist Uwe Poerksen came up with the concept of „plastic words“ in late eighties: he discovered that certain words, through migrating between the vernacular and the expert spheres, gradually lose their precise meaning and start deriving their power from positive societal connotations. They then act as modules that can be mutually combined to create new social realities and to identify new social needs that only experts can fulfill.

In my submission, I intend to show that even the words „ethics“ and „palliative“ are sometimes being used as such plastic words, making the whole field of paediatric palliative care rather muddy and somewhat difficult to navigate. I want to elaborate this on some practical cases where the child and the family were almost imperceptibly deprived of the free space they needed to maintain their hope and to interpret their situation as subjectively meaningful.

Parental spirituality changes following the loss of a child: A nationwide study

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Background and aim: The loss of a child is life-changing for affected families. Spirituality can encompass both religious and non-religious ways of understanding and relating to life and death. The aim of this study is to gain an understanding of how parents perceive that their spirituality has been affected after the loss of a child, an area that remains underexplored in previous research.

Methods: A nationwide cross-sectional questionnaire study was performed involving parents who had lost a child due to cancer 1-5 years earlier. Parents were identified through the Swedish Childhood Cancer Registry and the Population Register at the Swedish Tax Agency. Data origins from written responses to the question: "Has your faith or outlook on life been affected by the loss of your child? Data was analysed using reflexive thematic analysis.

Results: 77 parents responded to the open-ended question, 63% being mothers. The analysis resulted in three themes. The first "Perceived injustice and anger towards a god" describes bereaved parents' emotional contradiction between the existence of a good God and their child's death, sometimes leading to anger, among both religious and non-religious parents. The second, "Hope for continuing relations with the child in an afterlife," reflects how belief in reunion brings comfort and hope. The third "Transformed views on life" captures changes in perspective, including a deeper appreciation of life while for others, a loss of meaning and increased pessimism.

Conclusion: The boundary between life and death was not always experienced as absolute; instead, relationships with the deceased could continue in meaningful ways. The need to articulate personal forms of spirituality, and to receive support in this domain, points to a largely neglected area in clinical practice. This highlights the importance of healthcare professionals engaging with patients' existential and spiritual concerns, regardless of whether these are framed in religious terms or not.

Child-Specific Bioethics: A Rapid Review of Pediatric Palliative Care Ethics Guidelines

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Background and Aims: Pediatric palliative care is increasingly recognized as an established practice yet less than ten percent of children who need it access it worldwide. Contributing to this gap is an absence of pediatric-specific bioethics frameworks to guide the care of dying children. Because philosophies influence ethical care provision, the purpose of this review was to critically examine the international, scholarly literature on the ethical content of pediatric end-of-life care guidelines to ascertain what pediatric ethics approaches are used to guide the care of dying children.

Methods: A rapid review of international, scholarly literature was undertaken from September 2024 to April 2025. Documents were mapped for the presence of pediatric specific bioethics frameworks, care guidelines, ethical approaches, principles and values. Records were identified according to country, population, holistic care, child-centricity and pediatric, family, and ethicist involvement in ethical decision-making. Nineteen records were included. Findings were tabulated for synthesis and with narrative analysis.

Results: No pediatric-specific bioethics framework was identified. Although most ethical approaches focused on children, they relied on prevailing adult -centred iterations of principlism, care and relational ethics and single or matrix-based principal accounts.

Conclusions: Care for dying children needs to be consistently grounded in child philosophies. Expanding access to pediatric palliative care requires ethics education research toward pediatric-specific pedagogies and bioethics frameworks to support consistently, ethically robust, holistic, and child-centered care and to improve access across clinical, international and interdisciplinary settings.

Navigating Loss and Sexuality: Fathers' Experiences During Serious Illness and the Death of a Child

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Background and Aims: Sexuality is a fundamental but often neglected dimension of parental experience in pediatric palliative care. While parental grief has been widely studied, fathers' sexuality during a child's serious illness and after the child's death remains largely unexplored. Cultural norms around masculinity and care may further silence fathers embodied and sexual experiences. This study aims to explore how fathers experience and make sense of their sexuality in the context of serious illness and the death of a child.

Methods: The study used a phenomenological-hermeneutic design with semi-structured interviews with three bereaved fathers. Interviews focused on sexuality, intimacy, embodiment, loss, and meaning-making. Data were transcribed verbatim and analysed thematically.

Results: The child's illness and subsequent bereavement profoundly shaped fathers' experiences of sexuality, which often receded into the background as their energy became oriented toward care and survival. After the child's death, sexuality did not return to its former state but became intertwined with grief, bodily numbness, longing, and vulnerability. Sexual desire could feel absent, fragmented, or ambivalent. Intimacy within couple relationships was shaped by differing grieving styles, leading to both distance and moments of closeness. Over time, some fathers described a shift in how they understood sexuality from performance and desire toward presence, connection, and meaning.

Conclusion: Fathers' sexuality in the context of pediatric palliative care emerges as profoundly reshaped rather than simply diminished. Through illness and bereavement, sexuality becomes intertwined with grief, bodily vulnerability, and altered forms of intimacy. Greater clinical awareness of fathers' sexual and embodied experiences may support more holistic, family-centred palliative and bereavement care.

Factors Facilitating and Hindering the Implementation and Integration of Pediatric Palliative cCare

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Background: Pediatric palliative care (PPC) aims to improve quality of life for children with life-limiting or life-threatening conditions and their families. Despite international recommendations, PPC remains underdeveloped in many healthcare systems. This study aimed to identify factors that facilitate or hinder the implementation and integration of PPC and specialized pediatric palliative care teams (SPPCTs) within pediatric care.

Methods: An inductive literature review was conducted. Peer-reviewed studies published between 2013 and March 2024 were identified through searches in PubMed and CINAHL. Eleven studies met the inclusion criteria and were quality assessed using the Caldwell framework. Data were analyzed using Braun and Clarke's thematic analysis.

Results: Two themes and six subthemes were identified. The first theme, Stakeholders' perceptions of palliative care, highlighted limited knowledge, misconceptions, and fear associated with palliative care as major barriers. The second theme, The importance of specialized pediatric palliative care teams, emphasized interdisciplinary teamwork, accessibility, collaboration, and clear referral pathways as key facilitators. Lack of knowledge among healthcare professionals was the most frequently reported barrier, while interdisciplinary teamwork was the strongest facilitator of successful integration.

Conclusions: Knowledge deficits and misconceptions about palliative care remain major obstacles to integration within pediatric healthcare. Education, increased awareness, and accessible interdisciplinary palliative care teams may improve implementation and access to care. Although based on studies from diverse healthcare settings, the findings provide guidance for developing integrated pediatric palliative care services and strengthening support for children with palliative care needs and their families.

Wanting to Provide Pediatric Palliative Care but Lacking the Conditions to Do So

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Background: Pediatric palliative care aims to improve quality of life for children with serious illness and their families. During the development of a pediatric palliative care team in Sweden, focus group interviews were conducted to explore healthcare professionals' experiences and support needs.

Aim: To explore healthcare professionals' experiences of pediatric palliative care and their perceived support needs during the development of a pediatric palliative consultation team.

Methods: A qualitative study using focus group interviews and thematic analysis according to Braun and Clarke. Seven focus groups from different pediatric settings were included. Participants included nurses, physicians, social workers, hospital chaplain, pedagogues and nursing assistants.

Results: Three themes were identified: Quality of life as a central but challenged focus, Lack of shared understanding and communication in complex care situations, and A need for support, structure and accessible palliative expertise. Participants described quality of life as the core goal of care, encompassing physical, psychosocial and existential dimensions. However, organizational barriers, communication difficulties and lack of continuity limited the ability to provide care aligned with this goal. Participants described ethical dilemmas when balancing treatment and quality of life. Across professions, participants shared similar goals and concerns while contributing complementary perspectives, highlighting the importance of interdisciplinary collaboration and accessible palliative support.

Conclusions: Healthcare professionals expressed a strong ambition to provide pediatric palliative care focused on quality of life, while experiencing insufficient conditions to do so. The findings highlight the importance of interdisciplinary collaboration and accessible pediatric palliative consultation teams. Funded by Regional Cancer Centre Stockholm Gotland

Palliative Needs of Adolescents & Young Adults with Life-Limiting Conditions: A Systematic Review

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Background and Aims: Adolescence and young adulthood is characterised by complex developmental and psychosocial changes. The diagnosis of a life-limiting condition adds complexity and stress to this already turbulent period of life. Provision of developmentally appropriate palliative care to this group necessitates an understanding of the palliative care needs specific to this group. The aim of this study was to establish what evidence exists about the palliative care needs of adolescents and young adults with a life-limiting condition (both cancer and non-cancer conditions).

Methods: This systematic review was carried out according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) guidelines. Six databases were searched from time of inception until 18th December 2025. The databases searched included Pubmed, Scopus, CINAHL (EBSCO), Ovid MEDLINE, PsycINFO (EBSCO) and the Web of Science Core Collection. Articles were screened and extracted. Key themes were identified within and across articles.

Results: In total, twelve articles (nine qualitative and three quantitative studies) were included. Nine of the included studies focused on adolescents and young adults with cancer, while the remaining three studies focused on non-cancer conditions. Analyses generated five themes: (i) Shared core palliative care need domains, (ii) Parent and peer relationships, (iii) Normalcy, (iv) An adapted approach to communication and decision making, and (v) Continuity and coordination of health services.

Conclusion: This systematic review outlines the evidence on palliative care needs specific to adolescents and young adults with a life-limiting condition. These findings will inform the advancement of developmentally appropriate palliative care supports for this group.

Listening to Their Voices; Needs of Adolescents & Young Adults Known to Specialist Palliative Care

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Background: There is international recognition of the need for developmentally appropriate palliative care provision to adolescents and young adults with life-limiting conditions. To date research on the palliative needs specific to this group has been limited.

Research Question: The aim of this study was to explore the palliative care needs of adolescents and young adults with a life-limiting condition under specialist palliative care services in Ireland.

Methods: This study utilised semi-structured interviews with adolescents and young adults and their parent/trusted person. Interview templates exploring palliative needs were developed using key domains of palliative care, namely; (i) physical (ii) psychological (iii) social, and (iv) spiritual needs. Questions on communication preferences and service provision were also included. Participants recruited were; (i) referred to hospital-based specialist palliative care services (ii) aged 13-24 years (iii) deemed medically stable (iv) considered low risk of distress. Key codes from these interviews were analysed to produce themes, using reflexive thematic analysis.

Results: Nine adolescents and young adults and their parent/trusted person completed interviews. Analysis revealed aspects of care that are of particular importance to these young people and are reflective of their developmental stage. Themes included (i) relationships with parents (ii) developmentally adapted communication and decision making (iii) identity & normalcy (iv) spirituality and, (v) a reticence to reveal certain information.

Conclusion: Adolescents and young adults have distinct palliative care needs that differ from those of both younger children and older adults. The findings of this study highlight the priorities of this group and can inform the delivery of more effective, tailored palliative care services.

Adolescents & Young Adults with Severe Neurological Impairment in Specialist Palliative Care

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Background: Improving our understanding of the palliative care needs adolescents and young adults with a life-limiting condition is pivotal to the optimisation of palliative care provision to this group. There is a paucity of research on this topic, particularly for adolescents and young adults with severe neurological impairment.

Research Question: To explore the palliative care needs of adolescents and young adults with a severe neurological impairment, under specialist palliative care services in Ireland.

Methods: This study utilised semi-structured interviews with the parents of adolescents and young adults with severe neurological impairment. Despite best support, these young people were limited in their ability to share their experiences. Parents were interviewed as proxy respondents. Interview templates were developed using the key domains of palliative care as outlined by the WHO including;(i)physical (ii)psychological (iii)social and (iv)spiritual needs. Questions on communication preferences and service provision were included. Participants were parents of adolescents and young adults(i)with severe neurological impairment (ii)known to hospital-based specialist palliative care services in the Republic of Ireland(iii)aged 13-24 years(iv)and who were medically stable. Key codes from these interviews were analysed using reflexive thematic analysis.

Results: The parents of five adolescents and young adults were interviewed Assessing and meeting the palliative needs of these young people is contingent on the recognition of the advocacy role of parents. A fear of loss of this advocacy power during transition from paediatric to adult health services represents a source of distress to these parents.

Discussion: It is important to work closely with the parents of adolescents and young adults with severe neurological impairment in order to adequately respond to the palliative care needs of group.

PARAMOUNT: Pain Neuroscience Education for Parents of Children with Life-limiting Conditions

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Background/Aims: Effective pain management for children and young people with life-limiting conditions remains challenging, particularly for parents providing care at home. As part of a multi-site clinical trial, we developed PARAMOUNT, an evidence-based neuroscience education intervention designed to support parents in managing their child's pain. The intervention aims to improve parental knowledge and confidence, enhance child comfort, and reduce caregiver distress.

Methods: Guided by the Medical Research Council (MRC) framework for developing complex interventions, we undertook a systematic, multi-phase development process. This included systematic literature reviews, an examination of relevant pain management and educational theories, and qualitative research exploring barriers and facilitators to symptom and pain management at the end of life. Findings informed the intervention's content and design. Iterative consultations with parents, clinicians, and researchers were conducted to refine the content, format, and delivery approach, ensuring feasibility, acceptability, and relevance to end users.

Results: The intervention incorporates evidence-based information and practical strategies identified as priorities by parents and healthcare professionals. Key components include tailored education on pain assessment and management, guidance on medication use, non-pharmacological pain management strategies, communication with healthcare professionals, and emotional support resources. Stakeholder feedback highlighted the importance of accessible, parent-centred content that addresses both the practical and emotional aspects of caregiving.

Conclusions: This programme of research demonstrates the value of co-designed, theory-informed neuroscience education interventions in supporting family-led pain management in paediatric palliative care. The next phase will evaluate the feasibility, acceptability, and preliminary impact of PARAMOUNT on parent and child outcomes.

Supporting Goals of Care with a 24-Hour Pediatric Palliative Nursing Phone Line

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A free-standing hospice is the major provider of pediatric palliative care (PPC) for over 900 children with serious illnesses in western Canada. The hospice offers inpatient and community-based care, in-home visits, virtual care, and a nurse-led 24-Hour Clinical Care Line.

The purpose of the 24-Hour Line is to assess and advise parents who call with a medical concern about their child while considering overarching goals of care and advance directives. Evidence that telephone services reduce emergency department visits and hospitalizations is only prevalent in adult palliative care. We have previously presented data for a quality improvement project outlining usage patterns and family feedback.

This descriptive, cross-sectional retrospective chart review aims to investigate whether recommendations made by nurses operating the 24-Hour Line, and a child's subsequent clinical intervention, aligned with the family's goals of care.

Children were identified by paper call logs for fiscal year 2024. Using call tracking, interdisciplinary nursing notes, and the tertiary pediatric center electronic medical record, we report on demographics, call reason, and advance directives at the time of the call. We also collect assessment and advice provided by the nurse, action taken by the family, emergency and hospital admission information, follow-up by staff, and whether all the above aligned with documented goals of care.

Recorded are 577 calls during this study period. Analysis of these calls will be reported using descriptive statistics. A majority of calls came from caregiving parents. The median call time was 15 minutes. This study will compare proportion of calls resulting in ER or hospital admission, reasons for calling, follow up by our team, and congruence with goals of care. Findings will explore the ability of a 24-Hour Line within a pediatric palliative care program to support goals of care for children with serious illnesses and their families.

Palliative Care Opportunities in Pediatric Patients with Onco-Hematological Diseases

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Background and aims: pediatric cancer remains a major cause of morbidity and mortality. In Italy, about 2,400 new cases are diagnosed annually. Despite survival rates approaching 80%, children and families face significant physical, psychological and social burdens. Early integration of pediatric palliative care (PPC) is recommended, but access remains limited. The study's aims were to identify "palliative opportunities", assess their relationship with ACCAPED scores, and compare them with actual PPC referral.

Methods: this retrospective single-center study included patients treated at a Pediatric Hematology and Bone Marrow Transplant Unit who died between 2017 and 2022.

Results: thirty-four patients were included. Median age at diagnosis was 5 years and median age at death was 9 years. Acute lymphoblastic leukemia was the most frequent diagnosis (58.8%). A total of 168 palliative opportunities were identified, with a median of four per patient. The most common were HSCT/CAR-T therapy (24.4%), relapse (18.4%), and disease progression (15.4%). In 105 cases, the ACCAPED score was >29, indicating complex care needs; however, only 19% of these opportunities led to PPC involvement. All patients experienced at least one unrecognized palliative opportunity associated with an ACCAPED score >29. Overall, only 13 patients (38%) received PPC. The first palliative opportunity with ACCAPED >29 occurred a median of 5.3 months before death, whereas PPC referral was delayed by a median of 3.7 months and occurred only 38 days before death. All patients undergoing HSCT or CAR-T therapy had ACCAPED scores >50, but none were referred to PPC at that stage.

Conclusions: these findings highlight a significant gap between palliative care needs and actual PPC referral. ACCAPED appears to be a useful tool for identifying unmet needs and supporting earlier PPC integration. Dedicated PPC teams and improved staff training may facilitate timely referral and improve quality of care.

Early Integration of Perinatal Palliative Care for Complex Fetal Congenital Heart Disease

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Background & Aims: Complex fetal cardiac conditions are associated with uncertainty regarding quality of life, short- and long-term outcomes. Families and clinicians must navigate complex medical and psychosocial challenges across pregnancy, birth, and early infancy. The Infant Maternal Perinatal Advanced Care Team (IMPACT) is a collaborative perinatal palliative program in Toronto, Canada that supports pregnant patients and their families affected by complex fetal cardiac conditions. We sought to describe referral patterns and lessons learned over the most recent years of this program.

Methods: IMPACT is integrated routinely into fetal cardiac counselling after the diagnosis of a complex or severe form of fetal cardiac disease with anticipated significant morbidity and mortality. Palliative care support through pregnancy and the neonatal period is individualized depending on families' needs and goals and can include clarifying family values, shared decision-making, legacy creation, psychosocial and spiritual support, anticipatory guidance, quality of life interventions, and symptom management.

Results: From 2024-2025, 56 pregnant patients affected by a complex fetal cardiac diagnosis were supported by IMPACT. Diverse goals of care were identified prenatally, with the majority (44/56, 79%) opting for life-prolonging resuscitation efforts and surgical interventions. A minority (10/56, 18%) opted for comfort-focused end-of-life care, and few (2/56, 3%) chose pregnancy termination. Early outcomes ranged from pregnancy loss or early neonatal death to survival with ongoing surgical and medical needs, not necessarily predicted by prenatal goals of care.

Conclusions: Early perinatal palliative care support for families experiencing life-threatening fetal cardiac diagnoses promotes patient and family-centered care across complex and uncertain clinical trajectories, honoring diverse and evolving goals of care.

Quality Indicators for Children with Life-Threatening or Life-Limiting Diseases: A Systematic Review

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Background and aims: Pediatric palliative care (PPC) aims to improve quality of life for children and adolescents with life-threatening or life-limiting diseases and their families. However, standardized and validated measurable outcome quality indicators for PPC remain limited. The aim was to systematically identify and describe measurable outcome quality indicators in PPC.

Methods: Systematic review conducted in accordance with PRISMA guidelines. A systematic literature search was conducted in Embase, Scopus, MEDLINE, and CINAHL. Studies published between 2005 and 2025 that examined measurable quality indicators in PPC were included. Data extraction and synthesis focused on study characteristics and identified quality indicators. Studies were assessed using Mixed Methods Appraisal Tool.

Results: Twenty studies were included. The identified quality indicators covered multiple domains, including symptom management, communication and shared decision-making, psychosocial and bereavement support, advance care planning, continuity of care, and healthcare utilization at the end of life. Frequently reported indicators included pain and symptom control, avoidance of intensive care unit admissions and cardiopulmonary resuscitation near death, hospice involvement, preferred place of death, and family-centered communication. Most studies focused on pediatric oncology populations and end-of-life care settings. Considerable heterogeneity was identified in the terminology, measurement approaches, and operationalization of indicators across studies.

Conclusions: Measurable outcome quality indicators in PPC remain diverse and insufficiently standardized. Future research should prioritize development and validation of consensus-based specific quality indicators applicable across diagnoses, care settings, and illness trajectories to support consistent quality assessment and improvement of PPC services.

Evolving Use of Methadone in Pediatric Palliative Oncology: A 12-Year Case Series

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Background and aims: Complex pain is common for end stage pediatric cancers. Methadone is a unique agent in its ability to address somatic, neuropathic, and nociplastic pain. This study sought to describe the evolution of enteral methadone utilisation in children with cancer approaching end of life at a tertiary pediatric hospital over a 12 year period.

Methods: Retrospective chart review. Data included demographics and details of methadone, concurrent opioids, and adjuvant medications at initiation, 1-month, peak dose, and end-of-life (EOL). Patterns were examined across 3 near-equal time periods (≤ 2020 , $n=11$; 2021–22, $n=8$; ≥ 2023 , $n=10$).

Results: 29 patients were identified. Age range was 1–19 years (median 8). 22 had solid tumours. At initiation, 21 were on background opioid therapy including 12 on IV infusions, classified as moderate ($n=5$) or high ($n=1$) dose. Methadone was initiated as a co-analgesic ($n=8$), via full opioid rotation ($n=14$), or as initial long-acting opioid ($n=7$); median initial dose was 0.17 mg/kg/d (IQR 0.09–0.23) with no difference across approaches. Median duration was 60 days (IQR 19–108). Doses escalated to peak with a median 2.2-fold increase (IQR 1.1–4.0) at a median proportional rate of $\sim 1\%$ /day (IQR 0.3–2.4%), with wide individual variation. In the last 48hrs, 83% remained on methadone. All who discontinued transitioned to a continuous IV opioid. Of those who continued, 58% had a concurrent IV opioid and 40% received continuous IV midazolam. Over three periods, use as initial long-acting opioid increased (18% to 50%) and median duration rose from 57 to 86 days. IV opioid dose at EOL declined from 18% moderate and 18% high to 20% moderate and no high-dose cases. Adjuvant co-analgesics at EOL declined from 64% to 30%.

