6TH MARUZZA
INTERNATIONAL
CONGRESS
ON PAEDIATRIC PALLIATIVE CARE

ABSTRACT BOOK

FONDAZIONE
MARUZZA ONLUS
CHILDREN'S PALLIATIVE CARE

TOGETHER, FOR A BETTER TODAY.

SPECIAL THANKS TO

Vlček Family Foundation

WITH THE PATRONAGE OF

ISTITUTO SUPERIORE DI SANITÀ

SICP Società Italiana di Cure Palliative

Società Italiana di Pediatria

FEDERAZIONE CURE PALLIATIVE

SIN Società Italiana di Neonatologia

SIPINF

fimp Federazione Italiana Medici Pediatri

ACP ASSOCIAZIONE CULTURALE PEDIATRI

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unicef per ogni bambino

S.A.R.N.e P.I. Società di Anestesia e Rianimazione Neonatale e Pediatrica Italiana

CONSIGLIO NAZIONALE ORDINE PSICOLOGI

FNOPI

Famiglie SMA

Paliativos Sin Fronteras

African Palliative Care Association APCA Relieving Pain and Suffering

together for short lives

whpca

icpcn

IAHPC INTERNATIONAL ASSOCIATION for Hospice & Palliative Care

CITTADINANZATTIVA

PALLIUM INDIA

AIEOP ASSOCIAZIONE ITALIANA EMATOLOGIA ONCOLOGIA PEDIATRICA

ASSOCIAZIONE ITALIANA di FISIOTERAPIA

ONSP OSSERVATORIO NAZIONALE SPECIALIZZANDI PEDIATRIA

Asia Pacific Hospice Palliative Care Network

ÜNIAMO Federazione Italiana Malattie Rare

FIAGOP

SPONSORSHIP

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Scientific Programme

WEDNESDAY
16th OCTOBER 2024

17.30 - 20.00 **Opening ceremony**
Auditorium (Basement level)

- **Welcomes** - Silvia Lefebvre D'Ovidio, Franca Benini, Ann Goldman, Brian S. Carter
- **Keynote lecture:** *The Roots of PPC* - Joanne Wolfe
- **Presentation Vittorio Ventafridda Award**
- **Keynote Lecture :** *The Present Day* - Ana Lacerda
- **Presentation Mauro Sentinelli Scholarships**
- **Keynote Lecture :** *Future Horizons* - Sophie Bertaud, Victoria Salvo, Elizabeth Seashore (Young Professional Committee)
- **Young Researchers Awards** *presented by the Vlček Family Foundation*
- **Entertainment Interlude**
- **Icebreaker**

THURSDAY
17th OCTOBER 2024

08.30 - 09.00 **Plenary: Gaining Insights**

- *AI and Robotics in PPC* - Alessandro Masserdotti

09.00 - 10.30 **Plenary: *Pushing the Boundaries of PPC***
Moderators: Brian S. Carter, Danai Papadatou

- *High Tech: an Opportunity or a Limit?* - Daniel Garros
- *Extreme Preterm Neonates and Perinatal PPC*- Elvira Parravicini
- *Transitional Care of Young Adults: for Everyone?* - Ricardo Martino Alba

10.30 - 10.45 **Vlček Family Foundation Young Researcher Award-1st prize**
Cultural differences in shared decision-making in pediatric palliative care - Luca Nicot

11.15 - 12.15 **Oral Abstract presentation session**

Working session 1: Communication
Moderators: Justin N. Baker, Jared Rubenstein

- *Beyond illness: a qualitative exploration of talking about the future in pediatrics with IMPACT* - Julie Brunetta
- *Identification of age-appropriate ACP communication in children with chronic medical conditions* - Leonie la Rondelle
- *Compassionate communication with families during evaluation for death by neurologic criteria* - Regina Okhuysen-Cawley
- *Parents communication with a child with juvenile neuronal ceroid lipofucinosis about the diagnosis* - Torun Marie Vatne

Working session 2: Caregivers and Family

Moderators: Stefan J. Friedrichsdorf, Huda Abu-Saad Huijer

- *Evaluating PPI activities within a paediatric palliative care research centre* - Laura Barrett
- *Critical and often missed steps in launching advance care planning for youth: parental perspectives* - Lucie Hrdličková
- *Interdisciplinary collaboration in pediatric palliative care: perceived barriers and facilitators* - Maureen Kemna
- *Understanding the needs of pediatric palliative caregivers in Washington, USA* - Nikhita Vaddineni

Working session 3: Bereavement 1

Moderators: Anna Garchakova, Ulrika Kreicbergs

- *Working with bereaved parents to develop digital grief resources to help staff and bereaved parents* - Rebecca Candon/Breffni McGuinness
- *Bereaved parents' decision-making about location of end-of-life care for children* - Ashleen Crowe
- *Messages from heaven: unexplainable experiences among bereaved parents*- Eva De Clercq
- *Bereaved parents' experiences of paediatric end-of-life care: a UK multi-site qualitative study* - Julia Hackett

13.30 - 15.00 **Young Professionals Plenary: *Diversity, Equity and Inclusion in PPC***

Moderators: Sophie Bertaud, Elizabeth Seashore

- *Racism, Ethics, and Palliative Care* - Jonathan Koffman
- *Honouring Diverse Cultural and Religious Practices* - Joe El Khoury
- *Equity and the Delivery of PPC in Low and Middle-Income Countries* - Julia Downing

16.15 - 17.15 **Oral Abstract presentation session**

Working session 4: Young Professional Session

Moderators: Sophie Bertaud, Victoria Salvo

- *Parent and professional experiences of 24/7 paediatric end-of-life care: shining a light on inequity* - Laura Barrett
- *Transformed by song: the impact of music on adolescents and young adults living with advanced cancer* - Verna Hendricks-Ferguson
- *Breaking barriers: access to pain medicines for paediatric palliative care worldwide* - Julia Downing
- *Rapid review of patient and public involvement work with parents of children with serious illness* - Pru Holder

Working session 5: The Importance of Team

Moderators: Poh Heng Chong, Daniel Garros

- *Training teams in pediatric advance care planning: transfer of knowledge and communication skills* - Marijanne Engel
- *Resources required to provide neonatal palliative care: supporting the nursing workforce* - Alexandra Mancini-Smith
- *Successful implementation of a pediatric palliative care and hospital at home program* - Andres Piolatti-Luna
- *Collaborative working improves access to paediatric palliative care* - Joanna Woolley

Working session 6: Miscellaneous

Moderators: Mercedes Bernadá, Lorna Fraser

- *Systemic development of paediatric palliative care in the Czech Republic: lesson-drawing* - Jiri Krejci
- *Impact of a pediatric palliative care program on regional children's healthcare utilization and cost* - David Lawrence Lysecki
- *Bereavement in pediatrics: the experience of the nurses of an Italian pediatric hospital* – Federico Pellegatta
- *State-of-play in pediatric palliative care in Luxembourg: an exploratory mixed methods study* - Micha Massaad

17.30 - 18.30 **Focus Sessions**

Auditorium (Basement Level)

- *Self-compassion, Growth and Development for Healthcare Professionals in PPC* - Jared Rubenstein

Room A (1st floor)

- *Shared Care Planning - Why, When, Where* - Sergi Navarro Vilarrubí

San Francesco Room (Ground Floor)

- *Palliative Sedation: When and How* - Marco Bolognani

FRIDAY
18th OCTOBER 2024

08.30 - 09.00 **Plenary: Gaining Insights**

- *The Use of Telephone Interview for Emergencies at Home* - María Avilés Martínez

09.00 - 10.30 **Plenary: *Using Assessment Tools in PPC***

Moderators*:* Huda Abu-Saad Huijer, Poh Heng Chong

- *Quality of Care Assessment Tools* - Prasanna Ananth
- *Using Tools for Outcome Measurement in PPC* - Richard Harding
- *Opportunities and Limits* - Lorna Fraser

11.00 - 12.00 **Oral Abstract presentation session**

Working session 7: Pain and Severe Discomfort - Identification and Control

Moderators: Stefan J. Friedrichsdorf, Joe El Khoury

- *Advancing pediatric pain management: Global comfort promise successes in Latin America* - Ximena Garcia-Quintero
- *Transforming pediatric palliative practice: the comfort promise initiative for reducing needle pain* - Gezy Giwangkancana
- *Shedding light on sleep: evaluating diagnostic measures for children with life-limiting conditions* - Larissa Kubek
- *Neuro-irritability: the great unknown* - Anna Mercante

Working session 8: Tools and Technology
Moderators: Ross Drake, Richard Harding

- *A novel co-designed tool to support CPC providers worldwide explore and utilize their service data* -Laura Dale-Harris
- *Virtual Reality (VR) in palliative care within home healthcare for children and adolescents* - Daniel Kemppi
- *Quality of care on an inpatient pediatric palliative care unit* - Pia Schmidt
- *The use of social media for sharing information on PPC needs: a social media analysis* - Sofia Germinario

Working session 9: Siblings, Parents and Family
Moderators: Renée McCulloch, Danai Papadatou

- *Provision of psychological support for siblings of seriously ill children from parental perspective* - Grazina Kokesova Kleinova
- *Maternal role in caring for children with severe cognitive impairment in pediatric palliative care* - Anna Santini
- *Changing focus: parents reflecting on hope during hospice through photovoice* - Allie Superdock
- *MiniSIBS, a intervention supporting preschool siblings of children with life limiting disorders* - Torun Marie Vatne

13.30 - 14.30 **Oral Abstract presentation session**

Working session 10: Survey and Systematic Reviews
Moderators: Julia Downing, Ross Drake

- *Nationwide 24/7 paediatric palliative care in Denmark. Data from 2016-2023* - Maja Abitz
- *Survey of pediatric intensive care team professionals regarding pediatric palliative care* - Mercedes Bernadá
- *Factors affecting child development in the context of serious illness: a scoping review* - Leonie la Rondelle
- *Specialized palliative care in inherited metabolic diseases - a MetabERN survey* - Anja Lee

Working session 11: Miscellanous 2
Moderators: Ana Lacerda, Joanne Wolfe

- *The importance of specialized palliative care on pediatric cancer patients' choice of place of death* - Thea Marie Traun Andersen
- *Pediatric palliative care and emergency department: how taking charge changes admissions* - Valentina Folgheraiter
- *Coming of age: development of a pediatric palliative care program in the standard-of-care era* - David Lawrence Lysecki
- *Mapping trajectories of care in the last year of life in cardiovascular complex chronic conditions* - Ashley Ridley

Working session 12: End of Life Care
Moderators: Justin N. Baker, Joana Mendes

- *Professionals' experiences of delivering paediatric end-of-life care: a multi-site qualitative study* - Julia Hackett
- *Health and social care professional views on decision-making for place of a child's end-of-life care* - Rachel McCauley

- *Compassionate extubation at home (CEAH) in paediatric palliative care: a case series* - Mei Chan Grace Ng
- *Complex chronic conditions (CCCs) vs. life-limiting conditions (LLCs)...how do these lists compare?* - Samantha Smith

15.30 - 17.00 **Plenary:** ***Managing Serious Illness in the Home***
Moderators: Mercedes Bernadá, Anna Garchakova

- *Pain and Symptom Management* - Renée McCulloch
- *Support for Family Members and Strategies for Engaging the Community* - Ulrika Kreicbergs
- *End-of-Life Care* - Ricardo Martino Alba

17.00 - 17.30 Auditorium (Basement Level)
Closing Ceremony

- *Conclusions* - Ann Goldman, Brian S. Carter

Thanks & Arrivederci - Franca Benini , Silvia Lefebvre D’Ovidio

POSTER PRESENTATION - 17th October

SESSION 1 - MONITOR A

N°	Title	Presenting Author	Time
A1	Pharmacists and Compliance: Can counselling improve adherence?	Azza Abdel-Aty	12.30-12.40
A3	Novel needs tool supporting interdisciplinary collaboration around children with palliative needs	Emma AlKhabbaz	12.50-13.00
A4	Respite days in the pediatric palliative care Day Care in Emilia-Romagna: a pilot project	Sergio Amarri	13.00-13.10
A5	DMD-YOUNG: Paediatric palliative care for a life-limiting disorder in transition to adulthood	Ellen Johanne Annexstad	13.10-13.20
A6	Children with cancer and sibling’s experiences of participation in the Family Talk Intervention	Maria Ayoub	13.20-13.30

SESSION 1 - MONITOR B

N°	Title	Presenting Author	Time
B1	Formation of a Pediatric Palliative Care team at Astrid Lindgren´s Children’s Hospital, Sweden	Karin Bäckdahl	12.30-12.40
B2	Innovative Approach to Quality of Supporting children in PC: The Power of Visual Stimulation	Jitka Barlová	12.40-12.50
B3	Pain and discomfort in neonates eligible for Pediatric Palliative Care: assessment tools comparison	Giulia Baron	12.50-13.00
B4	Beyond pain - Emotional support project for perinatal grief	Monalisa Nascimento dos Santos Barros	13.00-13.10
B5	Joint Specialist Nursing Posts between Hospices & a Tertiary Palliative Care Centre	Julie Bayliss	13.10-13.20
B6	The Rehabilitator Between Intensive Care and Palliative Care: A Pediatric Clinical Case	Alessia Bellizzi	13.20-13.30

SESSION 1 - MONITOR C

N°	Title	Presenting Author	Time
C1	Advance Care Planning And Multiculturality In Pediatric Palliative Care: A Review of The Literature	Maria Beltrame	12.30-12.40
C2	Building Relations through Time and Music - Case Presentations from a newly startet PPW in Norway	Mathilde Bøås	12.40-12.50
C3	Holistic approach and palliative intervention in supratentorial brain tumors- A retrospective study	Alexandra Borda	12.50-13.00

C4	Care maps: an effective tool to evaluate complexity and needs in pediatric palliative care	Francesca Burlo	13.00-13.10
C6	Sleep difficulties are common in children attending a Hospice Service	Mairead Cassidy	13.10-13.20

SESSION 1 - MONITOR D

N°	Title	Presenting Author	Time
D1	Evaluation of a Perinatal Palliative Care Program by SWOT Analysis	Chiara Locatelli	12.30-12.40
D2	Children with Complex Chronic Condition in school setting	Giulia Cervi	12.40-12.50
D3	Development of a children's palliative care network in the Vysočina Region - Czech Republic	Magdalena Chvilova Weberova	12.50-13.00
D4	Transcending - self and frontiers	Cláudia Constantino	13.00-13.10
D5	Ensuring Quality Care: The Vital Role of Needs Assessment in Children’s Palliative Care Development	Alex Daniels	13.10-13.20
D6	Two letters compared: psychologist and adolescent dialogue about turning limits into resources	Valentina De Tommasi	13.20-13.30

SESSION 1 - MONITOR E

N°	Title	Presenting Author	Time
E1	Referral Predictors and Benefits of a Home-Hospital Palliative Program for Pediatric Cancer Patients	Iñigo de Noriega	12.30-12.40
E2	Oncological support measures while follow-up by a pediatric palliative care unit for cancer patients	Iñigo de Noriega	12.40-12.50
E3	Clinical Case: accompanying an educational center in the grief of a student	Luisa Silva Di Maggio	12.50-13.00
E4	Building Pediatric Palliative Care Leadership Capacities: A Collaborative Initiative for South Asia	Megan Doherty	13.00-13.10
E5	Pediatric palliative care attitudes and educational needs among humanitarian health professionals	Megan Doherty	13.10-13.20
E6	Palliative Care Perceptions and Educational Needs Amongst Humanitarian Healthcare Professionals	Megan Doherty	13.20-13.30

SESSION 1 - MONITOR F

N°	Title	Presenting Author	Time
F1	What Support Do Families Need Most in Perinatal Palliative Care? A Retrospective Chart Review Study	Hana Marie Dvorakova	12.30-12.40
F2	Navigating Needle Pain in Pediatric Cancer: Insights from a Low-Resource Setting	Samaher Fadhil	12.40-12.50

F3	Integration of research and implementation to support advance care planning: a nationwide approach	Jurrianne C Fahner	12.50-13.00
F4	Raising awareness: Real world data on palliative care for advanced pediatric cancers	Felicitas Ferrari-von Klot	13.00-13.10
F5	Acceptability and feasibility of the Paediatric Palliative Scoring Scale among nurses and physicians	Solfrid Gjevik Festøy	13.10-13.20
F6	Therapeutic Powers of Play Meeting the needs of children in Palliative Care	Helena Fitzgerald	13.20-13.30

SESSION 2 - MONITOR A

N°	Title	Presenting Author	Time
A7	Perceptions of Bereaved Mothers After Grief Support Groups: Analysis of Open-Ended Survey Responses	Ayaka Fujita	15.00-15.10
A8	Level of overload of the main caregiver of pediatric palliative patients when they begin follow-up	Antonia Gámez	15.10-15.20
A9	The volunteer role in Pediatric Palliative Care	Carlotta Ghironi	15.20-.15.30
A10	Lived experience of parents of a child in palliative care: a phenomenological study	Carlotta Ghironi	15.30-15.40
A11	Strategies to Alleviate Pain Undergoing Needle Procedures at a Pediatric Oncology Hospital	Angela Grassato de Carvalho	15.40-15.50
A12	Diffuse intrinsic pontine glioma: When is timing to Palliative care	Angela Grassato de Carvalho	15.50-16.00
A13	Pyridostigmine and neostigmine for intestinal dysmotility in pediatric palliative care: case series	Gabriella Guida	16.00-16.10

SESSION 2 - MONITOR B

N°	Title	Presenting Author	Time
B7	Bridging the Bereavement Support Gap in India: A Model for Global Application	Ximena Garcia-Quintero	15.00-15.10
B8	Need for training in psycho-emotional management front of serious illness and end-of-life	Anna Habimana	15.10-15.20
B9	The impact of Parent Involvement on a cohort study of home-blended diets in gastrostomy fed children	Julia Hackett	15.20-.15.30
B10	Supporting a Multidisciplinary approach to promote safe sleep at a childrens' hospice	Cate Harper	15.30-15.40
B11	Barriers and facilitators to paediatric palliative care referral: a scoping review of the evidence	Pru Holder	15.40-15.50
B12	Feasibility of implementing international pediatric palliative care standards in the Czech Republic	Lucie Hrdličková	15.50-16.00

B13	Palliative consultations tailored specifically to the unique needs of children with serious illness	Lucie Hrdličková	16.00-16.10

SESSION 2 - MONITOR C

N°	Title	Presenting Author	Time
C7	A rapid scoping review of sleep difficulties in children with palliative care needs	Laura Houlihan	15.00-15.10
C8	Pediatric Advanced Care Planning: development of tools for families and healthcare professionals	Chiara Hruby	15.10-15.20
C9	Parents long-term retention of the Family Talk Intervention in pediatric oncology	Kerstin Ivéus	15.20-.15.30
C10	Understanding Family Caregivers' Experience with Medically Complex Children at Home	Da Hye Je	15.30-15.40
C11	Parental Prespective of Children With Life-Limiting Conditions Availaing of a Respite Stay	Jiya Joy	15.40-15.50
C12	Experiences of Music Therapy in Paediatric Palliative Care	Victoria Kammin	15.50-16.00
C13	Volunteer team in the prevention and relief of pain in needle procedures – Comfort Promise Project	Carolina Kasa	16.00-16.10

SESSION 2 - MONITOR D

N°	Title	Presenting Author	Time
D7	How did the Preference for Child Home Deaths Change at GOSH, Through the COVID-19 Pandemic?	Mathura Kathirgamanathan	15.00-15.10
D8	Care doesn't end at death: provision of post-death care for children in England	Tara Kerr-Elliott	15.10-15.20
D9	Specialized palliative home care for children decreases hospital care needs - a pilot study	Jenny Klintman	15.20-.15.30
D10	Two entirely different stories. (From the communication "off stage".)	Marketa Kralovcova	15.30-15.40
D11	Forgotten Classics. Early Elisabeth Kübler Ross unread, misinterpreted and misunderstood	Jiri Kralovec	15.40-15.50
D12	Parents' experiences of a novel disease-modifying therapy for spinal muscular atrophy in Sweden	Ulrika Kreicbergs	15.50-16.00
D13	"Hero caravan" creating memories, normality and playful relations	Dorte Brinkmann Kristensen	16.00-16.10

SESSION 2 - MONITOR E

N°	Title	Presenting Author	Time
E7	Evaluating Pathways to Better Care for Pediatric Complex Chronic Conditions:The KoCoN Study Protocol	Larissa Kubek	15.00-15.10

E8	Effective communication in pediatric palliative care from the perspective of children and parents	Leonie la Rondelle	15.10-15.20
E9	Nurse parental support using a mobile App in symptom management for children with medical complexity	Winsome Y Y Lam	15.20-.15.30
E11	Factors associated with Paediatric Palliative Screening Scale (PaPaS) scores: A retrospective study	Ji Weon Lee	15.40-15.50
E12	Training and implementation of palliative care representatives at Astrid Lindgren Childrens Hospital	Therése Kjellin	15.50-16.00
E13	The Family Talk Intervention among families with palliative care needs - Social Workers' experiences	Tina Lundberg	16.00-16.10

SESSION 2 - MONITOR F

N°	Title	Presenting Author	Time
F7	20 years of Growth of Palliative Care Services in Ireland	Marie Lynch	15.00-15.10
F8	Introducing a Community Model of Palliative Care for Children: Family Feedback	Marie Lynch	15.10-15.20
F9	Babywearing as a child care tool in Pediatric Palliative Care	Priscilla Manfra	15.20-.15.30
F10	Utilizing Virtual Reality to Alleviate Anxiety in Severely Ill Pediatric Patients	Anna Zubkova	15.30-15.40
F12	From hospital to home: implementation of a hospital discharge checklist	Irene Martín Romero	15.50-16.00
F13	Family needs and health technology in home-based pediatric palliative care	Linda Johanne Martinsen	16.00-16.10

POSTER PRESENTATION - 18th October

SESSION 3 - MONITOR A

N°	Title	Presenting Author	Time
A14	"Parenting Pills": a project proposal for parental empowerment promotion	Chiara Mastella	12.15-12.25
A15	Meeting the individual needs of pupils in pediatric palliative situation	Susanne Mauss	12.25-12.35
A16	Who are the Children? Point Prevalence Survey to Understand who Needs Children's Palliative Care	Linda Maynard	12.35-12.45
A17	How do regional multidisciplinary children's palliative care meetings support system development?	Linda Maynard	12.45-12.55
A18	What Care Service Tools Can Help Palliative Care Teams Learn From Expected Childhood Deaths?	Linda Maynard	12.55-13.05
A20	Ultrasound guided long peripheral cannula: a pain control device in pediatric patients	Lucrezia Menotti	13.05-13.15

SESSION 3 - MONITOR B

N°	Title	Presenting Author	Time
B14	Quality of sleep in caregivers of children eligible for Pediatric Palliative Care	Anna Milani	12.15-12.25
B15	The effectiveness of a virtual physical therapy training program for carers with SMA at home	Reham Mohammed	12.25-12.35
B16	Enrollment Barriers on a Palliative Care Communication Trial for Parents of Children with Cancer	Karen Moody	12.35-12.45
B17	Guilt in caregivers of pediatric cancer and its associations with meaning-making processes	Valeria Moriconi	12.45-12.55
B18	Tracheostomy decision-making in pediatric palliative care: systematic review of qualitative research	Vera Morsellino	12.55-13.05
B20	Palliakid: Comprehensive Paediatric Palliative Care Approach	Sergi Navarro Vilarrubì	13.15-13.25

SESSION 3 - MONITOR C

N°	Title	Presenting Author	Time
C14	Organ donation in home-based Pediatric Palliative Care, is it possible?	Alvaro Navarro-Mingorance	12.15-12.25
C15	High-Flow Oxygen In Patients with Acute Respiratory Failure in a Pediatric Palliative Care Unit	Alvaro Navarro-Mingorance	12.25-12.35
C16	RESPECT: Recommendations for Providing Pediatric Palliative Care to Families from Different Cultures	Barbora Nebáznivá	12.35-12.45

C17	Shifting attention of children with life-threatening illness from needs to desires	Josef Nedorostek	12.45-12.55
C18	ePROMs for symptom assessment in pediatric palliative home care	Alexander Voelzke	12.55-13.05
C19	The Human Cost of the COVID-19 Pandemic: Implications for Pediatric Palliative Care Providers	Regina Okhuysen-Cawley	13.05-13.15
C20	The Plight of Migrant Children with Palliative Care Needs in the Americas	Regina Okhuysen-Cawley	13.15-13.25

SESSION 3 - MONITOR D

N°	Title	Presenting Author	Time
D14	A training curriculum to enable governance and operational arrangements: Education nurtures service	Aisling Ni Nualláin	12.15-12.25
D15	Storytelling to Support Legacy-Making for Bereaved Parents of Children with Cancer	Trisha Paul	12.25-12.35
D16	Post-traumatic growth in parents who lost a child to cancer: A multicentre survey in Switzerland	Eddy Carolina Pedraza	12.35-12.45
D18	The Pediatric Day Hospice: a place for Pediatric Palliative Care	Federico Pellegatta	12.55-13.05
D19	Training caregivers to care for italian children in pediatric palliative care: single-centre study	Federico Pellegatta	13.05-13.15
D20	Towards appropriate advance care planning in pediatric palliative care: a medical record review	Sophie Tooten	13.15-13.25

SESSION 3 - MONITOR E

N°	Title	Presenting Author	Time
E14	Training Caregivers of Children with Home Invasive Mechanical Ventilation: From the ICU to Home	Andrés Piolatti Luna	12.15-12.25
E15	How acces to a pediatric palliative care unit influences on the choice of place of death	Andrés Piolatti Luna	12.25-12.35
E16	Complex pain case management in a 12-year old girl with a severe form of epidermolysis bullosae	Andrés Piolatti Luna	12.35-12.45
E17	New strategies, old strategies: handling pain in an adolescent with cancer, a case report	Andreana Pipolo	12.45-12.55
E18	Palliative sedation in pediatric patients: preliminary data from a retrospective study	Andreana Pipolo	12.55-13.05
E19	Epidemiological estimation for paediatric end-of-life and palliative care in Greece	Dimitrios Protogiros	13.05-13.15
E20	Comprehensive well-being, wish to change and concerns of children in palliative care: scale qESNA-14	Daniel Toro Pérez	13.15-13.25

SESSION 3 - MONITOR F

N°	Title	Presenting Author	Time
F14	Characterization of resources provide PPC in LATIN AMERICA: PedPaLatam-2024 preliminary report	Jorge Ramos-Guerrero	12.15-12.25
F15	The experience of nurse managers supporting nurses caring for children at the end of life	Aisling Reilly	12.25-12.35
F16	Collaboration in Children's Palliative Care - Everyone Gains	Aisling Reilly	12.35-12.45
F17	Quality Office Role in KHCC Global Comfort Promise project	Dema Remawi	12.45-12.55
F18	Physician Lead Role in the Global Comfort Promise at KHCC	Dema Remawi	12.55-13.05
F19	Nursing Role in Managing Procedural Pain; KHCC (Global Comfort Promise)	Dema Remawi	13.05-13.15
F20	Coordinating Children’s Palliative Care in Municipalities: A Qualitative Study	Gro Trae	13.15-13.25

SESSION 4 - MONITOR A

N°	Title	Presenting Author	Time
A21	Every Moment Matters	Jana Krákorová	14.30-14.40
A22	Bridging Intensive and/or Palliative Care in Sma Type 1? A Case Report	Federico Pellegatta	14.40-14.50
A23	Which Minors are Eligible for Palliative Care? A Tool for the Training of Healthcare Professional	Federico Pellegatta	14.50-15.00
A24	The challenges of the pediatrics palliative care in Kharkiv	Olena Riga	15.00-15.10
A25	The best “quality of life” in PPC: from quality of life to quality of life relationships	Rossana Ruggiero	15.10-15.20
A26	Memory-Making Interventions in Pediatric Palliative and Bereavement Care: A Systematic Review	Razieh Safarifard	15.20-15.30

SESSION 4 - MONITOR B

N°	Title	Presenting Author	Time
B21	Palliative Care in Children: Italian translation and validation of a questionnaire	Claudia Sansone	14.30-14.40
B22	School inclusion of children and youth in pediatric palliative care: a retrospective study	Anna Santini	14.40-14.50
B23	KoCoN: A new horizon for children with chronic complex neurological conditions	Pia Schmidt	14.50-15.00
B24	"Your Presence Matters": A Journey of Pediatric Palliative Care in Nepal	Amrita Shrestha	15.00-15.10
B25	Syringe Driver Usage in Paediatric Oncology Patients at End of Life	Emily Skinner	15.10-15.20
B26	FamilieFOKUS Psycho-social support to families	Hilde Skrudland	15.20-15.30

SESSION 4 - MONITOR C

N°	Title	Presenting Author	Time
C21	Current Models of Providing Perinatal Palliative Care in 4 Perinatal Centres in the Czech Republic	Zuzana Stanickova	14.30-14.40
C22	Barriers & Opportunities for Perinatal Palliative Care: A Nation-wide Mixed-Method Study	Zuzana Stanickova	14.40-14.50
C23	Experiences of parents caring for a child with a life-limiting condition in an inpatient setting	Sophie Stößlein	14.50-15.00
C24	Palliative care for children with neuromuscular diseases (NMD) in Kazakhstan	Yuliya Streletskaya	15.00-15.10
C25	Spiritual Dialogue between Pediatric Neuro-oncologists, Patients, & Caregivers	Allie Superdock	15.10-15.20
C26	Understanding sleep and mental health outcomes in parents of children with LLCs/LTIs	Aoife Talbot	15.20-15.30

SESSION 4 - MONITOR D

N°	Title	Presenting Author	Time
D21	End of life care utilization in pediatric oncology patients in Latvia: An observational study	Sofja Tomase	14.30-14.40
D22	Methodology of system integration of palliative care in pediatric patients with high-grade gliomas	Katerina Trkova	14.40-14.50
D23	Psychosocial support in paediatric palliative care – a teamwork	Marie Nyström	14.50-15.00
D24	Navigating Emotional Turmoil: A Case Study in Paediatric Palliative Care for a Boy with Brain Tumour	Simona Ulrich	15.00-15.10
D25	There's always a way… to play. Insight into the diary of a child life specialist in palliative care	Michaela Váňová	15.10-15.20
D26	Shepherding parents in end-of-life decision-making for children with life-limiting conditions	Sid Vemuri	15.20-15.30

SESSION 4 - MONITOR E

N°	Title	Presenting Author	Time
E21	The impact of the war in Ukraine on pediatric palliative care: a study from our center	Vita Voloshchuk	14.30-14.40
E22	The realities of children's hospice in Ukraine with challenges and opportunities	Vita Voloshchuk	14.40-14.50
E23	Creation of an online GP referral app for inhouse requests within a Children’s Hospice	Fiona Woods	14.50-15.00
E24	Ethnicity and Cultural Diversity in a Children’s Hospice	Fiona Woods	15.00-15.10

E25	Access to 24/7 telephone advice from specialist paediatric palliative care nurses improves choice	Joanna Woolley	15.10-15.20
E26	A project to develop, implement and evaluate a blended learning model in paediatric palliative care	Joanna Woolley	15.20-15.30

Pre-Congress Workshop - Difficult Choices: Bioethical Strategy

J. Mendes[1], M. Friedel[2], D. Garros[3]
[1]Nursing School of Lisbon, Pediatric Nursing, Lisbon, Portugal, [2]University of Luxembourg, Department of Life Sciences and Medicine (DLSM), Faculty of Sciences, Technology and Medicine (FSTM), Esch-sur-Alzette, Luxembourg, [3]University and/or Hospital, University of Alberta, Faculty of Medicine; Stollery Children's Hospital, Pediatric Intensive Care Unit (PICU) Department, Department of Pediatrics, Division of Critical Care Medicine, Edmonton, Alberta, Canada

Background: Paediatric decision-making processes are key components of paediatric palliative care, essential for the provision of high quality of care. Specially, in the face of very complex health care needs, when dealing with disagreement, helplessness and uncertainty, decision-making, can become one of the most challenging aspects.

Decision-making in paediatric palliative care is often recognized as a long, emotional and challenging journey. Moral distress can occur frequently: when one of the members of the multidisciplinary team is uncertain/ uncomfortable about the course of action taken, has strong feelings about the decision to take/taken, but is unable to act upon it.

There can be differently approaches to decision making in paediatric palliative care: paternalistic, menu-choice and value building and the provision of medical recommendations. Each approach often relates with ethical, moral, cultural, political and legal context, emphasizing differently child’s and parents’ autonomy versus the clinicians sharing medical knowledge.

Bioethics play a very important role, to guide paediatric palliative care profession in the decision making, feeling more confident and comfortable, when confronted with these difficult scenarios. Some tools can be mobilized to support all the process of decision making regardless the context where it occurs, in a global perspective.

Aims: The Learning Goals of this pre-congress are: 1) Promote reflexive and ethical thinking about difficult choices in paediatric palliative care, in a global perspective; 2) Identify and test bioethical instruments to guide clinical shared decision-making processes that can help health care professionals deal with difficult choices; 3) Support a systemic approach about moral distress and how paediatric health care professionals can cope with difficult choices in paediatric palliative care.

Methods: This preconference used different educational methods such as expositive lectures and interactive learning with interdisciplinary and international group discussions on clinical scenarios and art Gallery methodology.

Results: During this precongress the main topics explored were: 1. Difficult Choices in PPC?- *Food for taught*; 2. Bioethical strategy and tools- *What might help?* (Four step decision making, Learning guide for ethical reasoning, Ethics Wind rose); 3. *Case discussion- And if this happened to me?*; 4. *Moral distress-This bittersweet taste in my mouth*. At the end participants evaluated the session by filling a small questionnaire and identifying a take-home message.

Conclusion: Bioethics principles and tools can be important to help pediatric palliative care teams deal with very complex decisions making processes. Framing moral distress can be helpful to help professionals cope with difficult decisions making, by raising self-awareness and improve communication between child, family and multidisciplinary teams, as well as promote more coordinated advance care planning. Education and interdisciplinary teamwork are key components to improve ethically decision making in paediatric palliative care.

Paediatric Palliative Care - the Present Day

A. Lacerda[1]
[1]Portuguese Institute of Oncology Lisbon Centre, Paediatrics, Lisbon, Portugal

From the past to the future, the only known constant is change. In the present day, migrations, humanitarian crisis, emerging and evolving societal values, receding economies, all represent challenges that palliative care is addressing while keeping pace with technical and medical innovations.
Ten years after the World Health Assembly's (World Health Organization's Governing Body) groundbreaking resolution calling for all member states to "strengthen palliative care as a component of comprehensive care throughout the life course", this year's World Hospice and Palliative Care Day campaign is asking "How are we doing?" (https://thewhpca.org/world-hospice-and-palliative-care-day/).
Standing in the shoulders of the giants before us (people and organizations alike), paediatric palliative care is at a crucial momentum where all stakeholders are demanding more – more child and family centered care, more symptom control, more survival, more education, more training opportunities, more support for exhausted staff and carers, more services, more resources, more "bang for the buck", more profit...
Fortunately, current developments in pediatric palliative care are shaped by four interconnected aspects:

- The establishment of national and international educational activities that can support sustainable service implementation at its different levels (basic, generalist, specialist);
- Increased collaboration across scenarios, including clinical, advocacy, education and research, as well as the arts and humanities;
- Greater integration into healthcare systems and disease trajectories, recognizing the benefits of early involvement, be it in primary or tertiary care, for oncological and non-oncological conditions, and including for survivors of life-threatening situations;
- Rising patient and public involvement ("nothing about me without me"), promoting person-centered care, addressing cultural sensitivity and decision-making processes, while laying the grounds for new models of care and education.

Yet, despite developments like compassionate communities, advance care planning and dignity therapy, challenges remain, such as unclear referral criteria, shaping of models of care delivery (artificial intelligence, telemedicine and robotic carers included), resource limitations... And while perinatal programs are growing, there remains a lack of support for young people, including transition programs for adult survivors of formerly fatal paediatric conditions.
Additionally, despite a rising body of evidence for positive evaluations of palliative care, a torrent of negative emotions persists, indicating a need for strong public health initiatives to better communicate its remit, strengths and limitations.
In a world shaped by commerce and marketing, how can we offer a better product and "sell" paediatric palliative care, recognizing that not all "markets" are the same? Let's take this networking opportunity to learn from each other and brainstorm together, as the future is NOW.

High Tech: an Opportunity or a Limit?