Conclusions: Methadone prescribing evolved toward earlier use as a primary long-acting opioid. Further research is required to understand comparative outcomes, and prospective data collection for more detailed outcome measures.

“Life-Changing”: A Mixed-Methods Study of In-Home Massage Therapy for Children with Serious Illness

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Background: Children with serious illness experience significant discomfort from both their condition and its treatments. Massage therapy is an evidence-based, non-invasive modality that can relieve negative sensations while also generating positive sensory and relational experiences.

Methods: Children enrolled in palliative care were offered six in-home massage therapy sessions. After completion, interviews were conducted with a parent. Transcripts were analyzed using grounded theory and a constant-comparison approach.

Results: Seven parents completed interviews. The most common baseline symptoms were tone disorders, pain, and anxiety. Parents rated the effectiveness of massage as 9/10 for tone (n=7), 8.1 for pain (n=7), and 8 for anxiety (n=5). Positive experience ratings (n=7) included 9.4/10 for relaxation, 9.3 for fun, and 9.1 for pleasure; happiness and connection were uniformly rated as 10/10. Qualitative analysis identified seven themes: (i) relief of illness-related distress and physiological dysfunction; (ii) positive sensory-motor experiences supporting body awareness and movement; (iii) positive emotional and relational experiences; (iv) safe-touch counternarrative to painful, non-consensual healthcare contact; (v) integration with and enhancement of existing care; (vi) access facilitated by home-based, financially supported delivery; and (vii) strong desire for ongoing and routine access. Total cost to the program for these seven patients was \$5,809.

Conclusion: Massage therapy alleviated distress related to serious illness, enriched children’s sensory and relational experiences, and provided a restorative counternarrative to painful experiences of healthcare contact. Parents expressed that massage therapy is a useful adjunct to standard care for children with serious illness, that it should be a routine aspect of their care, and that in-home, financially supported delivery effectively addressed barriers of cost and transportation.

Structured Pathway for Managing Refractory Hip Pain in Paediatric Palliative Care Patients

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Background–Context–Aims: Refractory hip pain in pediatric palliative care children often persists despite oral analgesics, physical and postural therapies, or analgesic-dose bisphosphonates. This study aimed to define a pathway using procedural analgesedation as an intermediate step between non-invasive treatments and orthopaedic surgery. The hypothesis was that a dedicated procedural setting could offer effective, proportionate pain relief with minimal anaesthetic risk and reduced hospital burden.

Methods: The pathway was developed within a tertiary paediatric centre, integrating pain management, orthopaedics, and rehabilitation services. The model was based on 4 patients who had ultrasound-guided hip procedures under sedation, with physiatrists managing post-procedure mobilisation and adjustment. A 2-year follow-up assessed safety and feasibility. Ethics, consent, and confidentiality were maintained.

Results: All patients presented chronic hip pain associated with long-standing subluxation or dislocation unresponsive to traditional interventions. Procedural analgesedation enabled safe execution of ultrasound-guided injections and immediate rehabilitative mobilisation in a day-care setting. All patients experienced clinically meaningful pain reduction lasting 4–6 months to 9–12 months before retreatment. The elective procedural setting, positioned between outpatient care and the operating theatre, proved feasible and reproducible, and improved quality of life.

Conclusions: This pathway provided sustained pain relief in a safe, child-centred environment, reducing caregiver burden, limiting hospitalisation, and supporting social participation. The model strengthens interdisciplinary collaboration and aligns with fluid, needs-based care for paediatric palliative patients. Limitations include the small sample size and the need to formalise access criteria and monitoring processes across hospital and community services.

Funding: internal institutional resources.

Transition to Adult Services for Young People with Life Limiting Conditions: Role of Primary Care

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Background & Aims: Young people (YP) with life-limiting conditions (LLCs) are a rapidly growing population with increasingly complex healthcare needs, more of whom are surviving into adulthood. The involvement of General Practitioners (GPs) and primary care teams reduces emergency secondary care use and facilitates person-centred care. However, primary care is infrequently engaged with YP with LLCs or in transition planning, and GPs have expressed concerns including lack of time or specialist knowledge and understanding of their role alongside specialist colleagues. The aim of this study was to understand and identify opportunities to enhance engagement of GPs in coordination and delivery of care to YP as they transition to adult services.

Methods: Semi-structured interviews were conducted with YP with LLC and their parents/ carers; with GPs; and with healthcare professionals (HCPs) and other staff working with child and adult hospices in England, UK. Interviews were conducted in-person, online (Teams) or via telephone, were audio recorded, and transcribed verbatim. Anonymised transcripts were entered into NVivo and analysed using thematic analysis.

Results: All groups indicated that YP with LLC interacted with GPs infrequently prior to transition, suggesting low continuity of primary care services from childhood to adulthood. Some families questioned the suitability of GP services due to lack of familiarity and confidence with specific conditions, but welcomed the idea of a point of contact to help navigate transition. GPs echoed some of the families' concerns but saw potential for involvement. Suggestions for roles for GPs within the transition pathways were put forward.

Conclusions: Interviews provided in-depth insight into diverse experiences of transition from the perspective of YP, families and HCPs. Themes relating to the transition pathway, gaps in service, and barriers and facilitators to primary care involvement at the point of transition were identified.

1990-2025: A Text-Mining Perspective on the Evolution of Paediatric Palliative Care Literature

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Background: Paediatric palliative care (PPC) has expanded since 1990 with major frameworks broadening its eligibility beyond oncology and promoting holistic, multidisciplinary care. However, it remains unclear whether the research literature has evolved in line with these developments. We examine longitudinal trends in PPC literature from 1990 to 2025.

Methods: We text-mined titles and abstracts of PPC-related publications indexed in PubMed. After data cleaning, 3,208 publications were analysed with a workflow in R. Publications were categorised using these keyword domains: people, conditions, treatments and care locations. Trends on publication aspects and vocabulary diversity were assessed.

Results: Publication output increased substantially, from 4 publications in 1990 to over 200 annually in the 2020s, peaking at 269 publications in 2022. People-related terms consistently dominated the literature. Cancer-related terminology was prominent in earlier years, while references to life-limiting conditions increased from the mid-2000s. In contrast, treatment-related terms remained underrepresented. Community-based and virtual care issues were also minimally represented. Analyses of vocabulary showed that, while the scope of PPC literature broadened over time, terminology became increasingly standardised.

Conclusions: PPC literature has grown in scale and scope since 1990, but developments have been uneven. Research has focused on patients, families and eligibility-defining conditions, while treatment approaches, community care and wider multidisciplinary involvement receive comparatively less attention. Although limited by its keyword-based methods and reliance on a single database, this study identifies persistent gaps between PPC frameworks and research priorities. Greater focus on care delivery, interventions and community-based models may help strengthen the evidence base supporting children and families affected by life-limiting and life-threatening conditions.

More Than Cancer: Changing Patterns of Referral to Paediatric Hospice Care Over Five Years

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Background: Advances in healthcare have enabled more children with life-limiting conditions to survive longer with increasingly complex needs. Understanding referral patterns is essential for paediatric hospice service planning and workforce development.

Aim: To examine changing referral patterns to paediatric hospice care over a five-year period, including referral volume, demographics and diagnosis.

Methods: A retrospective review of all accepted referrals to a specialist paediatric hospice service between 2021 and 2025 was undertaken. Data collected included age, sex and diagnosis. Diagnoses were categorised as oncology, neurological, congenital, circulatory, metabolic, perinatal and haematological conditions. Descriptive statistics were used to analyse trends over time.

Results: A total of 554 accepted referrals were received during the study period. Annual referrals increased from 51 in 2021 to 145 in 2025, a 184% increase over five years. Females accounted for 46–50% of referrals annually. Children under 10 years represented 71% of referrals, with infants under one year comprising the largest age group (25.5%). Non-oncological conditions accounted for 73–88% of referrals annually. Oncology referrals represented 12–27% of referrals. Neurological conditions consistently represented the largest diagnostic group (33–44%), while congenital conditions increased from 16% to 23% over the study period. Other diagnostic groups included circulatory, metabolic, perinatal and haematological conditions.

Conclusions: Referrals to paediatric hospice care increased almost threefold over five years, reflecting growing demand for specialist services. Despite perceptions linking hospice care with cancer, most referrals were for non-oncological conditions, with neurological conditions consistently accounting for the largest proportion. These findings highlight the need for expertise in caring for children with neurological, congenital and other complex conditions.

Domiciliary Cornea Ablation after Home-based End of Life in a Patient with Adrenoleukodystrophy

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Background: We describe the case of a patient with adrenoleukodystrophy whose advanced care plan included both organ donation and home-based death.

Case Description: We present a 9 year old patient at the beginning of home weekly visits by our team who had been diagnosed 4 months before with adrenoleukodystrophy without curative option. Since that moment we focused on comfort as goal of care. We worked in an advanced care plan while treating his progressive illness for two years, which included being an organ donor. We arranged a meeting with CUCAIBA (statal transplant coordination centre) and the nearest organ transplant institution to evaluate his case. Since he did not want to go to the hospital and we had agreed on his home as place of death, he could be a cornea donor with domiciliary ablation, which had never been done before. Palliative sedation was initiated for refractory symptoms at end of life after progressive deterioration, informing the situation to the ablation team. After his death, we started the specific eye care and the team came to proceed with the cornea ablation at home. During this time, both his mother and his sister gave great meaning to the fact that the patient could help other people to see. The ablation was successful.

Conclusion: In Argentina there are more than 9500 people waiting for an organ or a tissue transplant (more than 2100 cornea transplants). There are some reports of cornea ablation in hospices and donation after at-home programmed death in adults, but to our knowledge this is the first report of a pediatric domiciliary cornea ablation. Being a transplant donor could fulfill transcendancy and give sense to organic suffering, which is crucial in spiritual care. This aspect should be reflected in the advanced care plan. We should keep building connections between palliative care teams and organ ablation centres to be able in the future to fulfill both the organ donor wishes and the increased public health needs of transplants.

Introducing Implementation Science to Pediatric Palliative Care: A Regional Training Study

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Background–Context–Aims: Access to pediatric palliative care (PPC) remains limited in many countries, partly due to insufficient professional training. A region-wide PPC program based on a train-the-trainer model was implemented to support dissemination of PPC competencies. This study evaluates its system-level rollout using an Implementation Science approach, an emerging yet uncommon methodology in PPC.

Methods: A multi-year implementation study was conducted across all healthcare organizations within a regional health system. Following StaRI standards, the PPC training intervention was distinguished from the implementation strategies supporting its scale-up. Strategies were specified using the Proctor framework. Implementation outcomes—reach, adoption, fidelity, penetration, acceptability, and sustainability—were assessed through administrative data, instructor activity logs, and standardized participant feedback.

Results: The program achieved substantial reach, delivering 50 (1,304 participants) and 43 editions (721 participants) in two consecutive years. Adoption was high, with 89% of trained instructors active. Fidelity was supported by a standardised curriculum, structured supervision, and annual alignment processes. Penetration increased across organizations and professional groups. Acceptability was high, with participants reporting clarity, relevance, and applicability to practice. Sustainability was reinforced through governance mandates, integration into routine training plans, and the introduction of advanced instructor roles and organizational registries.

Conclusions: This study represents one of the first applications of Implementation Science to PPC training at a regional scale. A coordinated train-the-trainer model can be implemented and institutionalized within a complex health system, offering a replicable strategy to reduce inequities in PPC access. **System-level strategies are essential to ensure high-quality PPC for eligible children.**

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Home Non-Invasive Ventilation in a Pediatric Palliative Care Programme: A Cross-sectional Study

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Background: Non-invasive ventilation (NIV) is increasingly offered to children with life-threatening conditions to relieve respiratory symptoms and support chronic respiratory failure, yet evidence is largely observational and caregiver-reported outcomes are underexplored. We described its clinical profile, settings, adherence and caregiver-reported effectiveness in a pediatric palliative care unit.

Methods: Single-centre cross-sectional study of all patients on home NIV followed by the unit (N=27). Demographics, Feudtner category, complexity (PEDCOM), respiratory-failure type, NIV modality/interface/settings, adherence, adaptation difficulties and caregiver-reported effectiveness and sleep were collected. Anonymised data were analysed with medians [IQR], Fisher exact, Mann-Whitney U and Spearman tests ($p < 0.05$).

Results: 63% were male; median age 11.5y [9.4-18.4], 8 aged ≥ 18 y. 93% had neurological/neuromuscular disease; median extended PEDCOM 24; severe scoliosis 48%; hypercapnic/mixed failure 85%. 70% had prior PICU admission, 33% prior intubation; a no-PICU decision in 77%. NIV was BIPAP in 78% (buconasal 56%); median IPAP/EPAP 12/7 cmH₂O. Use exceeded 6 months in 85%, was nightly in 74% and ≥ 8 h/day in 48%; gastrostomy 74%, cough-assist 67%. Caregivers rated NIV effective/very-effective in 89% and improved sleep in 63%, despite adaptation difficulties in 63%. Greater exposure correlated with higher effectiveness (hours/day $\rho = -0.53$, $p = 0.005$; nightly use $\rho = 0.57$, $p = 0.002$). Care burden was high in 52%.

Conclusions: In a palliative programme, home NIV was feasible, well-adhered and perceived as highly effective in medically complex children, improving sleep despite frequent adaptation difficulties and substantial caregiver burden; greater exposure tracked with better perceived effectiveness. Limitations: small single-centre cross-sectional design with caregiver-reported outcomes. Findings support integrating structured NIV with palliative and family support.

Non-Cystic Fibrosis Bronchiectasis in Pediatric Palliative Care Patients

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Background and aims: Children and adolescents with life-threatening conditions, especially those with severe neurological impairment, have high morbidity and mortality, often due to respiratory causes. Non-cystic fibrosis bronchiectasis (NCFB), which are treatable and potentially reversible, are frequently underdiagnosed because chest computed tomography (CT) is rarely performed. The aim of this study was to document the frequency of NCFB in a pediatric palliative care unit and to describe its characteristics.

Methods: Observational, descriptive, single-center study in a tertiary pediatric hospital. Patients meeting clinical criteria underwent chest CT. Data were collected from medical records, analyzed descriptively and were anonymized. Informed consent was obtained in accordance with the Declaration of Helsinki.

Results: Of 23 eligible patients, a CT scan was performed; 3 died before completion and 8 showed bronchiectasis, all with severe neurological impairment. Median age was 18.2 years (6.8–23.4); four were male. The most common underlying condition was cerebral palsy (n=5). All patients received enteral nutrition (gastrostomy); six had suspected gastroesophageal reflux. All required daily airway suctioning; seven received oxygen therapy, one non-invasive ventilation, and one had a tracheostomy. *Pseudomonas aeruginosa* was the most frequent pathogen (6 cases, 75%). All had recurrent pneumonia; six had chronic wet cough and five previous episodes of bronchial aspiration. Treatments included bronchodilators (8), inhaled corticosteroids (5), inhaled antibiotics (5), hypertonic saline (2), and azithromycin (1), with a median of 3.5 antibiotic courses/year.

Conclusions: NCFB may be relatively common in this population. Chest CT in patients with persistent respiratory symptoms may enable earlier diagnosis and targeted treatment. Findings should be interpreted cautiously due to the single-center design and small sample; larger multicenter studies are needed.

Beyond Diagnosis: Identifying Palliative Care Needs in Children with Medical Complexity

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Introduction: All babies, children & young people (BCYP) with life threatening, life shortening conditions or severe medical complexity & their families should have access to high quality paediatric palliative care (PPC) from diagnosis through to end of life & into bereavement. Early Identification of those who may benefit from a palliative approach is essential to deliver timely, holistic, needs-based care & improve outcomes for them.

Method: The 'surprise question' within The Spectrum of Children's Palliative Care Needs Tool was used to identify BCYP & categorise need at 5 time points (2022-26) across 1 UK region (Green: survival to adulthood likely; Yellow: may live for many years; Amber: increasing instability or progressive deterioration may die in next few months; Red: survival not expected beyond weeks). Gender, age range, diagnosis, home postcode were recorded. Also asked (2026) if known to specialist PPC service & ethnicity. Associations between need, age range, diagnosis, home location, known to PPC service & ethnicity were made.

Results: 6,653 cases were identified (1,041–1,470 annually). Neurological conditions most common (n=2,566). Red category remained consistently low (n=15–41). Most BCYP classified as Green in 2023–2025, while Amber was highest in 2026 (n=517). Younger BCYP (0–12 years) were more often Amber, whereas older BCYP were more likely Green. Increasing diagnostic complexity correlated with higher need: BCYP with ≥ 3 conditions most frequently classified Amber. Geographic variation was evident, with higher proportion of Green cases in areas with greater service provision.

Conclusion: Greater clinical complexity & younger age are associated with higher palliative care need. Variation across geographical areas suggests that service availability & healthcare infrastructure may influence identification & management, highlighting potential inequities in access & provision. Further study of regional clinical multidisciplinary team role is required.

Regional Patterns of Clonidine Use in Paediatric Palliative Care: A System-Wide Review

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Background: Off-licence clonidine is increasingly used in paediatric palliative care (PPC), but evidence & national guidance on safe use remain limited, particularly for the transdermal route. This regional service evaluation describes demographics & clonidine use of babies, children & young people (BCYP) on a PPC caseload prescribed enteral or transdermal clonidine or previously received intravenous (IV) clonidine. Findings will inform a system-wide working group reviewing policy & standard operating procedures for BCYP across home, hospice & tertiary hospital settings.

Method: Retrospective case note review using Microsoft Forms survey to capture frequency of use; administration route & presence of dystonia escalation plan. Data were collected by nurses from PPC teams. Numerical data were analysed descriptively & qualitative responses using basic content analysis.

Results: 52 BCYP records were reviewed across 1 tertiary hospital & 4 hospice caseloads using 2 record systems. Data described cohort demographics; starting & maintenance doses for enteral & transdermal clonidine against APPM (2024) formulary guidance; frequency of patch use; where patches were started & titrated (home, hospice or hospital); availability of dystonia escalation plans; frequency & rationale for IV clonidine bolus / infusion; & reported adverse effects.

Conclusions: This review highlighted challenges arising from different documentation systems & the absence of standardised policy across a regional healthcare system. Increasing numbers of BCYP are transitioning from enteral to transdermal clonidine, & some receiving high-dose enteral clonidine may benefit from transdermal treatment. Variation in prescribing & titration of transdermal & IV clonidine may affect preferred place of care, symptom control & risk of adverse effects. A consistent regional approach to prescribing, titration & family support for BCYP with dystonia could improve safety, treatment choice & access across settings.

Reducing Administrative Burden in Paediatric Palliative Care: Foundations for Quality Improvement

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Background and aims: Admission to paediatric hospice for short stay breaks is a complex high-risk transition requiring coordinated information exchange. A clinical audit identified process variation, duplication and inconsistent documentation, contributing to inefficiencies, administrative burden and safety risks. Evidence shows families of children with complex needs experience significant administrative burden within fragmented systems. Local survey data reported up to 17 hours weekly on administrative tasks. This work aimed to establish a baseline (Stage 1) to inform a quality improvement (QI) initiative to streamline preadmission and admission workflows through standardisation and co-design.

Methods: A retrospective audit of 30 short stay break admissions over six months assessed compliance across preadmission, admission, discharge and follow-up using a structured tool. Findings were triangulated with family survey data and literature on caregiver burden. Process mapping identified duplication and variability. This Stage 1 phase informed development of a QI intervention using co-design within a structured framework, incorporating planned PDSA cycles.

Results: Clinical audit results showed compliance of 65%, with lower performance in discharge (55%) and follow-up (58%). Key issues included incomplete documentation, duplication and inconsistent communication. Only 48% of audited cases had up-to-date prescriptions preadmission and documentation of clinical changes was often incomplete. Process mapping identified multiple handoffs and repeated information collection. Family data highlighted high administrative workload.

Conclusions: This Stage 1 work establishes a baseline for a QI initiative targeting administrative burden and workflow inefficiency. Standardising workflows and improving systems may reduce duplication and improve safety. Planned implementation will test co-designed interventions to improve efficiency and family-centred care.

Mapping Ireland's Transition Framework in the Context of Specialist Palliative Care Services

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Background and Aim: Ireland's Transition of Care from Paediatric to Adult Services: A National Framework was published in 2025. There are nine summary standards identified. The National Adult Palliative Care policy (HSE 2024) identifies that palliative care services are important partners in the process of supporting the transition of adolescents from children to adult services. We aimed to assess the standards identified in the framework against national palliative care provision, to determine readiness and/or barriers to young people successfully experiencing transition in palliative care.

Methods: We examined the nine standards in the setting of specialist palliative care in Ireland.

Results: Standard 1, 2, 4, 5 and 9 were found to be met within current national palliative care service delivery.

Standard 3 and 7 require persons involved in transition and transition clinics to undergo palliative care training within their scope of practice as well as ensuring basic palliative care skills required by all health care professionals. We identified that within standard 6 (Readiness Assessment) whilst transition may be deferred within many specialties in times of crisis, it is likely that referral to palliative care at times of crisis will be appropriate and should not be deferred. An information resource would benefit patients who are undergoing transition so they may understand processes that are involved around palliative care consultation, supporting standard 8.

Conclusions: Adult specialist palliative care services are designed and determined to look after people of all ages including children towards the end of their life in the community in Ireland. This cross pollination of skills results in patients' needs being met irrespective of age, mitigating the need for specific transition pathways/clinics. However with the publication of a national framework for transition the development of resources identifying this within the realm of palliative care would be useful.

Gabapentin for Symptom Management of Self-Injurious Behaviour in Lesch–Nyhan Disease: 2 Case Reports

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Background: Lesch–Nyhan disease (LND) is a rare disorder characterised by neurological impairment, dystonia and severe self-injurious behaviour (SIB). SIB is often the most distressing symptom for affected children and their families, yet evidence for pharmacological management remains limited. Gabapentin has been used successfully in symptom management for children with severe neurological impairment, although evidence in LND is restricted to a single published case report.

Aim: To evaluate the effectiveness and tolerability of gabapentin in reducing distressing self-injurious behaviour in two adolescents with LND.

Methods: A retrospective review of two adolescents with LND referred to paediatric palliative care for management of severe SIB was undertaken. Clinical records were reviewed to evaluate symptom burden, treatment response, adverse effects and family-reported outcomes following initiation of gabapentin.

Results: Both adolescents demonstrated an initial reduction in SIB following commencement of gabapentin, with associated improvements in comfort and daily functioning. In Case A, treatment was complicated by a transient erythematous rash which resolved and did not recur following cautious reintroduction and dose escalation. Sustained improvement in SIB was observed at 12-week follow-up, with resolution of bite-related injuries and reduced family distress. In Case B, initial symptom improvement was observed; however, benefits were not sustained long term. Early adverse effects were transient and manageable through dose adjustment and shared decision-making. Overall, gabapentin was well tolerated in both cases.

Conclusions: Gabapentin may represent a useful and well-tolerated option for the management of severe self-injurious behaviour in children with LND. Responses may be variable; however, meaningful improvements in symptom burden and quality of life were observed. Further evaluation is warranted to better define its role in managing this distressing symptom.

Availability of Integrative Pain Management in Children: Themes from an International Survey

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Background and Aims: Pediatric pain management is best approached with a combination of medication and non-pharmacological interventions. The availability of integrative pain management (IPM) for children globally is incompletely characterized. This international survey of pediatric healthcare providers examines the availability of IPM approaches.

Methods: A survey exploring, among other variables, the availability of IPM for pediatric pain, was distributed through the International Children's Palliative Care Network and the St. Jude Global Alliance Network (an online community dedicated to helping children with cancer and other catastrophic diseases worldwide). Options were noted on a Likert scale, as "always", "most of the time", "sometimes", "rarely", and "never".

Results: Responders to the survey (n=341) were, in order of frequency, from the Americas (47.5%), South-East Asia (17.6%), Africa (15.8%), Europe (10.9%). Eastern Mediterranean (5%), and Western Pacific (3.2%). By profession, most responders were physicians (67.2%) and nurses (non-prescribers, 10.9%, prescribers 8.5%).

In order of frequency (n=315), cumulatively reported as "always" and "most of the time", the available IPM were: palliative care specialist (pediatric or adult/pediatric) (64.1%), physical therapy/rehabilitation/physiotherapy (62.5%), pain specialist/anesthesiologist (57.1%), psychologist/counselor (50.2%), child life specialist/play therapy (35.2%), massage therapist (9.8%), and acupuncture (4.1%).

Survey responders (n=311) reported being able to treat pain effectively in children "always" and "most of the time" as 11.3% and 63%, respectively.

Conclusion: The availability of palliative care specialists, physical therapy/rehabilitation/physiotherapy, and pain specialists, in almost 2/3 of cases, is encouraging. Support from psychology and child life specialists/play therapy remains only partially available and deserves attention to optimize pediatric pain management.

Bringing Care, Teaching and Research Together in an African Paediatric Palliative Care of Excellence

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Background and Aims: Around 50% of children needing palliative care in the world live in Africa- where children's palliative care remains under-developed. The aim of this presentation is to show how a model for a Center Of Excellence (COE) for Paediatric Palliative Care (PPC) being developed in Cape Town hopes to bridge the gap between research and clinical care and multiply impact increasing the integration of PPC across the continent.

Methods: Inspired by the 29 year old Cipla Palliative Care COE in Pune, India- two Cape Town NGO's (Paedspal and the Rohan Bloom Foundation), the University of Cape Town and a funder (Cipla SA) got together to co-create a COE for Paediatric Palliative Care in Cape Town. The presentation outlines this journey and the many steps that were needed to bring this all together.

Results: By definition a COE is a collaboration of partners working towards achieving a shared goal. Each partner contributes existing resources and works together with new external funders and donors to collectively develop and strengthen capacity in a field that benefits a larger area than just that in which the CoE is based.

Conclusions: The sum is indeed greater than the parts. The combination of diverse partners with different areas of influence and complementary strengths can expedite development. The best way to learn how to provide palliative care is at the bedside and the best way to ensure that this care is acceptable, evidence-based and culturally appropriate is through operational research. Combining clinical services, research and training under one roof can catalyze regional development of palliative care.

Pali4NPCare: Advancing Nursing in Perinatal, Neonatal and Paediatric Palliative Care

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Children and families facing life-limiting/threatening conditions require equitable access and quality palliative care across perinatal, neonatal and paediatric settings. Nurses are central to this care, yet curricula, competencies and standards remain unevenly defined. Pali4NPCare is an action-research project in Portugal to strengthen nursing education, practice, research and policy.

Methods: Pali4NPCare includes four work packages: (1) a scoping review on nursing competencies; (2) documentary analysis of national nursing curricula; (3) focus groups with neonatal/paediatric nurses on competence development, knowledge translation and educational needs; and (4) co-design of educational and regulatory guidance. Data analysis combines structured extraction, descriptive synthesis and thematic/content analysis. Ethics approval, informed consent and confidentiality apply to participant phases.

Results: Preliminary findings and outputs indicate impact across practice, education, research and policy. Clinically, the project supported a workshop on moral distress, a roundtable on nursing competencies, and contribution to an international neonatal palliative-care position paper. Academically, it generated an exploratory study and an ongoing scoping review. In research, it is building a programme to identify competency profiles, curriculum gaps, and barriers/enablers to knowledge translation. In policy and regulation, an advanced nursing competence proposal was submitted to the Portuguese Nursing Board. Expected products include a competency map, national curriculum profile, education framework and good-practice guide.

Conclusions: Although outcome data are still emerging, Pali4NPCare addresses an important gap. By translating evidence into competencies, curricula and guidance, the project has the potential to strengthen nursing capacity and promote more equitable, high-quality care provision for children and families.

A New Frontier in Pediatric Palliative Care: Organ Donation at the End of Life

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Background: Organ donation represents an underexplored field in pediatric palliative care (PPC). Although it may offer life-saving opportunities for recipients, it remains uncommon and particularly complex within PPC settings, where care is primarily focused on comfort, quality of life, and de-escalation of invasive interventions.

Objective: To explore the main ethical and operational challenges and opportunities of integrating organ donation within PPC pathways.

Methods: We present two clinical cases of patients requiring PPC in which organ donation after death was pursued. A qualitative approach was used, focusing on decision-making processes, communication with families, coordination between PPC and transplant teams, and organizational and ethical issues.

Results: In both cases, the possibility of organ donation emerged during end-of-life care discussions, rather than as part of a pre-established pathway. While it was positively received and supported by parents, this had to be balanced with several practical and organizational constraints, including the alignment of PPC principles with transplant feasibility, particularly in relation to the lack of physiological monitoring and the need to prioritize comfort-focused care alongside organ preservation requirements. On-the-spot coordination between PPC and transplant teams was required, with varying degrees of timeliness and system readiness. Collaboration between teams allowed for adaptation of processes and improved communication with families.

Conclusion: These experiences open new perspectives on the implementation of organ donation within PPC, highlighting the need for a more structured, multidisciplinary, and anticipatory approach. Early communication, shared decision-making, and integrated care pathways are essential to support families, preserve the child's dignity, and optimize donation opportunities without compromising end-of-life care goals and PPC principles.

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Pae Herenga – Family Experiences Informing Implementation of a National Model of Care

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Over 3,000 children in New Zealand require palliative care for serious illnesses, a number that is rapidly increasing. A new national paediatric palliative care (PPC) model is being developed over the next four years, funded by a budget of \$15.5 million from the New Zealand Government, but evidence to guide implementation is limited. The Pae Herenga study is working in partnership with the national health service, Te Whatu Ora Health New Zealand who have been tasked with implementing the new service. The study is collecting the first comprehensive data on family experiences, prioritising the voice of indigenous families to inform an equitable, efficient model of PPC.

Method: A qualitative approach drawing upon the principles of Indigenous research methods is being used. In-depth interviews with approximately 50 families explore access to healthcare and supports, including cultural or spiritual practices, using the Indigenous informed framework, Te Whare Kaiao (developed by our team). Data are being analysed using thematic and narrative methods informed by critical theoretical approaches.

Result: This presentation will describe the establishment of the study and the ways in which research collaborations, including with lived experience experts, have been embedded in the study design. Strategies to ensure the inclusion of Indigenous Māori whānau (families) in the research will be described. Initial findings will also be shared, focusing on facilitators and barriers to high quality, culturally safe, palliative care for children and their families.

Conclusion: Families currently receiving PPC in New Zealand describe this research as “desperately needed”, reflecting growing gaps between service provision and family needs. This study will influence service delivery, through the involvement of key decision makers in all study phases. We will co-create resources to support understanding of PPC concepts for children and families in New Zealand.

Lessons Learned from Developing a Sustainable Ambulatory Pediatric Palliative Care Clinic

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Background:

- Stanford Medicine Children's Health established an ambulatory pediatric palliative care (PPC) clinic. Existing literature on ambulatory operations in PPC remains limited. This report presents key lessons learned from implementing the ambulatory care clinic, accompanied by volume data.

Results: The following section summarizes six themes with lessons identified:

The first theme is **strategic growth and marketing, which should be balanced with team capacity**. A tiered approach facilitates rapid Plan-Do-Check-Act (PDCA) cycles, with each phase aligned to current capacity, priority needs, and realistic timelines. Strategic expansion may be supported by establishing a cap on patient volume to maintain quality of care. Program promotion should involve targeted outreach and consistent communication of the program's scope and benefits to key stakeholders. Partnerships should be prioritized with stakeholders who are most receptive to collaboration.

The second theme is **continuity of care throughout the care continuum**. Aligning inpatient and outpatient documentation ensures effective care handoffs. Standardizing documentation by ambulatory clinicians promotes clear, consistent communication and continuity of care. All workflows, processes, and systems should be documented as standard operating procedures to ensure consistent service delivery.

The third theme is the **diversification of ambulatory delivery modalities**. Adopting a hybrid model that integrates floating, embedded, and free-standing approaches is recommended rather than selecting a single model initially. Telehealth serves as an effective modality that accommodates family needs and is preferred for access to care.

Conclusion: Expanding the continuum of care to include ambulatory services requires strategic planning and continuous evaluation. Patients benefit from care delivery beyond inpatient settings, but careful planning and strong partnerships are essential for successful expansion.

End-of-Life Care and Treatment Decisions: A Major Source of Moral Distress in Japanese PICUs

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Background and aims: Healthcare professionals in pediatric intensive care units (PICUs) are deeply involved in end-of-life care, decision-making support, and caring for families facing the death of a child. These situations may generate ethical conflicts and psychological burdens, contributing to moral distress and burnout. However, little is known about how end-of-life-related concerns are positioned within the overall structure of moral distress among PICU professionals. This study aimed to clarify the structure of moral distress and examine the role of end-of-life care and treatment decisions within it.

Methods: A cross-sectional online survey was conducted among physicians and nurses working in Japanese PICUs. Moral distress was assessed using the Japanese version of the Measure of Moral Distress for Healthcare Professionals (MMD-HP). Exploratory factor analysis was performed, and the frequency and severity of individual items were analyzed.

Results: A total of 266 healthcare professionals responded. Factor analysis identified a three-factor structure consisting of (1) organizational factors, (2) end-of-life care and treatment decisions, and (3) workplace climate. The highest-scoring item was "Following a family's request to continue aggressive treatment that I believe is not in the best interest of the patient." Several other end-of-life-related items also showed high frequency and severity scores. End-of-life-related items clustered together as an independent factor and included several of the highest-scoring items, suggesting that they represent a distinct and clinically important domain of moral distress in PICU practice.

Conclusions: Conflicts surrounding end-of-life care and treatment decisions are an important component of moral distress among PICU healthcare professionals. These findings may help identify targets for support and ethical consultation in pediatric end-of-life care and contribute to strategies to reduce distress among healthcare professionals.

Prenatal integration of Pediatric Palliative Care: A case study of CHARGE Syndrome

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Background: Prenatal diagnosis of life-limiting conditions has led to a distinct patient group within pediatric palliative care (PPC). Early PPC involvement necessitates structured interdisciplinary collaboration and an approach that acknowledges prognostic uncertainty and individual differences in core values. Each case follows an unpredictable trajectory, underscoring the importance of flexible, individualized care planning from the outset.

Methods: A retrospective chart review was conducted for a fetus diagnosed with CHARGE Syndrome. Focus areas included family-defined goals, shared decision-making, and multidisciplinary, dynamic care planning.

Results: During ultra sonic assessment in GA 16, hypoplastic arcus aortae and cleft lip and palate were observed. CHARGE syndrome was confirmed after genetic testing. The parents had the impression that the child would be unable to survive more than few hours and proceeded with the pregnancy due to core values in the family. Ten weeks prior to delivery, the PPC team was involved as the parents realized, that the child might live for months to years. The parents wished for PPC with no disease targeted interventions, and home-based end-of-life care was coordinated. The PPC team and local health services provided home-based support, ensuring comfort and family bonding. 13 days old, following several days of clustered episodes of severe apnea, the infant was briefly admitted to the neonatal unit.

The next day the family was discharged to a children hospice where the whole family could be cared for. The child died well palliated few hours after admission.

Conclusions: Early PPC integration enables anticipatory guidance, adaptive decision-making, and individualized care in the context of prognostic uncertainty. This case highlights the importance of flexible care settings that honor parental core values. PPC mediates the transition from prenatal- to neonatal- and homecare, supporting families and care teams in optimizing QoL.

Mapping Clinical Risk Assessment Frameworks in Home-Based Healthcare

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Background and aims: Increasing numbers of children are living with paediatric palliative care (PPC) needs, and many families wish to receive care at home. Medical advances have enabled interventions previously delivered in hospital to be provided at home. Understanding how clinical risk (CR) is assessed and managed at home is essential. There is no evidence-informed framework to support structured risk assessment in PPC at home. This scoping review aimed to map CR assessment frameworks used in home-based healthcare, key risk domains, and their relevance to PPC.

Methods: Scoping review conducted in accordance with Joanna Briggs Institute methodology and PRISMA-ScR guidance. MEDLINE, EMBASE, CINAHL, PsycINFO and grey literature were searched. English language publications (2000–2025) from OECD countries were included. Eligible sources described CR assessment frameworks for home-based healthcare. Data was analysed descriptively and synthesised narratively.

Results: 23 papers describing risk assessment frameworks were identified, most frequently in adult dementia, frailty and community care. Frameworks demonstrated heterogeneity in structure, content and implementation. Common risk domains included clinical deterioration, medicines management, environmental safety, safeguarding, caregiver capacity, communication and escalation planning. Few supported holistic assessments across multiple domains or ongoing reassessment as needs changed. Risk was often conceptualised as a relational and negotiated process between professionals and families rather than clinician led.

Conclusions: CR assessment frameworks for homecare are limited, with little evidence developed for, or transferable to PPC. Frameworks tend to focus on individual risks rather than holistic assessments within the home. Development of a structured risk assessment process could support safe, equitable and family-centred palliative care for children receiving PPC.

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Comprehensive Palliative Care for Children with Pulmonary Hypertension: A Scoping Review

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Background: Pediatric pulmonary hypertension (PPH) is associated with a high symptom burden, morbidity, and mortality, often presenting late in its course, and progressing faster than in the adult. Syncope and sudden death may occur, or PPH may follow a more protracted course leading to right heart failure and declining quality of life. PPH may be idiopathic, due to congenital heart disease (CHD), developmental lung anomalies during fetal life, neonatal disorders including prematurity, de novo and heritable mutations, and other causes. Infection, malnutrition, and untreated CHD are leading etiologies in low and middle income (LMIC) countries, where most children with PPH reside.

Methods: A scoping review utilizing the PubMed® search engine was performed, with a focus on recent international collaborative proceedings, clinical practice guidelines, research articles, and meta-analyses, from 2020 through June 2026.

Results: PPH may improve with lung growth in children with developmental lung anomalies, or when secondary to a correctable cause. Supportive care includes management of symptoms associated with chronic respiratory and right heart failure. PPH medications, except for nifedipine and sildenafil, are extremely expensive, have side effects, and may ultimately fail. Given the complexities and limited availability of lung and heart/lung transplantation, an appropriately timed, relatively simple and more globally accessible left pulmonary artery to descending aorta (Potts) shunt may improve survival and quality of life, mitigating the evident and invisible burdens associated with targeted drug therapy.

Conclusions: Palliative care providers have important roles in promoting overall health maintenance, optimal symptom control of dyspnea and fatigue leveraging pharmacologic and non-pharmacologic interventions, context-appropriate complex medical decision-making, access to resources, and comprehensive psychosocial and spiritual support for PPH patients and families.

Pediatric Palliative Care in Türkiye: Bridging the Gap in Physician Competency

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Background and aims: Pediatric Palliative Care (PPC) is an emerging field in Türkiye, currently available in only limited number of specialized centers. Despite the growing need, a structured palliative care curriculum for pediatricians remains absent. In November 2025, the national palliative care congress hosted its first dedicated course on PPC and chronic pediatric patient management. This study aims to evaluate the self-efficacy, perspectives on pain management, and symptom control competencies of pediatricians who participated in this training.

Methods: This cross-sectional descriptive study analyzed 19 pediatricians who attended the PPC course. Data were collected via a comprehensive 20-item digital survey. The survey assessed demographics, clinical experience, and participants' expectations from the training. Competency levels in various domains were measured using a 5-point Likert scale.

Results: The majority of participants (63%) were aged 25-35, with 55% being residents and 45% specialists. While 47% had prior PPC experience, self-assessment scores showed room for improvement: symptom management (mean=3.37±0.90), respiratory problems (3.47±0.77), and terminal care (3.00±0.82). Notably, those with prior PPC experience showed significantly higher competency in symptom management (p=0.011), whereas professional titles (resident vs. specialist) did not impact scores. In-hospital analgesics were predominantly paracetamol (95%), fentanyl (79%), ibuprofen (74%), and morphine (63%). However, discharge prescriptions were limited to paracetamol (95%) and ibuprofen (74%).

Conclusion: Clinical experience remains the most effective factor in mastering symptom management. Integrating PPC training into pediatric residency programs is essential to address the clear demand for information and to improve care standards for this vulnerable patient group. Expanding such specialized trainings will significantly contribute to the advancement of the PPC field in Türkiye.

Beyond the brain: MALS-triggered PSH as a management challenge in Pediatric Palliative Care

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Background and aim: Pediatric Palliative Care (PPC) often requires managing refractory symptoms where multiple pathologies overlap. Paroxysmal Sympathetic Hyperactivity (PSH) is a clinical syndrome of recurrent sympathetic and motor overactivity following brain injury. When PSH coexists with Median Arcuate Ligament Syndrome (MALS)—a vascular compression causing chronic ischemic abdominal pain—symptom management becomes exceptionally difficult. This case is presented to emphasize the importance of considering and investigating diverse pathophysiological mechanisms when encountering refractory symptoms.

Case Description: We present a 16-year-old boy with severe hypoxic-ischemic brain injury following cardiac arrest due to genetic ventricular tachycardia syndrome. The patient experienced frequent PSH episodes characterized by tachycardia, hyperthermia, and severe opisthotonus. Following a brief symptom-free interval, the patient developed persistent vomiting. Extensive diagnostic investigation revealed a concurrent diagnosis of MALS.

Management: Managing this patient required a highly specialized and multimodal approach. The PSH Assessment Measure was utilized to monitor episode severity. Pharmacological management involved a combination of Propranolol for autonomic stabilization of heart rate and Gabapentin for neuropathic and visceral pain modulation. However, because MALS represented an anatomical obstruction, standard PPC interventions were only partially effective. Following surgical release of the median arcuate ligament, the patient's clinical status and autonomic stability significantly improved.

Conclusion: This case illustrates that managing symptoms in PPC can be truly exhausting when anatomical anomalies like MALS act as refractory triggers for PSH. A multidisciplinary approach focusing on both neurological and vascular components is essential to break the cycle of pain and sympathetic hyperactivity in these vulnerable patients.

The Transition Pathway to Adulthood: Where Do We Stand?

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The transition to adulthood for patients with complex chronic conditions represents an increasingly significant focus for Paediatric Palliative Care (PPC) teams. They should not be a brief event; rather, it constitutes a prolonged and individualized process aimed at ensuring the maintenance of a high and long-lasting quality of life during and after the shift to adulthood.

In 2022, our home-based PPC service started a structured and collaborative pathway with the services involved (hospice, adult palliative care (APC) and local community), aimed to define the procedures necessary for achieving an effective transition.