D. Garros[1]
[1]Stollery Children's Hospital, University of Alberta, Dept of Pediatrics, Divison of Critical Care, Edmonton, Canada

Background and Aims: From a simple NG tube for a child in palliative care at a Low Income Country, to a Ventricular Assistant Device (VAD) at a High income country setting, technology surrounds us, even in Pediatric palliative Care (PCC). What are the limits for our interventions? We aim to discuss some novelties available for better care for PCC patients and their families, looking at devices that we use to keep kids alive and well, and their implications for our daily practice. How to proceed when goals of care don't align with families' and patient's values, and we use such devices? We need to ask ourselves: are you medicalizing death further? Is high tech actually making death less humane? What are the limits of such technologies in PCC?
Methods: Through a literature review we will look at the evidence for benefits and risks of using new High-Tech devices for monitoring and helping patients to have better quality of life, starting in the Pediatric Intensive Care Unit and Hospital environment, and moving to the ambulatory. We are focusing on patients with complex and chronic conditions, many of them not at the end of life, but other simply living with technology that can fail at any moment.
Results: From simple NG tubes, to "wearables" (smartwatches, smart rings, sleep trackers, smart clothing, fall detectors, smart patches, and implantables) that can send vital sings to PPC clinics, all the way to small portable mechanical ventilators and extracorporeal life support (ECLS), technology surrounds us. Just because such devices are available, should we use them? We must align our objectives and goals with the patient's and families, and carefully establish the goals and objectives of each technological aid. An important question to ask ourselves to elucidate the shift between benefit and burden of such therapies and devices may be, “are we doing this to the child or for the child?" At the ambulatory level, telemedicine has become a common tool to check our patients. Would it be replacing the human contact? There is evidence that adult patients are satisfied with teleconference encounters, since it facilitates greatly their lives and minimizes significant investment and energy in traveling to see the PPC teams. Technology has also the potential to improve education and training in palliative care, through virtual reality, high fidelity manequins, online learning environments, etc. There are many challenges with high tech devices, such as ensuring data privacy, managing costs, and integrating these devices into existing healthcare systems. Some barriers exist from monitoring devices, such as the distress that family members and patients with obsessive monitoring can experience, rather than a peaceful, simplified care focused on the patient’s comfort.
Conclusion: The striking contrast of palliative care and the high tech environment is only buffered by the humans behind the technology, with patients in one side, and healthcare professionals in the other. Running the risks of getting lost in the "bells and whistles", we must strive for common ground on the choices we make along side our families and patients, cultivating relationships and trust. The living experience can be enhanced by the technology we apply, but only if it is done with the focus on enhancing the patient's quality of life and maintaining their dignity.

Extreme Preterm Neonates and Perinatal Palliative Care

E. Parravicini[1]
[1]Columbia University Irving Medical Center, Pediatrics/Neonatology, New York, United States

In this talk Dr Parravicini will discuss the option of Perinatal Palliative Care in the settings of periviability.
According to The American College of Obstetrics and Gynecology (ACOG) Perinatal Palliative Care "*refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting. With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment*."
The American Academy of Pediatrics (AAP) defines "*periviability as the gestational age period between 22 0/7 and 24 6/7 weeks. Periviability is the stage of fetal maturity when there is a chance of survival outside the womb, but the likelihood is not high*."
The role of Perinatal Palliative Care with periviable population is 4-fold. First, Perinatal Palliative Care providers offer pre-delivery consults discussing with families the wide range of outcomes for survival and short and long-term morbidities in case of admission to the Neonatal Intensive Care Unit (NICU) and active intervention. Second, Perinatal Palliative Care providers discuss post-natal plans of care including 'full intervention' or 'attempted intervention without heroic measure' or 'comfort care'. In the case the family elects full or attempted intervention, the Perinatal Palliative Care providers may continue the conversation with the family as the infant is admitted to the NICU and, in case of worsening of the infant's clinical status, facilitate redirection of goals of care towards palliative care. When the family elects comfort care management for their infant, Perinatal Palliative Care professionals develop and manage the plan of care focused on baby's comfort and mother/family support, with attention to social, emotional, and spiritual needs.
Outcomes of infants born at 22-24 weeks gestation in terms of survival and long-term morbidities remain uncertain and quite variable in different countries. International data show a very limited survival in this population, especially for infants delivered at 22 weeks, even on presence of active resuscitation, although numbers are variable according to different countries. Moreover, the rate of survival without major morbidities at GA of 22-24 weeks remains very low, despite active technologic and pharmacologic interventions.
A recent commentary authored by 20 neonatologists from major NICU in US and Canada and published on the Journal of Pediatrics, states that "*routine resuscitation at <24 weeks of gestation is not in the best interest of all infants and families. Such decisions are better if individualized*". Thus, recommendations for a cut-off gestation for mandatory active intervention is controversial.
In conclusion Perinatal Palliative Care remains a valid, medically sound, comprehensive and compassionate alternative option for this fragile population.

Transitional Care for Young Adults: For Everyone?

R. Martino-Alba[1]
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Introduction: To transition as a verb means "to change, or make someone or something change, from one form or situation to another."

Some individuals are required to change their primary healthcare providers due to age, undergoing what is commonly called a "transition." The goal of a planned transition is to optimize the care that any sick young person receives throughout their life, especially when they have special needs.

In pediatrics, we are accustomed to transitions as the child grows: neonates, infants, children, adolescents... This is done because, at the next stage, professionals and the organization will better address patients needs.

When a patient approaches the age at which the healthcare system provide adult care, a transition can be considered.

Can there be transitions in pediatric palliative care?

If the best interest of the patient guides decision-making, is it really in the patient's best interest to change teams?

In pediatric palliative care, transitions are considered because there are patients with long-term conditions, children with chronic and highly complex illnesses. The existence of such patients necessitates adaptations in healthcare delivery, incorporating into their care some important criteria:

- Person-centered care
- Needs-based care
- Interdisciplinary collaboration
- The value of symptomatic treatment
- Prioritization of care
- Support for the child and their family

To initiate a transition, these criteria should be guaranteed by the receiving teams. Generally, adult care teams are not habituated to treating patients for such long periods, nor do they manage patients with severe disabilities in a comprehensive manner.

Factors influencing the transition process in palliative care

a) **Patient-dependent factors:** If the patient has 1) an incurable disease, 2) in an irreversible phase (having passed the turning point), and 3) a life expectancy of years, a transition may be considered.

However, several complexity factors can limit the possibility of care by an adult team.

- Severe disability (GMFV)
- Dependence on all basic activities of daily living
- Pediatric body size and weight
- Metabolic or mitochondrial disease
- Difficult-to-control neurological problems such as dystonia or refractory epilepsy
- Severe intellectual disability
- Presence of devices supporting vital functions (gastrostomy, tracheostomy, mechanical ventilation, ventriculoperitoneal shunt, intrathecal baclofen pump)

b) **Exclusion criteria:**

- Expected death within less than a year
- Complexity too high for the adult team
- No receiving team available

Preliminary questions

Before initiating any transition process, it is essential to consider:

1. Who is the patient, and what do they need?
2. Is there a transition program developed for this type of patient?
3. Is there a receiving team?
4. Is the receiving team competent to provide the care the patient requires?
5. Can a transition be carried out?

The result of the evaluation may be **NOT TO PERFORM THE TRANSITION.**

Transition Process

Transition is not simply a change of doctor accompanied by a clinical report. It must be a structured process, over time, during which shared care is provided between the responsible team and the receiving team, until a sufficient trust relationship with the new team is established. The receiving team may not be from palliative care but from the child's underlying disease specialty. This guarantees part of the care but not comprehensive care.

Patients and families must be informed in advance about the necessity or opportunity of the transition, the progression of the process, and the shared care between the two teams based on the acquiring competence of the receiving team. Therefore, it is essential to ask: Which children should transition to adult care? To which professionals? (Between specialties or from palliative to palliative care). Which children should not be transferred to adult care?

Reverse Transition

Sometimes adult teams receive patients with conditions acquired during childhood, with complexity factors that make them unsuitable for adult care networks. When this occurs, reverse transition processes can be initiated. A high percentage of patients cared for by pediatric palliative care teams (20% in the case of Madrid) are over 18 years old.

In some countries, there are successful experiences where specific teams and units are created to care for these highly complex patients coming from pediatrics. Ideally, these units for Chronic Complex Conditions Acquired in Childhood should:

1. Be located in a general hospital,
2. Be multidisciplinary (including a pediatric neurologist and gynecologist),
3. Include surgical procedures,
4. Provide home care,
5. Respond comprehensively to the patient's needs

Benini, F.; Brogelli, L.; Mercante, A.; Giacomelli, L. Transition to Adulthood in Pediatric Palliative Care: A Narrative Review. Children 2024, 11, 860. https://doi.org/10.3390/children11070860

What Is the Evidence We Are Equal at the End of Life and How Can We Meet Our Core Mandate?

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Throughout history, individuals, families and groups have migrated from their original or previous homes for many reasons: as refugees to escape war, colonisation and domination by others, genocide famine, political torture or other conflicts, for the prospect of educational, economic or social advantage, or to reunite with other family members. Increasingly, globalization has brought with it an unparalleled number of people who have moved to high-income countries. The implications of this for palliative care is there is an increasing need for health and social care professionals, themselves from an increasingly diverse range of ethnocultural backgrounds, to provide care for those whose backgrounds are different to their own; patients may arrive at a critical junction with different repertoires for how they comprehend illness, symptoms, expectations of care and make use of services. Yet access to hospice and palliative care, while increasingly recognized as a fundamental human right, remains unequal across different sections of society. Evidence shows that these essential services are often reserved for those who inhabit positions of privilege. Many are excluded, particularly individuals from economically disadvantaged backgrounds, minority ethnic communities, and the oldest old. Canadian bioethicist Dr. David Roy poignantly asked, "*How do the poorest of the poor die? Do we really want to know?*" In this presentation, I will compel us to ask this difficult question, a question that has been amplified in recent times by movements of the tectonic plates of the ethnocultural landscape. I will critically examine the role of privilege in determining access to hospice and palliative care for those from minority ethnic communities, drawing on research from the US, United Kingdom, Canada, and Australia. I will reveal a number of inconvenient truths. I will focus on location of death, access to opioids, decision-making at the end of life, the Covid-19 pandemic, grief and bereavement services and the architecture of research itself in which I play a key role. The first step in addressing a problem is recognizing there is one. For many from minoritised communities, the experience of abandonment at the end of life is an immutable truth. Scrutiny of evidence arrives at a verdict that inadvertent racism is evident in palliative care and palliative care research guided by in inherent, structural and systemic superiority of the majority. This has become normalized and obscured from our line of sight. In 1967, British physician, Dr John Hinton, wrote, "*The dissatisfied dead cannot noise abroad the negligence they have experienced*". In 2024, we cannot permit this to continue. This may be an uncomfortable read. It was difficult to write. However, to tackle racism in palliative care we must get past our denial and shame of racism. While I do not aim to provoke feelings of guilt or helplessness, what I do want is to reach out to much-needed allies to tackle the pernicious pandemic of racism in healthcare and society. We must face our shadow and this will require courage.

Honouring Diverse Cultural and Religious Practices

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In pediatric palliative care, the significance of culture and religion in shaping patient and family experiences is increasingly recognized. These factors profoundly influence perceptions of illness, death, and care. Effective communication and care delivery require a nuanced understanding of how cultural and religious beliefs intersect with medical practices.

This exploration is illustrated through various contexts. For instance, in Lebanon, a family may choose not to disclose a terminal diagnosis to a loved one, reflecting a broader cultural reluctance to discuss death. Such scenarios raise questions about whether these practices stem from cultural norms or universal human fears regarding mortality. This presentation reviews how pediatric palliative care can be ethically delivered in a manner that respects cultural and religious contexts, thereby ensuring comprehensive care that honors diverse worldviews.

Culture encompasses the attitudes, values, beliefs, and practices that shape individuals' decisions regarding healthcare. It is a dynamic construct, evolving with personal experiences and societal changes. Cultural fluidity is evident in regions with diverse populations. For example, Christian and Muslim families in Lebanon may share traditions yet have distinct approaches to health and illness. Recognizing the multifaceted nature of culture is essential for healthcare providers.

Cultural attitudes toward healthcare, particularly regarding truth-telling, have evolved over time. In the United States, significant progress has been made towards full disclosure of cancer diagnoses, shifting from a historical reluctance to prioritize patient autonomy. Similar trends are observed in Italy, where informed consent has become a legal and ethical obligation. Lebanon has also witnessed changes in medical ethics, with increasing support for transparency in patient care. These shifts highlight the fluid nature of cultural attitudes toward medical practices and the importance of adapting care accordingly.

Cultural taboos surrounding death and communication about terminal illnesses can complicate patient care. Many healthcare providers encounter resistance to discussions about death, often attributed to cultural norms. However, such avoidance may reflect a universal human anxiety about mortality rather than a strictly cultural phenomenon. For instance, healthcare professionals frequently observe that patients and families may already be aware of terminal conditions but avoid direct conversations about them. This dynamic underscores the need for healthcare providers to engage in open dialogues that address these anxieties while respecting cultural sensitivities.

Cultural relativism challenges healthcare providers to understand practices within their cultural contexts. However, ethical dilemmas arise when cultural beliefs conflict with medical recommendations. For example, some cultures may view withholding terminal diagnoses as protective. In such instances, healthcare providers must navigate these complexities to provide optimal care while respecting family beliefs.

Practical strategies for delivering culturally sensitive pediatric palliative care include building trust with patients and families, respecting religious rituals, and tailoring communication.

In conclusion, navigating the intersection of culture, religion, and pediatric palliative care is essential for delivering effective, compassionate, and respectful care. As cultural attitudes continue to evolve, healthcare providers must remain adaptable, engaging with families to foster open communication and understanding. This approach not only enhances patient care but also contributes to a more inclusive and responsive healthcare environment.

The Use of Telephone Interview for Emergencies at Home

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Telephone interviews have proven to be highly useful in various areas of healthcare. In paediatric palliative home care, telephone consultations can be a valuable tool for both scheduled and urgent care. The Comprehensive Paediatric Palliative Care Unit at the Hospital Universitario Infantil Niño Jesús in Madrid (Spain) has extensive experience using telephone interviews to manage home emergencies. Currently, this unit cares for more than 80 children hospitalized at home, who receive 24-hour care, 365 days a year.

To provide the quickest possible response to any emergency that may arise at home, families have the phone number of their reference team, which they can contact directly from Monday to Friday, between 8:00 a.m. and 3:00 p.m. Outside these hours, they have two additional phone numbers to contact the on-call nurse or doctor. Families are informed about which emergency situations require them to call the doctor and which should be directed to the nurse. However, coordination between the on-call doctor and nurse is essential to ensure uninterrupted, adequate care for the children.

The use of telephone interviews and video calls in emergency situations is highly valuable for both families and healthcare professionals.

On the one hand, it allows the doctor or nurse to assess the child’s condition at the time of deterioration and provide families with early instructions on the care and treatments that should be administered to promote the patient’s comfort and well-being. To this end, families have at their disposal the necessary devices (oxygen tank, secretion aspirator, pulse oximeter, spare gastric button, etc.) and medication at home to treat potential emergencies. The operation of the devices and the administration of the medication are explained by the reference team when they are provided, and later by the nurse during a home visit to train the family in their use.

In addition, in order to standardize the care and instructions provided to families, the Unit has an emergency telephone care protocol for nursing, which outlines the care and treatments to follow in the most common emergencies in pediatric palliative care (respiratory distress, pain, seizures, accidental dislodgement of the gastric button, etc.), as well as when to reassess the child’s condition or when it is necessary to contact the on-call doctor.

On the other hand, telephone care is essential in deciding whether the on-call team should travel to the home. If the child’s condition does not require an urgent visit, the telephone interview or video call allows for follow-up on the child’s condition after the family has administered the treatment. However, if an urgent visit is determined to be necessary, this tool allows for the early initiation of treatment and evaluation of the child’s condition while the team is on its way to the home, in addition to anticipating which hospital devices, materials, or medications will be needed as part of the treatment.

Another important aspect of using phone or video calls in emergency situations is the ability to provide emotional support to families, as well as to guide those who need it in care techniques, helping them feel more confident when managing such situations at home.

Quality of Care Assessment Tools

P. Ananth[1]
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Background and Aims: Despite the burden of serious, life-limiting illness in children and variable healthcare delivery across the globe, with differential access to and receipt of pediatric palliative care, we do not systematically measure quality of care across the illness trajectory. Furthermore, until recently, little consensus existed as to what defines high-quality end-of-life care. Many individual programs have instituted approaches to assess patient and family satisfaction, but the assessments are not necessarily standardized, and cross-program comparison does not occur. This absence of quality measurement stymies efforts to improve the reach of pediatric palliative care programs and to ameliorate gaps or deficiencies.

Methods and Results: In this talk, we will discuss what patients with serious illness and their families define as high-quality end-of-life care, focused on the case example of children with cancer in the United States. We will review both traditional and novel modalities of quality measurement, extending into unique applications of artificial intelligence to measure care quality and questionnaire-based approaches. Additionally, we will share findings from recent studies exploring quality of care for children with advanced cancer. We will also explore limitations of existing quality measurement modalities and opportunities for innovation in this space.

Conclusions: As the adage often attributed to Lord Kelvin goes, we cannot improve what we do not measure. In order to optimize and equitably deliver pediatric palliative care, we must gather robust data on quality of care for children with serious illness. Much opportunity exists to leverage cutting-edge technology and questionnaires, as well as to automate data extraction from electronic health records or administrative data systems, to provide a comprehensive picture of care quality for children with serious, life-limiting illness. How to systematically collect these data remains an area of active investigation.

Using Tools for Outcome Measurement in PPC

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Background and aims: Children and young people with life-limiting and life-threatening conditions and their families experience varied and inter-related symptoms and concerns. In order to support children with life-limiting conditions a holistic, child and family-centred approach to care is required. The use of patient-centred outcome measures (PCOMs) have been shown to promote patient-centred care and promote service quality in adult care. The use of outcome assessment tools is also important to measure quality and effectiveness of care. The development of a PCOM for paediatric palliative care has repeatedly been highlighted as a research and clinical priority. The aim of the Children's Palliative care Outcome Scale (C-POS:UK) project is to develop a family- and patient-centred outcome measure for children and young people with life-limiting and life-threatening conditions and their families, and to evaluate its psychometric properties.

Methods: The C-POS:UK has been developed using a sequential, mixed-methods approach guided by Rothrock's measure development process and COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) methodology. Development involved identification of priority outcomes through semi-structured qualitative interviews, a modified Delphi survey, a consultation with children and young people, and an expert item generation meeting. Additionally, a systematic review informed the measurement design. Cognitive interviews were used to refine initial versions. Refined versions are undergoing psychometric evaluation.

Results: Physical, emotional/psychological, spiritual/existential, social and practical concerns important to children and young people with life-limiting and life-threatening conditions and their families were identified in interviews (n=106). A Delphi survey (n=82) obtained consensus on the priority outcomes to be included on the novel C-POS:UK. Acceptable and appropriate recall periods, response formats, and administration modes for the target population were established through interviews and a systematic review. This also highlighted the need for different versions of C-POS:UK to account for children's developmental stages and cognitive abilities. An expert item generation meeting (n=22) consolidated the evidence and developed five developmentally appropriate prototype versions of C-POS including both self- and proxy-report. These were refined through cognitive interviews (48), in particular to be more inclusive of non-verbal children and young people. Preliminary psychometric evaluation (n=529) is underway.

Conclusions: An outcome measure for paediatric palliative care has been developed with consideration of face and content validity, and acceptability to the target population. Further psychometric properties of the measure are being evaluated. This is the first patient-centred outcome measure designed for this population in the UK and it reflects the top priorities of children and families affected by life-limiting and life-threatening conditions. The next steps will be to implement the C-POS into routine clinical practice, to facilitate the assessment and monitoring of key outcomes.

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Opportunities and Limits

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Paediatric Palliative Care needs are changing, more children are living longer due to new therapeutics or the use of medical technologies such as home ventilation (1).

Whilst we have a growing body of evidence on the challenges of paediatric palliative care referrals and access (2) , we are lacking an evidence base on how to improve this care. These children deserve evidence based care

“Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (3).

One barrier to robust evaluation of paediatric palliative care interventions is the availability of validated tools to measure what is important to children and families and the health system (4). We know that from parents, good palliative care is co-led and co-planned with trusted professionals; is integrated, responsive and flexible; encompasses the whole family; and enables parents to not only care for, but also to parent their child to end of life (5, 6). We need to be able to measure change.

A review of available tools which measure the quality of dying, death and end-of-life care for children and young people, identified only 11 tools. All tools were completed by primary caregivers or healthcare professionals as ‘proxy’ assessments; all except one was undertaken after death. Question items about quality of life and preparation for death were found in all tools; items relating to cultural aspects of care, grief and financial costs were less common. Only 6/11 had undergone psychometric testing within a paediatric palliative care setting (7).

There are many existing tools for measuring for example symptom management within other paediatric specialities or adult palliative care – we need to learn from these sectors.

The priority for paediatric palliative care research is now to stop just describing problems – we need to move forward to develop, evaluate and implement the solutions, using robust measures of what matters to children, families and the health and care systems.

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Future Horizons

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In this keynote lecture the Young Professionals Committee will present their vision for the Future Horizons of Paediatric Palliative Care. Securing a bright and successful future for paediatric palliative care will rely on three core elements: caring for everyone, caring for the caregivers and caring for ourselves.

Creating the Culture You Want to Work in

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This session will aim to define workplace culture as well as helping participants recognize their role in creating workplace culture. We will discuss strategies for improving workplace culture including how to leverage strengths of colleagues in other disciplines.

Shared Decision-Making in Pediatric Palliative Care: Why, When and Where

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PPC has the aim of improving the well-being of those children who suffered from a life-threatening o life-limiting disease and also their families. Why shared decision-making (SDM) is crucial: it promotes a collaborative approach, ensuring that care aligns with both medical best practices and the values and preferences of patients and families. SDM encourages family strengthening, increases the satisfaction of care, and makes sure that the choices are both knowledgeable and humane. When SDM should occur is throughout the PPC journey, from diagnosis to the end-of-life stage. It is necessary at every significant decision point, including treatment options, transitions in care, and advance care planning, adapting to the evolving needs of the child and family. Where SDM takes place is in all settings where PPC is delivered, such as hospitals, outpatient clinics, and home care environments, ensuring the approach is consistent and tailored to each context.

What decisions are made in SDM is also crucial, as the type of decision can range from critical life-sustaining interventions, to more routine care choices. Every decision comes with a different level of complexity and emotional weight for families. **Who** is involved includes healthcare professionals, the child, parents, and sometimes the extended family, making an transdisciplinary and family-centered approach necessary. And how these decisions are communicated is critical; the way healthcare professionals talk about options can often differ from the language and concerns that families have. Using clear, empathetic, and culturally sensitive communication is essential for making sure everyone is on the same page.

In PPC, the process of SDM enables a solution to personalize to the individual patient, to be in accord with the family's goals, and to create trust among the family and the caregiver through the whole care process. As we are moving forward, it is very important to keep on enhancing and developing the best practices for SDM so that every child and the family will have access to meaningful, compassionate care across different healthcare settings.

Support for Family Members and Strategies for Engaging the Community

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When a child becomes ill with a life-threatening or life-limiting condition it affects the whole family. Support can be provided by a variety of professional and non-professionals throughout the illness and beyond death. According to the saying: "it takes a village to raise a child", similarly, it takes a community to care for the seriously ill child and the family. But what do we mean by community?

A community can be a social group of any size whose members reside in a specific locality, share government or have a common cultural, historical heritage. Beyond children hospices, school, church, and lay groups of people can represent a community, even virtually. But how do we best utilise the services available from these communities in paediatric palliative care? What strategies can be applied to educate and engage the community in a paediatric palliative approach?

In the Lancet Commission on the Value of Death: bringing death back into life, led by Dr Sallnow it is suggested that specialised palliative teams beyond the provision of care should promote education, research, and capacity among general health-workers.[1] At the Louis Dundas Centre (LDC), Great Ormond Street Hospital, staff engage in research and has provided over 2 100 hours of education in paediatric palliative care to health-workers within the trust and beyond in the last year. In addition, LDC has introduced joint positions for palliative nurse specialists alternating regularly between LDC and each of three children hospices, i.e., Noah's Ark, Haven House and Little Havens. From the perspective of staff this policy of joint positions has been found to increase competence, knowledge exchange, care continuity and also to reduce barriers to hospice services.

An interesting educational initiative has been reported from Germany by Bollig and co-workers involving thousands of school aged children. In the so-called Last Aid Course for Kids and Teenagers children received education about death, dying and grief. A vast majority found the course very good or good. Most children expressed appreciation of being given the possibility of discussing existential issues.[2] Such initiatives can increase death and grief literacy in the community.

Bereavement and grief are often held within the family and its social network. If additional support is needed it can be provided through different community services, i.e., church, school, or non-profit organisations as a complement to specialist palliative care. Internet may also be used for support of bereaved family members. According to a recent review no study could be found on grief interventions given to the whole family throughout the child's illness and death.[3] This might be explained by the obvious futility of elaborating a standard intervention for unique families with unique experiences, not seldom over a protracted course of child illness.

The movement "Compassionate Communities" aimed at building community capacity for end-of-life care has gradually expanded over the last decades around the world. Its' origin can be traced to the statement by Kellehear: "*dying, caring and grieving are social challenges with medical components, rather than medical challenges with social components*".[4,5] The concept Compassionate Communities refers to organisations and individuals passionate and committed to improve the situation for the seriously ill and the bereaved. Health care professionals can play an important role in facilitating a compassionate community by connecting and involving different actors. To date the movement has almost exclusively been described in an adult context. The paediatric palliative field has not yet been embraced, which may be explained by the difference in its unique needs and solutions. Although seriously ill children rarely stand alone the family may still need the support from a compassionate community.

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End-Of-Life Care

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Why?: The natural place to live is the home. In the past, the natural place to die was also the home. Currently, in the developed world, patients with greater clinical complexity are treated in hospitals. With so many problems to address and so many specialists available, it is commonly believed that the best care can only be provided in hospitals.

The goal of any healthcare service should be to provide each individual with what they need, ensuring that both the provider and the recipient are satisfied. This means offering the highest quality of care to each person attended to by the system.

Pediatric palliative care is a way of providing person-centered care: focusing on the children, their families, and the healthcare professionals.

If this type of care is provided during the patient's life, it should continue in the same way as they approach the end. Therefore, being able to offer end-of-life care at home is a matter of justice (giving each person what they need), non-maleficence (avoiding adverse effects associated with hospitalization), beneficence (seeking the patient's best interest), and autonomy (enabling the child to be with their loved ones and to do what is important to them).

What for?: End-of-life care is provided so that the child can live well, as best as possible, in this new stage of life.

How?: To provide good care, the following steps are necessary:

1. Diagnose "the end of life": This is done through signs and symptoms, changes in the patient's baseline condition.
2. Communicate the prognosis and anticipate how the dying process will be: This includes fluctuations in consciousness, death rattle, and the manner of dying.
3. Plan the care: This involves shared decision-making, scheduling planned visits, adjusting treatments, anticipating possible emergency situations, and considering aspects of nutrition and hydration.
4. Provide care: This includes planned care, telephone consultations, urgent care, and managing the death. Services must be able to guarantee all types of care to make dying at home possible.
5. Evaluate: Conduct continuous evaluation of the patient's progress and their response to modified treatments. Be guided by the patient and conduct debriefing sessions to assess the team's performance and learn from successes and mistakes in care.

Who? For whom?: Patients and their families are primarily concerned about the possibility of suffering, particularly due to physical symptoms. If suffering is a conscious experience and most patients fall into a coma before dying, they will not suffer during their death. In other cases, there is the option of sedating the patient.

Families and professionals often struggle with accepting the suspension of nutrition and hydration, as well as the withdrawal of oxygen during the dying process.

Providing care at home requires professionals to step out of their comfort zone, exposing them to greater emotional attachment, which can be a burden, as they may suffer more than necessary. If sufficient emotional distance is not maintained, one may not be objective in making decisions in the patient's best interest. Even in palliative care, there can be therapeutic obstinacy.

In home care, families and professionals often make statements “to empathize” that do not align with the patient’s best interest or the appropriate nature of the relationship between the team and the family. Understanding and responding appropriately to this are “survival rules” for professionals: “We are not a family,” “We are not a team,” and “If it were your child, what would you do?” — I would not be their doctor. Families often ask us when the patient will die. We tell them that what matters is not when, but how, and that is our responsibility.
To die well, to die with dignity, preserving the value of being human means to die: Clean (well-cared-for), Accompanied (with loved ones), Pain-free (with symptom control), and Conscious (living the moment).

Where?: Ensuring a good life and a good death determines the place (the location).
If we can provide this at home, then the patient can die there. Dying at home is not the goal. The goal is to die well. If we can ensure that, we can offer death at home. If we cannot ensure it, we should not offer it because we put the child at risk.
Families feel alone and powerless in coping with the situation and in supporting their child and siblings. For this reason, they want specialized and competent medical and nursing care, available 24 hours a day, with access to psychological, social, and spiritual support.
Conclusion: Any service or organization that wishes to provide end-of-life care must be able to guarantee 24-hour care from a trained, competent team that can meet the needs of the patient and their families

Managing Serious Illness at Home: Experience from the Front Line

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For palliative care teams managing serious illness at home, our aim is to offer safe, holistic care in the place of choice. We know our patients and their families put immense value on being at home.

The specialist palliative care team at Great Ormond Street Hospital, London have been caring for children at home for over 35 years. The model of care at the Louis Dundas Centre (LDC), Great Ormond Street Hospital (GOSH) includes on site working at GOSH itself but also delivering care across an operational network of hospitals, hospices and patient's homes in London and Southeast England. Whilst the LDC specialist palliative care team works directly in patient's homes, we often collaborate with a wider network of healthcare professionals (HCP) in the community offering specialist guidance and support including symptom assessment and management, 24/7. In 2023/24, 291 of our 447 patients had at least one face-to-face visit at home from the team. On average each patient was seen 8 times at home (with a median of 4 visits per patient). Some had as many as 35 home visits. The team provided care for 133 patients at the end of life in 23/24. Of those 26 patients (20%) died at home.

In this presentation, we bring the home care experience of our team to you in a short film. You will hear from an Advanced Nurse Practitioner (ANP), Clinical Nurse Specialist (CNS), Paediatric Palliative Medicine (PPM) Registrars (paediatric doctors, all in their final year of training about to become specialist PPM consultants) and a PPM Consultant who has recently moved from North America to London.

The clinical team will describe their recent experiences of delivering care at home. This will include the value of skilled, holistic assessment, paramount to aligning with patients and families, and building trust. Planning for home visits to optimise efficiency is crucial. Considering the psychosocial situation, the goals of the visit are and determining which health care professional is most suitable maintains a professional, respectful approach. Safeguarding staff and the child is always a consideration.

Preparing for rapid discharge for end of life or in children with significant complexity requires an operationally skilled multidisciplinary team (MDT) who can assess if it is safe to offer care at home and consider risks. Decision making is dependent on appropriate resourcing of a skilled workforce, symptom management plans and anticipatory prescribing to cover all possible scenarios, medication supplies with safe prescribing guidance, correct equipment with trained staff able to troubleshoot issues, clear documentation with the extended services notified (ambulance services, General Practioners and local hospitals) alongside honest discussion with parents/ carers as to what to expect. Plans must include sustainable delivery of care in the home should the child survive for longer than expected.

Colleagues notice how home assessment of patients offers a different depth of high value information to clinical assessment in hospital, not only for understanding symptoms and how they manifest but also a perspective for more informed advocacy and high quality, shared decision making. However, management relies on clinicians taking responsibility for often complex decision making without the usual institutional (hospital or hospice) safety and governance infrastructure in place. The skill to make safe, informed decisions relies on whole system knowledge and detailed planning, alongside continuing clinical enquiry. The value of striving to deliver excellent care whilst balancing uncertainty and clinical risk is acknowledged.

As prognostication becomes more complex and uncertain we consider the evolving challenge of delivering safe, truly holistic palliative care in the home.

Cultural Differences in Shared Decision-Making in Pediatric Palliative Care

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Background: In pediatric palliative care the decision-making process is challenging and the resulting burden is substantial. Although people with migration background often face difficulties accessing palliative care, professionals are increasingly confronted with cultural diversity. This study explores the role of cultural differences in shared decision-making within pediatric palliative care.

Methods: For this study, we recruited families with migration background whose child was being cared for at a pediatric palliative care center, as well as medical and psychosocial professionals and interpreters involved in decision-making discussions with these families.

Given the exploratory nature of the study, we chose a qualitative approach. Data collection was conducted through focus group discussions with professionals and interviews with parents and interpreters. Data were analyzed using Kuckartz's qualitative content analysis.

Preliminary Results: Cultural factors, particularly those encompassing interpersonal, communal, religious and linguistic aspects, play a significant role in discussions on end-of-life decisions. The topic of "hope" emerged as central, as professionals and families often have differing views on how to manage it. This often leads to frustrations: professionals tend to prioritize advance care planning with therapy limitations, while many families feel under pressure and constrained in their hopes. Conflicts primarily arise when trust between families and professionals erodes due to differences in worldviews or misunderstandings. Interpreters report that culturally influenced communication patterns can reflect these challenges.

Conclusions: Cultural differences require a nuanced approach and are potentially associated with conflicts and misunderstandings in shared decision-making. Participating families want to be taken seriously and feel respected in their needs, culture, religious principles and beliefs. The role of interpreters can be crucial.

Health and Social Care Professional Views on Decision-Making for Place of a Child's End-Of-Life Care

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Background: Decision-making pertaining to the place of a child's end-of-life care is poorly understood. Factors affecting shared decision-making between health and social care professionals (HSCPs), parents, and children have not previously been explored. The present study aimed to understand HSCP views on the key components of decision-making regarding the place of end-of-life care of a child across three settings: home, hospital, and hospice.

Methods: HSCPs with experience delivering end-of-life care across the island of Ireland were recruited for focus group interviews. Semi-structured topic guides were used to facilitate focus group discussions. Thematic analysis of transcripts was undertaken to identify key tenets of the decision-making process.

Results: Three focus groups were conducted with HSCPs (n=17) from six children's palliative care services. HSCPs across different settings held differing opinions of where a child should receive end-of-life care, often dependent on the condition of the child and risks involved in home care. HSCPs found palliative care communications difficult and subject to their own experience-based personal biases. Parents were perceived to advocate for a child's wishes even when these wishes were against medical advice. HSCPs strove to meet parent expectations but struggled between empowering parents and assisting parents in making safe and practical decisions.

Conclusions: The choice of setting for a child's end-of-life care is a co-decision between families and HSCPs. Parent autonomy is dependent on risk to the child, appropriateness of preferred setting, and personal biases of HSCPs. Further training for generalist HSCPs is required to bolster confidence in staff to communicate with parents, and facilitate shared decision-making.

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Compassionate Extubation at Home (CEAH) in Paediatric Palliative Care: A Case Series

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Background: Compassionate extubation at home (CEAH) offers a compassionate approach for children to pass away peacefully within the familiar surroundings of their homes. However, literature on CEAH in paediatric populations, particularly in the home setting, remains scarce.

Aims: To investigate the characteristics of paediatric patients who undergo CEAH and to present a protocol that was developed to guide healthcare providers.

Methods: We present a retrospective case series of five paediatric patients who underwent CEAH with the support of a paediatric palliative home care service between 2019 and 2023. Data such as demographic profiles, diagnoses, observed symptoms and administered medications were extracted from case records and analysed.

Results: From 2019 to 2023, five paediatric patients (aged 18 days to 20 years old) underwent CEAH, with diagnoses of congenital myopathy, organ malformation, neuro-degenerative disorder, brain tumour and intracranial haemorrhage. The time from extubation to death ranged from immediate death to 10 hours and symptoms observed post-extubation were mainly respiratory. All patients were administered medications such as sedatives, opioids and anti-secretory agents prior to extubation. All patients were transported home by ambulance and the process was supported by 6-9 healthcare providers. Families were given time for memory making and rituals such as prayers, taking photos and saying goodbyes. While goals of care discussions were conducted for all patients, none had a completed advanced care planning document. Insights from these cases informed the development of a structured protocol encompassing preparation, execution and post-extubation care.

Conclusions: This study sheds light on critical aspects of paediatric CEAH, contributing to the development of a protocol aimed at enhancing the facilitation and support provided to families, and in fostering confidence among providers to offer CEAH as a viable option.

Beyond Illness: A Qualitative Exploration of Talking about the Future in Pediatrics with IMPACT

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Aim. The Implementing Pediatric Advance Care Planning Toolkit (IMPACT) is a method to support advance care planning (ACP) conversations in pediatrics. Prior research shows that children, families, and clinicians value IMPACT in clinical practice. Implementation in different health care settings and populations of different diseases, ages and backgrounds remains challenging. To optimize the use of IMPACT for children with different ages and conditions, and their parents, this study reviewed its materials with relevant stakeholders.

Methods. An exploratory qualitative study was conducted to evaluate the content, structure and lay-out of IMPACT in semi structured focus group interviews with diverse target populations: children with life-limiting illnesses of different ages; parents of children with varying life-limiting illnesses and disease trajectories; and clinicians working in different health care settings. A thematic analysis was conducted.

Results. In total 8 children, 17 parents and 16 clinicians participated in 18 (group) interviews. These stakeholders valued the current content of IMPACT. Children and families supported the importance of talking about the future, with a preference of focusing on values and hopes of today. Clinicians were found to interpret the purpose of IMPACT differently. Children and families mentioned feeling distress and unease when questions about illness and future scenarios interfere with questions about their identity and personal values. Families and clinicians prefer to explore underlying life values separate from illness perception and (future) medical decision making

Conclusions. Content and structure of IMPACT was highly valued by children, parents, and clinicians. Children and families prefer to focus on their values and daily life. They express a willingness to discuss the illness and future of the child, preferable in a discrete part of the conversation. A clearer description of the aim of ACP conversations is needed.

Identification of Age-Appropriate ACP Communication in Children with Chronic Medical Conditions

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Aim. Pediatric advance care planning (pACP) is known to accomplish patient-centered care, in which children should be involved in a way adjusted to their level of development. Although an age-appropriate approach to participating in pACP has clear mandates, tools to integrate age-appropriate pACP elements into pACP interventions are limited and inadequate. It is essential to understand the developmental characteristics of children with chronic medical conditions in their discussions about pACP topics. The aim of this study is to identify how children of varying ages communicate about and value pACP topics.

Methods. A semi-structured picture-aided interview study was conducted, to elicit narratives regarding ACP themes and to explore initial associations and descriptions from chronically ill children. The interviews were thematically analyzed to gain an interpretation about developmental communicative characteristics.

Results. In total 14 children with chronic medical conditions between 4-18 years old were interviewed between January 2023 and September 2023. Findings suggest a development in children where they gradually evolve communicatively from a concrete, egocentric, impulsive and imaginative approach, to a more abstract, socially conscious, metacognitive and controlled communication process. Children prefer to discuss positive topics with their health care providers and favor communication that makes them feel more than their disease. They appreciate a direct approach when doctors try to explore their perspective.

Conclusions. Children are eager and able to engage in pACP-communication. This research enhances the understanding of developmental characteristics regarding the content, relational and comprehension levels of communication in children with chronic medical conditions concerning pACP-topics. Future research should focus on developing guidelines to create an age-appropriate toolkit to promote high-quality pediatric palliative care.

Compassionate Communication with Families During Evaluation for Death By Neurologic Criteria

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Background: Declaration of death by neurologic criteria (DNC) is fraught by potential communication difficulties. It follows an irreversible neurologic injury such that the functional integrity of the brain, as a whole, ceases. It can become emotionally charged, typically when unexpected. This complicates grief and bereavement, can generate conflict, and contributes to staff moral distress. Updated interdisciplinary consensus guidelines regarding DNC published in 2023, applicable to term infants over 28 days of age, outline a specific clinical examination sequence when indicated. Diagnosis of DNC is made clinically in most cases; ancillary confirmatory testing is performed only for specific reasons.

Methods: Extant literature published in the PubMed database as of May of 2024 was reviewed, with a focus on communication strategies, and summarized.

Results: Promotion of trust using clear, timely, transparent, compassionate, appropriately paced information is invaluable. Impeccable communication consoles, facilitates timely formal DNC examinations (DNCe), supports families when results are shared, and in bereavement. While informed consent is not necessary for DNCe, families should be offered the opportunity of observing the DNCe after receiving careful anticipatory guidance, preferably away from the bedside, focusing on portions of the DNCe which can be quite disconcerting. Reasonable accommodation may be required by some families before and after DNCe to facilitate supportive family presence. Adherence to DNCe checklists is recommended. Additional considerations include the optimal interface with organ procurement organizations when possible and available, safeguarding the dignity of the newly deceased, and compliance with local legal standards, when DNC is diagnosed.

Conclusions: Compassionate communication comforts and supports families and teams, can facilitate DNCe; available choices, and promote the best possible family, staff, and society-related outcomes.

Parents Communication with a Child with Juvenile Neuronal Ceroid Lipofucinosis about the Diagnosis

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Background: Juvenil Neuronal Ceroid Lipofusinosis (JNCL) is a neurodegenerative life limiting condition. Norwegian law and national guidelines safeguard children's right to information about their health, but also emphasize close cooperation with parents. Prognostic disclosure has been a long-debated topic within palliative care, but research on communication with children with neuro degenerative disorders such as JNCL is scarce. This study aims to describe how parents communicate with their children about JNCL throughout the illness trajectory and the reflections, decisions, and dilemmas this communication is based upon.

Method: Data were gathered through semi structured interviews with 13 parents of children with JNCL, transcribed verbatim and analyzed with reflective thematic analysis.

Results: Parents described communication with the child as a continuous project which changed throughout the illness trajectory. The central topic was labeled «Tailored communication to provide understanding". Four related topics were found:1) The appropriate age of information; old enough and still well enough 2) The content and amount of information; protect and still give autonomy 3) Information to others: a resource or a risk 4) Parents role: a huge responsibility and lack of support.

Discussion: Its evident that a dichotomous discussion about "sharing or not sharing" prognostic information does not cover the nuances of parental communication with their child about JNCL. It's important that health care personnel have a nuanced approach, minding aspects of the disease, personality, family environment, culture and context when supporting and advising parents in the process of communicating with children about JNCL.

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Evaluating PPI Activities within a Paediatric Palliative Care Research Centre

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Background and aim: Patient and Public Involvement (PPI) is recognised as an important component in healthcare research. There are sensitivities, and ethical and practical considerations when involving parents of children with life-limiting conditions or bereaved parents in paediatric palliative care research. Regular reviews of PPI activity are important. The aim of this study was to evaluate a paediatric palliative care research centre's PPI activity to determine what went well, or less well; and how future activities can be improved.

Methods: Two stage evaluation: first a review of PPI study logs; second a qualitative exploration using a survey and semi-structured interviews of parents engaged in PPI activity within a paediatric palliative care research centre and a focus group with researchers. Data were analysed thematically.

Results: The review of PPI logs for 15 studies highlighted the crucial role of funding in enabling PPI throughout the research process. 8 parents completed the survey, 4 parents were interviewed, and 12 researchers participated in an online focus group. Three themes were developed: Clarity of processes and purpose; balanced relationships created a safe space; and mutual respect and value for PPI. These themes highlight what is working well within the Centre's approach to PPI and the opportunities to improve.

Conclusion: Investment in time and resources are required to undertake meaningful PPI in paediatric palliative care research. Roles, processes, and expectations for all involved must be explicitly agreed. Establishing relationships ensures trust and enables authenticity and vulnerability. In addition to improving research, PPI provides opportunities for personal growth and development for both researchers and parents, and for parents it can also offer a sense of community and therapeutic benefit. The evaluation led to the development of a 'route map' for establishing an impactful PPI group for paediatric palliative care research.

Critical and Often Missed Steps in Launching Advance Care Planning for Youth: Parental Perspectives

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There is increasing support for the capacity of adolescents and young adults (AYA) living with a serious illness to participate in their healthcare decision-making throughout the treatment trajectory. Voicing My Choices (VMC) is an advance care planning guide developed for and with AYA facing cancer and other serious illnesses in the U.S. It was designed to help families communicate about difficult topics. Cultural adaptations of the document have been created in China, Brazil and Australia. We took the first steps towards adapting VMC in the Czech Republic.

In collaboration with the primary author of VMC (LW) and physician (MW), preparation work was initiated to translate the document, adapt it to the cultural specifics of the Czech Republic and implement it into practice. The document was translated into the Czech language and then critically evaluated by 5 members of the Pediatric Supportive Care Team (PSCT) in our hospital. Finally, the document was sent to 6 parents of 4 children referred to the PSCT for feedback.

The youth included a boy with recurrent osteosarcoma (age 20), girl with middle aortic syndrome (age 17), boy with primary pulmonary hypertension (age 15) and boy with pharmacoresistant epilepsy (age 13). All parents found the document well written, easily understandable, and useful both for parents and the children. Insightful suggestions for changes were provided (e.g., add an “I don’t care” option”) along with appreciation for having such a document (e.g., “It’s a good way to avoid family rifts and honor and follow the decisions of the sick“). The most challenging page reported was “How I want to be remembered. Half of the parents mentioned that completing the document may reduce regret.

Piloting VMC in Czech with parents of patients in palliative care confirmed the unique communication potential of the document. Parents perceived the VMC as a challenging yet useful document. AYA patients will review the document next.

Interdisciplinary Collaboration in Pediatric Palliative Care: Perceived Barriers and Facilitators

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Aim. Children qualifying for pediatric palliative care (PPC) increasingly reside and die at home. This necessitates close collaboration between parents, healthcare professionals (HCPs) in tertiary care with expertise on life-limiting diseases, and HCPs in primary care with expertise on daily care to facilitate living with illness. They collaborate in so-called situational care networks (SCNs), i.e., a partnership of HCPs involved in care for one child and its family. Interdisciplinary collaboration (IDC) within these networks is crucial, yet not self-evident. This study aims to identify barriers and facilitators for IDC within SCNs, as perceived by parents and HCPs.

Methods. A multiple case study using semi-structured interviews with parents of children who predominantly reside at home and involved HCPs. Data was thematically analyzed.

Results. 14 parents and 39 HCPs within 9 cases participated. Perceived barriers were the limited awareness of the existence of the SCN and failure to recognize other members' expertise and added value, resulting in organizational gaps: a lack of case overview, a lack of information exchange, and unclear roles and responsibilities. Parents felt responsible to fill these gaps. Facilitators were the HCPs' flexibility and personal involvement with the child and family. Both resulted in initiatives to resolve challenges in collaboration, such as using online communication tools or actively supporting and enhancing each other's expertise. IDC improved during the terminal stage, where consensus existed on comfort care and centralizing the family's needs as main goals.

Conclusion. IDC in SCNs involves numerous challenges, primarily related to unfamiliarity with the existence of SCNs and poor management of IDC, placing excessive organizational responsibility on parents. Perspectives for improvement are: start early, share goals, and increase awareness of the added value of the individual members to achieve patient-centered care and manage IDC.

Understanding the Needs of Pediatric Palliative Caregivers in Washington, USA

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In the United States, there are just six respite care facilities for pediatric patients. This underscores a significant gap in the availability of pediatric palliative care nationwide. Less than 30% of pediatric patients who could benefit from hospice services have access to them, often receiving care from adult-focused hospices, which do not meet their unique needs. Children with complex conditions rely on their parents and caregivers for round-the-clock support, leaving them exhausted and without respite. According to the National Hospice and Palliative Care Organization, most counties in the U.S. lack access to essential pediatric care options, with a majority of counties lacking access to essential care options.

In collaboration with Seattle University's College of Nursing, this study was designed to document the challenges, preferences, and needs of caregivers in Washington State caring for ill children through a thorough and comprehensive survey. A little under 300 caregivers participated in the survey to share their personal experiences. Before participating in the survey, caregivers provided consent. To analyze the survey data, regression analysis and other statistical methods were used to understand how caregivers can be better supported. The insights illuminate pathways to navigate the myriad of challenges inherent in providing daily care for their children.

Findings reveal compelling insights into the perspectives of caregivers in Washington State. Approximately 91.15%, would consider receiving care at an alternative facility than the hospital. Futhermore, 40.13% of caregivers report dedicating a staggering 16-24 hours per day to the care of their sick children. In addition, 87.23%, report a significant impact of their child's illness on both their physical and mental well-being.

Respite hospices for pediatric patients are a commodity needed throughout the country to support sick children and their caregivers.

Working with Bereaved Parents to Develop Digital Grief Resources to Help Staff and Bereaved Parents

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Background and Aims: In LauraLynn Hospice approximately 60 children die each year from life limiting illnesses. This is one of the most difficult losses that a parent can face. It is also challenging for staff who care for the child and family. Both can often be at a loss to know how to cope. LauraLynn Hospice and two bereaved parents (8 and 10 years post death of their child) identified a gap at Level 1 (Adult Bereavement Care Pyramid (2020)) for accessible and informed bereavement support information and guidance for newly bereaved parents (0-12 months post death) and staff.

Methods: LauraLynn worked with the 2 bereaved parents (one male and one female) and an external company to co-design and develop 2 x Level 1 digital bereavement support eLearning resources to support parents and staff after the death of their child, which could be accessed across a range of digital platforms (see courses below).

(Parents): https://learning.elucidat.com/course/65673dfd1a31d-6596787964db7

(Staff): https://learning.elucidat.com/course/659fbb7535bde-65a55e97e2463

Results: The two Level 1 eLearning resources have been co-developed and made available to newly bereaved parents and staff in LauraLynn. They have been used successfully in a newly bereaved parents support group. The resources are a key component in the LaurLynn Bereavement Care Pathway.

Conclusion: The co-creation with bereaved parents of these two digital bereavement resources, has been key to addressing a support gap for both parents and staff in the aftermath of the death of a child. These resources are appropriate, effective and accessible.

References:

The Irish Hospice Foundation (2020) Adult Bereavement Care Pyramid. A National Framework. Dublin: The Irish Hospice Foundation

Wiener L., Rosenberg A.R., Lichtenthal W.G., Tager J., Weaver M.S. Personalized and yet standardized: An informed approach to the integration of bereavement care in paediatric oncology settings. *Palliat. Support Care.* 2018;16:706–711.

Bereaved Parents' Decision-making about Location of End-of-life Care for Children

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Background: Children's palliative care strategic priorities across the island of Ireland emphasise providing the right care, at the right time, in the right place. This includes actively involving parents in decision-making and planning location of care for their child. The focus of this research was to explore factors affecting bereaved parents' decisions of the place of end-of-life (EoL) care for their child.

Methods: Using a qualitative study design, parents of a child with a life-limiting condition who died across hospital, home, or hospice settings within the last 4 years, were recruited to take part in semi-structured interviews. Ethical approval was sought and obtained from all study sites. Data were transcribed and analysed using thematic analysis.

Results: Twenty parents were interviewed across the island of Ireland. Four themes were identified: (1) Familiarity and freedom of home; (2) Safety and security of hospital; (3) Homeliness and support of hospice; and (4) The child first and foremost. The themes arising give a deeper understanding into parental decision-making regarding their child's place of EoL care. Making such a decision was complex and emotionally challenging for all parents. Support, information about potential choices, and timely guidance from health and social care professionals were crucial.

Conclusions: Communication with and support for parents were both areas that were highlighted as being important to parents when deciding on the location of EoL care for their child. Key implications from this research confirm the need for additional training for those providing EoL care. The results from this study will inform the co-production of a decision-making framework for planning the place of EoL care for children and young people.

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Messages from Heaven: Unexplainable Experiences among Bereaved Parents

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Background & aims: Bereaved parents may have sensory and quasi-sensory experiences of their deceased (SED) child, also known as after-death communication. It includes seeing the child, talking to them, hearing their voice, or feeling their presence. Although SEDs are common, they are unexplainable phenomena and therefore not always socially accepted. As a result, parents may feel pressured to hide or suppress these experiences. This study aims to increase our understanding of SEDs to improve grief support for bereaved families.

Methods: This study is part of a larger project on bereavement care for parents of childhood cancer patients. We are conducting a secondary analysis of the qualitative data obtained (between March 2022 and Sept. 2023) through 18 open-ended face-to-face interviews with parents whose child was treated for cancer in Switzerland (age at diagnosis ≤ 18 years, time since death ≥1 year). We are using interpretative phenomenological analysis for data analysis.

Results: Preliminary results show that spontaneous SEDs are quite common among parents, even in long-term bereavement and regardless of whether they are religious or not. Most participants welcomed these experiences as they supported and comforted them in the bereavement process and often allowed them to connect with their partners. A few mothers reported on seeking assisted after-death communication through a medium. While this was helpful for some, one parent expressed concern about losing rationality and control over themselves.

Conclusion: As a form of spiritual meaning-making and continuing bonds with the deceased child, SEDs can alleviate the parental grieving process. SEDs may also facilitate relational grieving. It is therefore important to make space for these spontaneous experiences by listening to parents in a non-judgmental way. Future research should focus on the potential health risks of mediumship especially if it profiles itself as a substitute for bereavement counselling.

Bereaved Parents' Experiences of Paediatric End-Of-Life Care: A UK Multi-Site Qualitative Study

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Background: Around 3743 infants and children die in the UK each year. However, evidence has consistently shown that availability, access, and delivery of palliative care is inconsistent and incoherent. Despite this, the need to support parents through this intensely painful and emotionally demanding experience should be a common key component of care. However, there is little high-quality evidence on ways in which this type of care is experienced by families, particularly about the factors contributing to decision-making.

Aim: To explore bereaved parents' experiences of receiving end-of-life care for their infant, child or young person.

Methods: A multi-site qualitative study, grounded in the phenomenological approach. In-depth; face-to-face, telephone or video-call; interviews with bereaved parents; whose child received end-of-life care in one of the four settings accounting for the place of death of >50% of children who die in the UK each year: neonatal and paediatric intensive care units, and children and teenage cancer centres. Interviews were audio-recorded and transcribed verbatim. Informed consent was obtained. Data were collected by 4 researchers. Data analysis of interviews employed narrative and thematic approaches. UK-wide ethics approvals were obtained.

Results: 55 bereaved parents were recruited, representing 44 children. Findings add new insights around family-centred care and shared decision-making. Parents valued time and continuity, enabling them to maintain some ownership and control. Themes around memory-making and parenting at end of life, clarify and add to the existing evidence base. Bereavement support was important, but lacking.

Conclusions: This is the largest UK based study on parents' experiences of end-of-life care for children. Shared decision-making between parents and professionals was limited. Offering choice and control is central to delivery. Parents need professionals to engage and understand their unique reality.

Parent and Professional Experiences of 24/7 Paediatric End-Of-Life Care: Shining a Light on Inequity

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Background and aims: Across the UK, children's end-of-life care is provided inconsistently, with a postcode and a diagnosis lottery. Not all families have access to hospice provision, although some do not want this. Current provision does not meet the government's quality standards or commitments.

To support planning and delivery of 24/7 paediatric palliative care in the North East and Yorkshire region, this study will develop components of a complex intervention by assessing parent and professional perspectives and needs, and patterns of care at end-of-life. The aim is to explore parents' and professionals' experiences of receiving and delivering 24/7 end-of-life care in the North East and Yorkshire.

Methods: A qualitative study using thematic analysis. Online focus groups with professionals. Semi-structured interviews with parents of children with life-limiting conditions receiving palliative care and bereaved parents.

Results: 54 professionals participated in 11 online focus groups and 26 parents were interviewed. Findings show the extent of regional inequity in access to out-of-hours support. Where available, local hospices integrate with tertiary teams to provide valued 24/7 support to families and other professionals. In other areas specialist advice is only available during office hours, leaving families feeling vulnerable and scared if something goes wrong. Parents stressed the importance of continuity and their child being known. Availability of children's community nursing was fundamental to families' experiences yet was the most inconsistent, with some teams reporting 'stepping up' out of good will to fill service gaps and support families.

Conclusion: Examples of good practice demonstrate that it is possible to provide families with 24/7 support, but there is a reliance on charity funding. Local commissioning, work force shortages, and lack of training and experience all need addressing to ensure all parents are equitably supported.

Transformed by Song: The Impact of Music on Adolescents and Young Adults Living With Advanced Cancer

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Background: Adolescents and young adults (AYAs) living with advanced cancer require ways to emotionally process their lived experiences with cancer yet have limited methods to process them. This study aimed to conceptualize AYAs' experiences with hope while living with advanced cancer.

Methods: A purposive sample of participants were virtually recruited from an academic medical center and online non-profit organization for this this Husserlian phenomenology-informed descriptive qualitative study. Each participant engaged in two semi-structured interviews via Zoom. Participants composed first-person narratives based on the interview guide which prompted them to verbally describe their lived experiences about hope while living with advanced cancer. Thematic analyses were iteratively performed on the narratives to identify final themes.

Results: Fifteen AYAs aged 12-21 years diagnosed with advanced hematological (80%) or solid (20%) malignancies participated in this study. Twelve (80%) participants were female, and three (20%) participants were male. Thematic analyses identified a main theme of Simple Supports of Hope, with a subtheme of Diversion. Participants described music as a form of diversion which supported their hope. Participants found listening to music calming and comforting and helped them cope with their distress. Performing music provided a creative outlet for negative feelings associated with cancer treatments. Creating music transformed and de-intensified the treatment environment and helped spread hope to healthcare staff.

Conclusions: AYAs may intentionally use music to improve emotional expression, empowerment, connection, and coping strategies throughout the treatment process for serious illnesses (i.e. advanced cancer). Additional research needs to be conducted exploring the use of music interventions such as therapeutic songwriting or compositional music therapy to promote a healing treatment environment for AYAs living with serious illness.

Breaking Barriers: Access to Pain Medicines for Paediatric Palliative Care Worldwide

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Background: At a global level, children are suffering needlessly with pain & other symptoms, without access to the medicines they need. A survey in 2023 mapped the development of children's palliative care (CPC) in countries around the world, including access to pain medicines.

Methods: A cross-sectional study was undertaken with a survey sent to CPC representatives in 167 countries between July & December 2024. Participants were asked 27 questions about CPC in their country, including questions relating to access to medicines for pain & whether PC medicines are included in their country's essential medicines list (EML). They were asked to rate accessibility on a 3-point Likert scale & to describe any specific issues with access.

Results: 130/167 countries completed the survey (78%). There was no response from 37 (22%) & no known CPC champion in the remaining 29 countries (17%). 68/130 countries (52%) said effective pain medicines were accessible, and 57 countries (44%) reported that they were somewhat accessible and 5 did not respond (4%). 74 (57%) reported that their country's EML included appropriate medicines for CPC, 30 (23%) reported that their EML did not, and 21 (16%) participants were not sure. Of those countries with limited/no access 50/57 (88%) were low- and middle-income countries (LMICs), which have the greatest need for CPC. 56/66 countries (85%) where there is no data are LMICs. Barriers to accessibility fell under a range of themes including: place of availability of medications; no paediatric formulations/ dosages; lack of education and awareness re their use; strict rules on prescription; lack of pain assessment skills; supply issues; & authorisations for use in children.

Conclusion: There remain many barriers to accessing pain medications for CPC around the world. An understanding of this is essential if we are to break down barriers and reduce suffering. Further research is ongoing to explore accessibility of specific medications and formulations.

Rapid Review of Patient and Public Involvement Work with Parents of Children with Serious Illness

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Background and aims: As the number of children with serious and life-limiting conditions increase, their needs for healthcare are also rising. As a result, public involvement activities with parents of these children have increased in priority. Guidance for patient and public involvement (PPI) work exist but are not specific to the needs of parents of children with life-limiting illness or bereaved parents. This study aimed to review the evidence on involving parents of children with life-limiting illness and bereaved parents in research, service planning and advocacy, and use this to develop best practice guidance.

Methods: This review followed the Cochrane Rapid Reviews Methods Group Guidance. MEDLINE and EMBASE were searched for primary studies of any design and literature/systematic reviews, and grey literature searching was conducted. Sources reporting on involving parents of children with life-limiting illness or bereaved parents in healthcare, research, or charity work in any setting, were included. Data were charted using the UK standards for public involvement in research. Two PPI consultation workshops were conducted with parents (n=13) and healthcare professionals/charity representatives (n=7).

Results: 23 articles and two grey literature sources were included. 17 reported benefits of parental involvement (68%); 3 reported burdens (52%). In relation to best practice, nine reported on the importance of inclusive opportunities (36%); 17 on working together (68%); 11 on support and learning (44%); nine on communications (36%); two on impact (8%); and two on governance (8%). PPI consultation workshops highlighted new factors which were not present in the literature around communication and understanding the impact of involvement.

Conclusion: Organisations working with this group should consider offering inclusive approaches to improve diversity, levelling power imbalances, ensuring flexibility of approach, and appropriate communication and impact.

Training Teams in Pediatric Advance Care Planning: Transfer of Knowledge and Communication Skills

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Background/Aim: Advance Care Planning (ACP) enables patients and relatives to define and share values, goals and preferences for future medical treatment and care. The IMplementing Pediatric Advance Care Planning Toolkit (IMPACT) is a method to support children, their parents and healthcare professionals in ACP. Healthcare professionals who were trained to use IMPACT, indicated their need for support to practice ACP communication skills optimally over time. Therefore, we developed a team-based learning program aimed at teaching participants how to transfer knowledge on ACP, continue practicing ACP communication skills and reflect on ACP within their own team context. The aim of this study was to evaluate the program's transfer of knowledge as well as the professionals' experience and team reflection on ACP.

Method: An IMPACT train-the-trainer course was developed and a selection of healthcare professionals from eight pediatric palliative care teams (PPCTs) from all seven Dutch university hospitals and the specialized Center for Pediatric Oncology were invited to participate. Participants were asked to educate their team members (learners) on ACP by organizing two guided coaching-on-the-job (COJ) sessions. Questionnaires and field notes were used to evaluate the level of knowledge transfer and the participants' experiences.

Results: Eighteen participants took part in the train-the-trainer course. In seven PPCTs one or two COJ session(s) took place, attended by 46 learners in total. Eleven participants indicated that they had transferred knowledge to their team members as intended. Most learners reported (somewhat) increased self-confidence for conducting ACP conversations and assessed team reflection positively. Dealing with workload within PPCTs however, needs more emphasis in the training.

Conclusion: The new team-based learning program resulted in intended transfer of knowledge and methodical reflection on ACP in COJ sessions in seven out of eight participating PPCTs.

Resources Required to Provide Neonatal Palliative Care:Supporting the Nursing Workforce

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The provision of equitable palliative care requires a dedicated workforce. In the UK, Neonatal nurses(NN) are trying to provide optimal palliative care as part of their daily nursing care in a resource limited & chronically understaffed environment with significant workforce gaps.The provision of unstructured & unsupported neonatal palliative care results in high levels of burnout & emotional fatigue in emotionally challenging environments, contributing to high levels of attrition in NN.

There are 184 'link' NN role for palliative & bereavement care across 193 neonatal units & only 11 of those roles are funded & form the Neonatal Palliative & Bereavement Care Nurses' Network connecting with each other via email, providing peer support, sharing guidelines & a national network of expertise.

This network was surveyed via the email, asking two questions

'What is the most challenging aspect of your role?' & 'What would help you be more effective in your role?'A response rate of 75% out of the 184 contacts

Themes for 'What is the most challenging aspect of your role?' include, limited support from management; little time to spend with families; demands of clinical work

'I'm broken. I have no dedicated time to care for families' (nurse)

Themes for 'What would help you be more effective in your role?' include dedicated time; respect & understanding from colleagues; time for training

We need to develop a resilient NN workforce able to provide safe, effective care including appropriate identification, planning, end of life care & continued bereavement support, develop a funded senior neonatal nurse regional roles,each neonatal unit to have a funded nurse,utilising the expertise provided by charitable organisations such as children's hospices and specialist palliative care community teams. The NN workforce are our most valuable resource & must be respected with financial investment, retaining expertise & specialist knowledge, whilst ensuring access to training & education.

Succesful Implementation of a Pediatric Palliative Care and Hospital at Home Program

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Background and aims: Many children with life-limiting/threatening diseases benefit from pediatric palliative care (PPC) services, but access is limited, especially for home-based care. Hospital-based PPC teams often struggle to provide comprehensive home care. The aim is to describe the implementation of an integrated PPC and hospital at home (HaH) program embedded within a children's hospital to improve access to home-based PPC.

Methods: Descriptive study reporting the implementation of an integrated PPC/HaH program in a spanish tertiary referral hospital. Care data were collected directly from the medical records of the admittted patients. The perceived level of satisfaction was collected through satisfaction questionnaires with a 0-5 Likert scale.

Results: The PPC/HaH unit opened in august 2021, staffed by an interdisciplinary team. In the first 29 months, the unit had 633 admissions, the team performed 1803 visits and attended to 12 ends of life. Most PPC patients (48.6%) had neurological life-limiting conditions. Other top diagnoses included gastrointestinal (8.8%), oncological (5.9%) and respiratory (4.4%) diseases. Most frequent reasons for HaH admission were symptom control, consultations related to life-sustaining technology and respiratory support during intercurrencies. Families who submitted the satisfaction questionnaire rated their care as 4.95 over 5.

Conclusions: The outpatient PPC team provides comprehensive consultations, care coordination, symptom management, psychosocial support, and community-based nursing services. Combining dedicated PPC and HaH services within a tertiary care children's hospital facilitated comprehensive, coordinated care for children with life-limiting/threatening across the hospital, clinic and home settings. Early outcomes demonstrate high family satisfaction and substantial volumes of activity for this new integrated program model.

Collaborative Working Improves Access to Paediatric Palliative Care

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Background: Nationally the prevalence of children with life-limiting conditions is increasing. Local data showed that in 2019 68% of children who died for an expected reason were not known to their local hospice. The hospice implemented new ways of working to reach these populations equally and to ensure national quality standards were met. This paper describes the impact of the introduction of hospice clinical nurse specialist within the local hospitals and tertiary centres.

Method: Analysis of quantitative data obtained from a data collection tool completed by the clinical nurse specialist (CNS) containing patient and non-patient contacts. Qualitative information from professional and family feedback.

Results: In the first year 4 CNS were integrated into neonates and paediatrics within the local tertiary centres. They reported 931 contacts with babies, children and young people demonstrating improved access to palliative care support this included 50 new referrals to the hospice and family support care.

In Year 2 2402 contacts were reported which included end of life care, symptom management support and advance care planning.

Discussion: Collaborative working increases access to palliative care and choice at end of life improving quality of care. There is an increase in the understanding of health care systems and barriers to the early introduction of palliative care. Health care professionals that are unfamiliar with the ethos of palliative care are empowered and educated to allow then to change their practice to meet quality standards.

Systemic Development of Paediatric Palliative Care in the Czech Republic: Lesson-Drawing

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Background and Context: Paediatric palliative care (PPC) in the Czech Republic has traditionally been practice-oriented. A decade ago, the first systematic approaches to its development began, driven by growing awareness among professionals, the public, and political representatives. This study reflects on the key pillars supporting this development and aims to draw lessons for future progress.

Aims: To analyze the development of PPC in the Czech Republic through a comprehensive review, identifying key systemic attributes and their impact on shaping future strategies.

Methods: A review study was conducted, drawing on a range of sources including literature, policy documents, and expert interviews. Key attributes were identified based on their relevance to the systemic development of pediatric palliative care, starting from the first Conference on Children's Palliative Care.

Results: The development can be categorized into three distinct phases:

Community Building (First Period): Establishment of a professional society and educational capacities.

Professional Education and Advocacy (Second Period): Training of key professionals and initiation of advocacy efforts.

Strategic Framework and Systemic Change (Ongoing Third Period): Implementation of the Strategy of Care for Children and Adolescents with Serious Life-Limiting and Life-Threatening Diagnoses, emphasizing intensive advocacy to influence system change.

Each phase was marked by specific initiatives and outcomes, highlighting the gradual yet systematic progress.

Conclusions: The phased approach to developing PPC in the Czech Republic underscores the necessity of building a strong professional community, establishing a collaborative network, and enhancing practical care delivery. These steps were crucial before formalizing a strategic framework to ensure coherent and impactful system-wide changes. Lessons from this experience can inform similar efforts in other regions aiming to develop their PPC systems.

Impact of a Pediatric Palliative Care Program on Regional Children's Healthcare Utilization and Cost

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Background: The impact of pediatric palliative care (PPC) programs on children's healthcare utilization and cost remains illusive. We examined the impact of an new PPC program on regional utilization and cost in children's last year of life relative to a contemporaneous positive control region.

Methods: A retrospective cohort study used administrative databases to identify all decedents age 31d to 17y from 2010-18 in Northeastern Ontario (NEO), with a PPC program throughout, and Southcentral Ontario (SCO), with a PPC program from 2016-18 only. Outcomes included mean healthcare utilization (days), costs ($CAD), and location of death. For 2010-15 and 2016-18, multivariable analysis (MVA) produced relative rates (RR) and odds ratios (OR) for SCO outcomes relative to NEO and counterfactual analysis (CFA) produced the mean difference in outcomes attributed to residing in SCO. Results were compared across periods.

Results: Results can be found in Table 1. We observed substantial reductions (>20%) in many MVA and CFA results; several CFA findings reached statistical significance, while MVA results did not. Both MVA and CFA findings estimate a reduction in total regional costs of $2.2million.

Conclusions: A part-time PPC program was associated with a decrease in regional healthcare costs and intensity near end of life relative to a positive control region. These results suggest PPC programs can be resource/cost-effective at a regional level.

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Table 1. Comparison of multivariable analysis (SCO outcomes relative to NEO) and counterfactual analysis (impact on SCO outcomes attributed to residing in the SCO region)

	Multivariable				Counterfactual			
	2010-2015 (RR/OR, 95%CI) n=810	2016-2018 (RR/OR, 95%CI) n=414	Change (%)	p-value	2015-2016 (mean, 95% CI) n=467	2016-2018 (mean, 95%CI) n=262	Change (%)	p-value
Total Days (RR, Days)	1.35 (1.11-1.64)	1.43 (1.06-1.93)	+6%	.72	+20.4 days (18.9-22.0)	+22.4 days (19.8-25.1)	+10%	.19
Acute Days (RR, Days)	1.14 (0.94-1.39)	1.23 (0.89-1.68)	+8%	.69	+4.8 days (4.4-5.2)	+9.0 days (7.8-10.2)	*+87%*	*<.001*
ICU days (RR, Days)	1.99 (1.41-2.81)	1.37 (0.89-2.12)	*-31%*	.19	+11.2 days (9.5-12.8)	+7.2 days (5.5-8.8)	*-36%*	*<.001*
Total Cost (RR, $CAD)	*n=801* 1.55 (1.24-1.93)	*n=409* 1.22 (0.89-1.67)	*-21%*	.22	*n=464* +$49,166 (44,992-53,340)	*n=251* +$22615 (18935-26294)	*-54%*	*<.001*

Table 1. Comparison of multivariable analysis (SCO outcomes relative to NEO) and counterfactual analysis (impact on SCO outcomes attributed to residing in the SCO region)

Acute Cost (RR, $CAD)	*n=801* 1.56 (1.24-1.96)	*n=409* 1.13 (0.82-1.55)	*-28%*	.11	*n=464* +$40,791 (37,198-44,394)	*n=251* +$13,013 (11,009-15,017)	*-68%*	*<.001*
In-Hospital Death (OR, %)	1.96 (1.43-2.69)	1.44 (0.93-2.26)	*-27%*	.27	+14.2% (13.9-14.5)	+7.8% (7.6-8.0)	*-45%*	*<.001*
ICU or ED Death (OR, %)	1.38 (1.01-1.87)	1.27 (0.82-1.95)	-8%	.76	+7.0% (6.9-7.1)	+5.4% (5.3-5.5)	*-23%*	*<.001*

Berevement in Pediatrics: The Experience of the Nurses of an Italian Pediatric Hospital

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Introduction Nurses working in pediatric contexts increasingly taking care children with chronic-complex conditions. The high frequency of these situations generates high stress. The aim of this work is to describe the experience of nurses in an Italian pediatric hospital regarding the management and berevement.

Methods A literature review was carried out aimed at identifying functional tools for the analysis. Only one study was conducted in the Italian context regarding the topic.

Results From 140 nurses working in the 6 departments of the hospital, 98 (70%) responses to the questionnaire were obtained. 72 nurses declare that they have participated in end-of-life care. On average, each nurse claims to have cared for 6 children (SD ± 6.41). The emotions and sensations felt when faced with death were then investigated: 20 nurses declared that they always feel sadness, 15 a sense of helplessness and 29 suffer from the death of their patients. The personal, social and professional consequences of the bereavement experiences were investigated: 22 nurses had sleep alterations on several occasions; 23 took on a hypercritical attitude on several occasions; 12 found changes in the way they interacted with patients. Finally, informal support methods in berevement process were investigated: 44 talk to colleagues about what happened; 12 instead prefer conversation with their partner; 8 with their family members.

Conclusions Death of a child is not such an uncommon event in pediatric contexts. Lived experiences influence not only professional life but also personal and social life. The incorrect management and processing of stressful situations could generate negative moods, feelings and emotions, which in the long run lead to conditions such as burn-out. It is necessary to implement bereavement support in pediatric departments in order to minimize negative outcomes.

State-of-Play in Pediatric Palliative Care in Luxembourg: An Exploratory Mixed Methods Study

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Background and aims: In Europe, 170,000 children lack access to palliative care each year in the WHO European Region. In Luxembourg, pediatric palliative care services are insufficient, despite the National Cancer Plan's 2014 estimate that 40 to 50 children annually would require these services. This study aims to explore the pediatric palliative care state of play in Luxembourg.