This pathway starts at the age of 14, involving a reassessment of the patient's need alongside the identification of a General Practitioner (GP) who will assume the role of the patient's Case Manager upon their 16th birthday.

At this age, the patient is introduced to the local multidisciplinary team, social care and APC services. The objective is to identify the healthcare professionals to whom the patient's specific characteristics and care needs will be progressively transferred during regular outpatient or home-based consultations, as determined by the ACCAPED score.

Upon reaching their 18th birthday, adult services will become the primary clinical caretakers and, in collaboration with the GP, will guide the patient and their family into adulthood. PPC teams will work like a consultancy service until the age of 25 or until adult services have achieved full confidence and proficiency in managing the patient and their needs.

To establish an innovative pathway the sharing of information and collaboration among the various services is necessary.

The definition and implementation of a pathway designed to facilitate the transition to adulthood is an essential process, given the increased survival rates of this patient population, however for a small percentage of patients, with greater clinical complexity, the transition is impossible.

A Review of Opioid Availability in Pediatric Palliative Care in Low- and Middle-Income Countries

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Background and Aims: Approximately 98% of children requiring pediatric palliative care (PPC) live in low- and middle-income countries (LMICs); their effective pain relief is essential. Morphine availability is a global measure of palliative care access; yet, research on opioids availability for pediatric pain management (PPM) in LMICs remains limited. From a systematic literature review on opioid availability for PPM in LMICs, we describe an analysis of opioids access for PPC populations.

Methods: Search key words included opioids/specific opioids, pain, pediatric/children, and LMICs/specific country names, across multiple databases: MEDLINE, Embase, CINAHL, Web of Science, WHO Global Index Medicus, and Global Health. The search was limited to publications in English, with no restrictions on publication date; gray literature was excluded. Two reviewers evaluated articles for inclusion and data extraction and identified those relevant for PPC.

Results: Of 6,727 studies identified, 5,041 titles and abstracts were screened, resulting in 790 articles meeting the full-text review criteria. Of these, 28 articles (3.5%) addressed opioid availability in PPC, mostly in quantitative studies (20, 71.4%), from 14 countries and all WHO regions, mostly from India (9, 32.1%). Most commonly (15 of 28), publications addressed the use of opioids in PPC for children with cancer. The most frequently reported opioids were morphine and fentanyl, in 25 and 10 articles, respectively, followed by codeine (7), tramadol (6), methadone (5), oxycodone (4), pethidine (3), tapentadol (2), hydrocodone and buprenorphine (one each).

Conclusion: The results reveal a critical paucity of research/publications and possibly suggest limited opioid access for PPC in LMICs. To improve the quality of life for this vulnerable pediatric population, further efforts are needed to advance pain relief strategies, strengthen advocacy, enhance accessibility to essential medications, including opioids, and support research.

Tailored Emergency Training in Pediatric Palliative Care: Integrating PPC and Emergency Medicine

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Background and aims: Managing emergencies in pediatric palliative care (PPC) requires balancing life-saving interventions, proportionality of treatment, and advance care planning. Standard pediatric emergency training programs are poorly adapted to children with complex, incurable conditions receiving PPC. This study describes the development of a tailored training program for PPC professionals, co-designed with an Italian emergency medical service, to improve emergency management and procedural sedation safety in residential and home settings.

Methods: PPC professionals and emergency specialists co-designed a dedicated training pathway. Five preparatory meetings were held to review standard pediatric emergency programs and identify PPC-specific educational needs. A customized program was then developed and implemented.

Results: Two 16-hour training editions were conducted in February and March 2025, involving 19 PPC professionals (5 physicians, 14 nurses) working in residential and home care. Teaching methods combined lectures and high-fidelity simulation scenarios. Simulation improved technical competencies, team communication, shared decision-making, and management of the emotional burden during emergencies. Collaboration with emergency medicine professionals promoted the development of a shared language and operational strategies between services. Ethical aspects of proportional treatment and advance care planning were explicitly integrated into the training process.

Conclusions: This experience represents a replicable model of collaboration between PPC and emergency medicine services to address a relevant educational gap in complex pediatric care. Co-design, contextualized training, and high-fidelity simulation promoted both technical and relational competencies while supporting reflection on the appropriateness of interventions and treatment proportionality in PPC.

Organ and Tissue Donation in Community-Based Pediatric Palliative Care: Challenges and Gaps

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Background and aims: Organ and tissue donation pathways in pediatrics are primarily structured around intensive care settings, where life-sustaining treatments, controlled timing of death, and rapid access to procurement procedures are available. In pediatric palliative care (PPC) end-of-life care frequently occurs in hospice or home settings, centered on comfort and reduced medicalization. This review aimed to explore organizational and clinical challenges related to organ and tissue donation in community-based PPC settings.

Methods: A literature review was conducted using major scientific databases to identify studies addressing organ and tissue donation, PPC, hospice and home care settings, and end-of-life decision-making.

Results: Most retrieved literature focused on organ donation within pediatric intensive care units, while evidence regarding hospice and home PPC settings was limited. Major barriers included prognostic uncertainty, limited time windows for organ viability, lack of intensive care infrastructure, and incompatibility between procurement requirements and non-medicalized end-of-life care models. Donation after circulatory death often requires rapid perimortem coordination, invasive monitoring, operating room availability, and organ-preserving interventions which may conflict with comfort-oriented PPC goals. Tissue donation, particularly corneal donation, appeared more feasible in community settings due to longer postmortem viability windows and lower procedural invasiveness. Few studies addressed operational pathways, professional competencies, or communication strategies to support donation discussions in hospice or home PPC.

Conclusions: Organ and tissue donation in PPC remains an underexplored field characterized by significant organizational and logistical challenges. Expanding donation opportunities in hospice and home settings requires the development of context-sensitive pathways balancing feasibility and the non-medicalized philosophy of PPC.

Tissue Donation as Meaning-Making in Pediatric End-of-Life Care: A Case Report

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Background and aims: Parental grief after a child's death is often marked by helplessness, loss of meaning, and identity disruption. In pediatric palliative care (PPC), donation requests may represent not only medical decisions but also attempts to construct meaning and symbolic continuity during anticipatory grief. In community-based PPC, organ and tissue donation pathways are difficult to implement because end-of-life care occurs outside intensive care. This study describes a case in which tissue and body donation emerged as part of parental meaning-making during pediatric end-of-life care in hospice.

Methods: Single-case study combined with a narrative literature review.

Results: A 16-year-old girl with progressive invasive brain glioma was admitted to pediatric hospice after a six-year oncological trajectory marked by progressive neurological deterioration and loss of autonomy. During end-of-life care, the mother struggled to accept the prognosis and expressed the wish to donate her daughter's organs, corneas, and body to science. Solid organ donation was not feasible due to oncological contraindications. Through collaboration with the regional procurement service, corneal donation was successfully performed in hospice. Body donation to science was also organized through a dedicated network involving forensic physicians and university services specifically for minors. The PPC team supported the process through non-directive communication, emotional containment, and integration of donation wishes into the global care plan.

Conclusions: In PPC, tissue and body donation may represent meaningful components of parental bereavement and legacy-making. Donation can act as a coping strategy, supporting symbolic legacy, parental agency, and meaning reconstruction during profound helplessness.

From Caregiver to Hug-Giver: Building a Sibling-Centered Framework in Pediatric Palliative Care

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Background/Objectives: Pediatric palliative care (PPC) adopts a family-centered approach, yet siblings of children with life-threatening and life-limiting conditions often remain underrecognized despite their significant emotional, relational, and developmental needs. This study aimed to identify key areas for sibling assessment and support and to develop expert-informed recommendations for professionals working in PPC.

Methods: A two-round Delphi study was conducted with the participation of a multidisciplinary panel of 28 PPC experts, including physicians, nurses, psychologists, educators, and academics from various Italian regions. Seventeen experts completed the first round and nineteen the second. Qualitative content analysis of the first round's responses informed the development of a structured survey used to reach consensus on practical recommendations for sibling support.

Results: Consensus was reached in key areas of sibling care, including emotional assessment, family communication, understanding of illnesses, future concerns, and access to psychological support. Experts strongly supported providing age-appropriate information about illnesses and treatment procedures, involving siblings in communication processes, facilitating emotional expression, and offering structured educational and support interventions. A consensus also emerged regarding the usefulness of practical tools, such as explanations of medical devices, visual materials, and dedicated discussion opportunities.

Conclusions: Siblings represent an often overlooked population within PPC. Structured approaches to assessment, communication, and support can strengthen family-centered care while promoting emotional well-being, healthy adaptation, and the preservation of sibling relationships throughout the illness trajectory. Further research is needed to translate expert consensus into validated clinical tools and treatment pathways.

Making Care Needs Visible in Pediatric Palliative Care: Exploring the Role of ICNP®

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Background and aims: Pediatric palliative care (PPC) generates multidimensional information that is often poorly captured by diagnosis-oriented documentation systems. While classifications such as ICD support epidemiological and administrative coding, they fail to adequately represent care needs, symptom trajectories, family support, decision-making processes, and multiprofessional interventions across care settings. This study aimed to assess whether standardized care-oriented terminologies, particularly the International Classification for Nursing Practice (ICNP®), may provide a more suitable framework to represent PPC complexity.

Methods: A narrative literature review on ICNP®, semantic interoperability, and pediatric applications of standardized care terminologies was conducted in collaboration with the Italian ICNP Research and Development Centre to assess their applicability in PPC.

Results: ICNP® is described as a standardized terminology capable of representing care needs, interventions, outcomes, and clinical reasoning while improving interoperability, continuity of care, and visibility of professional contributions. ICNP® catalogues have been developed in neonatal, pediatric, emergency, prenatal, and infectious disease settings to support structured documentation and integration into electronic health records. Recent neonatal and NICU applications showed high compatibility with SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms) and highlighted the potential of care-oriented terminologies to improve comparability and reuse of clinical data. However, no specific ICNP® application in PPC was identified.

Conclusions: PPC highlights the limitations of disease-oriented documentation systems in representing complex care processes. ICNP® may offer a promising framework to improve visibility of care needs, multiprofessional communication, semantic interoperability, and future development of integrated PPC documentation systems.

Co-designing an Integrated Pediatric Palliative Care Pathway Between Hospital and Community

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Background and aims: Children with life-limiting conditions often experience fragmented transitions between hospital and community services, delaying access to pediatric palliative care (PPC). This project aimed to develop a shared, integrated care pathway between a public pediatric hospital and a community PPC service to improve identification, referral, and continuity of care.

Methods: A formal collaboration was established in 2021. In 2023, a multidisciplinary working group (physicians and nurses from intensive care, neonatology, pediatrics, neurology, surgery, hospice, home PPC, and hospital PPC) co-designed a PPC pathway. Nine meetings and remote drafting activities were conducted. Shared terminology, eligibility criteria, assessment tools, referral indicators, and operational flowcharts for hospital-to-community transitions, including neonatal settings, were developed. Educational activities on PPC assessment tools were also provided to hospital staff.

Results: The project produced an inter-institutional pathway including referral criteria, differentiated pathways for new and previously known patients, and operational guidance for transitions to home PPC or pediatric hospice care. Since Jan 2025, regular joint consultations by community PPC professionals within the hospital have further strengthened integration between settings. Between Jan and Oct 2025, 24 new cases were jointly discussed; 16 children had ACCAPED scores ≥ 50 , and 12 were referred to the community PPC service. Referrals progressively expanded from pediatric wards to neonatal and pediatric intensive care, surgery, neurology, and outpatient services.

Conclusions: Co-designing structured pathways between hospital and community services may improve early identification, shared decision-making, and continuity of PPC. Beyond developing an operational tool, this experience promoted organizational and cultural integration across clinical settings and may represent a reproducible model for PPC networks.

The Illusion of Presence? Artificial Intelligence and Relational Care in Pediatric Palliative Care

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Background/aims: Artificial intelligence (AI) is increasingly integrated into healthcare through conversational agents, virtual assistants, and systems capable of recognizing emotions and generating empathic responses. Families of children in pediatric palliative care (PPC) often experience high caregiving burden, social isolation, and a persistent need for information, reassurance, and support. In this context, technologies offering continuous availability and relational interaction are attracting growing interest. This study aimed to explore the implications of AI for relational care in PPC.

Methods: A narrative review of literature on artificial empathy, human-AI interaction, relational care, family support, and ethical aspects of healthcare communication was conducted. Key findings were discussed among PPC professionals and ethics experts.

Results: Evidence suggests that conversational AI may facilitate emotional expression, improve engagement, and provide perceived support through continuous availability and non-judgmental interaction. These features may be particularly relevant for families facing prolonged caregiving demands and limited access to immediate professional contact. However, the literature highlights the risk that technological availability may be perceived as relational presence, blurring the distinction between support and genuine human connection. This challenge may be particularly relevant in PPC, where care develops through complex relationships among children, caregivers, and professionals.

Conclusions: The ethical question is not whether AI can simulate relational behaviours, but whether technological availability can be mistaken for human presence. In PPC, where care is inherently relational, AI may complement but not replace the processes of accompaniment, responsibility, and shared meaning that characterize professional care relationships.

From “Journal Club” to Learning Community: A Model for Education in Pediatric Palliative Care

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Background and aims: Pediatric palliative care (PPC) requires professionals to maintain competencies across a broad range of clinical, ethical, psychosocial, and organizational domains. “Journal clubs” are recognized educational strategies to promote evidence-based practice, critical appraisal, and knowledge translation.

This study aimed to describe the development and evolution of a training model (Journal club) designed to support continuous learning within a PPC service.

Methods: In the PPC service, a multiprofessional training project (Journal club) was established in 2022, and in 2024 it was redesigned as a pediatric-specific educational pathway. Four sessions were held in 2024 and five in 2025. Meetings combined the presentation of scientific literature with multidisciplinary discussion. Participation and educational evaluations were retrospectively analyzed.

Results: Following its redesign as a pediatric-specific program, attendance increased by 50% and participation expanded from physicians and nurses to a broader multiprofessional audience. Topics included symptom management, long-term ventilation, advance care planning, communication, moral distress, siblings, and clinical complexity. Participants progressively assumed active roles in selecting, presenting, and discussing evidence relevant to clinical practice. Educational evaluation improved over time, with global satisfaction increasing from 3.3/4 to 3.7/4 and overall event evaluation from 3.3/4 to 3.9/4. Participants particularly valued interdisciplinary discussion, peer learning, and opportunities to translate evidence into clinical practice.

Conclusions: A structured multiprofessional field training project (Journal club) may represent a feasible strategy to sustain continuous learning, interdisciplinary dialogue, and evidence dissemination within PPC teams. Continuous evaluation and adaptation of educational programs may help sustain engagement and support evidence-based practice in PPC.

When Adult Care Needs Pediatric Expertise: A Reverse Transition Case

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Background/aims: Transition from Pediatric Palliative Care (PPC) to Adult Palliative Care (APC) is increasingly recognized as a critical phase for young people with LLCs. However, some young adults continue to present needs strongly related to childhood-onset diseases, creating challenges for adult services. This report describes a model of temporary PPC consultation requested by an APC team to support care planning for a young adult with a rare neurodegenerative disorder.

Methods: A 23-year-old woman with GM1 gangliosidosis type II, severe dystonia, chronic pain, progressive functional decline, and complex psychosocial needs was referred to an APC service. Faced with uncertainty regarding symptom management, proportionality of orthopedic interventions, communication, and long-term care planning, the adult team requested consultation from a specialized PPC service. Joint multidisciplinary assessments involving adult and pediatric palliative care professionals, neurologists, rehabilitation specialists, psychologists and educators.

Results: The consultation led to a shared care plan focused on symptom control, psychological support, rehabilitation goals, and future care planning. A short assessment admission in a pediatric hospice enabled multidimensional evaluation of physical, psychosocial, educational, and family needs. The process identified previously unmet needs, supported reassessment of treatment goals, strengthened patient participation in decision-making, and promoted activation and coordination of community services. Following this specialist phase, care responsibility returned to the APC team with shared objectives, strengthened territorial supports, and ongoing consultation from the PPC service.

Conclusions: This experience illustrates a temporary reverse transition model in which pediatric expertise supports adult services, facilitating multidimensional assessment, service integration, and coordinated community care.

Fragile Evidence in a Complex Field: Rethinking Standards in Pediatric Palliative Care

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Background and aims: Pediatric palliative care (PPC) remains underrepresented in the scientific literature because many eligible children are not identified as “palliative” and are distributed across multiple specialties and disease groups. This study aimed to analyze challenges in PPC literature retrieval and to evaluate the distribution of evidence levels in PPC publications over time.

Methods: A methodological review of PPC literature and search strategies was conducted using keywords related to pediatrics, palliative care, complexity, and needs-based approaches. Different search string structures were compared to improve the identification of PPC-related studies across specialties. Publications were categorized according to simplified Oxford Centre for Evidence-Based Medicine (OCEBM) levels to analyze the distribution of evidence over 5- and 10-year periods.

Results: Broadening search strategies beyond traditional palliative terminology improved the identification of PPC-related literature, particularly studies involving neurological disorders, rare diseases, neonatal conditions, and children with medical complexity. Across all periods, most publications were concentrated in lower evidence levels. Over the past year, Lev 4 studies represented 40% of publications and Lev 5 30%, while Lev 1 evidence accounted for only 9% and Lev 2 for 10%; Lev 3 represented 11%. Similar distributions were observed in the 5- and 10-year analyses.

Conclusions: These findings reflect the intrinsic complexity of PPC, where small populations, heterogeneous trajectories, ethical constraints, and individualized goals of care frequently limit the feasibility of randomized controlled trials. Consequently, observational studies, qualitative research, and clinical expertise remain central components of evidence generation and decision-making. Lower-level evidence does not necessarily indicate poor-quality care, but rather reflects the methodological challenges of a highly individualized field.

Point-of-Care Ultrasound in Extra-Hospital Pediatric Hospice Care: Clinical Integration and Training

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Background and aims: Point-of-care ultrasound (POCUS) is increasingly used in pediatric care to support bedside assessment and reduce procedural invasiveness. However, evidence in pediatric palliative care (PPC) remains limited. This study aimed to describe the integration of POCUS within a PPC service and to evaluate its contribution to symptom management, procedures, and staff training.

Methods: Since 2021, a PPC service has implemented a progressive POCUS integration program. The literature was reviewed, and staff competencies and training needs were assessed among physicians and nurses. Between 2022 and 2024, a structured educational pathway combining theoretical and practical training was developed. From January 2025 onward, a prospective registry has collected data on ultrasound use, including examination type, clinical indication, operator role, and level of autonomy.

Results: Two of five physicians received formal pediatric ultrasound training, while all nurses completed bladder ultrasound training; six nurses also achieved certification in ultrasound-guided vascular access placement. During 2025, 82 ultrasound evaluations were performed in 66 PPC patients. Procedures included vascular ultrasound for venous access (40%), thoracic ultrasound (27%), bladder assessment (13%), cardiac ultrasound (11%), and abdominal ultrasound (9%). Forty-four procedures (54%) were performed by physicians and 38 (46%) by nurses. Ultrasound-guided vascular access achieved a first-attempt success rate above 80%. Bladder ultrasound avoided unnecessary catheterization in six non-communicating patients. Thoracic ultrasound supported the early management of respiratory symptoms.

Conclusions: POCUS integration in PPC improved bedside decision-making, reduced procedural invasiveness, and supported individualized care for highly fragile children. This experience suggests that POCUS may be a feasible and valuable tool within PPC services.

Shared Clinical Language Using ICNP® for Integrated Care Planning in Pediatric Palliative Care

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Background and aims: Integrated care planning represents a central component of pediatric palliative care (PPC), supporting continuity, shared clinical reasoning, and coordination of multidimensional interventions across care settings. However, documenting integrated care plans remains challenging when documentation systems are primarily organized around disease-oriented classifications and fragmented professional records. Standardized care terminologies may support a more consistent representation of evolving care needs, interventions, and outcomes within multiprofessional care pathways. This study aimed to describe the development and implementation of an ICNP®-based integrated care planning system within a PPC service.

Methods: An action research project was conducted between 2022 and 2026. The process included staff training on ICNP® terminology, analysis of clinical care needs, development of a shared care planning model, mapping of diagnoses and interventions using ICNP® and SNOMED CT, multidisciplinary validation, and progressive integration into an electronic record system.

Results: The project led to the identification of 84 standardized nursing diagnoses subsequently clustered into 43 shared diagnostic categories and 444 coded interventions. Diagnoses and interventions were reviewed by nurses, physicians and other professionals involved in PPC pathways to ensure semantic consistency and multidisciplinary applicability. Integration within the electronic health record improved consistency of documentation, visibility of care processes, traceability of interventions, and multiprofessional communication through a shared standardized language.

Conclusions: Standardized care terminologies such as ICNP® may support visibility and representation of care complexity in PPC. Developing an integrated care planning system based on shared clinical language represents a strategic step toward semantic interoperability, continuity of care, and integrated documentation models.

Artificial Intelligence in Pediatric Palliative Care: Support, Delegation, and Responsibility

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Background and aims: Artificial intelligence (AI) is increasingly integrated into healthcare through large language models, decision-support systems, and predictive algorithms. Recent evidence suggests that AI may enhance information retrieval, diagnostic reasoning, and clinical decision support. However, pediatric palliative care (PPC) is characterized by uncertainty, complex decision-making, and individualized goals of care that extend beyond technical problem-solving. This study aimed to explore the opportunities and limitations of AI in PPC, focusing on the distinction between clinical support and the delegation of professional responsibility.

Methods: A narrative review of the literature on AI-assisted clinical reasoning, decision support, and ethical implications of human-AI collaboration was conducted. Findings were analyzed from a PPC perspective.