Methods: In our study, we used an exploratory sequential mixed methods design. This approach consisted of two phases. We analyzed the data using qualitative content analysis and quantitative analysis. The first phase involved qualitative content analysis of data collected from documentary reviews, email contacts, and semi-structured interviews with participants involved in caring for children with life-limiting or life-threatening conditions, using snowball and purposive sampling. The second phase involved secondary quantitative data analysis.

Results: The analysis reveals a significant gap in structured models at the primary pediatric palliative care level, with approximately 500 children needing palliative care, which exceeds previous estimates. Existing legal frameworks, primarily tailored for adults and end-of-life care, fail to adequately address financial and social needs. There is also a lack of pediatric palliative care training and support from associations that mainly focus on children with cancer. Consequently, children are either transferred to neighboring countries with better resources and expertise or remain at home, receiving limited services that heavily impact parental care.

Conclusion: This study presents new data on unmet needs and underscores the urgent need for a structured pediatric palliative care service provision in Luxembourg. This is essential to support the implementation of the "*National Plan for End of Life and Palliative Care*", with a subchapter focused on children, from 2023 to 2026.

Advancing Pediatric Pain Management: Global Comfort Promise Successes in Latin America

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Background: Needle-based procedures are the primary sources of pain and anxiety for children globally. Research indicates that “Comfort Promise” principles (topical anesthetics, comfort positioning, age-appropriate distraction, breastfeeding or sucrose, and praise and reward) significantly reduce needle-based procedural pain (NBPP). However, strategies to reduce NBPP are lacking in low- and middle-income countries (LMICs). To address this gap, St. Jude Global implemented the "Global Comfort Promise" Quality Improvement (QI) project in six hospitals from Argentina, Brazil, Colombia, and Guatemala between August 2023 and March 2024. This study aims to assess the effectiveness of the QI project in increasing the implementation of the bundle and reducing NBPP.

Methods: Teams worked around a common aim, shared theory of change and measurements strategy. The implementation consisted of bi-weekly 90-minute virtual learning sessions (LS), team coaching, and office hours. Between LS, teams tested change ideas, collected and reported data for key indicators into a shared data repository. We used a t-test to compare data between the baseline period (BP) and the implementation period (IP).

Results: We analyzed data from 1,922 procedures. During the BP, 76.79% of patients/parents reported pain, compared to 47.17% during the IP, representing a 45% reduction ($p<0.01$) or 918 pain-free procedures. During the IP, teams reported 48% use of topical anesthesia, 70% adherence to distraction techniques, 91.7% adherence to appropriate positioning, 44.5% use of sucrose or breast milk, and 79.8% use of praise and rewards. Patient and parent satisfaction was reported at 95%, and healthcare provider satisfaction at 93.5%.

Conclusions: In this cohort of hospitals, "Global Comfort Promise" bundle contributed to reducing NBPP in pediatric cancer patients. This QI approach offers a viable model for enhancing patient care in LMIC, highlighting its potential for broader implementation.

Transforming Pediatric Palliative Practice: The Comfort Promise Initiative for Reducing Needle Pain

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Background: Despite painless healthcare being a fundamental right, pain from needle-based procedures is often overlooked in developing nations, particularly for children undergoing interventions. We implemented a quality improvement initiative at pilot unit, targeting children aged 0-18. We aimed to reduce procedural pain using Comfort Promise (CP) principles, seeking to decrease the median pain incidence from 70% to 35%.

Methods: This study took place at a tertiary referral and teaching hospital with a 1000-bed capacity, where the pilot CP (hematology-oncology) unit sees over 11,245 annual visits, primarily involving children over one-year-old. With an exemption from the institutional review board, we engaged directors, staff, patients, families, NGOs, and the public in supporting four CP steps: topical anesthesia, comfort positioning, distraction, and rewards. Various diagrams were employed for assessment, while matrix diagrams, impact-effort matrices, and the plan-do-study-act approach were used to implement driver ideas. The project was heavily promoted on social media. Data was collected through QR codes given to patients and parents for satisfaction (SAT) forms, provider self-report forms (SELF), and auditor forms (AUD) for balance. The SimpleQI app was used for run chart analysis.

Results: By April 2024, over 2,000 children underwent the CP protocol, and 344 completed the QR form. Patient-reported pain decreased significantly from 70% to 10%, with those experiencing pain scoring it at less than 4 on the Likert scale. Staff compliance reached a median of 100%, reflecting a cultural shift toward full CP protocol adherence.

Conclusions: Following successful implementation in one unit, the CP program was standardized across the entire hospital, inspiring three other national hospitals to consider joining. By recognizing staff innovators and applying improvement science, the program effectively transforms healthcare outcomes and culture.

Shedding Light on Sleep: Evaluating Diagnostic Measures for Children with Life-Limiting Conditions

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Background: Sleep disorders are common in children with life-limiting conditions (LLCs), posing significant challenges to their overall well-being, quality of life and daily functioning. There is a multitude of existing diagnostic options, but no overarching consideration of which instrument can be meaningfully applied in this vulnerable population given specific inquiries.

Methods: The applicability potential of a systematic professional caregiver-led observation protocol for objective, round-the-clock assessment of sleep and wakefulness, a newly developed sleep screening tool (Sleep Screening for Children and Adolescents with Complex Chronic Conditions, SCAC), and actigraphy (wearable devices) measured against the gold standard polysomnography (PSG) were investigated in four research projects involving a total of N=422 children with LLCs aged 1-25 years. Appropriate quantitative analyses, including descriptive statistics, Mann-Whitney U tests and Bland-Altman diagrams, were conducted.

Results: Chronic insomnia and circadian rhythm sleep-wake disorder are common in this population. Low-burden actigraphy yielded comparable results to PSG, indicating its reliability. The sleep protocol effectively highlights individual sleep characteristics, can objectify subjective (parental) sleep ratings, and especially reliably determines sleep onset/offset times. Sleep questionnaires like the SCAC offer valuable diagnostic insights but are insufficient for precise, standalone sleep disorder diagnostics. Nocturnal wake phases in children with LLCs may less reliably be determined by measures dependent on subjective judgment.

Conclusions: Alongside traditional PSG, innovative measures like actigraphy are emerging in sleep diagnostics for children with LLCs. These tools can be effectively employed depending on specific objectives and sleep parameters of interest.

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Neuro-irritability: The Great Unknown

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Background and aims: The term “neuro-irritability” has been used inconsistently to refer to a distressed behavioral state associated with recurrent, sustained crying or agitation in children with severe neurologic impairment (SNI). In addition to a combination of symptoms, neuro-irritability has been proposed as a diagnostic category, although its clinical features and pathophysiology are not yet comprehensively defined. Regardless of the definition, it is thought to represent an abnormal responsiveness to pain stimuli. This condition is persistent in pediatric palliative care (PPC), where it further impacts the child’s quality of life and affects the family’s global functioning.

The limited understanding of the exact nature of persistent pain and irritability in children with SNI is a significant barrier to adequate recognition and treatment. Literature on the topic is also lacking, and no guidelines or good practices are available.

Given the urgency of this matter, we started an international project to obtain a multidisciplinary, consensus-based definition of neuro-irritability and its management.

Methods: A two-round Delphi approach was employed. A group of experts in PPC and neurology worldwide from different disciplines and backgrounds was selected to identify the main discussion areas and elaborate on a questionnaire focusing on the current literature and their clinical expertise. An international, multidisciplinary expert panel was recruited to comment on the statements in the questionnaire, expressing their level of agreement through a 5-point Likert scale (1=total disagreement; 5=total agreement) and making suggestions to improve their formulation via online voting. Consensus was established when ≥75% of participants voted≥ 4.

Results and conclusions: Here, we present the first international consensus on neuro-irritability in PPC providing recommendations for its identification, assessment, and treatment.

A Novel Co-Designed Tool to Support CPC Providers Worldwide Explore and Utilize their Service Data

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Measuring services is essential for all children's palliative care (CPC) providers, but the process is complex due to the diversity of needs, services, resources, and settings. This user-focused research aims to create a tool driven by real-world experiences, to help CPC providers across settings understand which metrics support service improvement, share best practices in current collection methods and identify future measurement needs.

Methods: Building on existing research, the team engaged with over 30 purposively sampled CPC specialists from 20+ countries, representing different resource levels, service integration and maturity. Through co-design research, discussions focused on understanding current measurement practices, future aspirations, and existing challenges. The iterative development process included co-design workshops and feedback sessions, resulting in a continuously evolving tool with real-time user input.

Results: A new open source, interactive tool that can be used and adapted for individual settings, encompassing ten key information areas critical to CPC services, supplemented by extra resources and case study examples. Ver. 1.0 is currently in the dissemination stage and will be available online in Autumn 2024.

Conclusion: The tool has been co-designed with CPC providers across 20+ countries, helping new CPC teams determine which metrics to measure and assist mature organizations in refining their current practices. Limitations include the inability to interview CPC services from every region, which could be improved as users from more regions use it, and the tool's potential complexity for users unfamiliar with data collection, which could be counteracted by user support. Implications for practice include an open source, co-designed tool which can be used in a variety of settings to enhance CPC providers' ability to understand and improve care services for children and families living with palliative care needs.

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Virtual Reality (VR) in Palliative Care within Home Healthcare for Children and Adolescents

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Aim: To offer VR activities to children within SABH to promote distraction from symptoms and treatment, stimulate creativity, and encourage joy in movement.

Background: At SABH, children with complex medical needs, including those in the palliative phase. To meet their needs for meaningful and supportive activities alongside other care, a project was initiated autumn 2023 to introduce VR as a tool for distraction, creativity, and joy in movement to enhance quality of life.

Method: The project involved home visits by a VR educator where children and their families were given the opportunity to experience VR in forms ranging from of creative and experiential worlds to interactive games. The project was evaluated with a survey to the participating families.

Results: A total of 9 families participated in the project, with 5 families responding to the survey. The results indicated positive effects:

General experience: The majority of participants described the experience as very positive

Distraction and well-being: The VR activity significantly helped distract from symptoms and improve the mood of both children and family members.

Social interaction: The VR experience contributed to positive social interaction within the families.

User-friendliness: The VR equipment was easy for the children to use.

Comfort and safety: The children were comfortable using the VR equipment, and no safety issues were reported.

Frequency: Families wished for VR to be offered regularly, preferably every two weeks or 2-4 times per month.

Conclusion: The VR project in home healthcare for children with complex and palliative needs was successful and appreciated by both the children and their families. This project demonstrates VR's potential to provide meaningful engagement and improve the well-being of children in palliative care. We assess that it is important for participants to receive guidance from a VR educator to adequately and appropriately benefit from the VR experience.

Quality of Care on an Inpatient Pediatric Palliative Care Unit

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Background: When children with palliative care needs can no longer be cared for at home, such as due to crises or high symptom burden, they may be admitted to a pediatric palliative care unit. The core treatment goals of pediatric palliative care are to improve caregiver competencies and reduce symptom load.

Methods: We used the validated quality assessment tool “QUASI”, a short version of the Facets-of-PPC questionnaire, to assess caregiver competencies, symptom load, and the patient´s quality of life in an inpatient pediatric palliative care unit. Nurses completed the QUASI at both admission (pre) and discharge (post). Descriptive statistics and the Wilcoxon-Test were used to identify any changes during the inpatient stay.

Results: Data for n=429 patients were collected from October 20, 2020 to December 31, 2023. The average stay lasted 15.3 days. Significant improvements were seen in overall symptom severity, the child´s general condition, quality of life, and caregivers competencies (all $p<0.001$). For patients with initially high symptom burdens, significant improvement were noted in all assessed symptoms, including pain, agitation, sleep disturbances, seizures, secretion problems, respiratory problems, and spasticity. Those with initially low symptom load showed significant improvements regarding pain and sleep disturbances (both $p<0.001$). Families also saw benefits in all areas except “confidence in decision-making” and “assessing the child’s needs”.

Conclusions: The core treatment goals of pediatric palliative care can be achieved through specialized inpatient pediatric palliative care.

The Use of Social Media for Sharing Information on PPC Needs: A Social Media Analysis

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Background-aims: This study investigates how PPC are addressed on Social Media(SM). SM are tools capable of facilitating mutual support offering higher levels of information richness humanity and interactive dynamics typical of a real social network. The aims are to observe how the topic of PPC is addressed on SM and to analyze the information contained in caregivers' posts to identify possible areas for improvement.

Methods: A Social Media Analysis was conducted on Facebook. Groups were searched considering the International Standards of PPC, which identify five categories of minors eligible for PPC. 3 pathological areas were identified: Infantile cerebral palsies, Neuromuscular diseases, Prematurity. Data collection and analysis were carried out on Excel.

Results: 186 posts were analyzed: 106(57%) for the prematurity group, 58(31%) for the cerebral palsy group, and 22(12%) for the muscular dystrophies group. Of these, 158 posts (85%) were written by women. The posts were distributed as follows: 51(27%) in the afternoon, 46(25%) in the evening, 44(23%) in the morning, 13(7%) at night, and 32(17%) without a specified time. 116(63%) posts were written from Monday to Friday, 69(37%) between Saturday and Sunday. Posts were classified as follows: 92(50%) addressed clinical-assistance needs, 45(24%) psycho-communicative needs, 18(9%) socio-educational needs, and 13(7%) spiritual-value needs.

Conclusions: The topic of PPC is discussed by families on SM, but it is not explicitly clear; the terms "Palliative care" and "Pediatric palliative care" are never mentioned. It would be important to provide "ad hoc" training for each family, offering individualized and personalized care from the time of diagnosis. The fact that posts are mainly made during weekends suggests a correlation with the need to address clinical-assistance needs, possibly due to reduced services on holidays. Thus, it would be necessary to enhance PPC services to be available 24/7 to support these families.

Provision of Psychological Support for Siblings of Seriously Ill Children from Parental Perspective

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Background and aim: Psychological care is an integral part of pediatric palliative care (PPC). The International Standards for PPC from 2022 specifically address psychological care for the siblings. Yet the knowledge of psychological care for siblings is limited. The study aim was to assess the psychological support provided to healthy siblings by the Pediatric Supportive Care Team in university hospital.

Methods: We conducted an online survey among parents of children referred to PPC Team from January 2020 to December 2023. The questionnaire was administered to eligible parents, including bereaved parents, identified through the hospital database. The study was approved by the hospital Ethics Committee. Data were analysed by descriptive statistics.

Results: In total, the study included 67 parents (46 % response rate) of children with cancer (49%) and non-cancer diagnoses (51%). Bereaved parents also participated (N=22, 33%). Overall, 79 % of the respondents discussed topics related to the healthy sibling during own psychological care provided by the PPC Team and 86 % of them found the sessions with psychologist beneficial. The most frequently discussed topics included communication about the illness (58%), or worsening of the illness (47 %), and how to manage sibling´s needs (47%). Siblings personally met with the psychologist in 23 cases (34%). The reasons were to assess the emotional state of the sibling (61%) and to assess their understanding of the illness (43%). The in-person psychological intervention met the expectations of all parents (100%)

Conclusions: The results of our study indicate that psychological support for siblings is perceived as beneficial for families. Nevertheless, the use of the psychological service by healthy sibling in PPC is limited. To improve the provision, we suggest offering psychological care for siblings at the initializing of PPC, effective promotion of the service and active approach of healthcare professionals during referrals.

Maternal Role in Caring for Children with Severe Cognitive Impairment in Pediatric Palliative Care

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Background and aim: Becoming a mother is not simply a biological event but a complex and articulated process intertwined with a multiplicity of social, cultural and personal meanings. The relationship with a child is a central element in this process, nurturing a mutual emotional exchange that contributes to the definition of maternal identity. However, when a child has a severe cognitive impairment, his/her ability to communicate with the outside world is compromised, challenging the usual narratives on which the construction of the maternal self is based. The research aim is to explore the constructions of meaning that mothers of children with severe cognitive impairment elaborate on their role.

Methods: The research uses the intervention methodology defined as focus groups. Qualitative data analysis was carried out rigorously and systematically using the ATLAS.ti software.

Results: The analysis suggests that the mother's role is multifaceted and encompasses aspects of care, responsibility, and protection. The implications of an incurable disease with high care complexity on the mother's role lead to the roles of caregiver, assistant, nurse, and carer. However, mothers provide the same care in a much more personal and precise way, and they feel part of their role as mothers is expressed in it. The typically circular relationship takes on different connotations but remains a possibility and is part of constructing the mother's role. Recognition of their role by common sense and society sometimes takes the form of pity, detachment, or non-involvement.

Conclusions: Motherhood is a unique and precious experience for every woman. However, when a child has severe cognitive retardation, the construction of maternal identity takes on unique characteristics and requires specific coping strategies. Knowing these configurations of meaning makes it possible to work on suffering and existential difficulties in a new way.

Changing Focus: Parents Reflecting on Hope During Hospice through Photovoice

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Background: Parents of children with cancer say ‘hope’ influences coping, communication, and decision-making. The landscape of parental hope during hospice and bereavement is underexplored. Photo-interview methods like photovoice are well-suited for complex topics like hope and emotionally-rich experiences like hospice. Photovoice is an underutilized tool for research and support among bereaved parents.

Methods: This qualitative photo-elicitation study aimed to explore bereaved parents' reflections on hope during hospice. Parents (>18-years-old, English/Spanish speaking) were eligible if their child was treated at the study institution, was on hospice, and died 6-24 months prior. Participants chose 1-5 photos that depicted "hope during hospice," then shared their photos and reflections in a semi-structured one-on-one interview. Transcripts underwent reflexive thematic analysis, including memoing, coding, and theme construction.

Results: 20 participants were interviewed. The photos prompted deep discussion of ‘hope’ contextualized into experiences, feelings, and decisions during hospice. Parents chose images that reflected their child’s uniqueness, depicted poignant memories, and symbolized their faith/values. Parents often described hope as their child’s ability to embrace life, joy, freedom, and peace in any circumstance. Factors that supported/challenged hope included family, location, communication, and medical therapies. Parents sometimes lost hope, while also explaining hope is never fully lost, but “changes focus.” Parents described sharing photos as emotionally complex, but helpful, because it was therapeutic, spread their child’s legacy, and served the medical community and other families, thereby generating hope for the future.

Conclusion: Photovoice is useful for promoting reflection and exploring narratives about hope among bereaved parents. Parents’ reflections and narratives can inform future research, education, and supportive interventions for families.

MiniSIBS, an Intervention Supporting Preschool Siblings of Children with Life Limiting Disorders

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Background: Siblings of children with chronic and life limiting disorders (CLD) may have higher risk of developing psychological difficulties. Interventions to measure adjustment and prevent psychological difficulties among preschool siblings are lacking. The aim of this project was to develop an intervention for siblings of children with CLD aged 3 to 6 years for delivery in kindergartens. **Methods:** We identified and synthesized relevant research through a scoping review. Sibling experiences and common signs of distress was discussed in a parent focus group. We explored methods and materials that aid siblings' expression of illness related experiences in a creative workshop with child psychologists, nurses and kindergarten teachers. Finally, we conducted a workshop on constructive parent-teacher communication about siblings' needs with psychologists, kindergarten teachers and patient organization representatives. Findings: A scoping review identified 19 publications related to psychosocial outcomes for siblings aged 3-6. The identified research indicates elevated levels of psychological distress in this group. Based on the review and the parent focus group, a sibling adaption questionnaire for ages 3-6 was developed, measuring distressing situations, behavior adaption and signs of emotional distress. The creative workshop resulted in a play observation manual for sibling-kindergarten teacher play with illness related topics. The second workshop resulted in production of video material: 1) an educational video to increase awareness of sibling needs among kindergarten teachers, and 2) a series of videos supporting parent-kindergarten teacher conversations about siblings needs. The questionnaire, play observation manual and video resources constitute the new intervention called MiniSiBS. Discussion: To the best of our knowledge, MiniSIBS is the first age-adapted intervention to prevent psychological difficulties and support preschool aged siblings of children with CLD.

Nationwide 24/7 Paediatric Palliative Care in Denmark. Data from 2016-2023

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Background-Contex-Aim: Specialized paediatric palliative care in Denmark has evolved significantly in the last decade. Five regional hospital-based teams were established in 2016. Since then, 24/7 paediatric palliative care to families living with life-limiting or life-threatening disease has been available nationwide. This study aims to characterize the patient population and interventions performed by the PPC team in the Capital Region, PABU, through a retrospective cohort analysis spanning 2016-2023.

Method: Data, drawn from the Danish Palliative Database and electronic medical records, included diagnoses, interventions, duration of PPC contact, and bereavement support. Patient cases were categorized into five diagnostic groups developed by "Together for Short Lifes" (2018).

Results: Results from 225 cases showed a median duration of 216 days for PPC contact and 151 days for bereavement support. Majority belonged to "TfSL" groups 1 and 4, with group 2 being the smallest. Exactly two thirds of patients (66%) have a non-oncological diagnosis. Interdisciplinary care was achieved in almost all cases (94%). Over half of the patients (56%) died at home, while nearly 6% passed away in a children's hospice. Variations in place of death were observed across diagnostic groups, with home deaths predominant in groups 1-3 and hospital deaths in groups 4-5.

Conclusions: This study demonstrates PABU's success in achieving End of Life care at home supporting the patient and parents with 24/7 telephone availability. The mandatory interdisciplinary PPC approach is widely achieved, and our results shows interesting findings according to patient population, which is different than the adult population receiving PC in Denmark. The study provides a foundation for future research and contributes to both national and international understanding of paediatric palliative care dynamics.

Survey of Pediatric Intensive Care Team Professionals Regarding Pediatric Palliative Care

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Background: Pediatric palliative care (PPC) is an integral component of optimal critical care for children facing life-threatening conditions. Collaborative work between pediatric intensive care units (PICU) and PPC teams (PPC- t) may contribute to prevent, identify and address suffering for children and families.

Aims: To describe the national inclusion of PPC in PICU, reasons to consult; perception of PPC-t involvement usefulness; interest in PPC training

Methods: Self-administered survey; research ethics committee approval. Population: doctor and nurses working in PICU. Variables: demographic information of respondents; questions regarding: existence of PPC-t in the institution; whether they have requested/ suggested consultation with PPC-t, reasons for it; usefulness of the PPC-t participation; issues to improve PPC-t / PICU interaction; interest in PPC training and areas of interest.

Results: 241 respondents: 69% nurses, 31% physicians; 63% working longer than 10 years in PICU; 65% institutions had a PPC-t; 65% professionals had consulted it, being the reasons: decision making (28%), help with discharge (17%), support communication (12%); 85% said that PPC-t involvement was very/extremely useful; to improve PICU/ PPC-t interaction they selected earlier inclusion of PPC (30%), general training on PPC (30%), clearer criteria to call PPC-t (20%). Regarding training: 71% didn´t have any formal training in PPC, 92% consider it necessary for daily work; main themes suggested were: advanced care planning (21%), comprehensive pain management (18%), comprehensive end of life management (16%).

Conclusions: Despite progressive implementation of PPC- t in the country there is still room to their inclusion in PICU settings, either in number of consults or reasons for consultation. Making decision was the main reason for involving PPC-t in PICU. Important deficits and need of training were found being this an opportunity for greater approchement between both professional groups.

Factors Affecting Child Development in the Context of Serious Illness: A Scoping Review

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Background: Despite benefits for including children in their own (palliative) care, studies show that children are not sufficiently involved nor are their preferences sufficiently elicited in a developmentally appropriate manner. The aim of this scoping review is to provide an overview of factors affecting child development in the context of serious illness.

Methods: A scoping review was performed using methods from Arksey and O'Malley and the Joanna Briggs Institute. A structured literature search was conducted in four databases: Medline, Embase, Psychinfo and CINAHL. Articles were included until October 2022. Thematic analysis was performed to present domains and key factors influencing child development.

Results: We selected 24 out of 11246 articles. We found different factors describing the ongoing development of seriously ill children in early to middle childhood, early adolescence, and middle to late adolescence. Key themes were: psychological/emotional aspects, general cognitive aspects, social aspects, coping strategy, conceptualization of illness, conceptualization of death, communication about their illness. Several accelerators of ongoing development were found (e.g. cortical maturation, prior medical experience, social experience with adults) and several decelerators (e.g. stress, hospital admission, avoidance of illness-related communication in the family).

Conclusion: Our review highlights essential aspects to consider when discussing illness and healthcare preferences with children at various developmental stages. However, our findings also underscore a significant gap in understanding the factors that impact the development of children with a serious illness. It is recommended to monitor development throughout the illness trajectory to gather more evidence and utilize this information to support the child's engagement in their own healthcare in a developmentally appropriate way.

Specialized Palliative Care in Inherited Metabolic Diseases - a MetabERN survey

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Background: Specialized palliative care (SPC) should be an integral part of follow up for patients with life-limiting and life-threatening conditions, irrespective of age or diagnosis. Due to newborn screening programs and advanced treatment, children with inherited metabolic disease (IMD) constitute an increasing group of patients who qualify for SPC. More than 1900 IMDs have been identified, and their collective prevalence is estimated >1:800. The aim of this study was to learn how SPC is offered to paediatric (paed) IMD patients, and to collect the experiences of physicians regarding SPC for their patients.

Methods: The European Reference Network for Hereditary Metabolic Disorders (MetabERN) invited all member institutions (n=103) in Europe to participate in a digital survey of 60 questions.

Results: 91 physicians from 63 institutions in 23 countries responded. 84% of respondents were involved in follow-up of paed IMD patients, and 37% were paed metabolic physicians who also provided follow-up of adult patients. Almost 60% reported availability of paed SPC home care teams, 40% had access to hospital-based SPC units, and only 5% reported not having any SPC service in their institution.

In the last 5 years, 90% of respondents had referred at least one paed patient to SPC, while 10% had referred >20 patients, of whom a majority had a life expectancy of >6 months. Symptom burden (neurological, cognitive, respiratory, gastrointestinal) was the main reason for referral. Lysosomal storage disease was the most frequently referred IMD. Of deceased paed IMD patients, place of death most often was in hospital ward, followed by home and intensive care unit.

Conclusion: This study reveals that paed SPC service is available in most European IMD centres, yet only a small proportion of IMD patients receive SPC. Barriers to integration of SPC should be addressed. Both IMD physicians and patients may need to receive more information about available SPC services.

The Importance of Specialized Palliative Care on Pediatric Cancer Patients' Choice of Place of Death

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Background: An essential aspect of end-of-life care for pediatric patients is honoring their preferred place of death (PPoD). The Danish Health Authority established five regional Pediatric Palliative Care Teams (PPCTs) between 2015 and 2017 to better treat children needing specialized palliative care. This study examines the effect of PPCTs on the alignment between PPoD and the actual place of death.

Aims: i) Is there a better accordance with the preferred and the actual place of death now than before the implementation of PPCT?

ii) What is their PPoD?

iii) Do more children die at home after the implementation of PPCT?

iv) How do different factors influence the PPoD?

Methods: Demographic data, diagnosis details, and information regarding death were collected for 88 pediatric patients diagnosed with malignant diseases from 2002 to the end of 2023. A comparative analysis was conducted for periods before and after the implementation of PPCTs. Statistical tests, including logistic regression, were used to evaluate the alignment between the preferred and actual place of death and to identify influencing factors.

Results: Preliminary results indicate a significant improvement in the alignment between the preferred and actual place of death following PPCT implementation. The PPoD for most pediatric patients was at home, and the number of home deaths increased relatively post-implementation. Factors such as younger age at diagnosis were associated with a higher likelihood of preferring the hospital and older preferring hospice as the place of death.

Conclusions: The implementation of PPCTs in Denmark has positively impacted the alignment between the preferred and actual place of death thereby enhancing the quality of end-of-life care for pediatric patients. Data indicate a clear positive effect, and these findings underscore the importance of specialized palliative care teams in meeting the needs and preferences of children with life-threatening diseases and their families.

Pediatric Palliative Care and Emergency Department: How Taking Charge Changes Admissions

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Background: The complexity of patients eligible for Pediatric Palliative Care (PPC) results in multiple medical care needs.

At the same time, the emergency department (ED) is often a crowded and uncomfortable environment with waiting times that can be long.

Although these factors can be reduced by developing protocols for prioritising access for high-complexity patients, it remains imperative to find ways to prevent them from having to access the ED.

Aims: The purpose of this study is to assess how PPC services changes the number or the nature of accesses to ED.

Methods: We performed a retrospective study taking into account the number and the medical need of the accesses to the four ED in the province by 39 pediatric patients in charge by PPC at the end of 2023. Admissions were stratified into those occurring before and after PPC intake.

Results: Being taken in charge by PPC does not change the number of accesses to the ED in a statistically significant way (1.8 accesses/year and 2.2 accesses/year before and after intake respectively; P-value 0.72). However, PPC changes the nature of the access to the ED: before the PPC took over, the largest percentage of access diagnoses were related to respiratory (28.5 %) gastrointestinal (21.5 %) and infectious (14 %) diseases. After PPC took over, gastrointestinal pathologies remained the most common reason for access (23.7 %), but the need for surgical (18 %, vs 8.6 % before) and orthopedic (14.6 % vs 5.4 %) assessment increased greatly. In contrast, infectious and respiratory diseases decreased to 7.8 % and 16.5 % respectively.

Conclusions: Although the mean annual number of ED accesses remains essentially unaltered, improved home care and the network of health care support has meant that these accesses are no longer due to minor pediatric conditions. It remains clear that a palliative care patient is a complex patient who still needs major care that can't be fully-provided at home and often requires specialized assessment.

Coming of Age: Development of a Pediatric Palliative Care Program in the Standard-Of-Care Era

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Background and aims: With the changing landscape of pediatric palliative care (PPC), there is a need for ongoing reporting of new program data to inform resource planning. This study sought to describe the initial experience of a PPC program at a mid-sized tertiary pediatric institution founded in 2015.

Methods: This was a prospective database study (REB# 2203) over the initial 8 years (Nov 2015-Nov 2023) of a PPC program at a mid-sized tertiary pediatric hospital (165 beds) in Canada. During this period, program staffing increased from 0.72 clinical full-time equivalents in year 1 to 5.2 at study end. Patient data was entered at three time points: referral, consult, and discharge/death. Results are descriptive.

Results: The program received 651 pediatric referrals from 25 specialties and 55 maternal referrals (starting Feb 2021), and completed 620 pediatric and 51 maternal consultations. 223 patients died after being on program for a median of 50 days (5-172 days). Annual patient volumes increased by 3.6x over the course of the study while clinical FTE increased by 7.2x, and yet patient: clinical FTE ratio remained near 1.5x the national median at study end.

Conclusion: The rapid uptake demonstrated in this study suggests that the evolution of PPC over the past few decades has altered the initial experience of new programs. The notion of "starting small" may no longer be applicable in countries where PPC is standard of care for many conditions and scenarios. These findings may help guide institutions with new or nascent PPC programs plan for modern demands.

Funding: Nil

Table 1: Program growth by age, clinical full-time equivalents, and patients seen over the first 8 years of a tertiary pediatric palliative care program in Canada

	Study Program								Canadian programs in 2012 (median, IQR)
	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	
Year of Initiation	2015								1999 (1995-2004)
Age of Program	0	1	2	3	4	5	6	7	13 (8-17)
Clinician FTE	0.72	0.6	0.73	2	2.9	3.8	4.63	5.2	2.65 (1.3-4.8)
Patients seen	77	90	82	129	183	222	248	281	67 (54-110)
Patient:Clinical FTE ratio	108.3	145	113.7	64	63.1	59	52.7	54	35.4 (20-52)

Mapping Trajectories of Care in the Last Year of Life in Cardiovascular Complex Chronic Conditions

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Background: Cardiovascular complex chronic conditions (CCC) are the most frequent category of pediatric hospitalization and death among CCCs. Most pediatric cardiac deaths occur in the intensive care setting with invasive surgical and mechanical device interventions. The majority of parents evaluate their family's quality of life as fair to poor. Overall, about 15% of cardiovascular CCC patients receive pediatric palliative care (PPC) consultation. The aim of this study is to gain an understanding of the patterns of care over the last year of life in children with cardiovascular CCCs.

Methods: Monocentric, retrospective, and descriptive follow-back study of cardiovascular CCC patients at our hospital's cardiology department that died between 2013 and 2023. Data was collected through patients' electronic medical records. Patients in the following categories were excluded: < 1 yr or > 18 yrs at time of death; death from sudden unpredictable causes; or < 1 yr between diagnosis and death. Statistical analysis was performed using Excel and R Studio. The study was approved by the local research council and registered under #2024 0418171142.

Results: Preliminary results include 220 patients with a median age at death of 5 years, predominantly diagnosed with congenital heart defects and cardiomyopathies. Death frequently occurred from pump failure or pulmonary hypertension within the hospital setting, and with respiratory and neurological symptoms at end of life. Healthcare utilization, symptom burden and treatment intensity increased over time. PPC implication grew to 25% of cases and was predominantly initiated for discussing goals of care and community care coordination. However, death outside the hospital remained rare, and advanced care planning was often initiated late in the process.

Conclusion: We will outline pathways of end of life care in pediatric cardiology and present clinical factors to help teams discern timely initiation of PPC and strengthen collaboration.

Professionals' Experiences of Delivering Paediatric End-Of-Life Care: A Multi-Site Qualitative Study

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Background: Around 3743 infants and children die in the UK each year. Evidence has consistently shown availability, access, and delivery of end-of-life care is inconsistent and incoherent. Supporting parents during this time is challenging for staff and may not have been adequately covered in professional training. Whilst good care cannot remove parents' pain and grief, poor care can significantly add to their distress. There is little high-quality evidence on ways this type of care is delivered.

Aim: To explore professionals' experiences of delivering end-of-life care to infants, children and young people.

Methods: A multi-site qualitative study, grounded in the phenomenological approach. Online, semi-structured, focus groups were conducted with health professionals who deliver paediatric end-of-life care, recruited from the four settings accounting for the place of death of >50% of children who die in the UK each year: neonatal and paediatric intensive care units, and children and teenage cancer centres. All were audio-recorded, transcribed verbatim, and informed consent obtained. Data were collected by 4 researchers. Data analysis employed a thematic framework approach. UK-wide ethics approvals were obtained.

Results: 168 professionals were recruited. Data highlighted examples of best practice, as well as areas to be improved. Professionals were aware of what constitutes high-quality care, but were constrained by a number of factors. Although it was a privilege to care for families, providing end-of-life care had a heavy emotional impact on professionals and support was variable. There was substantial reliance on charities to provide bereavement support.

Conclusion: This is the largest UK-based study on end-of-life care for children. It reveals professional, personal, and organisational barriers to delivering optimal care. Many issues could be resolved by investment in funding, time, education, and support to enable delivery of increasingly complex care.

Complex Chronic Conditions (CCCs) Vs. Life-Limiting Conditions (LLCs)...How Do These Lists Compare?

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Background: Children's palliative care (CPC) planning requires accurate information about CPC need but quantifying need is hampered by challenges in population definition. Detailed lists of diagnoses considered to be life-limiting or to indicate chronic medical complexity have been used to quantify number of deaths with end-of-life care needs or estimate prevalence of CPC needs using health service use data. However, to date, no systematic comparison of the different lists has been undertaken. This paper compares two lists of diagnoses most frequently used to analyse population-level CPC need: life-limiting conditions (LLCs); complex chronic conditions (CCCs). We examine overlaps, differences, and implications for quantifying CPC need using Irish mortality data.

Methods: LLCs are coded according to the WHO International Classification of Diseases 10th Revision (ICD10). CCC diagnoses are coded using an adapted ICD10 applied in the US (ICD10CM). We develop a translated list of CCC diagnoses in ICD10 codes to allow for direct comparison with LLCs. Both lists are applied to Irish mortality data, 2007-2017, age 0-14, to examine and compare the proportion of deaths considered to have been eligible for palliative care using each list.

Results: The proportion of diagnoses included in the LLCs list that are also in the translated CCCs list ranges from 12-75% depending on the category of disease or diagnosis. Of note the CCCs list includes a higher number of perinatal and congenital conditions than the LLCs list. When applied to Irish mortality data, circa 15% of infant and child deaths over a ten-year period that were not attributable to an LLC were included in the CCCs list.

Conclusions: This paper provides a valuable resource for palliative care service planning by demonstrating core similarities and differences between two key lists of diagnoses used to analyse CPC need.

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Pharmacists and Compliance: Can counselling improve adherence?

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Background: Adherence to beneficial drug therapy is an essential component in improving and maintaining quality of life in Pediatric Palliative Care patients. The aim was to focus on the role of the hospice pharmacist in improving compliance and knowledge about opioids and psychotropics pharmacotherapy in children referred to hospice as there are a lot of misconception primarily due to cultural barriers.

Methods: Data collection included referrals received by the pharmacist due to poor compliance and/or reluctance to use opioids/ psychotropics including in-patients, out patients and homecare patients. Symptom management plans are reviewed and updated on regular basis. History of opioids / psychotropics use were extracted from patients' electronic records Jan 2022-Dec 2023.

Counseling sessions focused on the following:

- Overview of opioids and psychotropics and their effect on symptoms that patient may suffer from.
- Clarifying misconceptions including but not limited to, addiction, dependence and tolerance.
- Drug -drug interaction charts have been completed to advocate for the best opioids /psychotropics option.
- Emphasizing the importance of compliance to the prescribed drug regime.
- Clarifying adverse effect of medications and the various ways to overcome them.
- Balancing the benefits versus the risks in the context of changing clinical needs.
- Proper use of medications.

Counselling sessions were documented to track the improvement of symptoms.

Results: A total 15 cases were referred to the hospice pharmacist.

After reviewing patients records pharmacotherapeutic counselling sessions resulted in an 86% improvement in compliance and adherence to opioids and psychotropics.

Conclusion: The role of the pharmacist in counselling children and parents is a crucial and effective approach in improving overall compliance to opioids and psychotropics, as a result this contributed positive outcome to patients quality of life.

Formation of a Pediatric Palliative Care team at Astrid Lindgren´s Children's Hospital, Sweden

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Aim: In order to improve pediatric palliative care (PPC) at Astrid Lindgren's Children's Hospital (ALCH) Sweden's first hospital based PPC team providing palliative care to children both at hospital and at home was formed.

Background: Children with life-limiting or life-threatening illness have the right to palliative care in parallel with disease-oriented treatment. In Sweden there are few hospitals with a PPC team although none that will provide care at home. To enable care for children with palliative care needs at ALCH in Stockholm, project support for a PPC team was initiated in autumn 2023.

Method: A multidisciplinary project group was formed, and team members were identified. Literature research, international study visits, and an external analysis on how specialized palliative teams for children are organized internationally, was conducted. The prior knowledge and needs of support to the healthcare professionals (HCPs) at ALCH were identified through focus groups interviews (n=11).

Result: The analysis generated an organizational model for a PPC team with physicians, nurses and social worker, all experience in PPC. With focus on relief of symptom and quality of life, the team was named *SOL-teamet, i.e.* The SUN-team, (Symptom management and quality of Life). According to HCPs, the concept of palliative care was linked to the end of life, which led to delayed interventions of the child's palliative care. HCPs expressed a need for support in more complex patient cases. Since the start, in total 29 patients from different units had been referred to SOL-teamet and 13 of these children have as of now deceased. An important part of the team's work has been the emphasis on supporting the child and their family both at the hospital as well as at home.

Conclusion: A hospital based PPC team, giving support both in hospital and at home, has successfully been implemented and will continue to be developed in 2024 enabling children's palliative care needs to be met at ALCH.

Advance Care Planning and Multiculturality in Pediatric Palliative Care: A Review of the Literature

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Introduction and aim The already large population of immigrants and the estimates which show a strongly growing figure, identify the need for the healthcare system to adapt to this change in order to provide patient-centred care in compliance with beliefs and culture of the person, even more so when we talk about children suffering from chronic-complex conditions, even incurable ones. Advance Care Planning (ACP) tool is of fundamental importance in these situations. The ACP must take into account the ethnic background of each family. The aim of this study is to analyze the factors related to different cultures that can hinder the construction of an ACP in pediatric palliative care (PPC) context.
Methods A literature review of major databases was conducted. 33 articles were selected.
Results According to what was reported in the articles examined, ethnicity, language and communication, culture, faith and religion can significantly influence the process of drafting an ACP. Members of the same nation or ethnicity may differ in their thinking, behavior and values. Professionals must understand their own linguistic and spiritual limitations and integrate figures such as the cultural mediator and spiritual guide into the entire ACP process.
Conclusions Good ACP and quality PPCs must take into account the cultural background of the supported child and his or her family not only as members of an ethnic and religious community but also as individual units with unique needs and values. It is necessary to increase cultural competence within the multicultural team through specific training of healthcare workers. The adaptation and validation of new scales and interactive games as emerging from the latest literature studies could facilitate the task of professionals and be the key to the construction of an ACP.

Evaluation of a Perinatal Palliative Care Program by SWOT Analysis

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Background and aim: Perinatal Palliative Care (PPC) is individualized medical-nursing care aimed at improving the quality of life of newborns with life-limiting conditions and to support their families. This study draws on the analysis of the experience gained over ten years by a service of PPC called the “Percorso Giacomo” (PG). The aim of this research is to evaluate the 10-year experience of the PG and to assess the features that may allow its replication in other institutions.

Methods: We employed a SWOT analysis to identify the strengths, weaknesses, opportunities, and threats of the PG through a systematic retrospective review of 48 cases followed by the program over the course of 10 years, 21 unsolicited parents’ narrative and 27 experts’ point of view.

Results: Main strengths of the program were communication and parents’ involvement in shared decision-making. Main weaknesses included lack of knowledge of the presence and the role of the PG and lack of resources. For opportunities, the PG proved to be an innovative choice for pregnancies with a fetal life-limiting diagnosis, however threats were identified such as lack of knowledge of PPC and delayed referrals.

Conclusion: The analysis by SWOT method of the 10-year experience of the PG allowed the identification of limitations and areas of improvement, however demonstrated that the PG provided beneficial services to women faced with fetal life-limiting diagnoses.

Referral Predictors and Benefits of a Home-Hospital Palliative Program for Pediatric Cancer Patients

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Background and Objectives: In pediatric palliative care (PPC) for cancer patients, integrated home-hospital care programs may enhance coordination. Our objectives are: 1.Create a model of factors influencing attention by a PPC unit (PPCU) to deceased cancer patients. 2. Describe differences in the last month of life (LMoL) for cancer patients based on the provision of PPC.

Methods: Retrospective study in a tertiary pediatric hospital with oncology and PPC units from 2010 to 2019. Data from records of deceased cancer patients were collected to: 1. Perform logistic regression of explanatory factors for PPC provision.2. Compare the LMoL of support and invasive procedures, days hospitalized, in the Pediatric Intensive Care Unit (PICU), and place of death based on the provision of PPC. Statistical significance was set at $p<0.05$, using prevalence ratio (PR), mean difference (MD), and odds ratio (OR) in the logistic regression model as association measures.

Results: Of 198 patients, 99 were attended by the PPCU. The PPCU attention model included the following odds ratios (OR): solid tumor (OR: 1.0; 0.3-3.6), disease duration (months) (OR: 1.0; 0.9-1.0), progression/relapse (OR: 11.1; 2.3-53.4), and the interaction between disease duration and solid tumors (OR: 1.1; 1.0-1.2). In the LMoL, PPCU-attended patients underwent fewer surgeries (PR: 0.3; 0.1-0.8), red blood cell (PR: 0.4; 0.3-0.6) and platelet transfusions (PR: 0.4; 0.3-0.6), invasive procedures ($p<0.01$), and palliative sedation (PR: 0.3; 0.2-0.5). They spent fewer days hospitalized (MD: 16.8; 13.9-19.7) and in the PICU (MD: 8.6; 6.1-11.1) and died more frequently at home (PR: 0.7; 0.6-0.7).

Conclusions:

-The absence of progression/relapse events or hematologic cancer (especially in long-duration diseases) acted as barriers to PPC.

-Deceased patients with PPC spent more days at home, were more likely to die there, and underwent fewer procedures in their LMoL.

What Support Do Families Need Most in Perinatal Palliative Care? A Retrospective Chart Review Study

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Background and aims: Pediatric Supportive Care team (PSCT) provide palliative care support also for pregnant women with severe fetal diseases or other life-limiting or life-threatening conditions. With the increasing recognition of the benefits of perinatal palliative care, more families are being referred to the PSCT by gynecologists. The goal of this study was to identify which aspects of PSCT support are being most utilized by parents with a prenatally diagnosed severe fetal illness.

Methods: We analyzed six years of data (April 2018 to March 2024) from our hospital's electronic system for families who received PSCT support during pregnancy. We assessed the number of interventions, their duration, and the professionals involved. Interventions were defined as any care activity recorded in the electronic system by a PSCT member.

Results: Families primarily utilized professionals providing psychosocial support. During the study period, the PSCT initiated perinatal palliative care for 27 families, conducting 584 interventions totaling 382 hours. Interventions included 231 (39.6%) by doctors and 353 (60.4%) by psychosocial support professionals (psychologist 149 (42.2%), social worker 112 (31.7%), nurse 69 (19.5%), bereavement care 18 (5%), chaplain 5 (1.4%)).

Conclusions: Families with severe fetal diagnoses benefit from palliative care starting in pregnancy, needing psychosocial support more frequently than physician interventions. We propose creating a "Perinatal Care Therapist" position to make perinatal palliative care accessible to more families with severe fetal diagnoses.

Innovative Approach to Quality of Supporting children in PC: The Power of Visual Stimulation

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Background: This submission presents innovative approach to supporting children, focusing on developing visual functions. Recognizing vision's pivotal role in developmental progress, particularly in children with limited abilities, our work emphasizes personalized visual stimulation programs integrated into families' routines. Standard healthcare providers have limited developmental support. Visual stimulation (VS) is the best way to do it, based on individual assessment. Our organization, with 33 years of experience, provides visual assessments for 350 children annually. The aim is to guide utilizing VS as developmental support for children, preserving or enhancing residual visual functions crucial for communication and cognitive processes, enhancing overall quality of life.

Methods: We present 4 case studies illustrating the impact of visual stimulation on quality of life for children in palliative care. Personalized visual stimulation programs, integrated into families' daily routines, are informed by functional vision assessments. Parents receive training for implementing non-invasive, play-based interventions provided at home without professional facilitation.

Results: Findings showcase the effectiveness of VS in supporting children with severe illnesses. By preserving or enhancing visual functions, this evidence-based method enables improved communication, cognitive functions, and play skills, positively impacting the family's quality of life. Importantly, this approach empowers parents, mitigating feelings of helplessness.

Conclusion: Our findings illustrate that VS can be implemented through collaboration with healthcare or social care providers, bringing significant benefits to children and parents. Empowering parents affirms their vital role in their child's development, addressing feelings of helplessness. Emphasizing ongoing support for children with life-limiting conditions underscores their right to play and developmental opportunities until the very end.

Building Relations through Time and Music - Case Presentations from a newly startet PPW in Norway

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Background and aims: Pediatric palliative care (PPC) requires holistic interdisciplinary thinking in order to best meet the complex needs of the child and the family through all phases of the illness. Our pediatric palliative ward (PPW) was established as a project from the Norwegian Directorate of Health in January 2020. When the project first started the thought was to function more as an in-patient hospice. However we have experienced that most families want to stay at home, and so we have changed our services and by the time being we spend most of our time visiting and helping families at their homes.

As of May 2024, we follow around 40 families, but what they need differs. We spend a lot of time by building relations and trust and we visit the child and family where they are. We visit kindergartens, schools and if they have respite care. From experience, we see that patience and the use of time is the essence of pediatric palliative care. We have the opportunity to use time to build trust and relations and we experience that this is the cornerstone of what we offer the children and families we meet.

Method: In this presentation, we will look closer at two cases that will give examples of how we approach the families. In addition to this, we will present results from three qualitative interviews of families referred to our PPW.

Result: Among our findings is that the time used to build trust and the interdisiplinary work is of great importance. The use of music therapy is an important resource in working with the families.

Relevance to Pediatric Palliative Care: We will look closer on the challenges that we as health care providers meet, being a private provider of PPC. This presentation will be a resource for others starting up a pediatric palliative ward, trying to navigate a field in constant development - while still caring for the families with a biopsychosocial perspective.

Originality of Research: Our PPW is the first of its kind i Norway.

Children with Complex Chronic Condition in School Setting

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Background and aims: Schooling in pediatric age is hindered or interrupted by the presence/onset of a Complex Chronic Condition (CCC). In field literature there is no data regarding the impact of training interventions aimed at staff involved in the educational- schooling project of this population.

Our aim is to evaluate the trend percentage of children aged ≥3 years with CCC having an ongoing school project following the introduction of specific training interventions. The goal of this intervention is to ensure greater safety for children, families and all personnel involved in the training project within the care setting.

Methods: Nursing staff carried out personalized healthcare training in 2018 to give school staff the tools to to welcome children with CCC, carriers of devices and/or their users in schools. The training consisted of a theoretical phase, with lectures addressed to those designated by the pedagogical/disability managers, and a practical phase, held with child and caregivers present, directly in the classroom.

All school staff members involved were free to attend the theoretical lectures. The practical part -aimed at the achievement of a certificate for the child's assistance- was only provided to four people chosen by the schools. All operators received the same theoretical training, regardless of the child’s specific needs, to ensure uniformity of knowledge. During the meetings focused on the practical part, lessons were customized to meet each child's needs.

Results: As a result of the training intervention undertaken, the number of children aged ≥3 years with CCC and an ongoing school project has gradually increased going from 34 (out of a total of 54 children) in 2018 and reaching 86 (out of 93) in 2023.

Conclusions: By implementing a training program for school staff, the percentage of children with an ongoing school project increased from an average of 60% to the current 92%.

Oncological Support Measures While Follow-Up by a Pediatric Palliative Care Unit for Cancer Patients

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Background & Aims: Cancer patients receiving care from a pediatric palliative care unit (PPCU) may have specific oncological treatment needs that must be tailored to the patient's requirements. The aim of this work is to describe the support measures and oncological treatments used in patients with cancer attended by a PPCU.

Methods: Translation: Retrospective description of clinical records of cancer patients treated by a PPCU over a 10-year oeriod (2010-2019). General epidemiological data (gender, age at death, type of cancer, and follow-up time by the PPCU) were collected, along with the following measures applied during the follow-up: chemotherapy, radiotherapy, and surgery, analyzing the purpose of their administration, as well as the use of experimental treatments.

Results: Data was obtained from 159 deceased patients. 58.5% were males with a median age at death of 9.7 years (IQR: 5.8-14.1) and a median follow-up time by the PPCU of 1.4 months (IQR: 0.5-2.8). 44.0% had a solid tumor, 37.1% had a central nervous system tumor, and 18.9% had hematological cancer. Measures applied during follow-up are summarized in Table 1.

	Proportion and 95% confidence estimation interval	Objective
Chemotherapy	32.1% (24.9-39.9)	Palliative: 90.2% Curative: 9.8%
Red blood cell transfussions	24.5% (18,1-32.0)	Symptomatic treatment: 56.4% Mantain within range: 30.8% Not specified: 12.8%
Platelet transfussions	20.8% (14.7-27.9)	Symptomatic treatment: 27.3% Mantain within range: 66.7% Not specified: 6.1%
Radiotherapya	11.9% (7.4-18.0)	Palliative: 89.5% Curative: 10.5%
Experimental treatments	15.7% (10.4-22.3)	Immunotherapy: 55.6% Antiangiogenic drugs: 22.2% Chemotherapy: 18.5% Intra-arterial chemotherapy: 3.7%
Surgery	2.5% (0.7-6.3)	Palliative: 100%
Others	Alternative therapies: 4.7% Graft versus host disease treatment: 0.6%	

Conclussions: There is a relatively low application of measures primarily with palliative purposes and symptomatic control, except in the case of platelet transfusions, which were performed to maintain levels within range and prevent bleeding.

Navigating Needle Pain in Pediatric Cancer: Insights from a Low-Resource Setting

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Background and aim: Children Welfare Teaching Hospital (CWTH-Iraq) faces shortages in cancer treatment supplies, heightening pain during children's needle procedures. Global Comfort Promise project was adopted, aiming to halve discomfort and pain from the baseline with local anesthesia and distraction techniques.

Methodology: A cross-sectional study was carried out at CWTH-Iraq from September 2023 to April 2024, aligned with the "Global Comfort Promise" improvement initiative. Weekly, 10-20 patients were randomly chosen at inpatient ward. Local anesthesia was administered 20-30 minutes before needle procedures, assessment of pain levels and satisfaction levels of patients, families, and providers recorded. Various techniques including positioning, oral sucrose, and distraction were applied. Baseline measurements were conducted over two weeks.

Results: Between September 2023 and April 2024, 764 peripheral needle procedures were performed. Males 58%, and 79.6% of patients adhered to all Comfort Promise principles (≥4 interventions). Patient with leukemia were 60%. Initially, 69% of patients reported pain during needle procedures without local anesthesia (11.2% were under 2 years, 59.3% were 2-10 years, and 29.5% were over 10 years). After applying topical anesthesia, 29.64% of parents and patients reported pain during real-time cannulation. Severe pain was reported by 13.6% of patients equal and more than 4 years despite using topical anesthesia. Healthcare provider satisfaction after needle sticks was 91.5% while 93.5% of parents and patients were satisfied after the most recent procedure.

Study limitations include inadequate healthcare provider training and unfamiliarity with pain management. Concerns also include patient and parental hesitation due to prolonged wait times and shortages of local anesthesia.

Conclusion: The study reduced peripheral needle pain by 50% and resulted in high satisfaction among healthcare professionals and patients/families.

Novel Needs Tool Supporting Interdisciplinary Collaboration Around Children with Palliative Needs

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Background and aims: Children suffering from life threatening or limiting conditions and their families have multiple and complex needs which would benefit from an interdisciplinary collaboration and coordination of care. A tool co-created with an interdisciplinary team in a children's hospice, with insights from a retrospective children's palliative population cohort. This ethics-approved research aims to create, test and disseminate a tool in children's healthcare settings to assess interdisciplinary needs of the child with a palliative diagnosis and promote interdisciplinarity to support children and their families more holistically and effectively.

Methods: To compile the tool, interdisciplinary professionals (medical, nursing, allied health and psychosocial) were invited to contribute their provided services and support for a cohort of children referred from January 2021 – June 2023. A retrospective analysis of the same cohort of children was conducted using descriptive statistics. Data was also collected from medical reports, clinical and psychosocial documentation. Additionally, a review of literature and similar tools was done.

Results: A comprehensive tool was created to collect clinical, psychosocial, demographic, sociocultural and related needs, to be piloted in a government hospital using live actors as case vignettes in focus group format. It should provide a basis for first assessments, interdisciplinary discussions and improved care coordination, taking into account the voices and experiences of children and their families.

Conclusions: This tool has potential to create a more collaborative approach around children with palliative needs. Limitations include using data and inputs from a single centre, which will be rectified during pilot phase and as the tool evolves. This novel approach may be beneficial to promote holistic care and promote interdisciplinary collaboration for children in our setting and other countries.

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Pain and Discomfort in Neonates Eligible for Pediatric Palliative Care: Assessment Tools Comparison

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Background and aim: Neonates eligible for Paediatric Palliative Care (PPC) admitted to a Neonatal Intensive Care Unit (NICU) may be at higher risk of experiencing pain and discomfort, especially due to the presence of invasive devices and the exposure to painful and stressful procedures. The evaluation of these symptoms is both a key and a critical aspect of their management, also considering the physiological inability to communicate them. The aim of the study was the comparison of assessment tools for the evaluation of pain and discomfort in neonates eligible for PCC in a NICU.
Methods: This observational study was performed between July and September 2023. The sample included neonates admitted to the NICU eligible for PCC. Each neonate was evaluated at the time of inclusion and every 7 days until the discharge, the start of palliative sedation or at the end of the study. The EDIN6 and the N-PASS scale were used simultaneously. Data regarding the presence of medical devices, the need for mechanical ventilation and ongoing analgesic/sedative therapy were collected.
Results: A total of 12 neonates were included, 78 evaluations were collected. The administration of sedoanalgesia - intravenously, orally or in both ways - was detected in 32 cases: the most used drugs were morphine (n=24), and diazepam (n=14), followed by dexmedetomidine. The overall comparison of pain scores was made on a basis of 74 records: the scales simultaneously scored the absence of pain in most of the cases (n=54; 73%); in 23% of the surveys, the N-PASS detected pain whereas the EDIN6 indicated the absence of pain. The N-PASS scale also indicated pain more frequently than EDIN6 both in neonates undergoing sedo-analgesic therapy and in neonates with non-invasive and invasive mechanical ventilation.
Conclusions: Despite the limited sample size, the N-PASS seems to be a valid and more sensitive tool, as reported by other studies, for the assessment of pain and discomfort in neonates admitted to NICUs.

Holistic Approach and Palliative Intervention in Supratentorial Brain Tumors - A Retrospective Study

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Introduction. Brain tumors (BT) are the second most common cause of malignancy in children after acute lymphoblastic leukemia. Supratentorial tumors (ST) account for approximately half of all BT. These cases require a holistic approach from diagnosis involving a team consisting of oncologist, neurosurgeon, radiotherapist, endocrinologist and the palliative care specialist.

Objectives. We aimed to retrospectively analyze supratentorial BT from a multidisciplinary perspective over a 10-year period.

Material. The study group included 11 with ages at onset between 8 months and 17 years, 63% boys, most of them from urban areas.

Method. The data was collected from the observation sheets. The study group was retrospectively analyzed from a clinical, paraclinical and imaging point of view. Survival curves were traced, means and percentages were calculated.

Results. Analysing the study group revealed a distribution by pathology as follows: 45% of the tumors were represented by astrocytomas and glioblastoma. All cases were approached in a multidisciplinary manner. Symptoms observed at onset were as follows: headaches (n.82%) that were first managed with step II opioids; vomiting in 45.5% of the patients at onset and in 82% of the patients in terminal phase, various vision disturbances (n.54.5%), 18.1% diabetes insipidus and secondary dyselectrolytemia (n.36,2%). In 9% of the cases only palliative surgery was possible, where a ventriculo-peritoneal shunt was placed. All cases were treated with chemo- and radiation therapy. Evolution of BT was favorable in 27.3% of cases while 27.2% have died in < 3 months after diagnosis. All patients and families have received psychoemotional and spiritual support.

Conclusions. The holistic approach in supratentorial BT represents a necessity that must be implemented from the start by a multidisciplinary team. The overall unfavorable evolution of this disease justifies including palliative care from the diagnosis.

Development of a Children's Palliative Care Network in the Vysočina Region - Czech Republic

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Background: The poster shows the development of the care network. Pediatric palliative care has been developing in Czech Republic over the past decade. The Vysočina Region is one of the ten czech regions with a population of approximately 515 000.
Method: mapping the path of development between 2017-2024.
- Before 2018: Estimated need for early palliative care: 50-70 children per year. End-of-life care: 1-3 children/100 000 inhabitants per year. Perinatal deaths and serious neonatal diagnoses: 10-15 cases in the region/year. Care for children at the end of life was unsystematic and varied depending on the location. Families had limited options for home care. Adult mobile palliative care teams were hesitant to care for children. There were concerns about communicating with families of dying children. Development of a pediatric and perinatal palliative care strategy aligned with regional health policy. Financial and political support from the region for palliative care services.
- Advancement of pediatric palliative care 2019-2021: Education of mobile and hospital palliative care teams on pediatric care (conferences, written materials, mentoring, consultations with specialists). Establishment of links between health and social services.
- Pediatric Palliative Care System in the Vysočina Region 2021-2024: The system is based on the integration of social and healthcare services and the autonomy of teams in the districts. Care is multidisciplinary, providing both healthcare and social support - essentially community-based. Specialist guidance is provided by local mobile palliative care teams.
Conclusion: The Vysočina Region has made significant progress in developing pediatric palliative care system over the past decade (the statistics are on the poster). Accessible end-of-life care for children throughout the region within a few hours. Continued efforts are needed to further improve coordination, provide ethical counseling, and support palliative care teams.

Clinical Case: Accompanying an Educational Center in the Grief of a Student

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Introduction: Pediatric palliative care (PPC) aims to improve the quality of life of children with diseases that threaten and/or limit life. One of its central axes: maintain the link with their educational community despite prolonged treatments. School, through education and socialization, is a protective factor and quality standard in PPC. For educators, approaching grief and death care are pedagogical opportunities.
Methodology: Describe intervention of a PPC team from a private health institution in a public school.
Clinical case: 10-year-old boy, diagnosed with a central nervous system tumor 4 years previously, treated with surgery, radio and chemotherapy.
Since the diagnosis, the PPC team accompanies the child and his family, carrying out treatment of physical and psychosocial symptoms with early connection with school. In the stage of partial remission, the patient attends school, enjoying time with classmates and teachers. Helping them approach and empathize with the child's ailments and losses.
After the oncological relapse, a direct approach is carried out by the PPC team with the team of school directors, teachers, psychologists and social workers, explaining the illness and the patient's care, weaving networks of compassion.
Towards the end of life and after the death of the child, teachers were empowered to accompany the grieving of students, their families and other members of the educational community.
The PPC team's relationship with the school had unexpected projections:

- awareness-raising activities on “Death and grief in schools”, followed by training for teachers and administrators from our country
- meetings with national educational authorities, proposing the inclusion of the topic “death and grief in schools”

Conclusions: The intervention of the PPC in supporting educational institutions in cases of death and mourning favors a more natural and liberating approach to these processes.

Integration of Research and Implementation to Support Advance Care Planning: A Nationwide Approach

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Background and aims: The Implementing Pediatric Advance Care Planning Toolkit (IMPACT) supports children with life-limiting conditions, their families and health care professionals (HCPs) to be engaged in advance care planning (ACP). Implementation in practice remains challenging. Co-IMPACT is a national research and implementation project that improves the quality and use of ACP for children in need for palliative care in different healthcare settings.

Methods: Co-IMPACT started in 2023 and consists of four phases: 1) Update of IMPACT intervention materials and training by focus group studies among stakeholders and systematic reviews about effective communication and training. 2) Providing a 2-day ACP training to HCPs. 3) A two-year period of implementation and evaluation by a mixed-methods approach. 4) Integration of findings into a renewed version of IMPACT and implementation strategy for routine care.

Results: The design of the IMPACT materials will be more age-appropriate and suitable in different disease trajectories. Subsequently, 120 HCPs are trained to use IMPACT. Part of them participates in a 2-year coaching program to enhance implementation of ACP in their own setting. A part of the conversations will be recorded and analysed. Families and clinicians participate in interview studies over time to evaluate the meaning of the conversations for future treatment and care. Quality of life, patient satisfaction and quality of communication will be assessed in observational studies. An implementation strategy will be developed to share outcomes of ACP throughout the network of HCPs of the individual patient. In the final year, findings will be integrated into an overall implementation strategy of the improved IMPACT approach.

Conclusion: Co-IMPACT is a unique project that integrates research and implementation strategies in close collaboration with all stakeholders to promote engagement with ACP for all children with life-limiting conditions.

Respite Days in the Pediatric Palliative Care Day Care in Emilia-Romagna: A Pilot Project

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Background-context-aims: Pediatric palliative care (PPC) plays a key role in caring for children with life limiting/threatening and their families, with the goal to promote the best quality of life. To achieve this goal the Day Care Service developed “respite days” (RD). This pilot project proposes RD for PPC candidate children and their families: the aim is to provide temporary support and relief to caregivers.

Methods: The Day Care Center interdisciplinary team in a collaboration with volunteer association organized RD for children eligible to PPC. Two specific worksheets, one for health professionals and one for volunteers, were created to identify children’s clinical and care needs. The primary caregiver was involved in filling the worksheets. Data were collected from March 2022 to May 2024.

Results: The RD were offered to 19 children, whose average age was 10 years (range 2-19). The most commonly diseases were metabolic (3), neurological (4), neurodegenerative (3), infantile cerebral palsy (4), genetic (3), congenital malformations (1), and in the process of being diagnosed (1). 10 children attended regularly, 6 did not accept and 2 cancelled due to school or health reasons. During admission, the children had access to nursing, rehabilitation services and recreational activities. Caregivers were able to enjoy hours of relief from the fatigue of caring.

Conclusions: The RD provide temporary support to families in the regional PPC service. Respite programs demonstrated a positive impact on the well-being of caregivers, providing them with additional resources to face daily life and to take a better care of themselves. A comprehensive evaluation of the project's impact should more accurately include the families' satisfaction and the reduction in their perceived care burden through tools such as questionnaires or structured interviews.

Key words: pediatrics palliative care, respite days, caregivers, quality of life, clinical care needs

Beyond Pain - Emotional Support Project for Perinatal Grief

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The loss of a pregnancy at any age has a physical and emotional impact on the family. Perinatal mortality refers to fetuses and babies who die between 22 weeks of gestation and 27 days of life. This loss and mourning often causes irreparable ruptures in the lives of couples. To survive the couples have to invent something of themselves to return a habitable form to life and restore their rightful place to their dead baby. Giving your child a place in the family and society is fundamental for them. In addition to rekindling other unresolved traumas. For professionals who assist grieving women/couples, it involves being able to accept the suffering, misunderstanding, and anger that are fundamental in situations of great anguish. You must identify the degree of objectification of the fetus or baby, what it represents for this woman/couple before proposing mourning rituals, for example. Multidisciplinary work is essential. By building a perinatal bereavement assistance protocol adapted to the local reality, we commit to delivering a technical product to health managers. We aim to promote respectful, appropriate and dignified assistance to women/couples in perinatal grief. In assistance, the experience of clinical management of 60 women/couples by a multidisciplinary team that involves medicine, nursing and psychology provides those involved with an increase in their responsibility and social commitment. And by promoting the 1st Seminar on Perinatal Grief in Southwest Bahia, we broadened the discussions by bringing to the training the reflection on a topic that is made invisible and minimized in its importance for the mental health of women and couples. It is expected to promote socialization and exchange of experiences, with the involvement of the internal academic community, graduates and external public, for the debate on the training of doctors and psychologists and other health professionals, their possibilities and objectives in the face of perinatal grief .

Care Maps: An Effective Tool to Evaluate Complexity and Needs in Pediatric Palliative Care

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Background and Aim: Children eligible for pediatric palliative care (PPC) have complex needs that require the coordination of many different services. Care maps effectively represent this complexity and identify care coordination needs. The PPC network is often represented as a group of services and specialists supporting the child and his family. The child, parents, and siblings are often considered as a single unit, represented in the care map in the same square. This study aimed to analyze care maps of children cared for by the PPC network.

Methods: Parents, family pediatricians, and hospital specialists were asked to draw maps of the children's medical complexity, highlighting needs and the services that satisfy them. A psychologist assisted in comparing and interpreting these maps.

Results: Twenty maps from 11 children (3 females, 8 males, median age 6 years) were collected. The children had genetic (46%), acquired (36%), or unknown (18%) diseases, all with severe neurological impairment. Ten parents (91%), six family pediatricians (55%), and four hospital specialists (36%) created maps.

Parents' maps often identified the child with the disease, and parents usually did not represent themselves. These maps included a detailed list of services, including non-medical ones (e.g., financial support). Family pediatricians' maps, while detailed, usually omitted parents but always included psychological support, which was missing in the other maps. Specialists' maps represented the child and family together, were less detailed but noted all main services.

Eight parents (73%), five family pediatricians (83%), and all hospital specialists included PPC services in their maps.

Conclusions: Care maps are an effective tool to share with parents the child's needs and what is necessary to satisfy them. Therefore, we encourage clinicians to include care maps in their clinical practice.

Transcending - Self and Frontiers

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Background-context-aims: This work aims to highlight the relevance of the intervention of a paediatric palliative care (PPC) team in the various physical, emotional, social and spiritual dimensions of a young person diagnosed with an incurable disease and his family. The spiritual and religious dimensions will be emphasized, which greatly contributed to the experience and acceptance of the disease process.
Methods: Retrospective analysis of the journey of a 17-year-old boy from Guinea Bissau, who came to Portugal under a health cooperation agreement to be treated for a stage 4 osteosarcoma of the right femur. A young Muslim, in need of daily practices and rites, decontextualized from his cultural and religious roots, lacking effective family support, and having had no contact with his mother for many years due to his religious studies in another African country. His needs encompassed diverse human dimensions, so we seeked a holistic intervention by referring him to the PPC hospital team.
Results: The team implemented Interventions promoting dignity, in order to meet his emerging needs. There were evident gains in his quality of life, namely in the spiritual and religious dimensions: improvement in social interactions, acceptance of the disabilities resulting from the disease and treatments, search to rediscover one's essence, realistic hope in the face of losses and gains, planning and implementing a reunion with his mother in Guinea Bissau. He asked to return to his homeland shortly after, where he died next to his family, at the age of 19.
Conclusions: With this case we highlight the importance of PPC in recognizing the dismal prognosis, as well as of the multidimensional approach to the young person and family. Our approach to the spiritual dimension, fostering the connection between the person and the transcendent, allowed for the relief of total pain and the improvement in quality of life.

Building Pediatric Palliative Care Leadership Capacities: A Collaborative Initiative for South Asia

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Background: In South Asia, over 2 million children need palliative care (PC) to relieve serious health-related suffering, yet less than 0.4% have access to these services. To enhance pediatric PC capacity, healthcare professionals (HCPs) require leadership training and mentorship. This abstract describes the development and implementation of a regional leadership training program to support emerging healthcare leaders to expand children's PC to address the needs of children and families.

Methods: A leadership team of national, regional, and global children's PC leaders developed the year-long *Children's PC Leadership Program*. The curriculum, informed by a literature review and needs assessment, included 12 monthly online sessions and two in-person workshops. Key topics covered leadership practices, project management, advocacy, stakeholder analysis, mentorship, and emotional intelligence. Participants developed and implemented individual leadership change projects with mentorship from global experts.

Results: Twenty emerging healthcare leaders, including three nurses, fifteen physicians, and two allied HCPs, participated. During an in-person workshop in Hyderabad, India, in February 2024, participants worked on developing an "elevator pitch" and engaging donors to support their project idea. Monthly online sessions focused on sustaining changes and mentorship to support implementation of their projects. Program evaluation included surveys, interviews, and narrative case studies on participants' leadership projects and PC service developments.

Conclusions: The Children's PC Leadership Program is an innovative model of leadership development to address the needs of children with serious illnesses in South Asia. The program aims to impact 150,000 children and families across the region, advancing care practices and fostering new programs. Future efforts will focus on evaluating outcomes and refining the curriculum to better meet participants' and patients' needs.

Raising Awareness: Real World Data on Palliative Care for Advanced Pediatric Cancers

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Background: The early integration of palliative care in children and adolescents with cancer provides a variety of positive effects. Palliative evaluation is recommended at time of diagnosis, especially in high-risk settings. Nevertheless, there are several barriers that limit early deployment of palliative care.

Purpose: To provide real-world data on the current integration of palliative care in pediatric oncology in a high-income country with a focus on initiation of care and clinical benefits.

Methods: In this retrospective observational study, data derived from patients with refractory or relapsed malignancies under the age of 18 years were collected from 6 German pediatric oncology centers (2017 – 2022). In addition to palliative data, a variety of evaluable data such as disease entity,relapse/progress frequency,therapy and endpoints were collected. The timepoint of initiation, frequency and duration of palliative therapy were investigated. Differences in patient outcomes were analyzed based on the availability of palliative care.

Results: Of 373 patients only 157 received palliative care at any given point of their disease trajectory.The mean duration of palliative care was 5.96 months with a mean disease trajectory of 31.4 months for patients receiving palliative care.On average, palliative care was initiated in the last third of the trajectory. In addition, 65.3% of patients received palliative therapy only at the time of their last relapse,whereas only 16.8% received palliative therapy at the time of diagnosis.There was a significantly lower frequency of palliative care for hematological diseases in relation to CNS tumors which were used as a reference. Patients who received palliative care had a significantly higher functionality.

Conclusion: Despite the substantial benefits of palliative care for children with refractory or relapsed cancer, our data highlight significant deficits in the frequency and timing of palliative care in a high-income country.

DMD-YOUNG: Paediatric Palliative Care for a Life-Limiting Disorder in Transition to Adulthood

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Background and aim: Duchenne muscular dystrophy (DMD) is a life-limiting genetic neuromuscular disorder that causes progressive loss of muscle function. As life expectancy in DMD has gradually increased from 14 to 30 years, the disorder serves as an example of slowly progressive, childhood-onset conditions requiring attention to paediatric palliative care (PPC) in transition to adulthood.

DMD-YOUNG is aimed at adolescents with DMD, to explore how PPC principles can be applied in transition and assist the participants in developing independence, empowerment, and the best possible quality of life.

Methods: In project phase one, six young men with DMD, aged 14-28 years, were invited to discuss their challenges, coping strategies, and needs for knowledge and social networking via digital meetings. In phase two, all adolescents (14-23 years) with DMD in this country were invited to a weekend gathering offering lectures and group sessions, covering disease management, social life, housing, education and employment, as well as social activities, based on the results from phase one. Project phase three, which is the establishment of a digital platform for discussions, lectures and social networking among adolescents with DMD, is ongoing.

Results: 13 young men attended the weekend gathering. The participants experienced group discussions and social activities as educational, inspirational, motivational and empowering. They reported a sense of community and appreciated that the setting was tailored to them as adolescents rather than patients. The project group acquired important insight into the participants' concerns and needs, coping strategies, experiences and hopes for the future. This will be invaluable in the establishment of a digital platform for, as well as improved management of, DMD in transition.

Conclusion: The DMD-YOUNG project illustrates a successful approach to PPC for adolescents with a progressive, childhood-onset, life-limiting neuromuscular disorder.