Results: Current evidence suggests that AI may support information synthesis, knowledge retrieval, differential diagnosis generation, and professional education. These applications may reduce cognitive burden and improve access to specialist expertise. However, decision-making in PPC frequently involves the interpretation of values, proportionality of treatment, advance care planning, and best-interest evaluations. Such processes require contextual judgement, ethical deliberation, and accountability that cannot be transferred to algorithms. The literature consistently identifies the distinction between support and delegation as a critical challenge for the future implementation of AI in clinical practice.

Conclusions: AI may offer valuable support for clinical reasoning and decision-making in PPC. However, responsibility for interpretation, deliberation, and action must remain human. The central challenge is therefore not whether AI can assist clinicians, but how to define appropriate boundaries between support and delegation.

Learning Through Cases: Building Reflective Practice in Pediatric Palliative Care

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Background and aims: Pediatric palliative care (PPC) requires complex clinical reasoning, interdisciplinary collaboration, and continuous integration of evidence into practice. Structured case discussion may support professional development by fostering reflective practice, shared interpretation of complex clinical and ethical situations, critical appraisal of decision-making, and professional wellbeing through the collective processing of challenging experiences. This study aimed to describe a multiprofessional case conference model implemented within a PPC service.

Methods: In 2024 and 2025, ten monthly meetings per year involved professionals from different PPC settings. Cases were presented on a rotating basis by different professional groups and discussed through case analysis, focused literature review, and multidisciplinary reflection.

Results: All participated actively, alternating, in the preparation of the meetings increasing the skills of literature evaluation, exposure, and structured clinical reasoning. Multidisciplinary discussion facilitated the comparison of perspectives and the integration of knowledge across professions and care settings. Educational evaluations consistently identified discussion of real clinical situations, interdisciplinary exchange, and opportunities for reflection as major strengths. Case conferences also generated proposals for practice improvement, protocol revision, service development projects, and shared approaches to complex clinical and ethical challenges.

Conclusions: Structured multiprofessional case conferences may represent an effective educational strategy to promote reflective practice, interdisciplinary learning, and continuous quality improvement within PPC services. Beyond individual case discussion, they can support the development of a shared clinical culture and collective responses to complex clinical and ethical challenges.

Caregivers of Children in Palliative Care: Identifying Education and Training Needs

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Background/aims: Children receiving pediatric palliative care (PPC) often depend on family caregivers to manage complex care needs at home. Educational support is therefore a key component of PPC, enabling caregivers to develop the knowledge and skills required for safe and effective care. This study aimed to identify the educational needs of caregivers of children in PPC and explore the potential impact of caregiver training on caregiver wellbeing.

Methods: A narrative literature review was conducted using PubMed, Embase, and Scopus. Articles published between 2014 and 2025 addressing caregiver education, training needs, and caregiver burden in families of children eligible for PPC were included. Eighteen records met the eligibility criteria.

Results: Educational needs were identified across a wide range of clinical conditions and stages of illness. Caregivers required support in understanding the disease, managing symptoms and emergencies, administering medications, providing nutritional care, performing basic daily care activities, and managing medical technologies and postoperative care. Educational interventions were delivered in both hospital and home-care settings and included individualized teaching, practical training, simulation-based approaches, written materials, and structured discharge programs. Across studies, training was associated with improved knowledge, confidence, self-efficacy, and preparedness for caregiving responsibilities. Several studies also reported reductions in stress and anxiety and improvements in perceived wellbeing, although direct evidence linking educational interventions to reductions in caregiver burden remained limited.

Conclusions: Caregivers of children in PPC have substantial and evolving educational needs throughout the illness trajectory. Education should be considered a core component of PPC, requiring ongoing assessment and personalized approaches that support both caregiving competence and family wellbeing.

Savior Siblings: Hope, Ethics and Family Decision-Making in Pediatric Stem Cell Transplantation

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Background, Context and Objectives: Hematopoietic Stem Cell Transplantation (HSCT) may offer a curative option for children with cancer when conventional treatments are insufficient. When a sibling is identified as a compatible donor, families face complex decisions involving benefits for one child and risks for another. This study synthesized evidence on family experiences and decision-making involving sibling donors in pediatric HSCT and implications for paediatric palliative care.

Methods: An integrative review was conducted using the Whittemore and Knafelz methodology. Searches were performed in five electronic databases. Primary studies addressing family decision-making related to pediatric HSCT were included. Data were analysed through thematic synthesis, focusing on ethical, emotional, and relational aspects of sibling donor decisions.

Results: Decisions involving sibling donors were shaped by hope, responsibility, and ethical concerns. Families viewed donor siblings as a source of hope while expressing concerns about donor burden, wellbeing, and family relationships. Parents reported responsibility, uncertainty, and fear of harming either child. Decision-making was influenced by treatment urgency, communication with healthcare professionals, and psychosocial support. Transparent communication, recognition of donor siblings' experiences, and multidisciplinary support were essential for shared decision-making.

Conclusions: Sibling donation in pediatric HSCT raises ethical and emotional challenges beyond clinical considerations. Families must balance uncertainty, competing responsibilities, and hope while seeking the best interests of all children involved. The findings highlight the importance of shared decision-making, psychosocial support, and attention to donor siblings during transplantation. Paediatric palliative care principles may strengthen support for families facing these decisions and reduce family suffering.

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Bereavement Experiences in Pediatric Palliative Care: Results of a Regional Survey

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Background: Despite the recognized importance of bereavement care, little evidence is available in the Italian context regarding parents' experiences following the loss of a child. This study aimed to explore the experiences of bereaved parents whose children were followed by the Regional Pediatric Palliative Care (PPC) Center of Friuli Venezia Giulia. The objective was to identify strengths and areas for improvement within PPC services and bereavement support.

Methods: A cross-sectional survey was conducted among parents of children who died between 2020 and 2025 while receiving care from the PPC Service of the IRCCS "Burlo Garofolo" in Trieste, Italy. A questionnaire was administered to Italian-speaking parents of deceased children, between May and June 2025. Descriptive statistical analysis was performed, and qualitative responses from open-ended questions were analyzed thematically.

Results: Thirteen families participated, providing a total of 15 parental responses. Most respondents were mothers (73.3%), with a mean age of 41 years. Thirteen deceased children were represented; 77% had non-oncological neurological conditions. Most deaths occurred in hospital settings (77%), while 23% occurred at home. Decision-making at the end of life was universally perceived as a shared process between families and healthcare professionals. Symptom control was generally rated positively, particularly for pain and dyspnea management. Parents identified PPC teams as highly valuable, while psychological, social, and spiritual support services were perceived as less available.

Conclusions: This study confirms the central role of PPC in supporting families facing the death of a child, particularly through effective symptom management, shared decision-making and the development of trusting relationships with healthcare teams. However, important gaps remain, including limited access to home-based end-of-life care, insufficient psychological and social support.

Working Together: Professionals' Views on Volunteers Integration in Paediatric Palliative Care

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Background and aims: Volunteers are recognized as an integral component of Pediatric Palliative Care (PPC) multidisciplinary teams according to Italian regulations. However, most evidence on effective volunteer integration derives from adult palliative care settings. Italian PPC experiences suggest that volunteers may contribute to patient support, recreational activities with siblings, and practical assistance to parents. This study aims to explore professionals' views on volunteers integration in a PPC service over the past five years, following structured selection and training process.

Methods: In May 2026, an online survey was administered to the PPC multidisciplinary team (>30 professionals: physicians, nurses, healthcare assistants, psychologists, educators, social workers, rehabilitation therapists). The questionnaire explores perceptions of volunteers' training outcomes (post-training and at one year), team integration, role boundaries, impact on professional work, and required competencies. It includes three sections: sociodemographic data (6 items), structured questions (18 items, 5-point Likert scale), and two open-ended questions to identify critical issues and improvement strategies.

Results: Between 2021 and 2026, four training courses were conducted; 35 volunteers completed the program, with 29 active as of March 31, 2026. The PPC team expanded to 35 professionals. Survey findings are expected to inform volunteer management by identifying strengths, perceived impact on care quality and workload, and areas for improvement, particularly in relational and play-based support. Perceptions of integration and training needs will also be explored.

Conclusions: The survey provides an opportunity for structured reflection on the role of volunteers within PPC teams and on main organizational aspects. Findings may inform the development of targeted training programs and more effective processes for volunteer integration into multidisciplinary care in PPC.

Exploring End-of-Life Care in Pediatric Intensive Care Units: A Pilot Survey of Health-Care Providers

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Background: End-of-life (EoL) care in Asian pediatric intensive care units (PICUs) is complex and inconsistent, resulting in varied experiences for patients and families and a lack of agreement on best practices.

Aim: To describe pediatric intensivists' attitudes towards EoL care

Methods: This pilot survey involved PICU physicians from a single institution in Singapore. Questions adapted from the Asian Critical Care Group's survey on Withholding & Withdrawing of Life-Sustaining Treatments in Intensive Care Units in Asia, covered DNR practices, LST limitations, comfort care, ethics consultations and barriers to ACP.

Results: Of 15 PICU physicians from a single tertiary institution who replied, 46.7% were between 40-49 years old, 60% had >10 years of experience but 86.7% did not receive prior palliative care training. 86.7% supported withholding or withdrawing therapies but opposed active shortening of the dying process (SDP) with 60% citing legal concerns. 13.3% disagreed that withholding and withdrawing therapies were ethically equivalent. All physicians opted to withhold or withdraw inotropes, mechanical ventilation, CPR and haemodialysis at EoL. For limitation of LST, all considered caregivers' requests for limitation of LST, poor expected long-term quality of life and patient suffering with continued PICU therapies. 40% felt parents and caregivers requested for inappropriate LST and 6.7% were unaware that an ethics consult was available. 13.3% would continue MV until cardiac standstill after brain death. Primary barriers to ACP creation were family resistance to EoL discussions (80%), cultural reluctance to talk about death (60%), dislike of EoL conversations (60%) and uncertainty about prognosis (60%).

Conclusion: This pilot study highlights the heterogeneity and challenges of pediatric EoL care within a single institution, emphasising the importance of further assessment of EoL perspectives in Asia. Such analysis is essential to develop region-specific EoL guidelines.

Passion and Concerns: Reflective Practice in PPC Education

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Background, Context, and Aims: The first specialized pediatric palliative care (PPC) team in our country was established in 2018 at the tertiary children's hospital. As the need for regional PPC teams became evident, we developed a basic PPC training program for healthcare professionals from regional hospitals and primary care centers. Besides clinical competencies, the program emphasized teamwork, self-care, and reflection. This study explores participants' concerns about working in PPC and the key messages they intend to bring back to their teams.

Methods: A total of 126 healthcare professionals attended a five-day PPC course covering symptom management, palliative nursing, communication, psychosocial and spiritual support, and organizational aspects of PPC. Workshops and guided reflection complemented the lectures. Participants provided open-ended responses about their concerns and the lessons they would transfer to their teams. Responses were analyzed qualitatively using thematic coding.

Results: The main messages participants identified were communication, teamwork, self-care, compassion, positivity, and focusing on what can be influenced. Four overarching themes emerged: effective communication, team connectedness, self-care, and psychologically safe relationships.

The main concerns involved emotional burden, organizational uncertainty, communication with children and families, and professional competence, together with lack of team support and concerns about personal well-being.

Conclusions: Participants emphasized that high-quality PPC requires not only clinical expertise but also self-care, strong teamwork, and organizational support. They highlighted the need for communication training and systematic psychological support, while recognizing self-care, respectful communication, and team connectedness as essential foundations of effective PPC practice. These findings will guide future education and the further development of pediatric palliative care services.

A 10-Year Evolution of Perinatal Palliative Care in a Tertiary Perinatology Center

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Background: Ten years ago, perinatal palliative care (PPC) was virtually nonexistent in our tertiary perinatology center at the University Hospital Olomouc. Families facing life-limiting fetal diagnoses or extreme prematurity lacked structured support. This presentation outlines the transformative decade-long journey of our department to establish a comprehensive and standardized PPC program.

Program Description: We have successfully developed and integrated a multidisciplinary PPC program encompassing the entire trajectory of care. Key clinical components include early advanced care planning, continuous psychosocial support for families, standardized end-of-life care for dying infants, dignified post-mortem care, and a structured bereavement program. Recognizing the profound emotional toll on healthcare professionals, we prioritized staff well-being alongside patient care. This includes mandatory ongoing education in sensitive communication and crisis intervention, as well as a staff support system utilizing supervision, intervision, and debriefings.

Results and Impact: The paradigm shift in clinical practice has been massive. Families now receive holistic, empathetic care tailored to their values and needs. Simultaneously, our staff reports increased confidence and reduced moral distress when managing complex end-of-life situations. While the progress is profound, we acknowledge remaining gaps in care provision, which serve as driving forces for continuous quality improvement.

Conclusion: The transition from a complete absence of structured PPC to a well-developed, standardized program demonstrates that profound systemic change in perinatal care is achievable. Investing equally in family-centered care and staff support systems is essential for the sustainable delivery of high-quality perinatal palliative care.

Bereavement Preferences in Asian Home-based Paediatric Palliative Care: A 14-Year Review

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Background and aims: Bereavement support models in paediatric palliative care (PPC) are informed largely by westernized literature: emphasising group interventions and led by social workers. Though widely adopted globally, its inherent transferability has yet been verified. Set within a home-based PPC service, this study explored the current state of bereavement support by (i) describing deceased patients, (ii) identifying preferred interventions, and (iii) examining follow-up patterns.

Methods: A mixed-methods retrospective study combining analysis of (i) medical records for all 392 patients who died between 2012 and 2026; (ii) 86 completed bereavement surveys rating the helpfulness of four post-death interventions (psychoeducational leaflets, phone calls, bereavement support group, memorial service); (iii) medical records of 1,906 bereavement contacts from 2017-2026.

Results: The cohort was ethnically, religiously, and diagnostically diverse (46.2% Cancer). Median age at death was 10.9 years, and 22.4% were aged ≥ 18 years. Among 86 families who completed the survey, post-death leaflets (75.9%) and phone calls (85.5%) were rated most helpful. Bereavement support groups (52.0%) and memorial services (48.4%) were rated lowest, with high non-engagement (10.8–40.3% "don't know"). Among bereavement contacts, median time from death to first contact was 1.5 days; all bereaved families received phone calls and 45.6% received physical visits within the first 30 days. Contacts by individual provider: social worker or allied health 51.4%, nurses 44.7%, doctors 3.9%.

Conclusion: Preferences for support were inverse to literature. Despite a sizable oncology sample, personal contact was rated higher than group and event-based formats. Group-based bereavement support models may not always fit a multi-ethnic and multi-religious cohort. Our findings suggest the need to reimagine flexible approaches to bereavement care that are customized or nuanced.

An Integrated Service Model for Delivering Pediatric Palliative Care in a Resource-Limited Setting

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Background: Access to pediatric palliative care (PPC) remains limited in many low- and middle-income countries due to workforce shortages and fragmented healthcare systems. We describe an integrated PPC service model to improve access, continuity, and early PPC involvement.

Methods: An integrated PPC service model was developed to provide coordinated care across multiple settings. Core components included inpatient and outpatient consultations, integration of PPC into an existing home health service, a dedicated telephone support line, trigger-based referrals, and multidisciplinary collaboration with psychology, nutrition, rehabilitation, welfare support, and adult palliative care teams. The model leveraged existing institutional and community resources, including ambulance services, equipment and philanthropic partnerships to address practical and psychosocial needs. Data from 2023–2025 were reviewed descriptively.

Results: Service utilization increased from 556 encounters in 2023 to 659 in 2024 and 901 in 2025, with 2,116 encounters for 390 children over a three-year period. The service supported children with an estimated case mix of 35% malignant and 65% non-malignant conditions. Trigger-based referrals facilitated earlier PPC involvement and strengthened integration within pediatric oncology and intensive care, while maintaining on-demand support for other pediatric specialties. Integration of PPC into an existing home health service expanded care beyond hospital-based consultations and promoted continuity across settings. Collaboration with nutrition, rehabilitation, welfare support, and adult palliative care teams enabled comprehensive multidisciplinary care despite a limited PPC workforce.

Conclusion: Leveraging existing healthcare systems and partnerships enabled sustainable growth of a comprehensive PPC service despite limited specialist resources. This model offers a practical framework for expanding pediatric palliative care in similar settings.

Building Pediatric Palliative Care Capacity Through Tiered Education in Low-Resource Settings

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Background: Healthcare professionals shortages & limited training opportunities remain major barriers to pediatric palliative care (PPC) integration in many low- and middle-income settings. A tiered educational model was developed across undergraduate and postgraduate training programs.

Methods: A tiered PPC educational model was integrated into existing pediatric training programs. Undergraduate medical students received an introductory PPC session and clinical exposure during their rotation. Postgraduate training was delivered through structured rotations for pediatric subspecialty fellows focusing on core PPC competencies. Educational outcomes were assessed through post-session and post-rotation evaluations.

Results: Between 2024 and 2026, 220 undergraduate medical students and 10 pediatric subspecialty fellows participated. Fellowship rotation expanded from a single oncology fellow in 2024 to include trainees from oncology, emergency department, child and adolescent psychiatry, and pediatric intensive care by 2026. Undergraduate evaluations demonstrated consistently high ratings across teaching effectiveness domains, including clarity, engagement, clinical relevance, communication, and enthusiasm for teaching (mean scores 5.46–5.64/6). Qualitative feedback identified PPC as an underrepresented component of medical education, increased appreciation of holistic care, and the value of early exposure to PPC. Fellow evaluations available at analysis demonstrated high satisfaction with the rotation structure, supervision, learning opportunities, and work environment, with domains rated 4–5/5. Fellows reported enhanced understanding of PPC, greater confidence in communication, interdisciplinary teamwork and family-centered care.

Conclusion: Integrating PPC education within existing training programs is a feasible approach to building workforce capacity in resource-limited settings. Early exposure and experiential learning can enhance awareness and confidence in PPC.

The Impact of Shared Care Planning on Moral Distress in Paediatric Palliative Care

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Background: Moral distress is increasingly recognised as a significant challenge for healthcare professionals working in paediatric palliative care (PPC). This phenomenon manifests in circumstances where moral values and clinical decisions collide, particularly in contexts characterised by uncertainty, complex treatment choices, communication challenges (Jeong et al., 2024). Shared care planning (SCP) has become increasingly relevant in paediatric end-of-life care. Although SCP has been associated with psychological benefits for healthcare professionals (Yeun, 2021; Souza et al., 2024), its potential contribution to addressing moral distress has received little attention. The present work aims to explore the potential relevance of SCP in addressing factors associated with moral distress in PPC.

Methods: A narrative review of the literature on moral distress, SCP, and PPC was conducted.

Results: No studies directly examining the relationship between SCP and moral distress in PPC were identified. However, the literature on these topics reveals several areas of convergence. SCP promotes dialogue, anticipates difficult decisions, clarifies goals of care, and supports shared decision-making. Interestingly, the same factors (early communication, clarity regarding treatment objectives, and reduced disagreement surrounding care decisions) have been associated with lower levels of moral distress (Chen et al., 2025). These conceptual overlaps suggest that SCP may influence mechanisms known to be relevant to moral distress.

Conclusions: Although direct evidence is currently unavailable, literature suggests meaningful overlap between the mechanisms underpinning SCP and those associated with moral distress in PPC. Dedicated empirical studies are needed to investigate this relationship and inform future strategies to support healthcare professionals while improving the quality of care provided to children with life-limiting conditions and their families.

From Implementation to Sustainability: Maintaining the Comfort Promise in Pediatric Oncology

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Needle-related procedures are a major source of fear, anxiety, and pain in children undergoing cancer treatment. The Comfort Promise Project promotes evidence-based interventions to prevent and reduce procedural pain, including topical anesthetics, comfort positioning, distraction, breastfeeding or oral glucose for infants, and rewards. Although implementation has been widely described, sustaining these practices over time remains challenging.

The Comfort Promise was implemented in a pediatric oncology center in Brazil in 2024. To promote sustainability, multiple strategies were adopted, including leadership meetings, communication campaigns for patients, families and healthcare professionals, continuous educational activities, integration of the protocol into the electronic medical record, and monitoring of adherence indicators.

Data from 250 needle-related procedures performed between January and April 2026 were analyzed. Topical anesthetic use achieved 85.9% adherence, representing the most consistently applied intervention. Distraction techniques were used in 56.0% of procedures, rewards in 73.9%, and breastfeeding or oral glucose in 20.0% of eligible infant procedures. Variability among departments was observed in both reporting rates and implementation of pain-management strategies.

Staff turnover was identified as a major barrier to sustainability. In contrast, leadership engagement, integration into institutional workflows, regular monitoring, and family involvement were important facilitators. Priorities for improvement include regular audits, ongoing professional education, enhanced data collection, and achieving at least 95% adherence to all core Comfort Promise strategies. Systematic monitoring proved essential for sustaining the program by enabling teams to track progress, identify gaps, and maintain focus on procedural pain prevention. Sustaining the Comfort Promise reflects an institutional commitment to safer, more humanized, and child-centered care.

Balancing Analgesia and Safety: Fentanyl Use in Neonatal Epidermolysis Bullosa

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Background and aims: Wound care in neonates with epidermolysis bullosa (EB) is associated with severe procedural pain requiring rapid and effective analgesia without prolonged sedation or respiratory compromise. Neonatal physiology, including an immature central nervous system, limited respiratory reserve, and reduced hepatic and renal function, alters pharmacokinetics and pharmacodynamics, increasing the risk of drug accumulation and respiratory depression. Pain assessment is further complicated by the inability of neonates to communicate verbally, necessitating reliance on behavioural and physiological indicators. This study aims to describe the use of fentanyl for short-term procedural analgesia in a neonate with EB.