Joint Specialist Nursing Posts between Hospices & a Tertiary Palliative Care Centre

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Background-context-aims: The role of Joint Palliative Care Nurse Specialist (JPCNS) was introduced by Louis Dundas Centre for Palliative Care at Great Ormond Street Hospital, (GOSH) in conjunction with Haven House Children's Hospice in June 2021 and Noah's Ark Children's Hospice in August 2022. The purpose was to streamline the professional relationship between a Tertiary Palliative Care Centre (GOSH) and Children's Hospices and improve available support to babies, children, young people (BCYP) and families. We undertook a service evaluation to assess the impact of existing JPCNS posts and identify areas for improvement.

Measures: Descriptive statistics and content analysis have been used to examine professionals' perception of whether there has been a positive impact on care of BCYP with palliative care needs and identified areas for improvement.

Methodology: We collected data using an online survey sent by email to Children's Hospices and a Tertiary Palliative Care Centre, using open and closed-ended questions.

Results: We received 32 responses (12 from Tertiary Centre and 20 from Hospices) from nurses, doctors, and allied health professionals. Respondents highlighted benefits including improved continuity of care and reduction in barriers to accessing services. A majority (72%) of respondents strongly agreed the JPCNS has improved care provided by the hospices and 75% strongly agreed that role has improved communication between GOSH and the hospices. Respondents felt that the roles facilitated better access to hospice services, by ease of referral, early introductions to families and smoother team working around hospital discharges. Areas identified for development include equality of access and further understand the impact on BCYP and families.

Conclusion: Preliminary data suggests that Specialist Joint Hospice Nursing roles have improved the care provided to babies, children, young people and families.

Source of funding: None

Sleep Difficulties are Common in Children Attending a Hospice Service

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Background and aims: Children with life limiting conditions (LLC'S) present with a wide range of problematic symptoms often negatively affecting quality of life. Sleep disturbances are commonly reported in clinical care, representing a frequent source of distress for the child and family. This study is part of a larger quality improvement project to address sleep difficulties in a children's hospice and aims to identify the frequency, and the medications prescribed for sleep disorders, in this cohort of children.

Method: A holistic needs assessment (HNA) is completed with the family of all children accepted to the service. A HNA is a comprehensive report that identifies the child's needs and current issues. It provides information in relation to their current support network and family priorities prior to the child attending the Hospice. A retrospective review of all HNAs performed in 2022 and 2023 was completed. HNAs were analysed to determine the presence and characteristics of sleep difficulties and the frequency of prescribed sleep medications.

Results: A total of 89 children had HNAs completed in 2022 and 2023.

Sleep difficulties were recorded in 52(58%) of children. 14/52 had difficulties with sleep initiation, 13/52 difficulty with sleep maintenance and 25/52 both. 20/52 parents reported that sleep had been affected by problematic symptoms associated with the child's condition.

Sleep Medications were prescribed in 36/52 of children. 32 of the children were on a single medication for sleep (3 benzodiazepine, 1 risperidone, 3 chloral hydrate, 25 melatonin). 4 children were prescribed 2 medications (melatonin and clonidine, diazepine and levomepromazine, melatonin and chloral hydrate and melatonin and nitrazepam).

Conclusions: This study demonstrates high rates of sleep disorders in children with LLC's. It supports the development of a staff education and a training programme as a priority to facilitate detailed assessment and management of sleep disorders in the hospice.

Ensuring Quality Care: The Vital Role of Needs Assessment in Children’s Palliative Care Development

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Background: More than 21 million children globally need access to palliative care. The need for, and accessibility to, children’s palliative care (CPC) varies globally, with the need being highest across Africa. The need for CPC in Ghana was recognised and clarified through a needs assessment. This paper will discuss the vital role that this needs assessment has played in the ongoing development of CPC in Ghana, and identify lessons learnt for other countries.

Methods: Following recognition of the need for CPC, a plan was identified to help develop CPC services across Ghana. This strategy included: a) Discussions with key stakeholders including the Ministry of Health and Ghana Health Services; b) Development and implementation of needs assessment for CPC in Ghana; c) Review and finalisation of recommendations with key stakeholders; d) Securing funding to implement the recommendations; e) Implementation of project; f) Review recommendations, develop sustainability plan and review next steps.

Results: Alongside clarifying the need for CPC, three main themes were identified, along with subthemes, including a) General issues about CPC; b) The WHO conceptual model for PC development; c) Going Forward. Recommendations were developed across a range of topics and a grant applied for to build capacity of CPC in Ghana utilising the data and collaborations already developed through the needs assessment. Implementation is ongoing along with discussions around sustainability and next steps. Key lessons about the vital role of needs assessment in building capacity for CPC will be discussed, and applicability to other settings.

Conclusion: Through the identification of need, the stage was set for the implementation of recommendations, ongoing collaborations, access to grant funding, and importantly the strengthening of CPC development within Ghana. Lessons learnt can be applied across different settings to bring about improvements in CPC provision.

Pediatric Palliative Care Attitudes and Educational Needs among Humanitarian Health Professionals

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Background and aims: Palliative care is an essential component of humanitarian health responses, yet it remains largely unavailable. A lack of education for healthcare providers is a significant barrier to palliative care availability, which will lead to improved management of pain and other symptoms for children with serious or life-limiting conditions. There are no studies examining the palliative care knowledge of healthcare professionals in humanitarian settings. The aim of this study is to explore the extent of training, experience, comfort, and competence in children's palliative care among humanitarian healthcare workers (HHCPs).

Methods: An anonymous online survey was distributed to HHCPs, exploring palliative care knowledge, comfort, attitudes, and educational needs.

Results: 134 HHCPs participated. Participants were providing clinical care (64%), health management/administration (13%), or both clinical care and management, with the majority working in hospitals (62%). The majority (>60%) of participants felt uncomfortable with common palliative care situations including talking about impending death with parents of a dying child or caring for dying children. More than 70% of respondents reported having some training in palliative care including training during their health professional training (49%), or through online courses (43%) or continuing medical education (39%). The majority (>98%) were interested in further training in palliative care, with online live teaching sessions being the preferred training modality.

Conclusions: There is a substantial need for and interest in children's palliative care education among HHCPs, with a preference for online teaching and continuing medical education training. Educators should develop online training programs in children's palliative care to meet the educational needs of HHCPs.

Acceptability and Feasibility of the Paediatric Palliative Scoring Scale among Nurses and Physicians

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Background and aims: Paediatric palliative care (PPC) begins when a child is diagnosed with a life-limiting or life-threatening (LL/LT) condition. However, in our country, for various reasons, health care personnel are hesitant about involving paediatric pallaitive care (PPC) teams. This study aimed at evaluating the acceptability and feasibility of the Paediatric Palliative Scoring (PaPas) scale [1] among paediatric nurses and physicians.

Methods: This was a quantitative study taking place in the Division of Paediatric and Adolescent Medicine of a large university hospital over a period of 2 months in the spring of 2024. The study team identified eligible patients prior to regular morning rounds. If the child's primary nurse and physician agreed to participate, they were asked to fill in the PaPas scale together. Acceptability was calculated by the ratio of nurses and physicians willing to participate. On a scale from 1 to 5, feasibility was evaluated by each of them separately answering four questions: about the difficulty of answering, the time spent, having to cooperate, and the degree of usefulness.

Results: 38 patients with LL/LT conditions had a PaPas score range of 5-35 (median 17). Paediatric nurses (n=37) and physicians (n=33) rated the scale in 97 and 87% of cases, respectively. More physicians (6%) than nurses (0%) stated that the time it took to fill in the scale was somewhat too long, and that it was inexpedient that nurses and physicians should do it in cooperation. However, both groups found the PaPas scale useful.

Conclusions: Acceptability of the PaPas scale was higher among nurses than physicians. A majority of both nurses (90%) and physicians (76%) found the PaPas scale useful for evaluation of whether a patient should be referred to the PPC team or not. We suggest that primarily nurses should be responsible for applying the PaPas scale in eligible patients, and to consult the attending physician as needed.

[1] Bergstraesser, 2013, 2014

Children with Cancer and Sibling's Experiences of Participation in the Family Talk Intervention

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Background and aim: Children in pediatric oncology report unmet needs related to communication and illness-related information, care involvement and psychosocial support. The ambition to support the whole family involves challenges and there is a risk that children's voices are lost in the stronger voices of the adults. To support children's voices and their right to participate in processes that affects them, Article 12 of the United Nations Convention on the Rights of the Child has been a catalyst. The aim of this study was to explore how children with cancer and their siblings experienced participation in a family-centered psychosocial support intervention, the Family Talk Intervention (FTI).

Methods: FTI contains six meetings with family members in various constellations and is led by two FTI-educated healthcare counselors. Interviews were performed with 35 children (ill and siblings) from 26 families cared for at a pediatric oncology unit in Sweden after having ended FTI. A deductive content analysis was undertaken. The study received ethical approval from the Regional Ethical Board in Stockholm (No. 2018/250-31/2 and 2018/1852-32).

Results: Children's experiences of the opportunity to express their views, being listened to and involved during FTI were mainly positive. This was related to taking part in individual meetings where they could raise their concerns and views, by doing small activities while talking, and by having their voices and needs mediated to relevant adults such as parents and professionals.

Conclusions: The overall findings of this study showed that FTI for families in pediatric oncology created opportunities to promote child participation. These findings indicate that by offering the children an individual space where they can express themselves freely and supporting them to communicate their views to those who are able to give them effect, the children's voices, and involvement in family interventions, such as FTI, is strengthened.

The Rehabilitator between Intensive Care and Palliative Care: A Pediatric Clinical Case

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Background: In pediatric palliative care (PPC) the patients show a clinical condition with a different evolution depending on the incurable disease. Thus, a modification of the individual rehabilitation project is needed.

The main purpose of rehabilitation is to foster the patient’s body perception while maintaining comfort and emotive support.

Our team comprises 5 professional figures from the rehabilitation area (physiotherapists and speech therapists) and we work inside the Hospital, at home, and in a specialist clinic.

Methods: Among the most emblematic cases, we report the case of a newborn VLBW (PMA 26+6; weight 636 g) born in our NICU. She was born by emergency C-section for a placental abruption. For this reason, she was taken charge to sustain neurodevelopment and starting oral feeding.

At 35+4 PMA a cardio-respiratory failure occurred as a consequence of inhalation and it was followed by tracheal intubation and mechanical ventilation. Subsequently, a severe neurological impairment condition developed, confirmed by instrumental investigations, with progressive clinical deterioration. After numerous consultations between neonatal staff, pediatric palliative care team and parents, the Shared Decision Making was signed.

Results: Considering the deterioration of general clinical conditions, rehabilitation goals were modified and adapted to give quality and wellness in end-of-life setting, through Basale Stimulation® and oral stimulation together with neonatal care.

Conclusions: rehab in PPC must be proportionate to the multidisciplinary care project and modulated on functional limitations, child age, disease experience and prognosis. Finally, it is fundamental to take into account child needs, always preserving the identity and dignity of the person and his family.

Two Letters Compared: Psychologist and Adolescent Dialogue about Turning Limits into Resources

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Background and Aims: Adolescence is a period of complex and delicate transformation, characterized by an ongoing search for identity and belonging. The peer group plays a crucial role in addressing emerging issues related to adolescent identity. It is proposed to explore the importance of dialogue between a psychologist and an adolescent in the context of pediatric palliative care, analyzing how limitations can be transformed into resources through peer communication and integration. The main objective is to highlight the complementary perspectives of the mental health professional and the young patient, highlighting the importance of these exchanges in supporting personal growth and management of their clinical condition.

Methods: This study is based on the narrative analysis of two open letters written by a psychologist and an adolescent involved in paediatric palliative care, respectively.

Through the study of the contents of both letters, it is intended to explore the theme of paediatric and adolescent palliative care.

The comparison is between the perspectives of a mental health worker, engaged in facilitating, mediating communication and integration between peers, and an adolescent on a delicate path, free to express his vulnerability and energy.

Results: The findings highlight how the experience of confronting the two perspectives, that of the practitioner and that of the adolescent, can lead to greater understanding and acceptance of adolescent challenges, especially in pediatric palliative care settings.

Conclusions: The findings emphasize the importance of creating spaces for dialogue and discussion between psycologists and young patients to foster an environment of mutual support and understanding. This approach can contribute significantly to emotional well-being and the management of difficulties related to identity and illness during adolescence.

Palliative Care Perceptions and Educational Needs Amongst Humanitarian Healthcare Professionals

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Background and aims: Palliative care is needed to prevent and relieve serious illness-related suffering for children with life-threatening and life-limiting conditions; however, limited palliative care knowledge and skills amongst humanitarian healthcare professionals (HHCPs) is a significant barrier to access. This study aimed to explore HHCPs' perceptions about implementing palliative care for children and to identify their educational needs and challenges, including learning topics, training methods, and barriers to education.
Methods: HHCPs were interviewed regarding their perspectives on children’s palliative care and preferences and needs for children’s palliative care training. Interviews were transcribed, coded, and arranged into overarching themes. Thematic analysis was performed using qualitative description.
Results: Ten HHCPs were interviewed. Patient and family-related barriers included misconceptions that palliative care was synonymous with end-of-life care or failure. Health-system barriers included time constraints, insufficient provider knowledge, and lack of standardized palliative care protocols. Important learning topics included strategies to address stigma surrounding serious illness and palliative care, empathic and culturally sensitive communication skills, and pain and symptom management. Preferred learning modalities included interactive lectures, role-play/simulation, and team-based clinical case discussions. Participants preferred online training for theoretical knowledge acquisition and in-person learning activities to enhance their ability to conduct serious illness conversations.
Conclusion: HHCPs are highly motivated to learn about relieving serious health-related suffering for children through the provision of palliative care in humanitarian settings, but they require adequate health system resources and training. These findings can guide educators in developing palliative care education packages for HHCPs.

Therapeutic Powers of Play Meeting the needs of children in Palliative Care

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Background: Play is important for all children, especially children with palliative care needs. Play helps children feel safe and secure, enhances coping and resilience, and provides a pleasurable distraction and temporary respite from the illness.

Aims: The aim of this research was to develop a broader understanding of the Therapeutic Powers of Play (TPoP) active in children's palliative care. By highlighting and exploring the practice of play in paediatric palliative care it was hoped to advance a professional sharing of knowledge and team support where play becomes an integrated part of practice.

Method: A literature review provided the theoretical base for the research. Four semi-structured interviews were carried out using a purposeful sample from a palliative care team. A Deductive Thematic Analysis was utilised to analyse the data, applying the framework of the TPoP.

Ethical approval for the research was applied for through the college and children's hospice before commencement.

Findings: The findings indicated that the therapeutic powers of play are incorporated in all aspects of the child's care through to end-of-life.

Communication is facilitated by providing activities that foster self-expression, such as music, memory making, storytelling, sensory and developmental play activities.

Personal strengths and emotional wellness are supported by the participants attunement to the child's needs, offering choices and provision of suitable activities.

The importance of building a secure relationship with the child and family to enhance social relationships was highlighted, and children were provided an opportunity to extend connections through group activities.

Conclusion: Professionals supporting children with palliative care needs and their families are sensitive and attuned to their needs and play was used to put the therapeutic lens onto their work. Further research could explore how to enhance the therapeutic powers of play in professionals work practices.

Perceptions of Bereaved Mothers After Grief Support Groups: Analysis of Open-Ended Survey Responses

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Background: The loss of a child is a deeply distressing experience that leaves parents and families grieving. Support systems play a crucial role in helping them cope emotionally. Grief support groups provide a space for bereaved individuals to share their experiences, feelings, and coping strategies. However, the experiences of bereaved mothers in these groups are not well understood. Gaining insight into their perceptions is essential for developing targeted interventions that meet their specific needs.

Aims: This study aims to explore the perceptions of bereaved mothers regarding their participation in grief support groups.

Methods: Participants were mothers who attended grief support meetings held by our organisation three to four times per year since 2017. Data was collected through online surveys conducted after each meeting held since 2020, with survey completion indicating consent. Responses from the sixth to the thirteenth meetings were analysed, focusing on open-ended comments about the significance and perceptions of participation. The analysis focused on surveys completed from April to May 2024. Content analysis was used to develop codes and categories. The study was approved by our institution's Research Ethics Committee (Approval No. R04-0009).

Results: Out of 58 participants, 37 mothers (64.9%) provided responses. Eight categories emerged from 106 codes: "Space to talk about the deceased child," "Listening and being listened to," "Empathy and shared experiences," "Expressing suppressed emotions," "Realising they are not alone," "Emotional relief," "A place to remember the deceased child," and "Facing grief."

Conclusion: The results indicate largely positive perceptions of the grief support groups. Participants reported increased awareness and improved management of their grief, although daily challenges persist. The variable and fluctuating nature of grief underscores the importance of sustained and regular support meetings.

Bridging the Bereavement Support Gap in India: A Model for Global Application

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Background: The death of a child is profoundly traumatic. In low-and middle-income countries (LMICs), limited bereavement support coupled with higher mortality rates may increase the risk of complicated grief. This gap highlights the need for effective bereavement strategies. We aim to describe the early outcomes of a bereavement workshop developed with a culturally and regionally sensitive approach.

Methods: We conducted a one-day workshop at the Indian Association of Palliative Care (IAPCON) in February 2024. This workshop engaged stakeholders and healthcare professionals (HCPs) in care strategies for dying children. The evidence-based strategies were adapted to cultural contexts using an impact/effort matrix. Role-play and group discussions enhanced communication skills for engaging bereaved families.

Results: Forty HCPs participated in the workshop. Sessions included insights from bereaved parents, underscoring the practical importance of these programs. Participants identified high-impact, low-effort strategies tailored to South Asia's context, such as follow-up calls, memory-building activities, and annual remembrance events. More intensive strategies included home visits and training bereaved family members to mentor others. Essential communication materials distributed included guides, scripts, and condolence letter templates. A month after the workshop, the Golden Butterflies Children’s Palliative Care Foundation and Sri Ramachandra Institute of Higher Education and Research in Chennai, India, launched the Bereavement Circle, bringing together fifteen grieving parents to support each other and share their experiences.

Conclusion: The IAPCON 2024 bereavement workshop showcased a model for bereavement training adaptable across various cultural contexts and settings. The successful implementation of the Bereavement Circle underscores the effectiveness of this approach, suggesting potential for broader application to enhance global bereavement support networks.

A Rapid Scoping Review of Sleep Difficulties in Children with Palliative Care Needs

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Background: Children with palliative care needs present with a wide range of complex symptoms, which negatively affects their quality of life. Sleep disturbances are commonly reported and represent a frequent source of distress for both children and their families

This rapid scoping review was completed as part of a larger quality improvement project which aimed to address sleep difficulties in a children's hospice.

Method: A search was carried out on databases including PubMed for articles relating to sleep disturbances in children with palliative care needs. The abstracts that were found were then imported to COVIDENCE for further screening and data extraction.

881 articles were identified in total. 482 were duplicates. The titles and abstracts of the remaining 399 were screened. 373 articles were not relevant. 26 full-text articles were assessed for eligibility of which 10 articles were included for final data extraction.

Studies were categorized into 3 distinct populations; Children with advanced cancer (5 studies), children with life-limiting conditions associated with severe neurological impairment (4 studies) and single disease profiles (Duchenne muscular dystrophy and advanced heart disease) (1 study).

Results: A variety of assessment tools have been used for quantifying the prevalence of sleep difficulties in children with palliative care needs.

Reported frequency of sleep difficulties ranged from 24% to 63% but variation in child population and lack of agreed assessment tool limited comparison.

Conclusion: Sleep disturbance is common in children with palliative care needs, unfortunately there is a paucity of quality research in this area. Disparity in measurement tools limits comparison and the evidence for effective management needs further investigation.

Further research is required to elucidate the nature of sleep disorders in children with palliative care needs to inform meaningful intervention and improve children's quality of life

How did the Preference for Child Home Deaths Change at GOSH, Through the COVID-19 Pandemic?

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Background The Louis Dundas Palliative Care team (LDC) at Great Ormond Street Hospital (GOSH) maintains rigorous records of parents' preferences for their child's place of death. While existing literature suggests that most parents prefer a home environment, minimal research exists on the impact of the COVID-19 pandemic on the preferred place of death in paediatric palliative care.

Aims This study aims to investigate any significant changes in the frequency of preferred home deaths among patients referred to the Louis Dundas Centre before, during and after the pandemic. It seeks to determine whether these changes are attributable to the pandemic or if parents' wishes were compromised.

Methods An anonymised dataset will be extracted from the EPIC database from January 2018 to October 2023 inclusive. Since the dataset excludes postcodes and names, ethical approval is not required for this project. Statistical tests will assess the significance of any observed data changes.

Results Preliminary findings from GOSH indicated a rise in home-deaths during the pandemic. However, the statistical tests did not indicate a significant difference in variation.

Conclusion This study is novel in recognising the importance of meeting parents' preferred place of death, during a pandemic. It highlights the need for additional research to improve palliative care for children during future global health challenges, with potential applicability to both adult care and resource-limited settings.

Evaluating Pathways to Better Care for Pediatric Complex Chronic Conditions:The KoCoN Study Protocol

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Background: Children with complex-chronic conditions (CCC) are a growing population in pediatric (palliative) care, needing multifaceted medical attention due to interconnected health issues. Caring for these children is challenging, necessitating coordinated, interdisciplinary care and substantial healthcare resources. However, the current system often falls short, resulting in both under-, and overuse of services. The new "KoCoN" care model aims to sustainably and comprehensively improve care for children with CCC through a modular inpatient pathway.

Methods: KoCoN involves six pediatric hospitals recruiting N=938 patients. Evaluation occurs in a randomized controlled trial employing a stepped-wedge design and mixed methods. Quantitative data are collected before inpatient admission (T0) and at discharge (T1), as well as at three follow-up time points (T2-T4) via online surveys. The primary endpoint for assessing KoCoN's effectiveness is the FACETS-OF-PPC at T2, with a focus including general quality of life. Secondary endpoints, such as symptom burden and (in)direct illness costs, are measured using validated instruments. Routine health insurance data are included. Mixed linear models analyze KoCoN effectiveness using intention-to-treat and per-protocol analyses. Cost-effectiveness analyses describe health economic aspects. Interviews and a corresponding qualitative content analysis capture the experiences of families and care professionals with the new KoCoN model.

Results: KoCoN is expected to be effective, positively perceived by families and caregivers, and thus superior to current standard care. A positive cost-benefit ratio is anticipated. Results will be available in 2025.

Conclusions: The new care model KoCoN, with its included comprehensive evaluation study, holds promise to sustainably improve the lives and care of highly vulnerable children with CCC, serving as a model for care optimization efforts.

20 years of Growth of Palliative Care Services in Ireland

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Background and Aims: In 2005, A Palliative Care Needs Assessment for Children document was published, by the Department of Health and Children. The first of it's kind in Ireland as result of a growth in demand and interest for the provision of Children's Palliative Care. Ireland's only Children's Hospice opened September 2011, earlier this year they launched their strategic plan 2024 - 2028: Advancing Our Vision, Extending Our Community Of Care. The purpose of this abstract to is to mark the development of children's palliative care services since 2005 and demonstrate the future vision.
Method: A qualitative review of the relevant literature on identification of services and supports for children and their families with palliative care needs was undertaken, including Irish government policy's, guidelines, organisational service development and strategic plans to identify the needs for children with a palliative care need and their families, along with the professionals educational needs, to map their development and progress over 20 years.
Results: Great strives have been achieved in supporting children at home, in hospice and hospital. Evidence of better *communication* with the development of the 'Our Story' folder, improved *coordination* with the establishment of the Clinical Nurse Coordinator for Children with life-limiting Conditions role, *learning* needs met with the introduction of a Masters in Health Science (Children's Palliative Care/Complex Care), provision of *respite* to relief the' burden of care' with short breaks in the Children's Hospice, and '*keeping things normal*' care delivered by a community of nursing and family support team in the child's home.
Conclusions: Effective Palliative Care requires the involvement of a broadly skilled multidisciplinary team that is committed to working together, services need to be structures to accommodate the needs and wishes of the child and family.

Level of Overload of the Main Caregiver of Pediatric Palliative Patients When They Begin Follow-Up

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Background and aims: to analyze the level of overload perceived by the main caregivers of pediatric palliative patients through the abbreviated Zarit Scale at the beginning of follow-up by a Pediatric Palliative Care Unit.

Methods: cross-sectional descriptive study in which 74 main caregivers between 19 and 58 years of age have been included.

Results: from the results of the forms we find that there is no significant deviation, probably because the majority of the main caregivers are mothers who were already providing multiple care for their children, sometimes being more aware of the overload with respect to the that they are going to start care either due to worsening of their child's illness or due to a new diagnosis.

Conclusions: taking on the role of caregiver for a sick child and recognizing that it represents an overload can cause varied effects on people. It is important to reflect that from a Pediatric Palliative Care Unit we are here to support the primary caregiver in recognizing when care tasks become overload and being able to recognize the anxiety or frustration that it entails without feelings of guilt. That they can look for solutions in stressful situations and be able to ask for help if they need it.

Need for Training in Psycho-Emotional Management Front of Serious Illness and End-Of-Life

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Background-context-aims: Continuous work with children, adolescents and young people with a serious illness or end-of-life situation can have a psychological impact on professionals. Training in accompaniment are protective factors that can improve this work. Objectives: 1)To learn about the end-of-life experiences of health professionals of different profiles. 2) Identify needs for training, capacity building and emotional regulation strategies.

Methods: Design: retrospective, descriptive/inferential statistical study.

Population: health professionals in contact with children, adolescents or young people with severe/end-of-life illness (pediatric hospital/adult hospital)

Instrument: *Ad hoc online* survey.

Variables: demographic profile, perceptions/experiences, psycho-emotional coping scales [Brief Resilience Coping Scale (BRCS) / Coping Strategies Inventory (CSI)/ Emotional Regulation Questionnaire (ERQ)]

Research ethics committee consent (15 November 202. C.I. PIC-177-21).

Results: n= 116 responses

The percentage of professionals working in the Palliative Care Service who have received training in end-of-life (53.3%) is significantly higher (p-value<0.001) than professionals working in onco-hematology (19.0%) or other services (17.4%). Likewise, professionals in the Palliative Care Service score higher the need for specific training during residency (9.7 points) than the rest (9.3 and 8.7 points). All professionals who have received previous training obtain higher scores than the rest in resilience scales (p-value=0.004) and adaptive capacity (p= 0.062).

Conclusions: Most healthcare professionals working with children and young people with serious illnesses have had experience at the end of life. Despite this, the training they have received to do this work is poor, so they make a request to formalize it during their specialty training. Professionals who have received previous training may have a greater capacity for resilience and adaptation.

Pediatric Advanced Care Planning: Development of Tools for Families and Healthcare Professionals

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Background: An essential part of pediatric palliative care (PPC) in children with life-limiting and life-threatening diseases is advanced care planning (ACP). Italian legislation offers general guidelines on adult and pediatric ACP, but operational indications on ACP process, especially in the pediatric context, have to be drawn by single PPC centers. Tools to inform and support both families and healthcare professionals during ACP are therefore much required.

Aims: The aim of our project was to enhance the ethical competencies of a multiprofessional team of PPC professionals and to produce shared tools to be used in ACP process.

Methods: The project, whose duration was of about a year, was divided into several progressive phases, the first consisting of two frontal lessons on ethical principles applied to pediatric age and ACP; participants were then divided into two groups that participated in three workshops on ACP. Both groups decided to elaborate documents for families and healthcare professionals to support ACP's application.

Participants were then divided into three groups (each one composed by physicians, nurses and psychologists) and elaborated three different documents that were afterward revised and presented to the entire team.

Results: The first document produced was 1. an informative brochure, written in plain language, addressed to the families; 2. a pamphlet that summarized the practical aspects of ACP and included some examples of conversation, to the use of healthcare professionals; 3. a draft for formalization modality of the APC process.

Conclusions: Improved survival of children with medical complexity requires healthcare professionals to become more confident with ACP. Informative pamphlets, conversation tools and shared formalization modalities may support both families and professionals in this circumstance.

Care Doesn't End at Death: Provision of Post-Death Care for Children in England

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Background: Whilst caring for our dead is something human beings have done for millennia, the fact that on average a funeral in England takes between ten and 21 days to arrange means that this care is increasingly being done over an extended period of time. After an expected death in England, a child can be cared for in a mortuary or funeral home, or in a "cold bedroom" within a children's hospice. The increasing use of cooling technologies mean that more families are choosing to care for their deceased child at home.

Methods: An online questionnaire was circulated to Children's Community Nursing teams and hospital teams. Questions were based on a similar questionnaire previously developed by another research team who scoped provision of post-death care by Children's Hospices. Questions included those about the use of cooling technologies to allow families to spend longer with a child after death, choices offered to and made by families, and training and support for staff. Data was analysed using descriptive statistics and thematic analysis of free-text answers.

Results: 39 responses have been received and mirror the hospice work in demonstrating a wide variety of practices across different teams and organisations. For example, some teams have multiple cooling technologies, whilst others have none. In many circumstances the time a family can spend with their child after death is limited, whereas others offer unlimited access to the child's body. There also appears to be no agreed method or standard for nurse education who provide this care.

Conclusions: A lack of evidence regarding post-death care has led to services developing based on a variety of rationales such as capacity, concern for staff or professional opinions. Consequently, the wide variation of practices means that there is inequity in terms of choices offered. Further research is needed to understand the experiences and needs of all involved in caring for children after death.

Effective Communication in Pediatric Palliative Care from the Perspective of Children and Parents

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Background. To achieve high-quality pediatric palliative care, it is crucial to communicate effectively. This involves creating a safe and inviting interaction where children and parents feel free to share their needs, goals and preferences for treatment and care. Although the importance of effective communication is widely recognized, families often experience a lack of appropriate care. This literature review aims to identify, from the perspective of children with an advanced life-limiting illness and their parents, how healthcare providers can communicate effectively.

Methods. A systematic review was conducted. The search was performed in PubMed, Embase and CINAHL. Empirical studies published between January 1, 2016 and January 26, 2024 were included. Thematic analysis was performed to identify experiences of (non)verbal communication, including descriptions of attitude, behavior or communication interventions.

Results. 54 publications were included giving the child's or parents' experiences and views on diagnostic and prognostic communication, Advance Care Planning communication, end-of-life communication and palliative care communication in general. Key elements of effective communication include feeling well-informed, feeling empowered, experiencing collaboration and feeling that the healthcare provider is committed to the care, is establishing a sustainable connection with child and family, provides care aligned to family values and maintains hope and optimism.

Conclusions. In most studies, children and parents emphasize the importance of a person-centered communicative approach by healthcare professionals in which the child and family are seen as human beings and the family's environment and resilience are seen and respected. Future research should focus on developing and implementing specific interventions focused on effective communication that health care providers can apply in various contexts to promote high-quality pediatric palliative care.

Introducing a Community Model of Palliative Care for Children: Family Feedback

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Background: Palliative care for children with life-limiting conditions is best provided close to, or in the family home. As a national children's hospice service with one hospice located in Dublin, Ireland, we set a goal to expand and extend our community of care and established a regional community service to provide targeted support to families in southern Ireland. As the child and their family are the primary stakeholder for this service development, a family feedback form was designed to obtain valuable feedback from families after targeted visits were complete.

Aims: To obtain information from families on the quality of the services being provided by the team.
To establish how families would like to see the service grow in the future.

Methods: Literature was reviewed to identify what was important to families when receiving palliative care in community setting and a Family Feedback form (Boyden et al. 2021) was designed. Following review by internal stakeholders including the medical and nursing teams, and quality, risk and safety, it was shared with the family engagement committee for feedback from parents. Once all comments had been reviewed and amendments made, it was presented at the Clinical Effective Committee as a Service Development project with standard operations procedure (SOP) on implementing the project.

Outcomes: From December 2022 to December 2023- 80 feedback forms have been sent with a 62% response rate. 100% of families have found the service to be beneficial and would recommend it to other families within the service. Other feedback in relation to benefits and responsiveness of service, additional services required, and quality of care have been obtained.

The Volunteer Role in Pediatric Palliative Care

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Background: Volunteers must be considered members of the Pediatric Palliative Care (PCC) team. This means specific and continuous training of both volunteers and professionals, to lead to integration.
Aim: To understand key elements for the PPC volunteer's role.
Methods: In a PPC Italian organization, 8 volunteers, coming from adults, were selected and trained for entry into paediatric hospice, supervised by the educator and the volunteer coordinator. Periodic meetings were organized between coordinators to monitor the project. This led to a more focused selection of new volunteers and to a specific training program: multiple motivational interviews;21 hours classroom course; six months tutoring; monthly psychologist supervision group.
Results: After three years' experience, with 35 selected volunteers, continuous exchange with people involved, focusing on family and minor needs, it is possible to define some key elements for the PPC volunteer's role. They can give relief during long stays in hospice; deal with siblings; have relationship with parents and other family members;carry on activities with minors;accompany to specialist visits;play activities;transport from home to hospice/hospital.
Conclusions: Three years' experience (home, day hospice, hospice) suggests that it is necessary to investigate their motivation and aptitudes, the ability to listen to other people and to work in a group. The volunteer must commit himself personally and be able at the same time to develop a high level of adaptation to different needs: understanding the situation, proposing different activities, connected to ages, physical and cognitive conditions. The volunteer must always respect the relationship, the culture, and the way of living of the family unit, and align with the clinical team programme. The participation in team meetings is fundamental for real integration with professionals, to develop a common language, to understand patient and family needs, and to share common purposes.

The Impact of Parent Involvement on a Cohort Study of Home-Blended Diets in Gastrostomy Fed Children

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Background and aim: There are growing numbers of children living in England who require long term feeding through gastrostomy. Recommendations in England are that formula feeds should be used when children are fed by gastrostomy, but there are growing numbers of parents who are choosing to feed their children a diet of home-blended foods. There is currently a lack of research evidence on the symptoms or safety of this approach in comparison with formula feeds. We wanted to explore this, through ensuring the views and experiences of parents of gastrostomy-fed children were central to this study, resulting in findings having a greater impact on parents' lives and the lives of their children.
Methods: We worked with PPI-partners from grant application stage through to dissemination. Involvement extended across considerations around research design, development, iteration of participant facing documents, study management, interpretation of the data, and writing and dissemination of study findings.
Results: Parent involvement has been woven throughout all stages of the research cycle. The parent advisory panel came up with the study title. They piloted study materials, processes, and data collection tools. They advised on blended diet recipes, enabling the study team to visualise typical recipes for food diaries. They ensured appropriateness and accessibility of a training video for collecting anthropometric data. Throughout the study they provided input on strategies for improving participant engagement and retention, from how best to approach new families, to the most appropriate way to send reminders to complete study questionnaires.
Conclusions: The active involvement of Parent Involvement has been vital at all stages. Through this, the research is more impactful. We have shown that Parent Involvement can be conducted in a meaningful and reflective way with this population, whilst remaining sensitive and flexible to family's ever changing and unpredictable lives.

Parents Long-Term Retention of the Family Talk Intervention in Pediatric Oncology

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Background and aims: The psychosocial needs of families with severely ill children are extensive. Despite this, there are few family-based psychosocial interventions that target all family member's needs that have been scientifically evaluated. Even fewer have been evaluated in a long-term perspective. This study describe parents' retention after having participated in a psychosocial family-based intervention, the Family Talk Intervention (FTI), 4-5 years earlier in pediatric oncology.

Methods: This interview study was conducted during spring 2023 and included 30 parents from 18 families (16 mothers and 14 fathers) who participated in FTI 4-5 earlier. FTI consists of 6-11 manual-based meetings, often led by an FTI-educated social worker. The main goals of FTI are to facilitate family communication about illness-related topics, support parenting, and making the children's needs visible. Data were analyzed with content analysis.

Results: Parents learned strategies during FTI some of which they still use 4 to 5 years later, i.e., strategies that help them to continue to share their thoughts and emotions and to keep an open communication within the family. Parents perceive this helps to reduce stress in the family. Strategies also helped them to put the spotlight on the children in the family, and to increase the democracy in the family. Their participation in FTI was a springboard and contributed to a willingness regarding participation in new contexts outside the hospital with other bereaved parents where the most difficult feelings and emotions can be shared.

Conclusions: From the Family Talk intervention parents of children with cancer, express they learned strategies that persists the long-term. These strategies have helped them to keep an open communication in their daily family life and to put the spotlight on the children. It seems that what parents learnt in FTI increased their resilience when facing adverse life events long-term.

Specialized Palliative Home Care for Children Decreases Hospital Care Needs - a Pilot Study

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Background: Southern Sweden has specialized palliative home care (SPHC) for patients of all ages, but for children with cancer the service is under-utilized. The aim of this study was to map the specialized palliative care (SPC) needs and availability to SPHC in pediatric cancer patients. We present data from a pilot cohort.

Methods:

A retrospective chart review was performed on all children aged 0-20 dying during 1 Sep 2022 - 31 Aug 2023 (n=83). Cancer patients were further analyzed. We collected data on age, family situation, diagnosis, symptoms, utilization of emergency-, inpatient- and specialized palliative care, place of death etc.

Results: Eight cancer patients (n girls 6) aged between 4 and 20 years (median 14 yrs) were included in the pilot. Diagnoses were: brain tumor (n=2), lymphoma (n=1), sarcoma (n=2), leukemia (n=1), neuroblastoma (n=1) and cancer of unknown primary (n=1). Survival time from diagnosis to death was in median 19 months (range 0-149 months). Five patients (62.5%) received SPC at some timepoint, but only three patients (37.5%) were fully enrolled to a 24/7-SPHC service. Notable for the SPHC-patients were that after SPC enrollment they utilized neither emergency care nor inpatient hospital care, but were taken care of in a home-based palliative care setting. Two patients died at home while one was transferred from home to a SPC unit for end-of-life care. A serious illness conversation including decision to terminate oncologic treatment and to initiate palliative care was held in all cases. However, median timepoint from conversation to death was 79 days for SPHC-patients vs. 16 days for patients that stayed in oncologic care until death.

Conclusions: The pilot study indicates that full SPC homecare enrollment decreases the need for inpatient hospital care and facilitates earlier serious illness conversations and also the possibility of dying at home. We aim to expand the cohort to a 10-year cohort.

Nurse Parental Support Using a Mobile App in Symptom Management for Children with Medical Complexity

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Background: Children with medical complexity (CMC) experience one or more physical and psychological symptoms simultaneously that seriously affect their QoL. Literature suggested that increasing parental self-efficacy in managing child's symptoms could improve child's health. Home-based nursing services for CMC and parent are available in Hong Kong, but the service faces challenges because of serious nursing workforce shortage. Nurse parental support using a mobile App in symptom management is another method considered more accessible and nurse-parent interactivity to continue home-based support. The study aims at testing the effects of this mobile App in enhancing parental self-efficacy in symptom management and reducing CMC's symptom burden, and health service use.

Methods: A single-blinded randomized controlled trial with two-armed repeated measures were conducted to evaluate the effects between intervention and control groups by comparing study group receiving the mobile App with nurse support, and the control group receiving usual community care. 74 parents were recruited and 40 parents (20:20) were completed the intervention. Outcome including parental self-efficacy, symptom burden, and health services use were evaluated at pre-post-intervention, and 3-month after intervention. The intention-to-treat principle and a generalized estimating equation were used to analyze data.

Results: Positive preliminary result in parental self-efficacy were observed within the intervention group over time ($P = 0.005$). The intervention could decrease CMC's Accident and Emergency visits.

Conclusion: Positive outcomes support nurse parental support using a mobile App is a feasible delivery mode in symptom management for the CMC and their parents. The evidences of this study contribute to the development of other symptom management programs for other pediatric patient groups.

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Babywearing as a Child Care Tool in Pediatric Palliative Care

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Background and aims: In the Neonatal Intensive Care Unit (NICU) most of the human interactions experienced by hospitalized newborns are represented by clinical and care procedures. The clinical complexity of some conditions and the need to protect the newborn from stress-generating events lead to a reduction in the possibility for parents to create a bond with the child. The complexities just described are typical of children eligible for pediatric palliative care (PPC). The benefits of Babywearing (BW) in terms of clinical and relational stability for children have been widely reported. The aim of this study is to analyze the possibility of using BW and the related benefits for patients in PPC.
Methods: A narrative review of the literature was conducted to identify inclusion and exclusion criteria for a BW program. Data from electronic medical records of 65 patients admitted in a italian pediatric hospice (PH) over a 20-month period were analyzed.
Results: The sample was made up of newborns and minors weighing less than 10 kg at admission in PH and 25 patients met the inclusion criteria. All the children had complex care needs but none of these represented an absolute contraindication to BW as reported in the literature. 27% (n=3) of children had a tracheostomy tube; 37% (n=4) had Percutaneous Endoscopic Gastrostomy; 36% (n=4) had a venous catheter; 36% (n=4) had neuromotor deficits.
Conclusions: From the data collected and the analysis of the literature it can be seen that all the children in our sample have no absolute contraindications to the practice of BW. BW in the context of PCC is feasible and can benefit the child and family by promoting contact and relationship between parent and child, above all for children with severe illnesses, facilitating breastfeeding and developing caregiver skills. Finally, the promotion of ergonomic supports ensures the safe transport of the child and the BW is configured as a valid tool to be included in the CPP path.

Lived Experience of Parents of a Child in Palliative Care: A Phenomenological Study

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Background-aims: In Italy, it is estimated that between 20540 and 32864 patients are eligible to pediatric palliative care (Benini, 2022). Parents looking after children in pediatric palliative care (PPC) have a unique role as advocates, protectors and experts in their child's condition (Hain and Goldman, 2021). They are at risk of a lower quality of life and higher stress levels, compared to parents of children not in PPC (Collins et al. 2020; Feudtner et al. 2021). The aim of our research was to explore the lived experience of parents of children admitted to a pediatric hospice in Italy.

Methods: A phenomenological study was conducted. Purposive sampling was used to recruit participants who had direct experience of the phenomenon under investigation. Data was collected through semi-structured interviews conducted between September 26, 2022 and February 10, 2023.

Results: Twelve completed interviews were included in the study. Two main themes reflected the experiences and stressors faced by mothers of children in PPC: 1. Motherhood in PPC (description of the processes and constructs within which mothers searched and found meaning, within their experience of becoming a parent to a child in PPC); 2. Discovering and managing the condition (e.g., all participants described being or having been in a long and arduous search for a diagnosis, symptom treatments and management).

Conclusions: This is the first study providing a voice to mothers of children accessing PPC in an Italian hospice. The phenomenological methodology allowed participants to express their thoughts, feelings, and attitudes, building a framework of their parental role experiences, especially those leading to stress. By emphasizing their everyday challenges, we hope to improve the holistic care and support that these and many more families will receive.

Supporting a Multidisciplinary Approach to Promote Safe Sleep at a Childrens' Hospice

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In August 2023 the MHRA issued a safety critical National Patient Safety Alert after reports of deaths and serious injuries from entrapment and falls relating to medical beds , bed rails and other equipment. This alert had 7 actions that needed to be completed to by the 1st March 2024. All care providers throughout the UK were required to respond to this.
At our hospice a coordinated approach and strategy in response to this was steered by the Physical Therapies Lead and Head of Nursing and Therapies. Each of the actions were responded to and consideration was given to the beds we offered to both service users, siblings and families sleeping at our hospice. Equipment with bed sides were risk assessed, safer systems of work and training needs were considered. Risk assessment were developed and care plan templates reviewed. Relevant stakeholders were involved in the response including Occupational Therapists, facilities , education , learning and the SystmOne manager. In addition there was liaison with other childrens' hospices facilitated through an already established physical therapies network. Information was shared with families. Policies and procedures were developed .These also considered other factors to promote safer sleep - this included responding to guidance produced around the use of weighted blankets for children and evidence produced by the Lullaby Trust to support safer sleep for babies.
An equipment replacement programme has been identified and all of our standard care beds now meet the safety standards for children. Training has been rolled out including an on-line module linked to our learn platform to capture compliance. Risk assessments have been introduced alongside updated care plans. Multi-professional meetings and board rounds incorporate discussion around safe sleep. Evaluation of practice is ongoing and audits are scheduled.
Safe sleep is high on the agenda at our hospice and continues to be reviewed and developed to support safer care.

Understanding Family Caregivers' Experience with Medically Complex Children at Home

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Background and aims: Family caregivers of children with medical complexity face challenges throughout their journey due to the uncertainty of the illness trajectory and the difficulties in providing medical care at home. This study aims to investigate the caregiving experience and identify the factors that impact caregivers' quality of life, including emotional and physical health.

Methods: This descriptive, cross-sectional study is a survey conducted with the main caregivers of children who use one or more medical devices at home. Along with the patients' and caregivers' demographics, the study investigated scores on the Preparedness for Caregiving Scale (PCS), Competency Scale (CCS), Reward Scale (RCS), Patient Health Questionnaire-9 (PHQ-9), EuroQol-5 Dimensions (EQ-5D) Scale, and Carer-QOL Scale.

Results: A total of 63 caregivers responded to the survey, of whom 93.7% were female and 95.2% were parents. The children of these caregivers needed an average of 4.7 medical supports, and the caregivers had been providing care for an average of 5.7 years. 49.2% reported experiencing moderate or higher levels of stress in their daily lives, with major stress factors being family health issues (52.4%) and financial problems (22.2%). Caregivers with longer caregiving durations tended to have higher scores on the PCS ($p=0.007$, $r=0.338$), CCS ($p=0.018$, $r=0.296$), and RCS ($p=0.015$, $r=0.305$). Additionally, higher PCS scores were associated with higher CCS ($p<.001$, $r=0.781$), RCS ($p<.001$, $r=0.043$), and EQ-5D ($p<0.003$, $r=0.372$), Carer-QOL ($p<.001$, $r=0.580$) scores, and lower PHQ-9 scores ($p=0.002$, $r=-0.388$).

Conclusions: Helping caregivers to be well-prepared has a positive impact on their competence and sense of reward, which in turn affects their quality of life. It is crucial to understand the current status of family caregivers of children with medical complexity and to provide systematic support for them.

Two Entirely Different Stories. (From the Communication "Off Stage".)

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Paediatric palliative care seems to be well established and respected today, and its importance is widely recognised - the fact that it isn't more widely available is usually attributed to a lack of money and inappropriate health care systems.

Death and dying are no longer taboo subjects, and dying children are increasingly featured in the media, often used for advertising purposes.

In our review of publications on palliative care for children, identifying the needs of both the sick child and their families emerges as one of the key issues.

But how do we know what these needs really are? And how valid are the answers we get?

As part of our doctoral research, we carried out in-depth analyses of the hospital and illness-related experiences of thirty families of seriously ill children with whom we have had very personal contact since 1988 (initially as volunteers, later as representatives of a supporting charity running a children's respite hospice).

The truly open and intimate sharing of feelings, needs and experiences is often influenced by many factors that may distort the information we receive - very much in the spirit of Erving Goffman's classic work "The Presentation of Self in Everyday Life".

Contact with the care team is always - to some extent - a 'performance' on the part of the family: a performance shaped by what the parents think is expected of them and what they think is in the best interests of the child.

When we have the opportunity to talk to families 'off-stage', figuratively speaking, we often hear things that are quite different from what the parents have presented to medical professionals or members of the palliative care team. The difference is quite substantial - it's not just in tone, vocabulary or scope: it often shows a completely different perspective from which the family's whole life story is presented.

In our presentation, we would like to use practical examples to show what lessons can be learnt from this discovery.

Utilizing Virtual Reality to Alleviate Anxiety in Severely Ill Pediatric Patients

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The poster presents a study using virtual reality (VR) to mitigate psychological symptoms in severely ill pediatric patients. Reflecting modern technology trends and non-pharmacological symptom management, this research aligns with evidence-based pediatric practices. Children with life-threatening conditions, such as cancer or organ failure, often face stressful procedures and prolonged hospitalizations, leading to high anxiety. Research suggests VR can reduce stress and anxiety by diverting attention, allowing relaxation, and immersing patients in a calm virtual environment.

The study evaluates two VR interventions - experiential and relaxation techniques- and compares their effectiveness in alleviating anxiety in children with severe diagnoses. Designed as a randomized controlled trial (RCT), this research builds on positive results of our previous feasibility and RCT studies with experiential VR (manuscript in preparation), expanding to include relaxation with biofeedback.

Structured as an RCT with a between-subjects design, participants (N=30; children aged 8 -17) are randomly assigned to one of two experimental groups: 1) experiential VR followed by relaxation VR; 2) relaxation VR followed by experiential VR. Each participant experiences both types of VR interventions in the sequence determined by random assignment. The procedure involves questionnaires and scales in the presence of a psychologist or researcher before and after each intervention. Measured constructs include anxiety, fear, pain, immersion, distraction, system usability, intervention acceptability, and cybersickness.

This poster summarizes our previous findings and details the study's methodology, highlighting the design, randomization process, intervention protocols, and assessment tools used to measure psychological symptoms and other relevant constructs.

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Strategies to Alleviate Pain Undergoing Needle Procedures at a Pediatric Oncology Hospital

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Introduction: Pain management remains a critical challenge in pediatric hospital settings, especially during procedures such as venous punctures, which often cause pain, fear, and distress in patients and their families. In pediatric oncology hospitals, where treatments are intensive, strategies to alleviate pain are crucial for improving the quality of life of children and adolescents. Despite the availability of scientific evidence and tools to address needle-associated pain, there is a significant gap between the knowledge of these tools and their application in clinical practice. This study describes a quality improvement project implemented in our hospital.

Objectives: The main objective of this study was to implement comfort measures during needle procedures, aiming to reduce pain and improve the experience of patients and their families."

Method: Data were collected through direct observation of procedures and entered into an online quality management platform. Surveys were conducted with families and healthcare teams to assess the effectiveness of comfort measures during procedures.

Results: Between August 2023 to March 2024, 435 venous puncture procedures were evaluated in pediatric patients, with an average patient age of 6 years. The majority of healthcare professionals (95.24%) reported satisfaction with the procedures. While 68.64% of patients experienced pain during the procedures, parents and patients reported that the healthcare team addressed the pain adequately. The use of comfort measures, such as topical lidocaine, age-appropriate distraction methods, comfortable positioning, breastfeeding, and the use of sucrose when appropriate, contributed to reducing pain and distress during procedures.

Conclusion: Incorporating comfort measures into daily clinical practice can lead to sustainable changes and significant improvements in patient experience.

Barriers and Facilitators to Paediatric Palliative Care Referral: A Scoping Review of the Evidence

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Background and aims: Although palliative care (PC) is an essential component of children's health services, it is accessed by far fewer children than could potentially benefit. This study aimed to appraise the evidence to identify factors influencing referral and access to children's PC, and interventions to reduce barriers and improve referrals.

Methods: The review followed the six stages of the Arksey and O'Malley scoping review methodological framework, and incorporated recommendations by Levac et al. CINAHL, MEDLINE, PsycINFO, EMBASE, and Cochrane Library were searched for primary studies of any design, and literature/systematic reviews. Studies reporting barriers/facilitators and/or interventions in relation to referral of children with a life-limiting condition to PC, in any setting, were included.

Results: 195 articles were retained (153 reporting barriers/facilitators; 40 interventions; 2 both). Multiple factors were identified as barriers and facilitators: Individual level: child demographics, parental attitudes, treatment expectations, staff understanding/beliefs; Interpersonal level: family support, patient-provider relationships, interdisciplinary communication; Organisational level: referral protocols, workforce, leadership; Community level: cultural norms, community resources, geography; Society level: policies and legislation, national education, economic environment, medication availability. Most of these factors were bi-directional in terms of influence. Interventions (n=42) were mainly at the organisational level e.g., educational programs, screening tools/guidelines, workplace champions and new/enhanced services; one-third of these were evaluated.

Conclusions: Barriers/facilitators to paediatric PC referral are well described. Interventions are less well described and often unevaluated. Multi-modal approaches incorporating stakeholders from all levels of the socio-ecological framework are required to improve paediatric PC referral and access.

Parental Prespective of Children with Life-Limiting Conditions Availaing of a Respite Stay

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Purpose: The aim of this qualitative evidence synthesis (QES) is to identify and synthesise the available qualitative literature on the experiences of parents of children with life-limiting conditions, with palliative care needs, availing of respite services, internationally.

Method: A systematic search strategy was developed, and a rigorous search of the literature was undertaken through five databases. Grey literature was identified through Lenus and forward and backward citation tracking was also performed. The screening software Rayyan was used to enable blind screening for eligible studies. Quality appraisal was carried out using the CASP framework and confidence in the findings of the synthesis was assessed by applying the GRADE-CERQual tool.

Results: Ten studies (eight qualitative studies and two mixed-method studies) were utilised for this QES. Three key themes emerged through the process of thematic synthesis- Initial perceptions of Parents about Out-of-home respite, The Impact of Out-of-home Respite on Family and Improving Respite: Parental suggestions for Enhanced Child and Family Experiences. Sub-themes included: The stigma associated with the word 'Hospice', Parental Decisions regarding utilisation of respite. Positive Impact on Families, Navigating Worries: Unveiling Parental Concerns in Respite Journeys, access of Respite services and Enhancing Operational Efficiency and User Experience of Respite services.

Conclusion: This QES highlighted key themes in experiences of parents of children with life-limiting conditions, with palliative care needs availing of respite stays. Parents grappled with stigmas associated with hospices, making decisions on utilisation of out-of-home respite services, while respite positively affects family dynamics. Parental recommendations involved enhancing respite provision by addressing accessibility challenges, refining operational efficiency, and fostering open communication.

Forgotten Classics. Early Elisabeth Kübler Ross Unread, Misinterpreted and Misunderstood

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A few years ago, while attending a large conference of child life specialists in the USA, we attended a seminar on dying children. Two young psychologists running the seminar made a brief and cursory mention of Elisabeth Kübler Ross (EKR) and her seminal book On Death and Dying, which in the late 1960s had focused the attention of doctors, nurses and other helping professionals on their dying patients and their needs and feelings. In their presentation, however, the two ladies described Dr Ross's work - and they did use the word - as "crap". To them it was just an outdated theory from the past, irrelevant to our modern times. The lecturers however, as the following discussion later revealed, didn't really read the books. What they waved away as irrelevant has been very dear and helpful to us for many years: and even if Dr Ross's later professional career might be considered somewhat controversial, her early books were truly eye-opening, frank, characterised by deep insight and surprising foresight. And our knowledge of the books was really intimate as we translated them to Czech.

If we are to discuss the roots and horizons of paediatric palliative care, it's clear that we really need to know the past - otherwise the past cannot properly shape our present and future.

Our intention is to show how important it is to know the roots and show on practical examples how many "present" problems are wisely dealt with in the classic books of the EKR: be it communication about the diagnosis of a serious illness, end-of-life care or euthanasia. "On Death and Dying and Questions and Answers on Death and Dying, two books published almost sixty years ago, can still be of great help to anyone caring for a dying patient today: we just need to read them carefully and reflect and elaborate on them personally - without expecting explicit and ready-made instructions. And we also might learn not to keep asking questions that have already been answered.

Factors Associated with Paediatric Palliative Screening Scale (PaPaS) Scores: A Retrospective Study

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Background and Aims: The Paediatric Palliative Screening Scale (PaPaS) is an effective tool for ensuring timely referrals to pediatric palliative care (PPC). This study assesses the effectiveness of PaPaS in clinical practice by examining its relationship with clinical outcomes and identifying factors associated with PaPaS scores.

Methods: This retrospective study included 137 PPC patients at a tertiary care hospital in South Korea from January to December 2022. Demographics, clinical characteristics (including the presence of pain, Lansky/Karnofsky performance scores, primary diagnosis, and death status), PaPaS scores, and other measures of health-related quality of life were gathered from medical records and the PPC registry database.

Results: The median age at referral was 5.7 years, with 57.7% of patients being male. Primary diagnoses included cancer (35.8%) and non-cancerous conditions (64.2%), with neurological diseases being the most common (24.8%). At referral, 45.2% of patients presented with pain. Of the 137 patients, 21.9% died within a year, with a median survival of 173.5 days. Multiple regression models revealed highly significant associations between PaPaS scores and pain ($p<.001$). Lansky/Karnofsky performance scores under 40 ($p=0.021$) were also associated with higher PaPaS scores. Additionally, there was a correlation with the likelihood of death within one year ($p=0.021$). No significant issues of multicollinearity were detected in this study.

Conclusions: Patients with pain, performance status scores below 40, and a higher likelihood of death within one year had higher PaPaS scores, indicating that severe symptoms and conditions might affect the scores. PaPaS is useful in PPC settings for understanding and predicting patient condition severity and planning appropriate care at the time of referral. Further studies are needed to validate these findings and explore the score's utility, and association with clinical outcomes and caregiver support.

Diffuse Intrinsic Pontine Glioma: When Is Timing to Palliative Care

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Introduction: Diffuse intrinsic pontine glioma (DIPG) is a rare malignancy of the brainstem and the leading cause of brain tumor-related death in children. It mainly affects children with a median age of 6-7 years old, with a median overall survival (OS) of 11 months. Currently, they are treated only with focal radiotherapy or in combination with antitumor agents. Our focus is to provide an overview of patients with DIPG over the last 13 years in a specialized Pediatric Oncology service emphasizing the importance of early integration of pediatric palliative care to improve quality of care.

Methods: Data collection was carried out according to the electronic medical records of all patients with DIPG admitted from 2010 to 2023 at a Pediatric Oncology Hospital, based in São Paulo - Brazil.

Results: From 2010 to 2023, 55 patients with DIPG were admitted,. The average age of patients at diagnosis was 6 years old.

All patients underwent radiotherapy as first-line treatment and had a mean recurrence of 8.5 months post-irradiation. Only 21 patients underwent re-irradiation. All patients experienced a decline in abilities, including walking, swallowing, and effective communication. Optimal care should involve a specialized team.

In our service, all patients were referred to Palliative Care, with an average referral time of 2 months and 26 days from diagnosis. Regarding the place of death, only 3 patients passed away at home, while all others were in a hospital environment.

Our survival was 12.8 months, and this time must be of quality for children and families and the early integration of palliative care is essential.

Feasibility of Implementing International Pediatric Palliative Care Standards in the Czech Republic

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The 2022 Global Overview - PPC Standards (GO PPaCS) represent consensus recommendations for the provision of pediatric palliative care (PPC) in children with life-limiting illness. In post-communist countries, features of paternalistic medicine persist to a greater degree in comparison to Western European and North American countries, potentially impacting their ability to implement standards, like those focused on autonomy and specific culture issues. The aim of this study was to determine the extent to which clinicians in the Czech Republic support GO PPaCS and to identify recommendations that may be challenging to implement.

An online survey was conducted among pediatric professionals between August 2023 and February 2024. Respondents were recruited via the National Pediatric Society website. The survey included questions about the feasibility of implementation of each of the 99 published standards. A standard was rated as difficult to implement if more than 20% of respondents reported “low feasibility” or “not at all feasible”.

A total of 100 respondents participated, mostly pediatricians (62%) and pediatric nurses (28%). The standards were rated as generally implementable. Nine of the 99 standards (9%) were identified as difficult to implement: regular assessment of patient´s needs, ensuring the availability of a multidisciplinary team 24/7, supporting parents in their social role, availability of respite services, integration and availability in humanitarian crisis, availability in the ER, ensuring continuity and providing psychological support for bereaved family members.

Assessing the feasibility of implementation of standards is the first step to ensuring high quality PPC for patients and families. Despite cultural differences in the Czech Republic, few standards are believed to be difficult to implement. Further research is needed to assess barriers to implementing the standards and how to overcome them.

Experiences of Music Therapy in Paediatric Palliative Care

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Background and aims: Children and young people with life-limiting conditions and their families need physical and emotional support to manage the challenges of their lives. There is a lack of synthesised qualitative research about how music therapy is experienced by children, young people and their families supported by paediatric palliative care services.

Methods: This paper presents the Systematic Review and Qualitative Evidence Synthesis undertaken on experiences of music therapy in paediatric palliative care from stakeholder perspectives. A Qualitative Evidence Synthesis was conducted using Thematic Synthesis. Qualitative or mixed methods studies (if qualitative data was reported separately and could be clearly extracted) reporting the experiences of children aged 0-18 years, parents, music therapists and professionals who had experience of music therapy in specialist children's palliative care settings were included. Patient and Public Involvement was embedded throughout.

Results; 5 studies met the eligibility criteria reporting the experiences of 14 mothers, 24 family members and 4 staff members in paediatric palliative care. There were five overarching themes: emotional and physical reprieve, opportunity for normalised experiences, thriving despite life limited condition, enhance family wellbeing and therapeutic relationship central to outcomes.

Conclusion: Music therapy provides unique benefits for this paediatric population particularly in supporting child and family wellbeing. The therapeutic relationship, interpersonal skills of the therapist and experience in paediatric palliative care are perceived as central to these positive outcomes. Further high-quality research is required to develop an understanding of child and family experiences of music therapy in this setting. Limitations included that only five papers met the inclusion criteria and represented the experiences of only 18 individuals and 24 families from three different geographical areas.

Parents’ Experiences of a Novel Disease-Modifying Therapy for Spinal Muscular Atrophy in Sweden

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Background and Aim: Currently, only a handful of studies have investigated caregivers’ views on disease-modifying therapies for SMA. There is a paucity of information on parents’ sources of information and families’ experiences of these treatments, in particular over time. To help bridge these evidence gaps, the objective of this longitudinal study was to explore parents’ perspectives and experiences of a novel disease-modifying therapy for SMA in Sweden.

Methods: Patients with SMA and their parents/legal guardians were identified in the National Patient Register and the Multi-Generation Register, respectively. Data on the parental perceptions of the decision to initiate treatment with nusinersen, sources of information, experiences with nusinersen, and thoughts about the future were recorded using an electronic questionnaire administered at study entry/baseline, and after 6, 12, and 18 months.

Results: In total, 47 parents to 33 children with SMA (30% with type I, 30% with type II, and 40% with SMA III) participated. All parents reported that they wished their child to be treated with nusinersen and that they were in agreement about this decision with the other parent/legal guardian. Most parents (81%) reported that they had sufficient information to make an informed decision about the treatment. Inadequate information was noted concerning the short- and long-term treatment effect, as well as side-effects. Across follow-up, almost all parents reported having a positive experience of nusinersen, with very few (<7%) ever considering terminating the therapy.

Conclusions: Our study provides unique insights into caregivers’ real-world experiences of a novel disease-modifying therapy for SMA. The findings should be helpful to inform approaches for interactions with families to children with SMA at the timing of diagnosis and therapy initiation, as well as the development of information material about the disease, available therapies, and expected outcomes.

Training and Implementation of Palliative Care Representatives at Astrid Lindgren Childrens Hospital

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Background: Astrid Lindgren Children’s Hospital (ALCH) provides care for children with life-threatening and life-limiting medical conditions. Some of these children require palliative care. Identifying those in need is crucial to ensure they receive appropriate palliative interventions from the perinatal period through adolescence.

Purpose: The goal is to meet the palliative care needs of children at ALCH.

Method and Approach: A work group within ALCHC´s palliative network has developed a multidisciplinary pediatric palliative care training program, previously available only in elderly care. This includes a detailed job description to address children´s palliative care needs. Representatives focus on early identification and integration of palliative care, ensuring children with such needs have updated care plans.

Result: The multidisciplinary palliative care training covers key areas such as symptom relief, communication and relationships, family support and teamwork. It includes care programs, local guidelines, and educational films on pediatric palliative care. In spring 2023, 25 staff members from various professions, including pediatric nurses, general nurses, doctors, and hospital clowns, were trained as palliative care representatives.

Conclusion: To meet the palliative care needs of children at ALCH, a comprehensive, hospital-wide multidisciplinary training program for pediatric palliative care representatives was established and implemented in spring 2023.

From Hospital to Home: Implementation of a Hospital Discharge Checklist

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Background: given the fragile conditions of children eligible for paediatric palliative care (PPC), hospital admission may be necessary due to different reasons (complex symptom management, acute process, respite, etc.). The medical complexity of children often makes them dependent on many drugs and complex medical equipment and devices. To ensure the safety of the child hospitalized at home and that all the care needs are met, hospital discharge must be done in a comprehensive manner, involving the family and the entire interdisciplinary team. Checklists has been already used in other healthcare settings and are recommended by the WHO. Therefore, the aim of this project is to implement the use of a hospital discharge checklist in PPC to improve continuity and quality of care in the transition from hospital to home, as well as safety.

Methods: a hospital discharge checklist in PPC was designed in May 2024. The following items were included in the checklist: Need 1 - Breathe normally: to ensure that the home is properly equipped not only for a routine respiratory care but also for an emergency respiratory care; Need 2:Eat and drink adequately: to ensure that family has all the necessary material equipment to feed the child and spare devices to use in case of dislodgment; Need 3:Elimination of body waste; Need 8:Keep the body clean and well-groomed and protect the integument, if there is any alteration of skin integrity;Other:medication, healthcare education and continuity of Care Nurse.

Results: following the review and considering the potential benefits this hospital discharge checklist in PPC, it is intended to be implemented for all patients admitted to the paediatric palliative care ward to improve the transition from hospital to home.

Conclusions: checklist offer several significant advantages: the reduction of human errors, the standardization of processes by establishing a clear a and unique criteria and the reduction of the variability of care.

Pyridostigmine and Neostigmine for Intestinal Dysmotility in Pediatric Palliative Care: Case Series

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Background and aims: Pyridostigmine and neostigmine have shown promise as safe and well-tolerated treatments for severe pediatric intestinal dysmotility (ID), a frequent and debilitating issue in children with life-limiting and life-threatening conditions. However, specific literature is limited, with most studies focusing on adults and pediatric data primarily derived from case reports. This study aims to describe the use of pyridostigmine and neostigmine in children with ID refractory to standard treatment, assisted by a pediatric palliative care team in Northern Italy.

Methods: A retrospective analysis of children with ID treated with pyridostigmine or neostigmine was conducted. Data collected included demographics, clinical information, therapeutic history and outcomes.

Results: The sample included 7 children (5 males, 2 females) aged 2.6-21.6 years. Conditions included neurological disorders, prematurity complications and genetic disorders. Symptoms included intractable constipation, retching, abdominal distension, and pain, refractory to standard treatments, leading to feeding intolerance. All patients were tube-fed and received enteral pyridostigmine; 1 patient switched from neostigmine due to discomfort from subcutaneous administration. Pyridostigmine was administered for an average of 14.2 months (range 1.5-36 months) at 0.54-2 mg/kg/day. 5 patients are currently in therapy with symptoms resolution and improved quality of life; 1 discontinued due to worsening abdominal pain; 1 died due to the underlying disorder. No major adverse effects were reported.

Conclusions: This study supports pyridostigmine as a safe, effective, enterally administered treatment for severe pediatric ID. Dosages used align with previous studies. Despite a small sample size, this represents the largest single-center case series. Further research is needed to fully understand the role of pyridostigmine and to establish guidelines for managing intestinal motility disorders in children.

Palliative Consultations Tailored Specifically to the Unique Needs of Children with Serious Illness

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Initial palliative consultation is a key moment for the patient, family, and pediatric palliative care (PPC) team to address issues related to the preferences, values, and expectations of the patient and family. The type of approach and topics discussed can have a major impact on seriously ill patients and their families.

PPC provision commenced at our hospital in 2016. By 2021, five approaches to PPC consultations were developed and continue to be used: 1. traditional (e.g. child newly diagnosed with high-risk neuroblastoma), 2. one-time (one contact only to solve a specific problem, e. g. shared decision making regarding next treatment plan), 3. statim (urgent, to be done in 24 hours), 4. terminal (i.e. child in end-of-life care to be discharged with home hospice), and 5. prenatal (pregnant women expecting child with life-limiting illness). Each type of initial consultation represents a specific way of conducting the family meeting depending on the child´s illness status and trajectory. This abstract describes early process outcomes for each type of PPC consultative approach.

Between January 2021 and December 2023, in total 238 initial inpatient PPC consultations were conducted. Most consultations were provided in the PPC team family room. The vast majority were traditional consultations (180, 76%). Most of these referrals were made by oncologists, pediatricians and neurologists. Eleven (4,5%) prenatal, 11 (4,5%) one-time, and 28 (12%) terminal consultations were provided. Only 8 statim consultations (3%) were conducted, usually at the ICU.

While the majority of referrals were traditional, current efforts to reduce the number of late referrals are being made. The five different types of inpatient initial consultation approaches developed by the PPC team provide a unique framework and opportunity for PPC team members to introduce PPC in a way that honors the unique needs of all hospitalized sick children and their families.

Volunteer Team in the Prevention and Relief of Pain in Needle Procedures – Comfort Promise Project

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Introduction: The Comfort Promise Project aims to reduce pain in needle procedures in pediatric hospitals worldwide, including GRAACC (Support Group for Children and Adolescents with Cancer) in Brazil. Supported by St. Jude Children's Research Hospital and the Institute for Healthcare Improvement (IHI), the project employs effective, low-cost measures such as topical anesthesia, proper positioning, distractions, breastfeeding/sucrose for babies, compliments and other types of rewards. Process analyses at GRAACC revealed challenges faced by the healthcare team, leading to the involvement of volunteers as an effective alternative solution.

Certified by a significant Brazilian accreditation seal, the volunteer group partnered with project management through planning and evaluation of action outcomes in weekly meetings with the team.

Objective: To examine how the volunteer team facilitated and ensured the implementation of project stages.

Method: An analytical observational study validated the hypothesis that involvement of the volunteer team enabled the implementation and maintenance of the project in GRAACC's examination room, overcoming numerous barriers.

Results: Indicators reveal that following the training of the volunteer team, their performance in providing age-appropriate distractions led to progressive improvement in outcomes. Figure 1 shows that distraction usage increased from 50% to 80% in procedures where volunteers were participating, enhancing care and reducing pain.

Conclusion: The volunteer team enabled the successful implementation of the Comfort Promise Project at GRAACC, a non-profit institution offering free treatment to 70% of its patients.

"Hero Caravan" Creating Memories, Normality and Playful Relations

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Background: All children and teens will have the need not to be different. Especially kids with serious or life-limiting disability/illness. For parents, play and creativity serve as a way to alleviate the burden of grief/sadness and stress. Witnessing their children smile and laugh can be a source of comfort and hope. Play allows the family to focus on the positive and create valuable memories together.

Context: The “Hero caravan” is an ongoing three-year project that is a collaboration between the Children's Accident Fund and the Child & Youth Palliative Team (CYPT).

The Heroes are play therapists occupied on the hospital. The Heroes offers the families of palliative children, visits to the home or institution, where the family can gather about initiatives that target their wishes.

Aims: To create joy through a creative free space. To help children maintain their ability to cope and their confidence in their own abilities. To invite the participation of parents and siblings to support the experience of normality and counteract the feeling of isolation and offer a way out of the difficult emotions. To support relationships and communication in difficult situations and environments.

Method: Visitation via CYPT. The first visit is arranged via phone contact with the parents of the "Hero Caravan". Monthly evaluation meetings with the CYPT. Construction of a Hero car and purchase of special toys/creative remedies. Possibility of supervision for the Heroes. Visits at home, at an institution or at the hospital.

Result: 20 families have been visited by the “Hero Caravan”. Everyone accepts the offer. Generally three to five visits, some longer courses. It is mostly creative activities and play involving the siblings.

Conclusion: The children recognize and are happy that the Heroes are also at the hospital. Siblings feel seen and involved. It stimulates the family so that they themselves can do more together.Founded by A.P. Moeller Foundation.

The Family Talk Intervention among Families with Palliative Care Needs - Social Workers' Experiences

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Background and aims: Hospital social workers (HSW) have an important role in supporting children and siblings psychosocially when a child has severe illness. However, there is a lack of scientifically evaluated psychosocial interventions focusing on the children and their families. In an effectiveness-implementation study, HSWs were educated in a family-based psychosocial intervention, The Family Talk Intervention (FTI). In this study, focus is on the HSW's experiences of using FTI in clinical practice among families having a child with palliative care needs.

Methods: Interviews were performed with 13 HSWs working in a paediatric hospital care or at a children's hospice in Sweden. The interviews were conducted about 18 months after FTI education and focused on the implementation of FTI. Qualitative content analysis was used.

Results: FTI was described not being revolutionary or a perfect method, however it had changed the work with children. Addressing siblings was described as something new. FTI offered a more structured way of working, giving access to children and making their voices heard. FTI enabled difficult issues to be addressed and it was beneficial to use it in a flexible manner, for example were questions adjusted in relation to the child's age. Establishing a relationship with the children, especially teenagers were a considered a prerequisite for offering FTI, however it was difficult timing the offer of FTI. FTI brought attention to the siblings needs, such as providing time for the sibling or relieving the sibling from responsibility.

Conclusion: FTI offers HSWs a useful and structured psychosocial support method in the work with families having palliative care needs. FTI provides an important contribution to the poor research on family-based psychosocial interventions when a child has a severe illness. FTI has the potential to successfully contribute to the support of these families.

Family Needs and Health Technology in Home-Based Pediatric Palliative Care

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Background and aim: Pediatric palliative care (PPC) concerns optimal quality of life for a child with a life-threatening and/or life-limiting condition and the child's family and should primarily be home-based. Good communication between providers from the services around the child and family is crucial. Health technology is suggested to support home-based PPC, however, knowledge on family needs in health technology supported PPC at home remain scarce. The aim of this study was to explore the needs for health technology when communicating with healthcare personnel in home-based PPC, from the parents` perspective.