Methods: This single-case study describes the use of fentanyl in a 20-day-old neonate with EB. An initial dose of 4 micrograms was administered under clinical supervision, followed by continuation in the home setting. Pain was assessed through observations by caregivers and healthcare professionals. Due to persistent pain signals, the dose was titrated to 6.75 micrograms and subsequently to 8.5 micrograms. Timing of administration in relation to wound care was also evaluated.

Results: Optimal analgesia was achieved when fentanyl was administered 30 minutes prior to wound care, without clinically significant sedation or respiratory complications. Over time, improvements in wound care, partial healing, and stabilisation of the wound pattern allowed gradual tapering and discontinuation of fentanyl. Transition to non-opioid analgesia proved sufficient, suggesting partial adaptation to chronic pain.

Conclusions: This case demonstrates the feasibility of opioid use in the home setting for neonates with EB and underscores the importance of careful dose titration and regular assessment. Despite limited evidence, it provides practical insights into safe and effective pain management in this vulnerable population.

Implementation of a Home-Based Rescue Protocol in Paediatric Palliative Care

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Background and aims: When curative treatment is no longer possible and patients are primarily managed at home within a pediatric palliative care setting, a structured rescue protocol can support timely and effective symptom control. This approach is based on advance care planning and aims to improve symptom management through close collaboration between the treating physician, hospital team, and home caregivers.

Methods: Following multidisciplinary discussion, expected symptoms related to disease progression, potential side effects of comfort-focused treatment, and appropriate emergency medications were identified. Medication was prescribed and dispensed as a single package by the hospital pharmacy. A personalized rescue protocol was developed for each patient, tailored to diagnosis, condition, weight, and anticipated symptoms, with pre-calculated doses according to established guidelines. The protocol was discussed with home nurses, general practitioners, families, and patients when appropriate. It was provided in paper and digital formats, regularly updated, and continuously evaluated according to the evolving clinical situation. After death, unused medication was returned to the hospital pharmacy and the process was evaluated.

Results: Since implementation, 112 rescue protocols have been developed, with 107 patients deceased and 5 active protocols remaining. Although not all medications were used, their availability enabled rapid symptom control in acute situations. Of the 112 protocols, 57 were actively used.

Conclusions: This structured approach improves patient comfort, reduces the burden on hospital services, and enhances the sense of security for caregivers and families. It represents a valuable tool in paediatric palliative care and supports effective home-based symptom management.

Flexible Use of Fentanyl for Procedural Pain in Children: Insights from Four Cases

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Background and aims: Procedural pain in paediatric patients, particularly in oncological, traumatic, and chronic conditions, remains a significant clinical challenge when standard analgesics provide insufficient relief. This case series aims to describe the use of fentanyl for short-term procedural pain management in paediatric patients across different care settings.

Methods: This case series included four paediatric patients receiving fentanyl for pain during wound care, medical manipulations, and radiotherapy when conventional therapy, including paracetamol, non-steroidal anti-inflammatory drugs, and/or morphine, proved inadequate. In two cases, fentanyl was initiated directly in the home setting without prior in-hospital test dosing. In one case, treatment was started under hospital supervision before continuation at home. In another case, fentanyl was prescribed and dispensed but not administered. Dosing was individualized based on weight and clinical response, ranging from 4 µg to 75 µg, with stepwise titration. Intranasal administration was used in all patients.

Results: Fentanyl proved effective in achieving procedural analgesia when appropriately timed and titrated, while background analgesia was maintained. In some cases, additional doses were administered shortly after the initial dose to optimize pain control during procedures. No clinically significant respiratory complications were observed.

Conclusions: These cases highlight the flexibility and safety of fentanyl for procedural pain in paediatric patients, including its use in the home setting without prior hospital initiation. Careful titration, timing, and multidisciplinary support are essential to optimize outcomes within a multimodal analgesic approach.

Approaches and Challenges to Communicating Poor Prognosis in Pediatric Advanced Cancer in LMICs

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Background: In low- and middle-income countries (LMICs), many children and young people (CYP) present with advanced cancer at diagnosis. Physicians face complex decisions about curative versus non-curative treatment while communicating difficult information before establishing a therapeutic relationship. This study explored physician communication with families at diagnosis in LMICs.

Methods: Semi-structured interviews were conducted with 36 physicians caring for CYP with cancer across diverse LMIC settings. Interviews were conducted in English, audio-recorded, and transcribed. Hybrid content analysis identified communication approaches, determinants, and challenges at diagnosis, informed by existing frameworks, including the Functional Model of Communication in Childhood Cancer.

Results: Thirty-six physicians participated; most were female (n=24; 67%), ≥36 years (n=32; 89%), and practiced in lower-middle-income countries (n=20; 55%). Physicians described established communication goals; however, their implementation differed in poor-prognosis contexts. Supporting families often involved facilitating decisions about second opinions or traditional medicine, while maintaining hope required reframing expectations and offering conditional optimism. Common practices (e.g., emphasizing positives, provider continuity) were not reported. Determinants operated at individual and institutional levels, including clinical urgency, prior training, and access to private space. Key challenges included supporting family acceptance of poor prognosis, clinician emotional burden, and navigating conflicting information within health systems.

Conclusion: Communication at diagnosis in LMICs requires adaptation of established practices to address poor-prognosis disease and resource constraints. Context-specific strategies, including voices of families, are needed to improve family-centered care and support clinicians.

Gabapentin in Children with Complex Healthcare Needs: A Retrospective Analysis

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Background and aims: Children with medical complexity (CMC) frequently experience pain and distressing symptoms. Although gabapentin is increasingly used in pediatric pain and palliative care (PPC), evidence remains limited. This study describes indications, dosing, and clinical outcomes of gabapentin use in a specialist PPC service.

Methods: We retrospectively reviewed gabapentin treatment episodes in patients with CMC actively followed between November 2025 and January 2026. Records were screened for indications, dose, outcome, and adverse events. Response was classified as none, partial, or complete according to clinician assessment. Associations were analyzed using appropriate non-parametric tests.

Results: Sixty-seven treatment episodes were included. Underlying conditions were predominantly severe neurological and neurodevelopmental disorders. Pain was the most common indication (59.7%), followed by spasticity/muscle spasms/dystonia (17.9%), epilepsy (7.5%), other indications (6%), sleep disorders (4.5%), and irritability/agitation (4.5%). Mean maximum maintenance dose was 20.6 ± 12.1 mg/kg/day (range 3–58.5). Response data were available for 60 cases: 11 (18.3%) showed no response, 33 (55%) partial response, and 16 (26.7%) complete response. Response did not differ by indication. Higher maximum maintenance doses were associated with better response (Kruskal-Wallis $\chi^2=10$, $p=0.007$). Partial and complete responders received higher maximum doses than non-responders ($p=0.031$ and $p=0.009$). Dose was positively associated with ordinal response (Spearman's $\rho=0.388$, $p=0.002$). No treatment-related hospitalizations occurred.

Conclusions: Clinical improvement was frequently documented during gabapentin treatment, but the retrospective design, absence of standardized outcome measures, and polypharmacy preclude conclusions on effectiveness. Prospective studies are needed to define gabapentin's role, optimal dosing, and safety in CMC.

Emotional Care Demands in Caring for a Child and Family at the End of Life in a Children's Hospice

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Background & Aims: End-of-life (EOL) care for Children presents significant emotional and ethical challenges for nurses, particularly in hospice/respite settings where care episodes are intermittent. While emotional burden in specialist palliative care is well documented, little is known about nurses' experiences in a Children's hospice/respite care. This study explores the emotional challenges faced by nurses, their impact on care delivery, and strategies to support resilience and translate research into bedside care improvements.

Methods: A qualitative descriptive exploratory design was employed. Purposive sampling recruited 12 registered nurses with a minimum of one year of experience in caring for Children and their families at EOL. Data were collected through in-depth interviews and analysed thematically in line with COREQ guidelines. Ethical principles were adhered to throughout.

Results: Four key themes emerged:

1. Emotional demands of care: Nurses experienced profound emotional strain, particularly in witnessing parental distress and grief.
2. Moral Responsibility: Ethical uncertainty related to ensuring a "good death" led to moral distress.
3. Professional Meaning-Making: Despite challenges, nurses described their role as a privilege centred on relational, family-focused care.
4. Sustaining Compassion: Peer support, reflective practice, and boundary-setting supported coping, though formal organisational supports were inconsistent.

Conclusions: Nurses in Children's hospice/ respite settings navigate complex emotional and ethical landscapes that directly influence the quality of care. Embedding emotional support, resilience training, and ethical guidance into organisational systems is essential to translate research into sustainable bedside practice.

Implications for Practice: Recognising a high level of emotional work as core clinical work can inform workforce planning, enhance staff wellbeing, and improve the delivery of compassionate, high-quality children's palliative care.

Communication and Maternal Meaning-Making of Artificial Nutrition in Paediatric Palliative Care

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Background-Context-Aims: Transitioning to artificial nutrition (AN) is vital for mothers caring for children with severe cognitive impairment in pediatric palliative care (PPC). Limited communication makes feeding symbolic, boosting mothers' confidence. Moving to AN is necessary but threatens maternal identity, leading to fear, resistance, and uncertainty. This study examined factors influencing mothers' understanding of AN to enhance communication.

Methods: A qualitative pilot study comprising 3 online focus groups with 6 mothers. Each 90-minute session was facilitated by a trained team, audio-recorded, transcribed, and accompanied by field notes. Data were analysed using reflexive thematic analysis within a constructivist-interactionist framework, with iterative coding and peer debriefing. Ethics, consent, and confidentiality were maintained.

Results: Two sets of factors were identified. Barriers included interrupted oral feeding, the medicalisation of nurturing, fear of harm, emotional isolation, and the view that AN was protocol-driven rather than a shared decision. Severe cognitive impairment worsened these issues by limiting signals and increasing uncertainty. Facilitators included clinical stabilisation, reduced anxiety, hands-on training that boosted confidence, and emotional communication, which helped mothers manage ambivalence. Peer support was highly valued, offering validation, reassurance, and guidance, and aiding mothers in re-signifying AN.

Conclusions: The findings emphasise communication strategies that recognise the symbolic meaning of feeding, validate maternal ambivalence, and avoid rigid protocols. Gradual training reduces anxiety, while stabilisation allows rethinking AN as protective. Peer support, valued by all, should be central to PPC for validation and guidance, aiding shared understanding during transition.

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Establishment of a New Model of Community Pediatric Palliative Service

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Background and Aims: The growing prevalence of children with life-limiting conditions (LLC) and medical complexity has increased the need for comprehensive pediatric palliative care (PPC). Despite legislative support for holistic care in Israel, access to community-based PPC remains limited, particularly in the Southern region. This initiative aimed to establish a multidisciplinary community PPC service providing individualized, goal-oriented care tailored to the clinical and cultural needs of the Southern periphery.

Methods: A community PPC service was developed based on four components: (1) a multidisciplinary PPC clinic; (2) specialist consultation for primary care physicians; (3) support for home hospice and continuing care services; and (4) training for community healthcare teams. The core team includes a PPC physician, clinical nurse specialist, and social worker. Care begins with a comprehensive assessment of socio-demographic, clinical, and family factors. Evaluation of symptom burden and family prognostic awareness informs individualized goals of care and an integrated care plan, delivered through multidisciplinary collaboration and ongoing care coordination.

Results: The service reached a diverse population, including secular and religious families, Jewish and Muslim communities, and children from urban, rural, and Bedouin populations. Preliminary outcomes showed reduced hospitalizations, improved symptom management, and high family satisfaction.

Conclusions: Community-based PPC is a feasible and effective approach for children with LLC and medical complexity. This model demonstrates the value of person-centered, culturally adapted care and may improve access to specialized PPC services in peripheral and underserved regions.

Childhood Cancer from Diagnosis to End-of-Life Care: Implications for Paediatric Palliative Care

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Background and aims: Childhood cancer requires ongoing family adaptation to changing clinical, emotional and relational challenges. Although paediatric palliative care promotes family-centred support from diagnosis onwards, evidence on family experiences throughout illness remains limited. This study aimed to understand family experiences of childhood cancer, including end-of-life care and bereavement.

Methods: A qualitative Grounded Theory study (Strauss and Corbin) included 16 parents of 11 children with cancer, including bereaved parents. Fourteen interviews were analysed using constant comparison, theoretical sampling and iterative coding.

Results: Families described childhood cancer as a dynamic process shaped by uncertainty, changing priorities and repeated transitions. End-of-life care emerged as a significant phase, characterised by a gradual shift from pursuing cure to prioritising comfort, quality of life and meaningful family experiences. Parents described balancing hope and acceptance while seeking reassurance that all reasonable treatment options had been explored. Families valued honest communication, shared decision-making and care aligned with family values and preferences, including children's participation in discussions about their care. Challenges included difficulties discussing prognosis, the absence of formal advance care planning and limited access to coordinated palliative care services, affecting preparedness and preferred goals of care. After the child's death, families emphasised the importance of emotional support and opportunities to preserve meaningful connections and memories.

Conclusions: Findings highlight the importance of integrating PPC principles throughout the illness trajectory. Communication, shared decision-making and advance care planning supported preparedness and family-centred care. Early, coordinated and relationship-centred PPC may improve care aligned with family values and preferences in paediatric oncology.

Every Minute Counts - Increased Registration of Deceased Children in a National Register

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Background: The Swedish Register of Palliative Care (SRPC) is a national quality registry that has contributed to quality improvement in adult palliative care, with a coverage rate of approximately 60% of all adults who die. For children (0-17 years of age), however, the coverage rate in the SRPC is only about 10%, which leads to unequal prerequisites for the use of registry data as a basis for care development and research in pediatric palliative care.

Aims: To describe the implementation and preliminary results of a national intervention to increase the registration of children in the SRPC.

Method: A national educational intervention was launched 2025. In the first step, five training videos describing how the registry works, the use of registry data in quality improvement efforts, and symptom assessment in children at the end of life was produced and released in October 2025. In a second step healthcare unit managers in Sweden were offered training sessions for healthcare staff. In a third step, the project has been promoted on social media and at national and regional conferences. Data from the SRPC will be collected on children registered 2024 – 2026 and analyzed to illustrate effects in total registration as well as regional and diagnosis-related variances throughout the country.

Results: The intervention is ongoing and is being monitored through analysis of number of registered users and the number of registered children, both showing a positive trend. The poster will present preliminary results after one year of intervention.

Conclusion: Through increased registration of children in the SRPC the project will enhance possibilities for clinical improvement, knowledge development and more equitable palliative care for children.

Beyond Translation: Adapting EPEC Pediatrics and Learner-Centred Education in the Czech Republic

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Background and aims: As pediatric palliative care (PPC) develops in the Czech Republic, the need for professional education is increasing. Between 2024 and 2026, EPEC Pediatrics, an internationally recognized curriculum, was implemented through translation of background materials, faculty development, and creation of a national course model. An accompanying educational research programme evaluated participant experiences and faculty delivery of learner-centred teaching methods during the first Czech pilot course in April 2026.

Methods: A mixed-methods evaluation combined pre- and post-course questionnaires, participant reflections, lecturer self-assessment and parallel evaluation of faculty competencies, peer observation, structured feedback, and ethnographic observation. Outcomes included perceived relevance to clinical practice, psychological safety, engagement, and acceptance of interactive learning methods. IBM SPSS was used for descriptive analysis of quantitative data, thematic analysis for open-ended responses, and interaction analysis for ethnographic observations.

Results: 24 healthcare professionals participated. Compared with previous educational experiences, participants reported greater applicability of course content and acquisition of meaningful new knowledge and skills despite prior PPC training. Psychological safety emerged as a key finding: participants reported high engagement, greater comfort asking questions and expressing opinions, and valued the multidisciplinary learning environment.

Conclusions: Preliminary findings support the feasibility and acceptability of implementing EPEC Pediatrics in a new educational and cultural context. Ongoing evaluation will examine the sustainability of learner-centred teaching methods, faculty development, and participant outcomes during wider implementation and may inform adaptation of international PPC curricula in other countries.

Worldmaking from the Edges and the Gaps: (Re) Imagining Objectivity and Subjectivity in PPC Research

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Background: The Declaration of Helsinki reflects biomedical tradition in which the physician serves as an objective observer, the intervention as the object of study, and ethics as the protection of participants from harm. Its 2024 revision advances toward participatory engagement. Yet, families (patients and their kin) remain, within this framework, stakeholders to be consulted rather than subjects whose knowledge is constitutive of the research itself. Vulnerability, where acknowledged, is framed as a risk factor to be managed, rather than a condition that generates irreplaceable knowledge and specific relational obligations.

Method: In PPC research, the researcher is never singular. Multiple professional subjectivities enter the research space, each shaped by distinct disciplinary formations, none of which is neutral. The protective logic of do no harm cannot exhaust the ethical demands of encounters with families navigating loss, illness, and institutional power. The ethical question: *what must we not do?* - must be transformed into: *what are we doing together, and how does the research process perform or fail to perform care?*

Results: Objectivity in PPC research emerges from subjectivity: a negotiated performance of care produced at the peripheries where multiple subjectivities intersect - entailing a rethinking of families as epistemic subjects whose lived experiences constitute forms of knowledge that no single discipline can fully contain.

Conclusion: Drawing on Joan Tronto's *caring with* as a political act, PPC research participates in a paradigm of care as relational, temporal, and performative. Care surfaces as a political category: a commitment to those rendered vulnerable by illness, loss, and discursive formations that determine who counts as a knowing subject. PPC research becomes a form of worldmaking - emerging from the edges where temporalities, vulnerabilities, and subjectivities intersect to reconfigure what counts as knowledge, care, and participation.

Building Compassionate and Ethically Sustainable PPC Research Cultures

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Background: This presentation addresses challenges in PPC research culture by describing the establishment of an interdisciplinary research lab. It outlines how shared values were collectively articulated during the lab's formation.

Method: Grounded in a relational epistemological approach, the process involved facilitated co-creation sessions among lab members, followed by an individual reading of an inspirational article: *"Professionally Strong and Compassionate Research Environments – Perspectives from Within and Beyond"*. Exploring how research environments can combine high academic performance with compassion, respect, and create sustainable research cultures.

Two sessions were facilitated by a group member and carried out as a collective process of mapping keywords through shared discussion. The keywords captured both individual and shared values, visions, and reflections, exchanged through collaborative sense-making and a reflexive thematic approach. We articulated a set of core values, discussed their relative prioritization, and identified the most central ones in relation to one another.

Results: The process was condensed into the following statement: *We aim for our research community to be grounded in shared and individual excellence and ambition, sustainably integrated into a culture of connectedness, care, and kindness*. This collaborative approach has clarified priorities and established principles for an ethically grounded research culture, and continuous work of revisiting and actively engaging with the values as the research lab evolves.

Conclusion: Creating intentional space for value-based formation within PPC research communities fosters ethical attunement, strengthens alignment with clinical practice, and supports interdisciplinary collaboration. By articulating shared principles through a structured, participatory process, such approaches can model research cultures responsive to the relational dimensions of conducting research in the sensitive field of PPC.

***ShareHope*: A Photo-narrative Approach to Understanding and Supporting Hope in Pediatric Oncology**

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Background: Hope can shape how children with cancer and their families cope, communicate, and make decisions. Few tools exist to support hope as cancer advances. Photo-narrative interventions use stories and images to foster therapeutic reframing and meaning making—key mechanisms for nurturing hope in serious illness. Photo-narrative has demonstrated feasibility, acceptability, and impact in adult oncology and pediatric critical care, but is underexplored in pediatric oncology.

Methods: *ShareHope* is a longitudinal study with two aims: 1) to characterize hope trajectories among children with cancer and their families using participant-generated photo-elicitation interviews, and 2) to co-design a theory-informed photo-narrative intervention that supports hope across the cancer trajectory. First, patients and parents meet with a researcher every 3 months for one year to share photos depicting their hopes. Second, patients, parents, and clinicians join focus groups to refine a photo-narrative intervention that nurtures hope for families facing cancer.

Findings: *ShareHope* is ongoing. Here, we present preliminary insights on the acceptability of photo-narrative hope research in the pediatric cancer community. Patient and parent advisors expressed enthusiasm for the photo-narrative approach, appreciated its therapeutic potential, and recommended attention to diverse hope experiences. Oncologists and clinical trialists affirmed the need for novel ways to support hope and the opportunity for partnership between therapeutic and supportive care trials. Psychology, child life, and spiritual care clinicians shared how the research questions address patterns they observe clinically, including how hope anchors meaning-making.

Conclusion: Our experience launching *ShareHope* supports the feasibility and relevance of photo-narrative approaches to foster hope. Future work will evaluate intervention prototypes, equitable engagement strategies, and measurable outcomes for efficacy trials.

From Concept to Care: Implementing Hungary's First Integrated Paediatric Palliative Care Programme

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Background: Until recently, children in Hungary with life-limiting conditions had no access to a formal, integrated paediatric palliative care (PPC) service. This gap is striking in a tertiary children's hospital that cares for roughly 65% of the country's paediatric haemato-oncology patients. In May 2025, we set out to change this, launching a structured PPC programme for children with both malignant and non-malignant conditions. Here we describe what it took to build the service from the ground up, and what we learned along the way.

Methods: We documented the development process prospectively from May 2025 onwards. Progress was tracked across five parallel domains: multidisciplinary team recruitment, integration with existing hospital departments, care pathway and documentation design, AI-assisted workflow development, and patient enrolment. Each domain was evaluated against milestones defined at the outset.

Results: Twenty children were referred within the first two months, across both malignant and non-malignant diagnostic categories. A multidisciplinary team of eight was established, with active collaboration across eight hospital departments and ongoing expansion. The principal challenges were rarely clinical: cultural resistance, limited infrastructure, staff recruitment, and the negotiation of role boundaries with established teams. A purpose-built documentation framework and AI-assisted tools were developed to support clinical workflow and continuity of care.

Conclusions: Building a country's first integrated PPC programme is achievable, but it demands more of culture and relationships than of clinical protocols. Our early referral data point to a substantial unmet need. We hope this experience offers something useful to others starting out, or working with limited resources, elsewhere in Europe.

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Beyond Prognosis: Hope and Meaning-Making Among Families of Children with Edwards Syndrome

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Background, Context and Objectives: Edwards Syndrome (Trisomy 18) is a life-limiting condition associated with prognostic uncertainty and anticipatory grief. Families often receive narratives centred on mortality, yet little is known about how they construct meaning and sustain hope throughout their child's illness trajectory. This study explored meaning-making among families raising children with Edwards Syndrome and its implications for paediatric palliative care.

Methods: An interpretive qualitative study was conducted with ten families of children diagnosed with Edwards Syndrome. Semi-structured online interviews explored experiences from diagnosis through care. Data were analysed using reflexive thematic analysis informed by a meaning-making perspective.

Results: Families described profound disruption following diagnosis, marked by anticipatory grief and prognostic narratives focused on death. Meaning-making emerged through three interconnected processes: reconstruction of maternal identity, reinterpretation of life, death and caregiving, and transformation of suffering into purpose through advocacy and support for other families. Hope remained a central resource, not as denial of prognosis but as a way of sustaining connection, possibility, and purpose despite uncertainty. Spirituality, supportive relationships, and access to information strengthened families' capacity to navigate challenges and reframe experiences beyond biomedical expectations.

Conclusions: Adaptation to Edwards Syndrome involves ongoing reconstruction of meaning in the face of uncertainty and potential loss. Hope and meaning-making coexist with anticipatory grief and contribute to family resilience. Paediatric palliative care should support meaning-making, foster compassionate communication, recognize parental expertise, and create space for hope alongside realistic prognostic discussions. Such approaches may strengthen family-centred care for children living with life-limiting conditions.

From Cultural Humility to Ethical Action: Nurses in Family-Centred Paediatric Palliative Care

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Background, Context and Objectives: Family-centred paediatric palliative care requires nurses able to communicate across cultural differences, support shared decision-making, and respond ethically to the needs of children and families. This study explored how an international Collaborative Online International Learning (COIL) experience contributed to competencies relevant to paediatric palliative care.

Methods: A conceptually informed educational study was conducted with undergraduate nursing students from Brazil and the United States. Participants engaged in intercultural learning activities addressing family-centred care, family nursing, and global perspectives on health and care. Reflective narratives and discussions were analysed using thematic analysis.

Results: Three learning processes emerged. First, students expanded their understanding of family experiences with chronic illness, caregiving, vulnerability, and healthcare decision-making across cultures. Second, intercultural dialogue promoted ethical reflexivity by challenging assumptions about family roles, parental authority, quality of life, and decisions involving children with serious conditions. Third, participants reported greater readiness for family-centred communication, partnership with families, and ethically responsive care. Cultural humility emerged as a key element supporting ethical sensitivity and responsiveness to family values. These competencies are highly relevant to paediatric palliative care practice, particularly in situations involving uncertainty, complex decision-making, and caregiving.

Conclusions: Preparing nurses for paediatric palliative care requires ethical competence, cultural humility, and engagement with families facing uncertainty and complex decisions. International collaborative learning may strengthen these competencies and support the preparation of a compassionate, ethically grounded, and family-centred workforce.

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Referral to Neonatal Palliative Care in Hypoxic-Ischaemic Encephalopathy: A Five-Year Cohort Study

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Background and aims: Hypoxic-Ischaemic Encephalopathy (HIE) remains a major cause of neonatal mortality and severe neurodevelopmental impairment. Prognostic uncertainty, high-intensity treatment and time-sensitive decision-making make neonatal palliative care (NPC) particularly relevant in this population. This study aimed to identify clinical and neuroradiological factors associated with referral for NPC in newborns with HIE and describe care trajectories.

Methods: A retrospective observational study was conducted on 90 newborns with HIE undergoing therapeutic hypothermia between 2020 and 2024. Clinical, biochemical and neuroradiological variables were analysed, including brain magnetic resonance imaging (MRI) severity scoring. Factors associated with referral for NPC were assessed through univariate analysis. Palliative care trajectories were described.

Results: Eight of 90 newborns (8.9%) were referred for NPC. No significant differences were found in prenatal or intrapartum factors. Referred newborns had lower Apgar scores at 1 and 5 minutes ($p=0.004$ and $p<0.001$), more severe metabolic acidosis (pH $p=0.006$; base excess $p=0.008$), higher HIE severity (median Sarnat stage 3 vs 2, $p<0.001$), and more frequent seizures (88% vs 5%, $p<0.001$). All referred newborns had abnormal MRI findings (100% vs 33%, $p<0.001$), with higher severity scores and greater deep grey matter involvement. Care trajectories differed according to the timing of NPC activation and the degree of shared decision-making with families.

Conclusions: Referral for NPC was strongly associated with severe neurological injury defined by clinical and MRI markers. The findings provide a basis for developing structured referral criteria and a dedicated neonatal palliative care pathway for infants with HIE. Limitations include the retrospective single-centre design and the small number of referred patients. Standardised NPC pathways may improve care planning and family support.

Funding: no external funding.

A Changing Landscape: Thirty Years of Family Narratives in Paediatric Spinal Muscular Atrophy

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Background: Spinal muscular atrophy (SMA) is a progressive inherited neuromuscular condition caused by SMN1 gene loss, historically associated with early death or severe disability. Three approved disease-modifying therapies have fundamentally altered prognosis, yet the psychosocial implications for families remain poorly characterised. This review examines how the scientific literature on parental and patient perspectives has evolved across thirty years and what this means for clinical practice.

Methods: A structured PubMed search identified 42 peer-reviewed English-language publications (1990-2026) examining parental and patient perspectives in paediatric SMA. Publications were grouped into three eras: Supportive Care (1990-2009), Translational (2010-2014), and Post-Approval (2015-2026). Thematic synthesis was combined with term-frequency analysis in R. Four themes were identified: evolving psychosocial burden, decision-making under uncertainty, therapeutic hope alongside pragmatism, and access to information and peer support.

Results: During the Supportive Care and Translational eras, literature centred on grief and end-of-life decision-making. In the Post-Approval era, themes shifted toward treatment navigation and the emotional complexity of caregiving under uncertainty. Prognosis-related language featured in all Supportive Care Era publications but fewer than 10% of Post-Approval Era papers, while treatment-related and patient-centred outcome terminology was absent before 2015 and emerged in approximately 20% of Post-Approval Era publications.

Conclusions: Grief remains central to the SMA family experience, refigured alongside hope and uncertainty within a treatment landscape that barely existed a decade ago. Clinicians may consider tailoring communication strategies and integrating psychological support alongside disease-modifying therapy. As current treatments remain non-curative, palliative care involvement may be valuable for all affected families.

Recommendations on Documentation and Sharing of Pediatric ACP Outcomes: A Modified Delphi Study

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Background: Inconsistent documentation and sharing of advance care planning (ACP) outcomes hinders the care that aligns with values, goals, and preferences of children with life-limiting conditions and their families. Current guidelines provide limited guidance on these processes. This study aimed to develop consensus-based recommendations for documenting and sharing ACP outcomes in pediatric palliative care in the Netherlands.

Methods: A modified Delphi consensus study was performed between January and May 2026. Recommendations were informed by previous qualitative studies involving parents and healthcare professionals (HCPs), and a scoping review of literature and guideline recommendations. A multidisciplinary expert panel rated the recommendations on agreement and feasibility using 9-point Likert scales. Consensus was predefined as $\geq 70\%$ of participants scoring within the highest tertile. Recommendations not reaching consensus were discussed during a multidisciplinary consensus meeting, which also explored implementation requirements.

Results: Seventy experts from various disciplines and care settings completed the Delphi questionnaire. Consensus was achieved for 16 of 17 recommendations in this round, and no additional recommendations were proposed. The recommendation on keeping up-to-date ACP documents physically available near the child did not initially reach consensus (68%) and was revised during a consensus meeting attended by 21 experts. The final recommendations addressed what ACP outcomes should be documented, where they should be recorded, and how they should be shared within the care network. Key implementation requirements included a uniform location for documentation and sharing, clear agreements on responsibilities, and training for HCPs.

Conclusions: Consensus was achieved on recommendations for documenting and sharing ACP outcomes in pediatric palliative care. Future efforts should focus on supporting implementation through practical guidance and tools.

Factors Influencing Documentation and Sharing of Pediatric Advance Care Planning Outcomes

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Background: Advance care planning (ACP) is increasingly embedded within pediatric palliative care. Despite guidelines recommending documenting and sharing of ACP outcomes within the involved care network, this is not consistently achieved in practice. This study aimed to gain insight into factors influencing the documentation and sharing of ACP outcomes within pediatric palliative care.

Methods: Semi-structured interviews were conducted with 15 parents of ten children with life-limiting conditions, and focus group interviews were held with involved healthcare professionals (HCPs) (n=31). Data were analyzed thematically and findings were categorized according to the Grol and Flottorp framework (innovation, HCP, parent/patient, social, organizational, economical/political).

Results: In total, 77 barriers and 69 facilitators were identified across all framework domains. HCPs described challenges in documenting sensitive content of ACP conversations without losing nuance and unclear responsibilities within the care network. Both HCPs and parents reported a lack of guidance on how ACP outcomes should be documented and shared. Parents' need to maintain control over communication between HCPs and challenges related to privacy legislation, were identified by both groups. Facilitators included a proactive attitude of HCPs toward information sharing, as identified by both parents and HCPs. HCPs additionally highlighted existing interprofessional relationships and the use of communication platforms that facilitate accessible multidisciplinary consultation, such as multidisciplinary team meetings.

Conclusion: The documentation and sharing of ACP outcomes are influenced by factors at multiple domains. Developing practical guidance and clear interprofessional agreements on the documentation and sharing of ACP outcomes may help address these challenges and facilitate care aligned with the values, goals, and preferences of children with life-limiting conditions and their families.

Feasibility of CSNAT-I Paediatric for Identifying and Addressing Parents' Support Needs in PPC

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Background: Following the establishment of a national paediatric palliative care (PPC) unit in Norway in 2020, the Carer Support Needs Assessment Tool Intervention Paediatric (CSNAT-I Paediatric) was introduced to systematically identify parental support needs and tailor services for families. We aimed to explore feasibility from the perspectives of parents and intervention providers, and to identify parents' prioritised support needs.

Methods: Intervention providers received formal training in CSNAT-I Paediatric, and an internal implementation guide was developed. Feasibility was assessed across acceptability, demand, implementation, practicality, integration, and adaptation. Cognitive interviews explored parental (n=34) acceptability and potential adaptations. Parent-reported feasibility was collected using an electronic questionnaire (n=12), and parents' identified support needs were extracted from the children's medical records. A focus group explored intervention providers' (n=6) perspectives.

Results: Thirty-four parents of 17 children with severe neurological impairment, including neurometabolic disorders, participated in the feasibility study. CSNAT-I Paediatric was considered acceptable and relevant across domains. Parents suggested adaptations to better capture care coordination and children's daily activities. Support needs were diverse and often required coordinated cross-sector input. Providers reported that the tool supported structured identification of needs and tailoring of care, but highlighted challenges in implementation and follow-up within routine workflows.

Conclusions: CSNAT-I Paediatric appears feasible in a Norwegian PPC setting. Feasibility findings indicate acceptability, demand, and practicality, but also highlight implementation challenges. Effective implementation requires strengthened interprofessional and cross-sector collaboration to address complex family needs. Further refinement may improve integration into clinical practice.

Hope4Kids: Holistic Oncological Palliative Care for Europe's kids. A European Joint Action

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Background-context-aims: Each year, an estimated 25,000 children and adolescents in Europe are diagnosed with cancer. Paediatric Palliative Care (PPC) focuses on prevention and relief of suffering in patients, and their families, with life-threatening or life-limiting illness, starting from diagnosis. Whilst the benefits of PPC are well established, access to PPC services, knowledge, and expertise varies significantly across Europe. The European Joint Action Hope4Kids, co-funded by the EU, aims to bring together European countries to advance PPC in paediatric oncology, focusing on increasing access to PPC, strengthening collaborations, and expanding knowledge to reduce inequalities through sharing models and best practices, pilot-testing interventions, and improving resources available to parents and healthcare providers.

Methods: Hope4Kids consists of four cross-cutting Work Packages (WPs): Coordination, Dissemination, Evaluation, and Sustainability, and four content generating WPs: landscaping of European PPC, developing evidence-based guidelines, pilot studies, and education and training. Six core themes are embedded across the project: symptom management, advance care planning, shared decision making, psychosocial care, pre-loss and bereavement, and models of care.

Results: Participants in the Hope4Kids project include more than 70 organisations, including hospitals, health authorities, research organisations, and patient/parent organisations, representing 22 European countries. The project results will be finalised by September 2029.

Conclusions: The aim of Hope4Kids is to improve the availability and quality of PPC and reduce inequalities across Europe. By bringing together policy, practice, and research, the action will deliver concrete benefits for patients, their families, and healthcare providers, ultimately improving quality of life for children with cancer and their families.

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Psychosocial Well-Being in Preschool Children Affected by Life Limiting Childhood Illness

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Background: Healthy siblings of children with life-limiting conditions may be at increased risk of psychosocial difficulties, yet little research has focused on preschool-aged siblings. This study aimed to explore psychosocial adjustment and mental health among preschool siblings and evaluate the preliminary validity of a screening questionnaire for siblings aged 3-6 years called the MiniSIBS questionnaire.

Methods: Twenty-five preschool siblings (2-6 years) of children with chronic illness, disability, or life-limiting conditions were recruited through pediatric palliative care services in Norway. Parents completed the MiniSIBS questionnaire and the Child Behavior Checklist (CBCL 1½-5).

Results: Parents reported attention-seeking behavior, increased vigilance toward the affected sibling, limited understanding of the sibling's condition, and stress-related reactions. While mean CBCL scores were within the normal range, comparison with Norwegian norms indicated moderately to substantially higher levels of emotional and behavioral difficulties (Cohen's $d = 0.69$). MiniSIBS total scores were significantly associated with CBCL total problem scores and demonstrated acceptable internal consistency (Cronbach's $\alpha = 0.72$).

Conclusions: Preschool siblings of children with life-limiting conditions may show higher levels of psychosocial burden than those reported in normative samples, despite generally normative functioning. These findings highlight the importance of routine sibling assessment in pediatric palliative care. MiniSIBS shows promise as a brief screening tool for identifying sibling support needs, although further validation is required.

Supporting Young Siblings Through Play: A Pediatric Palliative Care Intervention

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Background: Siblings of children with chronic health conditions are at increased risk of psychosocial difficulties, highlighting the need for preventive interventions. This study evaluates the play-session component of MiniSIBS, an intervention designed for children aged 3–6 years who have a sibling with a chronic condition and/or life limiting disease.

Methods: Eleven children participated in three individual play sessions with an educator (33 sessions in total). Video-recorded sessions and follow-up interviews with educators were analyzed using content analysis. Observer agreement on themes and emotions expressed in play was also examined.

Results: Children most frequently engaged in everyday-life and medical play, expressing emotions such as joy, fear, sadness, and anger. Observer agreement was high. Educators reported increased awareness of the importance of appropriate play materials, active involvement in children's play, and recognizing siblings as next of kin. They also identified areas for improving the intervention.

Conclusions: MiniSIBS play sessions appear to provide a safe space for young siblings to express experiences and emotions related to living with a sibling who has a chronic condition and/or life limiting disease. The findings also suggest benefits for educators. Further research with larger samples is warranted

Early Implementation of Pediatric Palliative Care in Inherited Metabolic and Muscular Diseases

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Background: Pediatric Palliative Care (PPC) is an approach aimed at improving the quality of life of children with life-limiting or life-threatening conditions and their families. Children affected by inherited metabolic disorders (IMDs) and neuromuscular diseases (NMDs) often present complex clinical, psychosocial, and organizational needs that justify early PPC integration. However, despite international standards and legislation in Italy, PPC admission of these patients remains delayed and inadequate. This study aimed to identify and stratify patients with IMDs and NMDs eligible for PPC in an Italian tertiary pediatric hospital.

Methods: A single-center observational study was conducted at the Inherited Metabolic and Neuromuscular Diseases Unit of Meyer Children's Hospital IRCCS (Florence, Italy). All pediatric patients (<18 years) admitted through inpatient or day-hospital services were included. Eligibility for PPC was assessed according to GO-PPaCS criteria and clinical red flags. A representative sample of eligible patients underwent evaluation with the ACCA-PED scale.

Results: Among 1,113 evaluated patients, 831 met inclusion criteria: 592 with IMDs, 113 with NMDs, and 126 without a definite diagnosis. Overall, 372 patients (45%) were eligible for PPC (47% of those with IMDs and 78% of those with NMDs). ACCA-PED was administered to 244 eligible patients. Stratification identified 161 children (66%) with low-complexity needs, 62 (25%) with medium-complexity needs, and 21 (9%) with high-complexity needs. Among high-complexity patients, 4 had already been referred to the PPC team.

Conclusions: A substantial proportion of children with IMDs and NMDs are eligible for PPC and may benefit from its early integration. The ACCA-PED proved effective in stratifying clinical complexity, supporting a personalized PPC model. Early activation of PPC services may improve quality of life, optimize resource allocation, and promote continuity of care for patients and families.

The Value of Talking about Death & Dying Workshops for Children's Health Professionals in the UK

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Background & Aims: Effective communication about death and dying is core to children's palliative care. Professionals often report challenges addressing these topics with families, highlighting training and emotional support needs. Drawing on Narrative and Systemic Therapy approaches, Talking about Death & Dying workshops aim to develop professionals' confidence and skills, providing reflective spaces to share experiences and approaches to death-talk and opportunities to practice conversations. This study explores the impact of delivering these one-day workshops to UK health professionals.

Methods: 60 professionals attended 7 workshops and completed pre-and post-workshop questionnaires. Self-rated scores were analysed using Wilcoxon Signed-Rank Test. Thematic Analysis was used for qualitative data.

Results: There were statistically significant improvements in participants' comfort levels for talk with adults ($z=6.031$, $p<.001$) and children ($z=6.222$, $p<.001$) and overall confidence for death-talk ($z=6.447$, $p<.001$). There was a significant increase in their ability to signpost to relevant services ($z=6.309$, $p<.001$) and increased confidence managing their own feelings ($z=4.994$, $p<.001$).

All participants reported new learning about how to talk about death and dying and increased confidence to engage in conversations. Participants had new ideas about how to approach talking and not feel afraid. They named listening more, asking questions and allowing pauses as useful techniques, alongside acceptance of not being able to fix or have answers to everything and taking time to prepare, reflect and respond-rather-than-react. Participants planned to be more involved in co-working, seek advice from colleagues, support each other, share resources and practice more self-care.

Conclusions: Talking about Death & Dying workshops significantly enhanced professionals' skills and confidence to talk about death and understanding of the importance of collaborative working and self-care.

Who was Providing What for Whom in UK Children's Palliative Care Psychological Services in 2025

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Background and Aims: Definitions of children's palliative care include emotional and social support for the whole family. There is no UK national guidance on what psychosocial provision should look like in terms of workforce professions/therapeutic skill mix, service offers for families or consultation to multidisciplinary teams (MDTs). This project explored who was providing what for whom in UK children's palliative care psychosocial services in 2025.

Methods: Leads for all children's palliative care psychosocial services across the UK were asked to complete a 24 item survey to describe who in the family was offered therapy, how many sessions were offered, types of therapy offered and therapist qualifications.

Results: 24 (75% of) Children's Hospices and 15 NHS Children's Palliative Care Services in England and Wales returned the survey. Most services offered individual therapy to parent/carers (92%), siblings (90%) and children with palliative care needs (87%). Most Hospices provided therapeutic groups. Only half of services provided family therapy. 11% of service offered up to 6 appointments, 22% offered up to 12 sessions and 67% offered more than 12 sessions/had no limit. Across 39 services, practitioners were qualified to provide more than 20 different types of psychological therapy, with no single therapy offered by all services. Counselling and Cognitive Behaviour Therapy were most frequently available. Services employed over 25 different professional groups, with no single profession present in all models. Most services offered joint-working, consultation, teaching and facilitated MDT debriefs.

Conclusions: There was wide variation of children's palliative care psychosocial service models in England and Wales in 2025. Findings could inform development of "What Good Looks Like" guidelines for services. Follow-up studies will map staffing ratios, referral pathways, assessment approaches and explore the impact of different models on family experience and outcomes.

Supporting the Multi-agency Network When a Child Dies: The Value of On-line Co-memorating Meetings

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Background and Aims: Drawing on key concepts and approaches of Narrative and Systemic Therapy, Fredman (1997) developed Co-memorating Meetings as a model for all professionals involved in a child's care to Re-member a child who has died. The meeting format invites professionals to reflect on connections between professionals and with the child and family and to celebrate new learning as gifts to improve care. Previous evaluation of In-person Co-memorating Meetings found consensus that this approach provided effective staff support, created new learning, improved collaborative working and enabled development of individualised bereavement care for families. During the COVID-19 pandemic, evaluation of Online Co-memorating Meetings showed similarly positive outcomes. This study further examines impact of online delivery, evaluating participant feedback from 45 On-line Co-memorating Meetings.

Methods: Content analysis of anonymous semi-structured feedback forms completed by health, education, and social care professionals who attended 45 Co-memorating Meetings convened by an NHS regional children's palliative care service psychologist over a 3.5-year period.

Results: 79 of the 234 professionals who attended the 45 meetings returned feedback forms (34% response rate). 98.7% of respondents rated meetings as extremely useful (49/79) or somewhat useful (29/79). Feedback about "usefulness" included Value of 'Shared reflection, remembrance and emotional processing', 'Hearing different perspectives', 'Team working' and "Learning about the family's journey'. When asked what they would like to be different, themes were 'No Changes Needed' (39/79) and 'Wider Attendance' (12/79). "Take home messages" included the Importance of 'Communication, relationships & partnership working' and 'Family-centred care & wishes'.

Conclusions: Co-memorating Meetings are valued and useful practice in children's palliative care with potential to support all members of the multi-agency network around a family.

Developing a Psychosocial Regional Managed Clinical Network for Children's Palliative Care in the UK

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Aim: To share learning from the first UK project to develop the psychosocial component of a Children's Palliative and End of Life Care (PELoC) Managed Clinical Network (MCN).

Background: NHS Specialist PEOLC Service Specification stipulates the *"workforce must include... experts in provision of psychosocial support in the context of PEOLC and bereavement"*. However, there is no guidance on psychosocial service structure and there is wide variation of models in the UK. National Institute for Health and Care Excellence recommends creation of MCNs to provide coordinated clinical leadership, promote effective collaboration across organisational boundaries, improve quality and provide equitable PEOLC. However, networks had not focused on psychosocial service development across a region before now.

Methods: (1) A survey mapped children's PEOLC psychosocial provision across a region.
(2) Key stakeholders attended engagement meetings to develop a networked approach.
(3) The first children's PEOLC MCN Psychosocial Conference was evaluated using thematic analysis of delegate feedback.

Results: Mapping identified absence of psychosocial service provision in 14/18 NHS hospitals in region. Families could access psychological therapies from 5 children's hospices.

Hospice psychosocial leads established a Children's PEOLC MCN Psychosocial Steering Group with the NHS regional consultant psychologist and MCN Co-ordinator, and organised a regional psychosocial conference.

Delegates gave highly positive experience ratings (4.83/5, N=30). Qualitative feedback included: Valuing connection, learning and sharing; Inspiration and motivation to improve services; Hopes for collaboration.

The Steering Group created a regional strategy and education program including partnering with a systemic institute to provide accredited family therapy training.

Conclusions: Taking a networked approach supported the children's PEOLC psychosocial workforce to feel valued and motivated and enabled collaboration to improve skills.

The Child–Caregiver–Nurse Triad in Pediatric Palliative Care

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Background/aims: Pediatric palliative care (PPC) is a holistic and family-centred approach that addresses the physical, emotional, psychological, social and spiritual needs of children with LLCs or LTCs. Within PPC, care develops through complex relationships involving children, caregivers and healthcare professionals. This study aimed to explore how communication and interpersonal relationships within this triadic framework influence care experiences and outcomes.

Methods: A narrative literature review was conducted using PubMed, CINAHL and Embase. Studies addressing communication, child participation, family involvement and the role of nurses in PPC were analyzed to identify recurring themes related to relational care.

Results: Thirty-eight publications were included. Across studies, effective communication emerged as a central component of PPC, supporting trust, reducing uncertainty and facilitating shared decision-making. Children benefited from developmentally appropriate involvement in discussions regarding their care, promoting emotional expression, participation and a sense of agency. Families were consistently identified as an integral part of the unit of care, requiring information, emotional support and active involvement throughout the illness trajectory. Nurses played a pivotal role in facilitating communication, advocating for the child's voice, supporting caregivers and promoting continuity across care settings. The literature also highlighted the importance of relational competence in addressing emotional distress, strengthening therapeutic alliances and supporting adaptation to changing clinical circumstances.

Conclusions: The child–caregiver–nurse triad represents a fundamental relational framework in PPC. Strengthening communication, participation and family engagement may contribute to improved quality of life, greater satisfaction with care and more holistic and family-centred models of support for children with serious illness and their families.

Catalyzing Compassion: Paediatric Palliative Care Global Academy Impact in Limited-Resource Settings

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Background & Aims: Globally, almost 98% of paediatric palliative care (PPC) needs are in limited-resource settings. An empowered and educated workforce is essential to accelerate PPC integration in these contexts. To address this need, we implemented the Global Academy Palliative Care Training Seminar (PCTS) and evaluated its impact.

Methods: Between March and May 2026, a mixed-methods survey was conducted among three PCTS interprofessional cohorts (2022, 2023 and 2024). The PCTS combined a 3-day Education in Palliative and End-of-Life Care (EPEC)-Pediatrics Train-the-Trainer workshop, a 1-day Pediatric Palliative Oncology Symposium, and a 1-day hands-on training in integrative therapy. The impact survey covered items evaluating participants' intent to action, output, estimated patient reach, and personal growth. Data was analyzed using descriptive statistics and rapid thematic analysis.

Results: One hundred participants from 46 countries replied (response rate=82%). They included 68% physicians, 16% nurses, 13% allied health, and 3% others. To date, all have been active in PPC development, including efforts in quality improvement (n=59), research (n=45), education (n=80), program development (n=56), and policy (n=18), with 32 initiatives completed. In each domain, more than 50% of respondents noted that the PCTS helped "a lot" in conducting these projects. Cumulatively, participants estimated that over one million children and families globally have benefited from initiatives conducted after the PCTS. The qualitative analysis revealed a multilevel PCTS impact. Key themes comprised a mindset shift aligned with best PPC practices, local empowerment to overcome barriers, and multilateral collaborations resulting from participation.

Conclusion: This study unveiled the promising impact of the PCTS. Further research and program replication are essential to understand the impact of such programs beyond knowledge gains and leverage educational pathways for PPC development.

Too Little, Too Late? Timing of Referral to Specialist Paediatric Palliative Care

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Background: Early integration of paediatric palliative care (PPC) is associated with improved symptom management, advance care planning and family support. Despite increasing recognition of these benefits, concerns remain regarding the timing of referral to specialist PPC services. This study evaluated referral timing and clinical complexity within a hospital-based specialist PPC service.

Methods: A retrospective service evaluation was undertaken of all children and young people referred to the Paediatric Supportive and Palliative Care Team (PSPCT), Royal Hospital for Children, Glasgow, between September 2023 and August 2024. Routinely collected demographic, diagnostic and outcome data were analysed. For children who died during the study period, the interval between referral and death was examined.

Results: Seventy-five children were referred during the study period. Ninety percent had non-malignant conditions. Children demonstrated substantial clinical complexity; 84% required at least one long-term medical technology and 92% were classified as unstable, deteriorating or dying at referral. Thirty-five children died during the evaluation period. Of these, 26% died within one week of referral, 52% within one month and 80% within 100 days. Four children were referred on the day of death or after death had occurred. Only 20% survived beyond 100 days following referral. Referrals originated from multiple specialties and health boards across Scotland.

Conclusions: Children referred to specialist PPC services represent a highly complex population with significant palliative care needs. Referral frequently occurred late in the illness trajectory, limiting opportunities for longitudinal symptom management, advance care planning and relationship building with families. Earlier identification and integration of specialist PPC may improve access to comprehensive support throughout the course of life-limiting illness.

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Beyond End-of-Life: Complexity in a Hospital-Based Paediatric Palliative Care Service

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Background: Children with life-limiting conditions are increasingly medically complex, yet limited data describe those requiring specialist paediatric palliative care (PPC). Understanding the needs of this population is essential for workforce planning and service development. This study describes the characteristics of children referred to a hospital-based specialist PPC team.

Methods: A retrospective service evaluation was undertaken of all children and young people referred to the Paediatric Supportive and Palliative Care Team (PSPCT), Royal Hospital for Children, Glasgow, between September 2023 and August 2024. Routinely collected demographic and clinical data were analysed.

Results: Seventy-five children were referred during the study period. Ninety percent had non-malignant conditions, with neurological disorders the largest diagnostic group. Thirty-seven percent lived in Scotland's most deprived communities and 27% were from minority ethnic backgrounds. At referral, 92% were classified as unstable, deteriorating or dying. Eighty-four percent required at least one long-term medical technology and 55% required two or more technologies to sustain life. Feeding devices were present in 76%, respiratory support in 51% and vascular access devices in 33%. Thirty-one percent required intensive care support, including invasive ventilation and extracorporeal life support. Over half of referrals originated from health boards out with the tertiary centre.

Conclusions: Children referred to specialist PPC services represent a highly complex population with substantial medical and technological care needs. The predominance of non-malignant disease, technology dependence and clinical instability challenges traditional perceptions of PPC as primarily end-of-life care. These findings have implications for workforce planning, service design and equitable access to specialist PPC expertise.

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Parent and Health Professional Differing Priorities for Pediatric Palliative Care Quality Outcomes

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Background and Aims: Internationally endorsed core outcome sets are essential for advancing consistent assessment of the impact of specialized pediatric palliative care (PPC) to allow comparisons and aggregation of findings across studies. A key component in developing core outcome sets is involving patients, families, and health professionals (HP) in selecting the most important outcomes to include. Using a systematic, international, consensus-building process, we developed core end-of-life (EOL) (last 30 days of life), and PPC (earlier in the disease process) outcome sets and examined similarities and differences in parent- and HP-prioritized outcomes.

Methods: As part of the consensus process, we conducted best-only maximum difference (MaxDiff) scaling surveys. Parents and HP were shown four outcomes at a time from either the EOL or PPC outcome sets, and asked to choose the most important one, ultimately creating rank ordered lists of outcomes for each group. We compared similarities and differences in the order of items in the parent and HP lists for both the EOL and PPC outcome sets.

Results: A combined total of 55 parents and 70 HPs from 21 countries ranked 47 EOL or 47 PPC outcomes. Across both sets, parents and HPs agreed on the highest ranked outcomes which focused on reducing suffering from symptoms and experiencing a quality of life meaningful to the child. Notable differences included higher parent prioritization of outcomes related to supporting parents to provide care, respecting parent expertise, and advocating for family needs and higher HP prioritization of child-reported outcomes.

Conclusion: Differences between parent and HP priorities underscore the importance of including both perspectives in developing core outcome sets. Our findings also highlight the need to understand parent priorities to guide PPC planning, delivery, and evaluation of care quality.

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Voices First: An Anticipatory Communication Model

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Background: Children with diffuse midline glioma (DMG) and high grade glioma lose the ability to communicate verbally as they approach end of life. Communication supports are reactive, limiting uptake and benefit. *Voices First* is a quality improvement initiative informed by bereaved parents that aims to prepare children and families for expected speech loss. Seeking to preserve voice, choice and dignity through planning and coordinated interprofessional care.

Methods: This multi-phase quality improvement (QI) project is based at The Hospital for Sick Kids in Canada. Bereaved parents of children in this patient population, followed by the Pediatric Advanced Care Team (PACT) between 2020-2025 can participate in semi-structured narrative interviews. Exploring preparedness for communication changes, speech loss, support gaps, and recommendations. Qualitative thematic analysis will guide the development of a standardized anticipatory communication pathway involving speech-language pathology (SLP), nursing, psychosocial clinicians, palliative care, and family caregivers.

Results: Data collection and preliminary analysis are underway. Anticipated outcomes include identifying family-defined best practices, barriers to communication support, and strategies to improve preparedness for progressive speech loss. Early findings suggest families often feel unprepared for rapid communication decline and report delayed introduction of Augmentative and Alternative Communication (AAC) supports. Emerging themes highlight the importance of early communication planning, normalized AAC use, and timely access to tools and community resources, insights that will inform Phase 2.

Conclusions: Informed by families and supported by interprofessional collaboration across hospital and community settings, *Voices First* aims to shift communication support from reactive to anticipatory. Early, proactive intervention may help preserve connection, participation, identity, and dignity for these children.

Ten Years of Educating Professionals Caring for Children and Youth with Life-Limiting Conditions

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Background and aim: Fifteen years ago, pediatric palliative care for children and adolescents was scarcely recognized in Norway, either as a concept or as a form of care for those with life-threatening or life-limiting conditions. Following the introduction of national guidelines, it became clear that professionals working with this population needed specialized competence. Our institution was tasked with developing an interdisciplinary educational program tailored to this group. The aim is to describe the development of a specialized interdisciplinary educational program in pediatric palliative care in Norway and to align its curriculum with international standards for care of children and adolescents.

Methods: We conducted a retrospective review of successive program plans (2016 to present) and a descriptive analysis of student records from the institutional database. Curriculum content was mapped against relevant international standards and recommendations.

Results: Since 2016, more than 150 participants, including healthcare professionals, chaplains, psychologists, social workers, and teachers, have completed the program. Participants work with children and adolescents across primary care, specialist services, and residential or educational settings. Preliminary analysis indicates increasing alignment between successive program plans and international standards.

Conclusions: The program has evolved in step with advances in pediatric palliative care and user identified needs and largely aligns with international recommendations and standards. We will present preliminary findings and outline priorities for further development.

Use of Antenatal Symptom Management Plans for Families Known to Paediatric Palliative Care Services

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Background and Aims: Antenatal referrals to our specialist paediatric palliative care (PPC) service requesting support with future care planning and symptom management are increasing. This study aims to evaluate the use of bespoke symptom management plans (SMPs) as part of future care planning in these cases.

Methods: A single-centre retrospective chart review of all cases referred to a tertiary PPC service over a 6-year period from 2020 to 2026.

Results: Forty antenatal referrals were made to the PPC service over a 6-year period. 21 (52%) cases were provided with bespoke SMPs. The three most prevalent diagnostic groups receiving SMPs were abnormal brain/spinal cord development (29%, n=6), Trisomy 18 (24%, n=5), and cardiac disorders (19%, n=4).

Documented SMP use was seen in less than half of cases (43%, 9/21), with a majority being used for babies over 24 hours old. SMPs were not used at all in the six cases who died within the first 24 hours of age. Despite their prevalence, babies born with abnormal brain/spinal cord development were one of the least likely groups to receive symptom management as per their SMP (17%, 1/6), whilst the most likely groups were skeletal dysplasia (100%, 1/1) and cardiac disorders (75%, 3/4).

SMPs were more likely to be used in cases where first PPC assessment occurred later in pregnancy (75% [3/4] in cases met at 35+ weeks), than if met earlier (40% [2/5] in cases met at 21 – 30 weeks, and 36% [4/11] in cases met at 30 – 35 weeks).

Conclusions: SMPs are an important part of future care planning in antenatal cases across a wide range of life-limiting conditions. They appear to be more commonly used in babies with ongoing survivorship, and less commonly used to provide symptom management in the first 24 hours of life – although it is recognised that these findings are limited by sample size. On-going inter-disciplinary collaboration across the paediatric spectrum is required to ensure optimal symptom management for these children.

Say Their Names: Bereaved Parent Partners in Pediatric Palliative Care Education

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Background and aims: Preparing clinicians to provide family-centered pediatric palliative care requires meaningful engagement with family perspectives, which remain underrepresented in health professional education. Grounded in Transformative Learning Theory, this study evaluated a pediatric palliative care workshop co-designed and delivered with bereaved parent partners for clinicians in a pediatric hematology-oncology setting.

Methods: A workshop for the multidisciplinary pediatric hematology-oncology team was co-designed and co-facilitated by bereaved parent partners. Parents shared lived experience narratives in guided discussion and reflection. Additional content included communication, spiritual care, bereavement support, symptom management, and end-of-life care. Evaluations used Likert-scale and open-ended questions assessing reflection, family experience understanding, communication confidence, and practice change.

Results: Twenty-three participants completed evaluations: primarily nurses (75%), social workers (13%), and one child life specialist, physiotherapist, and patient care attendant. Most had more than 10 years of experience (67%). All reported parent narratives provided new perspectives, prompted reflection on their professional role, and would influence future communication. Participants described improved understanding of the emotional, psychosocial, and spiritual impact of serious illness and greater preparedness for end-of-life conversations (91%). Three themes emerged: (1) deeper understanding of family experiences; (2) changes in communication emphasizing validation, empathy and transparency and (3) bereaved parent involvement in identifying care gaps and making learning clinically meaningful.

Conclusions: Integrating bereaved parent perspectives promoted reflective learning, empathy, and communication preparedness. Future research should explore this family-centered model's applicability beyond pediatric oncology.

How Do Children Die? End-Of-Life Circumstances in a Dutch Tertiary Pediatric Population

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Background and aims: Understanding how and where children die is essential for improving paediatric palliative care (PPC) services. However, data on end-of-life circumstances in children with life-limiting or life-threatening conditions (LLC/LTC) remain scarce. This study describes end-of-life characteristics of a single center cohort and explores differences according to LLC/LTC status.

Methods: We conducted a retrospective cohort study of deceased children aged 0–17 years at the University Medical Center Groningen between 2018 and 2023. Pregnancy terminations, intrauterine fetal deaths, stillbirths, and cases with insufficient information were excluded. Clinical and end-of-life characteristics were analysed descriptively and compared between children with and without LLC/LTC.

Results: Among 448 deceased children, 54.5% had an LLC/LTC and 8.3% died after trauma/suicide. Overall, 60.9% died as a result of their underlying disease. Other documented causes included respiratory failure, organ failure, sepsis and neurological complications. Most deaths (77.8%) occurred after withdrawal (or withholding) of life-sustaining treatment due to refractory suffering and absence of further disease-directed treatment options. The majority of children died in the hospital (76.5%), mostly at the intensive care unit (59.9%).

Compared with children without LLC/LTC, those with LLC/LTC were more likely to receive support from the Pediatric Palliative Care Team (PPCT) (24.3% vs 10.3%), receive palliative sedation (32.3% vs 20.3%), die at home (20.7% vs 10%) and die following withdrawal or withholding of life-sustaining treatment (91.9% vs. 75.6%) (all $p \leq 0.005$).

Conclusions: Children with LLC/LTC experience distinct end-of-life trajectories characterised by greater involvement of PPC services, more frequent palliative sedation, and a higher likelihood of dying at home. These findings highlight opportunities for earlier integration of PPC and may support service planning and policy development.

Who Needs Paediatric Palliative Care? a National Multicenter EHR Study

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Background and aims: Although pediatric palliative care (PPC) services are well established in the Netherlands, there's no national overview of children eligible for PPC. This hampers timely identification, equitable access, and service planning.

This study aims to map PPC at a national level and estimate the number of children potentially eligible for PPC using routinely collected electronic health record (EHR) data.

Methods: We are conducting a nationwide retrospective study using EHR data (2023–2024) from all Dutch university medical centers (n=7), the national pediatric oncology center, and three randomly selected general hospitals.

The study population includes children aged 0–17 years and follows a five-step approach: (Step 1) (Step 2) Identification of diagnoses and care characteristics among children receiving care from Pediatric Palliative Care Teams (PPCTs) and among deceased children. (Step 3) Synthesis of these diagnoses with international literature and expert input to develop a comprehensive diagnosis list, (Step 4) application of this list to identify children with potential PPC needs not receiving PPCT care, and (Step 5) validation through clinician survey and development of a traffic-light referral model for PPC.

Results: The results will generate the first national estimates of the number of children with life-limiting and life-threatening conditions (LLC/LTC) in the Netherlands and quantify current PPCT involvement. It will also deliver a validated diagnosis list and identify unmet PPC needs and reveal variation in access to PPC services.

Conclusions: By enabling systematic identification of children with potential PPC needs, this approach may facilitate earlier referral, improve equitable access to PPC, and support evidence-based service planning. The methodology is scalable and may be transferable to other healthcare systems.

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Bone Fragility in Children with Medical Complexity: Predictors and Clinical Management

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Background and Aims: Bone fragility is a clinically relevant condition in the pediatric population, particularly among children with medical complexity (CMC) affected by chronic or rare diseases. The lack of shared guidelines contributes to heterogeneity in clinical management. The aim of the study was to identify potential predictors of bone fragility in CMC and to contribute to the development of a structured and reproducible diagnostic-therapeutic approach.

Methods: A monocentric cross-sectional observational study was conducted in patients older than 3 years with conditions associated with secondary bone fragility risk. Subjects were divided according to densitometric Z-score values (≤ -2.5 vs > -2.5), with values ≤ -2.5 considered pathological. Clinical, anthropometric, functional, biochemical, imaging, and densitometric data were collected. Associations between Z-score and variables of interest were analyzed using univariate and multivariate logistic regression models.

Results: A total of 51 patients were included; 40 patients showed reduced bone mineral density (BMD) with Z-score ≤ -2.5 . Age, sex, ethnicity, underlying disease, anthropometric parameters, feeding modality, and pubertal stage were not significantly associated with reduced BMD. Functional status and neuromotor impairment emerged as the main determinants: non-ambulatory patients had a significantly higher risk of pathological Z-score values ($p = 0.02$), as did patients with spastic tetraparesis ($p = 0.01$). Reduced BMD was also significantly associated with the use of antiepileptic drugs ($p = 0.001$) and proton pump inhibitors ($p = 0.04$).

Conclusions: Bone fragility in CMC results from a multifactorial interplay in which motor impairment and chronic pharmacological exposure play a predominant role. These findings support the need for a multidisciplinary and proactive approach based on early identification of at-risk patients, systematic monitoring and periodic reassessment of clinical care pathways.



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