Methods: This qualitative study employed an exploratory-descriptive design. Five focus groups with 18 parents of children with a life-threatening and/or life-limiting condition living in Norway were conducted between December 2023 and March 2024. The data were analyzed using reflexive thematic analysis.

Results: Preliminary results indicated that the parents acknowledged the potential of health technology as they wanted more home-based care to minimize the burden on the child and the family. Mostly, parents were positive to use health technology in their child's care, provided it is easy to use and does not add additional burdens. Parents wished for health technology solutions that reduce their administrative and coordination work and enhanced access to healthcare services and providers. The importance of ensuring the child's safety and privacy when using such technology was highlighted.

Conclusion: Parents of children receiving PPC express a need for more home-based care to alleviate the burden on both the child and the family and healthcare system. Key priorities for health technology in home-based PPC include reducing administrative tasks, improving access to health services, and ensuring the child's safety and privacy. Healthcare providers should consider opportunities for health technology solutions when planning care and consultations for the child.

"Parenting Pills": A Project Proposal for Parental Empowerment Promotion

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Background and aims: Spinal muscular atrophy (SMA) is a genetic disease affecting the nervous system and the voluntary muscle movement.

SMA type 1 children present the lowest level of functioning and need constant assistance with daily life activities to achieve greater autonomy, inclusion and opportunities in social and relational dimensions. To date, some pharmacological therapies are available but the impact of assistance on caregivers is still burdensome. Parents became informal caregivers and are constantly involved on health and rehabilitation aspects at the expense of playtime and socialization that are useful to ensure a good Quality of Life (QoL) for all family members. For 30 years SAPRE has been helping parents to build consciousness about their know-how and networks.

Methods: "Parenting Pills" aims to generate network opportunities and increase caregivers awareness and competences in their child development.

The project is designed for families living in the same area with children between 0 and 3 years recently diagnosed with SMA type 1, treated with drug at diagnosis. A dedicated multidisciplinary team of healthcare professionals trains the parents in reading aloud and sharing play with their children, creating a time for discussion among participants. The program provides ten monthly meetings, two hours each. At first and last session QoL scales are submitted to the family unit.

Conclusion: The project encourages the creation of networks inside and outside the family unit stimulating peer-to-peer communication. Families are inspired to activate virtuous practices that can be replicated independently. The project leads a positive impact on self-efficacy and QoL in order to fight against isolation and prejudice due to disability condition, also educating to prevent ableism.

Quality of Sleep in Caregivers of Children Eligible for Pediatric Palliative Care

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Background and aim: Families of children eligible for Pediatric Palliative Care (PPC) have to face a lengthy and high caregiving burden on a daily basis, since they have to manage the numerous and complex needs of these children. These caregivers may then suffer from a significant sleep deprivation, as well as stress and fatigue. The aim of this work is to evaluate the sleep quality of caregivers of children in charge of a PPC service. Consequently, other sample's variables were analysed to correlate them with the caregivers' sleep quality.

Methods: This single-centre descriptive study consisted in the administration of a questionnaire including the "Pittsburgh Sleep Quality Index (PSQI)" rating scale to 29 caregivers of children in charge of a PPC service. Clinical, caregiving, and socio-demographic data about caregivers and children were then collected through computerized medical records.

Results: A total of 20 valid answers were collected. Most of the children (91%; n=18) are characterized by a high level of care complexity and need numerous devices, both for ventilation and enteral feeding, have their vital parameters monitored at night, and likewise are not autonomous in managing their hygiene. Data pointed out that 90% (n=18) of caregivers have significant sleep deprivation, as shown by a PSQI scale score ≥ 5, which indicates the possible impairment of the circadian cycle. When caregivers were asked if they had enough energy to face the day, 52% answered "enough" and for 43% of them the sleep quality was "fairly bad".

Conclusions: Caregivers of PCC-eligible children have severe sleep impairment related to the high daily care burden, which may negatively affect their quality of life and the effectiveness of the care they can provide. Nursing interventions should be focused on limiting this issue by investing more resources in the caregivers' support.

Organ Donation in Home-Based Pediatric Palliative Care, Is It Possible?

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Background and aims: Organ donation in home-based palliative care (HPC) patients presents a unique challenge. Traditional pathways to organ donation, are often not feasible for HPC patients. Recent guidelines have outlined procedures to make organ donation possible in this population.

The aims of this study is to describe the organ donation process in HPC patients and evaluate its impact on families.

Methods: A retrospective multicenter descriptive study was conducted by reviewing the medical records of HPC patients whose families requested organ donation between January 2018 and May 2024.

Results: A total of 22 organ donation requests were identified. Of these, 8 patients were able to proceed with donation. Primary reasons for exclusion were underlying disease (11; 78 %) and family refusal of non-heart-beating donation (2). Among donors, median age was 10 years (range: 15.09). Main underlying disease were neurological and neuromuscular problems (87.5%) . Median duration of HPC follow-up was 3.4 years (IQR 5.55). The most frequent cause of death was acute respiratory failure (87.5%). 6 families expressed a prior preference for hospital death, while 2 preferred home death. 7 patients were admitted to the general ward prior to ICU transfer with a median stay of 5 hours (IQR 504). Causes of loss of consciousness were disease progression in 5 patients and palliative sedation in 3. Median ICU stay was 28 hours (range: 62.1). All parents were able to accompany their children in the ICU. The median time to asystole was 5.5 minutes (IQR: 43). All patients were Maastricht III type controlled non-heart-beating donors. All families evaluated the process positively.

Conclusions: Organ donation in HPC is possible, but not in all cases. Most patients have a long follow-up in HPC. ICU and asystole times can be relatively long, and the accompaniment of HPC team members during these moments is essential. Organ donation is a positive experience for families.

A Training Curriculum to Enable Governance and Operational Arrangements: Education Nurtures Service

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Background: Clinical governance and operational arrangements supporting a model of care for children with life limiting conditions towards the end of life in the community in Ireland were published in 2020. Each child with end of life needs has an identified core team of healthcare providers. The team consists of a named paediatrician in the hospital closest to their home, the local specialist palliative care (SPC) team (services developed originally for adults), GP and aligned Clinical Nurse Coordinator. The core team is supported by children's palliative care specialists nationally.

In 2023 a new (adult) palliative medicine higher specialist training (HST) programme curriculum was launched. During its development, particular consideration was given to the above defined arrangements. We reviewed how the new curriculum supports the development of specialist palliative medicine physicians to care for children with SPC needs.

Methods: The curriculum is outcome based. Training goals reference how the outcomes might be applied in the paediatric setting. Comparison was made between the governance and operational arrangements and the new curriculum.

Results: Paediatric palliative care is woven throughout the goals, particularly goals 1 (Principles of Palliative Medicine) 2 (Communication) and 3 (Optimising Comfort and Quality of Life).

Specific outcomes include demonstrating trainee collaboration as part of the core team of paediatric palliative care providers, communicating within the governance arrangements, and optimising comfort and quality of life of children with life-limiting illness.

Conclusions: A key recommendation of the 2020 publication was to incorporate curricular content and training in paediatrics within the 'adult' palliative medicine HST programme. The new 2023 curriculum has achieved this, giving outcome focused goals of training through which the graduates of the programme can enhance the care for children in Ireland through excellence in care delivery

Training Caregivers of Children with Home Invasive Mechanical Ventilation: From the ICU to Home

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Introduction and Objectives: The transition of children with home invasive mechanical ventilation from the ICU to their homes is complex. Families must acquire knowledge of care from multiple health professionals while coping with their child's serious illness. We developed a training protocol to provide clear and progressive instruction, optimize families' learning, and facilitate a safe and effective transition of the child with home invasive mechanical ventilation to home.

Methods: Literature review. Elaborating a protocol adapted to the pediatric department of a tertiary hospital, considering previous experiences and practices from other hospital. The guide sequences the visits of the home care team, specifying objectives, content delivery, documentation, skills evaluations, evaluation of the caregiver's emotional state, interprofessional collaboration, and final evaluation of competencies before discharge.

Results: The implementation of the training protocol for caregivers of children with home invasive mechanical ventilation to transition from the ICU to their homes.

Conclusion: Having a protocol with which to work in a more systematic, coordinated and respectful manner to train caregivers of children with home invasive mechanical ventilation will allow us from now on to evaluate whether safety increases, teamwork is energized, and family stress is reduced.

Characterization of Resources Provide PPC in LATIN AMERICA: *PedPaLatam-2024 P*reliminary Report

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Background: Pediatric palliative care (PPC) is an approach to care for children with life-limiting conditions and their families. They focus on improving the quality of life and relief suffering.

Context: Although PPC is part of comprehensive health care and is an ethical imperative for health systems, 98% of children who need PPC live in developing countries, where universal access to such care It remains a utopia for most of them; Latin America (LA) as a region, is very heterogeneous and although have been significant advances in the development PPC, the gap between the need and its provision continues to be a problem.

Aims: Characterize the *care resources that provide PPC* (r-PPC) in LA countries.

Methods: Cross-sectional, observational study through an interview and directed survey guided by a monitor to the leaders of r-PPC identified in a) Directory of PPC resources (Pediatric Commission, ALCP 2023) and/or if they exist b) National reports or directories. The data will be analyzed by country.

Results: Preliminary data of r-PPC in Central America, Brazil, Chile, Colombia, Mexico, and Uruguay, described according to *staff, population, level of care, settings, complexity of care, team academic training, coverage and teaching, research, or lobbying activities.*

Conclusions: r-PPC in LA show a diversity in care characteristics and non-care activities, with different stages of development and complexity between the LA countries and within the same country. The analyzed variables allow us to observe the current state of the art in the PPC provision in LA.

Originality of Research: There is no work carried out with this exploration methodology in the LA.

Relevance to PPC: Knowing the heterogeneity of r-APPs by country and discuss the findings from a perspective of development of PPC in LA to move forward, plan specific that addresses the needs and gaps identified.

Meeting the Individual Needs of Pupils in Pediatric Palliative Situation

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Background-context-aims: Why do children and youngsters need school in this situation? – is an often heard question, when talking about teaching in hospital. We need to increase awareness of the special situation of students in palliative settings because every child has a right for this very moment. Based on a comprehensive view of the human being the main aim of this study was to show there are many possibilities even in this very vulnerable period of life. Research on this subject seems to be very rare.

Methods: Study inclusion criteria: Pupil in pediatric palliative care.

Descriptive study including case reports from children aged 6-15 on a neurooncology ward.

10 children were taught in classroom on neurooncology ward, day hospital or at home. Period of study: 2019-2024

Observation of lessons – however unique they were.

The main research question was: What needs do pupils have in this period of their life regarding school/related to their learning experiences at school?

Results: There is a great desire to understand and create good moments – teachers are keypersons because they are looking at strengths and adaptions for challenges.

All 10 children loved their school lessons until the end. In the spirit of lasting memories, the families also speak appreciatively of the “new adventures” that their children were able to do during this time with school.

Conclusions: How do we best learn various subjects from these children and adolescents to improve our educational practice? As teachers, as interdisciplinary team, as society we are responsible to meet the needs of young people who are (still) learning with curiosity– also in palliative situation.

The Effectiveness of a Virtual Physical Therapy Training Program for Carers with SMA at Home

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Background: Physical therapy in pediatric palliative care is an integral component in the clinical management of children diagnosed with (SMA). Over the past decade, the wider body of literature has significantly improved standards of care among home care patients. Respiratory complications, such as hypoventilation and poor secretion clearance are major causes of morbidity and mortality in children diagnosed with neuromuscular disease.

Methods: A retrospective cohort study was utilized for this study. Educational competency prior to and after educational interventions was measured. The training program was carried out virtually over a 10-month period. Training modalities included basic physiology training, berthing patterns, respiratory problems, secretion management, dyspnea management and chest physical therapy incorporating the use of equipment at home. Additionally, the training program included musculoskeletal and deformity prevention.

Results: A total of 24 participants caring for children diagnosed with SMA type 1 took part in the educational home care program over a 10-month period while receiving treatment from a physical therapist. The average theoretical assessment score improved following the training program. Participants self-rated their degree of knowledge using a Likert scale in each conceptual domain on a scale of 1 to 10. After the 10-month period, participants education improved by 60.3% (20.1% pre-training and 80.3% post training), this indicates a marked improvement from the original evaluation.

Conclusion: Carers supporting SMA type 1 patients at home demonstrated a high level of improvement in both knowledgebase and skillsets necessary to develop their role after completing the 10-month physical therapy educational program. An educational program can enhance abilities and improve self-reliance amongst carers caring for children diagnosed with SMA type 1.

High-Flow Oxygen in Patients with Acute Respiratory Failure in a Pediatric Palliative Care Unit

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Background and aims: Acute respiratory failure (ARF) is a common cause of admission to pediatric palliative care (PPC). High-flow oxygen therapy (HFO) can be an effective alternative to manage hypoxemia, respiratory distress, and dyspnea in these patients. The SpO2/FiO2 ratio, a non-invasive measure, may be useful to assess ARF severity and monitoring treatment response. The objective of this study was to describe the use of HFO in the treatment of ARF in a PPC unit.

Methods: A retrospective descriptive study was conducted reviewing medical records of 36 patients treated with HFO between 2018 and 2024. Epidemiological and clinical variables were analyzed.

Results: A total of 36 patients received HFO. Median age was 6.5 years (interquartile range [IQR]: 12). All patients had an underlying neurological disease. Infectious cause of ARF was observed in 81.4% of cases. Median duration of HFO was 5.5 days (IQR: 6). Median initial FiO2 was 0.6 (IQR: 0.3) and median initial flow was 1.25 l/kg/min (IQR: 0.91). The median SpO2/FiO2 at admission was 160 (IQR: 94), improving to 200 (IQR: 126) after 8 hours HFO therapy ($p = 0.031$). 18 (50%) patients had total recovery after this episode, 13 (36,1%) of them had partial recovery, Five patients (13.9%) died; no improvement in SpO2/FiO2 was observed in these patients in the first 8 hours (median SpO2/FiO2 at admission: 173 vs 159, $p = 0.57$). Heart rate and respiratory rate improved in all patients (128 vs 113, $p=0{,}001$ and 37 vs 25, $p=0{,}005$). HFO therapy was classified as effective therapy in 30 patients (86%).

Conclusions:

HFO emerges as an effective therapy to treat severe ARF in PPC patients with underlying neurological diseases. SpO2/FiO2 ratio may be useful to assess severity and predict treatment response in severe ARF. Improvement in vital signs may indicate improvement in dyspnea. This study is limited by its retrospective design and small sample size, further research is needed.

Storytelling to Support Legacy-Making for Bereaved Parents of Children with Cancer

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Background/Aim: The field of narrative medicine explores how attention to storytelling impacts clinicians and patients alike. Honoring a child's legacy is an essential aspect of meaning-making for bereaved parents, yet little is known about storytelling as a mechanism. Understanding legacy-creation through story may inform narrative interventions for caregivers. Through analysis of bereaved parent interviews focused on legacy, we aimed to identify and characterize the role of storytelling in creating and sustaining legacy.

Method: In this qualitative study, 19 parents of children who died from cancer participated in semi-structured interviews centered around their child's legacy. Participants were asked to describe their child's legacy, including how their child directly and indirectly impacted others and their child's impact after their death. Interviews were audio-recorded, transcribed, and analyzed inductively with narrative analysis to classify key concepts related to legacy that were highlighted by parent stories.

Results: Nearly all bereaved parents told stories illustrating their child's legacy (17/19). Of the 4/19 participants who felt unsure about how to describe their child's legacy or described the task as "hard," two (50%) used storytelling as a path to find their answer. Narrative analysis identified two themes: 1) *Child Impact* – storytelling generated examples of how a child impacted others during and after their lifetime, and 2) *Parent Coping* – recollections of how their child experienced illness shaped parent perspectives on coping after their child's death.

Conclusion: Inviting narrative creation and reflection about a child's legacy may offer a meaningful tool for supporting pediatric cancer patients and their families in legacy-making, both preceding and following a child's death. Future work should focus on piloting narrative-based legacy activities to explore the possible impact of storytelling on parent meaning-making across the illness course.

How Acces to a Pediatric Palliative Care Unit Influences on the Choice of Place of Death

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Background and aims: Children and their families should have the chance of choosing where to receive palliative care, through the illness process until their last days of life. The possibility of choosing where to stay is related to higher perception of quality of life. The aim of the study was to determine if there are significant differences in the choice of place of death of patients with life-threatening or life-limiting diseases treated at a tertiary referral hospital before and after the Integral Pediatric Palliative Care Unit was inaugurated.

Method: Descriptive and analitic restrospective study. Death registry study of a tertiary referral hospital between 2000 and 2020. Demographic, clinical and healthcare data from before and after the inauguration of the Integral Pediatric Palliative Care Unit were compared.

Results: Since the Pediatric Palliative Care Unit activity started, home deaths from non-curable conditions went from 0% to 48.6%. The highest rate of home deaths was observed in congenital diseases and chromosomal diseases (70%) and neurological conditions (60.1%). Age <1 year (OR 8.2, 95% CI 1.5-42.6) and suffering from a congenital malformation and/or chromosomal disease (OR 7, 95% CI 1.2-39.7) were predictors of home death.

Conclusions: This evolution in home deaths reflects the need for continued home based pediatric palliative care services, 24/7. Age and diagnostic group seem to be predictors of home death.

The Experience of Nurse Managers Supporting Nurses Caring for Children at the End of Life

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Background and aims: While the preferred location of end-of-life care for children is at home, many children continue to die in hospital. Despite their critical role, little is known about the experiences of managers who support nurses in providing this care. The aim is to explore their experiences.

Methods: A qualitative study using in-depth semi-structured interviews and Interpretative Phenomenological Analysis. Purposeful, convenience sampling was used to recruit seven participants in an urban paediatric hospital.

Results: Four superordinate themes were identified:'Nurse manager responsibility''The impact of providing end-of-life care''The importance of educational opportunities and experience' and 'The availability of adequate resources'.Findings provide novel insights into the experiences of managers and demonstrate how they are impacted as they support nurses in providing this care.Results indicate that the participants have a strong sense of obligation to staff and feel a heavy burden of responsibility when supporting staff.While participants acknowledged the privilege of caring for children at the end-of-life,stress and emotional fatigue are prevalent adverse consequences.The protracted care of children with complex care needs is challenging as close relationships develop with patients and their families,adding an additional layer of complexity to this care.Opportunities for education are valued. However, lack of resources, including time, a suitable and well-staffed environment, and appropriate skill mix, renders it difficult for managers to provide the care and assistance to their teams that they aspire to

Conclusions: There is limited evidence exploring experiences of managers.These findings assist in understanding their needs by providing an insight into their experiences.Further study is recommended to determine how educational requirements may be addressed and to the incidence and impact of the provision of end-of-life care to children with complex care needs.

Who are the Children? Point Prevalence Survey to Understand who Needs Children's Palliative Care

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Background: Point prevalence surveys have been conducted effectively in recent years to inform development & resourcing of services for children with life-threatening & life-limiting conditions. Our surveys in a UK region in 2022 & 2023 involved hospital, community & children's hospice services, & reviewed 1801 (2022) & 2619 (2023) Babies, Children & Young People (BCYP). In this paper we compare previous years with our 2024 survey & make recommendations.

Method: The Spectrum of Children's Palliative Care Needs, a prognosis-based framework was used with demographic data: gender, age, diagnosis, partial postcode & NHS number. Data collected by palliative care nurse specialists with professionals from children's hospices (n=5), hospitals (n=13), and community nursing teams (n=11). Information governance maintained via regional Managed Clinical Network process.

Results: 2022: 760/1801 42%; **2023**: 1207/2619 46%; **2024**: 839/2309 36% of BCYP reviewed were unlikely to die because of condition. Surprised if died before 18th birthday **2022**: 26%; **2023**: 22%; **2024**: 24%. Surprised if died in next few years 14%; 14%; 17%. Surprised if died in next few months 14%; 13%; 18%; in next few weeks 3%; 4%; 3%. Survival not expected beyond few weeks 1%; 1%; 2%. Largest proportion diagnosed with neurological 29%; 38%; 37%, genetic 33%; 18%; 14%, oncological 8%; 12%; 12% conditions. Age <1yr 6%; 5%; 7%; 1-4yr 23%; 31%; 25%; 5-11yr 41 %; 45%; 39%; 12-18yr 30 %; 19%; 28%. Prevalence compared with Fraser (2020) estimates showed survey sample represented 10-20% of expected cases based on population estimates in six health care system areas.

Discussion: Our surveys provide essential information about those known to services at a given time. They do not identify all who could benefit from care as there will be those not in contact during data collection periods. Data supports service development but must be used alongside patient outcomes and BCYP / family stories to provide a holistic narrative.

Enrollment Barriers on a Palliative Care Communication Trial for Parents of Children with Cancer

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Background: The objective of this study was to identify accrual barriers in a multicenter randomized-controlled trial (RCT) of an interprofessional (oncologist and nurse)-delivered palliative care (PC) communication intervention for parents of children with advanced cancer.

Methods: A 31-question survey was distributed confidentially to research staff across all 7 study sites. Parent-reported reasons for declining study participation and enrollment rates were tracked. Data analysis is descriptive.

Results: Surveys were received from 42 of 66 (63.6%) research team members, including 14 physicians (33.3%), 10 advanced-practice providers (23.8%), 7 registered nurses (16.7%), and 11 (26.2%) in other study roles. Most were female (83.3%), white (90.5%), and aged 35-54 years (81.0%). Thirty-five (83.3%) reported it was challenging to find the right time for enrollment as parents adjusted to the child's diagnosis and declining health. Delays in approaching families were mostly (59.5%) due to concerns that parents were not ready to hear study-related communication. Twenty-five (59.5%) did not approach families when they appeared overwhelmed, and 33 (78.6%) thought parents were, in general, too overwhelmed to participate. Of 140 families approached, 36 (25%) declined participation. Parents most often declined participation because they were "too busy/overwhelmed."

Conclusions: Team-reported barriers to approaching parents of children with advanced cancer for this RCT enrollment related to perceptions that parents were too overwhelmed or not ready to hear study-related PC communication. "Overwhelmed" was a top reason for declining participation. However, hesitancy in approaching parents may unnecessarily limit accrual and exclude parents who, despite feeling overwhelmed, may want to participate in a PC-communication trial. Strategies are needed to support providers and overwhelmed parents to facilitate enrollment onto PC communication trials for this critical population.

RESPECT: Recommendations for Providing Pediatric Palliative Care to Families from Different Cultures

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Background and aims: Due to demographic changes related to migration and armed conflicts healthcare professionals increasingly encounter patients from different cultures and foreign countries. Culturally sensitive communication fosters mutual understanding, increases compliance, reduces tension and eases hospital staff exhaustion. Ineffective communication can complicate parental grieving leading to long-lasting feelings of guilt. The aim of this work was to develop clear recommendations for providing high-quality culturally-appropriate Pediatric Palliative Care (PPC).

Methods: The author interned at a PPC team in Tel Hashomer Hospital, Tel Aviv, Israel and conducted a literature review by searching for terms such as "PPC in multicultural context", culture-sensitive PPC” or “cultural diversity in end of life care” in ResearchGate, SAGE and GoogleScholar. Findings were consulted with an organization focused on foreigner integration, Centrum pro integraci cizinců, and the Department of Care for Foreigners at the largest pediatric hospital in the Czech republic.

Results: Based on experiences and knowledge gained from international internship and the literature data from over 20 articles (2002-2023), and existing guidelines from Australia, recommendations for providing culturally sensitive PPC were developed. For clarity, recommendations were organized into the acronym RESPECT, which itself is the most important principle for working with families from diverse culture backgrounds. The letters stand for Reflection, Emotions, Spirituality, Paraphrase, Education, Community and Team.

Conclusions: Methodology of RESPECT acronym supports high-quality care for children with palliative needs from diverse cultural backgrounds. Further research and validation of these recommendations with experts through a Delphi study or implementantion into practice is needed to ensure multicultural care in PPC is optimally provided. The project is supported by the Vlček Family Foundation.

Post-Traumatic Growth in Parents who Lost a Child to Cancer: A Multicentre Survey in Switzerland

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Background: Around one in seven children in Switzerland dies from cancer, causing significant distress for parents. Even though parents go through enormous hardship, they can experience positive changes known as post-traumatic growth (PTG). This study aimed to describe PTG in bereaved parents who have lost a child to cancer and to compare it with PTG in parents of childhood cancer survivors.

Methods: This multicentre cross-sectional study in Switzerland (conducted in the years 2022-2023) included parents who lost a child to cancer more than one year since death (diagnosed before 18 years of age). Data from the Swiss Childhood Cancer Survivor Study-Parents were used for comparison. PTG was measured using the Posttraumatic Growth Inventory (PTGI), which assesses five domains on a 6-point scale (appreciation of life, new possibilities, personal strength, relating to others, and spiritual change). Univariable linear regression identified factors associated with PTG.

Results: We included 103 parents (mean age 53.7, SD 8.3 years, 66% female) of 81 deceased children. The most frequent diagnosis was CNS tumours (n=37, 46%). The mean age at death was 9.5 years (SD = 6.0), and the mean time since death was 11.3 years (SD=5.6, range: 2-24 years). The mean PTG score was 59.8 (SD=21.0, range: 9-104), which was higher than parents of survivors (mean = 52.3; $p < 0.001$). Bereaved parents reported higher scores in appreciation of life (3.3, SD=1.1 vs 3.1, SD=1.2; $p < 0.048$) and personal strength (3.3, SD=1.2 vs 2.8, SD=1.2; $p < 0.001$), but no significant difference in spiritual changes (1.7, SD=1.7 vs 1.7, SD=1.5; $p < 0.690$). Overall, those for whom the death of their child was less than 10 years ago and those practicing religion reported higher PTG.

Conclusion: Despite the distress of losing a child to cancer, bereaved parents may experience significant positive psychological changes, with higher PTG levels than parents of childhood cancer survivors.

Shared 1st and last authors.

Complex Pain Case Management in a 12-Year Old Girl with a Severe Form of Epidermolysis bullosae

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Background and aim: Dystrophic epidermolysis bullosa (DEB) is a genetic condition causing epidermal fragility and severe ulcerations requiring complex wound management. The aim is to describe the successful intervention by a pediatric palliative care team.

Methods: Descriptive case report.

Results: A 12-year-old girl with severe DEB was referred to the palliative care unit. She had moderate fatigue, insomnia, nocturnal pruritus, and basal pain (BP) 7/10 associated with almost full-body skin wounds, preventing school attendance for 2 years. Pain was under-managed with acetaminophen on demand and hydroxyzine/diazepam at night. A multi-modal plan was established. Oral morphine (OM) titration found 0.2 mg/Kg effective for BP, so it was prescribed every 4 hours and on demand. After 48 hours, BP was 2/10, needing 2 extra doses daily, so total daily OM was adjusted to 0.27 mg/Kg every 4 hours. After another 48 hours, BP was 0-1/10, so immediate-release OM was switched to sustained-release morphine 10 mg every 12 hours. Irruptive pain during wound-care sessions was 8/10 despite extra OM, but diazepam 5 mg and intranasal fentanyl 1.5 mcg/Kg pre-session were found to be effective. Additionally, virtual reality reduced anxiety and fentanyl use during inpatient wound care. Gabapentin 30 mg/Kg/day successfully treated pruritus. After 6 months, the patient reported 0-1/10 basal pain, good incidental pain management, no pruritus, and gradual return to school without adverse effects. Psychological/psychiatric management continued as a multi-disciplinary, holistic approach.

Conclusions: Basal and procedural pain in DEB can be very disabling. OM remains the opioid of choice for moderate to severe pain in children. Early palliative care referral is key to improving DEB patients' quality of life.

Collaboration in Children's Palliative Care - Everyone Gains

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Background and aims: The Clinical Nurse Specialist (CNS) plays a pivotal role ensuring that all healthcare professionals work in collaboration when caring for a child and family with palliative care needs. Working together is necessary in order to plan and provide high quality care. The CNS team in Ireland's only Children's Hospice provide holistic care for children and families by working with healthcare professionals in the child's home, hospital and hospice. The aim of this abstract is to demonstrate the important of collaboration and communication for seamless and comprehensive care with multiple disciplines and teams in a variety of settings.

Methods: A content analysis of correspondence and contacts between healthcare professionals over a 3 month period from January 1st - March 31st 2024 were collated. The inclusion criteria was contact only between healthcare professionals, both internal and external to the organization. A random selection of children's case notes were examined recording professionals meetings, phone calls and emails which involved discussion, planning and implementation of care.

Results: A total of 10 children's case notes were reviewed, 8 children's care involved at least 1 professionals meeting with 4 or more disciplines, with representation from the hospice, community and hospital settings. A small cohort of children were transferred between hospital, hospice and home. Email threads were found to have been the most frequent method of collaboration, with the greatest number of healthcare professionals included.

Conclusions: Communication and information sharing among healthcare professionals is essential for successful collaboration in children's palliative care. Multiple teams working together across a variety of healthcare settings can ensure the child and family receive comprehensive and coordinated care tailored to their individual needs.

How Do Regional Multidisciplinary Children’s Palliative Care Meetings Support System Development?

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Background: Quality standards for Specialist Children’s Palliative Care (CPC) Services across England identify the multidisciplinary team (MDT) meeting as a key mechanism for safe, effective, clinical consultation & decision making for babies, children & young people with deteriorating & end of life care needs. This paper describes survey findings of professionals participating in MDT meetings about reasons for attendance & makes recommendations on what works & what could be better for practice & service development across health care systems.

Method: Electronic survey to participants of weekly MDT meetings from two regions between 01.03.24 & 31.5.24. Region A an early adopter of the MDT & Region B established within 6 months. Participant attendance between 1.1.24 & 31.5.24.

Results: Participant numbers ranged 18-28 (Region A), 15-29 (Region B). Responses n=20 & n=22. Extremely useful: overall (n=23); for own practice (n=24); >50% for clinical decision making, learning & professional development; & working relationships. Attendance reported to influence day to day practice through broadening clinical knowledge of symptom management, case-based learning, pharmacological discussion, networking, building confidence & learning from colleagues from different backgrounds. Supported planning for out of hours work. Areas for improvement: Psychological / supportive care input, succinct case presentation, understanding clinical rationale, discuss cases by priority/complexity according to consistent classification.

Discussion: Well-led weekly MDT case discussion supports delivery of high-quality palliative care, enhances participant professional development, increases understanding of health care systems. Those embracing the MDT approach became more confident & competent to provide care out of hours with enhanced case knowledge supporting safer decision making across the 24/7/period. These data influence regional service strategy & support development of specialist CPC teams.

Guilt in Caregivers of Pediatric Cancer and its Associations with Meaning-Making Processes

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Background and aims: Family caregiving of pediatric cancer patients is linked to significant levels of psychological distress in caregivers. One emotion frequently experienced by caregivers is guilt and it has been linked with higher distress. However literature about guilt feelings is scarce. On the other hand, literature has shown that the meaning a person assigns to a stressful life situation is relevant for the well-being. Therefore, the meaning the caregiver assigns to the diagnosis and illness may by playing an important role in the impact of caregiving on its health. To our knowledge meaning-making processes have not been studied in this population. The present study was aimed at exploring the presence of guilt feelings in caregivers of pediatric cancer patients and its associations with meaning-making processes in that population.

Methods: A total of 55 family caregivers of pediatric cancer patients composed the sample of the study. Face to face interview were done assessing sociodemographic variables (age, gender, kinship), guilt (Caregiver Guilt Questionnaire, Losada et al., 2010), integration of stressful experience (Integration of Stressful Experience Scale, Holland et al., 2014) and the disruptions in meaning (Global Meaning Violation Scale, Park et al., 2016).

Results: Women who were taking care of the patient and have other children reported higher levels of guilt. Lower levels of integration of the stressful experience were significant predictors of stronger guilt feelings. Also, higher perceptions of disruption in intrinsic values were positively associated with guilt.

Conclusions: The findings suggest the relevance of guilt feelings in pediatric cancer caregivers and its impact on emotional wellbeing and the meaning-making processes. Interventions tailored to family caregivers should promote the search of meaning and techniques aimed at addressing guilt feelings, especially for mothers caregivers.

Shifting Attention of Children with Life-Threatening Illness from Needs to Desires

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Background-objectives: Children with life-threatening illnesses go through many situations that put a strain on their psyche. Previous work has shown that wish granting has a positive effect on the psyche, reducing anxiety levels and developing hope. It also reduces the likelihood of complications.
The aim of the presentation is to introduce the wish granting project, which has been running in close collaboration with treating physicians, psychologists, and parents continuously since 2015. We present experiences confirmed by families of seriously ill children and the most important principles of the project with a positive impact on the quality of their lives.

Methods: The inclusion criteria for children are life-threatening illness or illness with uncertain prognosis and age 5-18 years. Since 2015, 1716 children have been enrolled and over 1310 wishes have already been granted. 69% of children participate in the program on the recommendation of a health professional. The wish is always expressed during a face-to-face meeting with the child. Our input data includes 3695 interviews with children and 662 feedback questionnaires from parents and children. We work through qualitative observation, case study method and results of feedback questionnaires.

Results: Using case studies, we present our 3 basic principles:
- Shifting attention from needs to desires
- Focusing on the whole process, not just wish fulfilment
- Being aware of the impact on different areas of the child's and family's life

Parents of the children confirm them to be important and to have a positive impact on the child's psyche as well as the family.

Conclusions: The process of wish fulfilment and its associated emotions can bring joy, reinforce hope, and provide strength for a difficult time. In terms of grieving, it is important for parents and health professionals to feel that they have done their best for the child, both physically and emotionally.

New Strategies, Old Strategies: Handling Pain in an Adolescent with Cancer, a Case Report

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Background and aims: Pain is the most common and distressing symptom in cancer patients and represents a major burden on individuals, families and their quality of life. Different pharmacological strategies and multidisciplinary approaches are recommended for its management.

Methods: We describe the pain management pathway of P., a 15-year-old diagnosed with sacral osteosarcoma.

Results: At the time of Pediatric Palliative Care team involvement, local disease progression resulted in left lower limb plegia and difficult pain control. Pain consisted mainly in a deep somatic nociceptive component in the lumbosacral region and in neuropathic pain involving lower limbs with paresthesia and allodynia. P. was receiving treatment with opioids and adjuvants with partial symptom control; moreover, he exhibited mood deflection and irregular sleep.

Rotation of opioids (change from morphine to transdermal fentanyl) and adjuvants (amitriptyline, gabapentin, dexamethasone and lorazepam replacing duloxetine, pregabalin, methylprednisolone and clonazepam) was partly effective. Admission to a Pediatric Hospice was necessary for therapy adjustments.

Transition to intravenous oxycodone with ketamine and methadone addition, alongside with scramble therapy initiation, failed to achieve adequate pain control. Following a consultation between palliative care specialists and hospital pain team anesthesiologists, an epidural catheter was placed and continuous ropivacaine administration via CADD pump was initiated, obtaining satisfactory pain control. P.'s family was trained in device management, enabling P. to return home.

Conclusions: This case highlights the importance of considering alternative therapeutic approaches and routes of administration in non-responsive pain and emphasizes the value of interdisciplinary collaboration and individualized care planning in complex cases. Further research and teamwork are warranted to identify innovative strategies for managing this challenging symptom.

Quality Office Role in KHCC Global Comfort Promise Project

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Background: The Global Comfort Promise initiative focuses on enhancing patient care and comfort across healthcare settings, with a particular emphasis on pediatric oncology at King Hussein Cancer Center (KHCC). This quality improvement project is central to optimizing needle-based procedures to increase treatment efficacy and patient satisfaction through strategic quality oversight.

Methods: A comprehensive methodology employed to evaluate the effectiveness of current practices and to pinpoint areas for improvement in patient care. This involved collecting and analyzing satisfaction data from staff and parents, followed by quality audits performed by the quality assurance team to assess and guide ongoing improvements.

Results: Preliminary findings have demonstrated significant enhancements in patient comfort metrics. Procedural pain has decreased from an initial rates of 90% to near the interim goal of 40%. Patient satisfaction scores have impressively reached 100%. Quality audits have been instrumental in identifying both strengths and areas needing improvement. Effective interventions, prompted by audit findings, have improved protocol adherence among staff. While some departments show consistent protocol adherence and receive positive patient feedback on pain management, other areas exhibit variability in protocol application and pain management effectiveness, indicating a need for further refinement.

Conclusion: The role of quality management is pivotal in the success of the Global Comfort Promise at KHCC, markedly boosting patient outcomes and satisfaction. Employing structured quality improvement strategies, such as the PDSA cycle, has been crucial in the continuous enhancement of patient care practices. This rigorous approach to quality assurance ensures that the highest standards of comfort and care are met, fulfilling the overarching objectives of the Global Comfort Promise to deliver compassionate and effective care in pediatric oncology.

Top of Form

What Care Service Tools Can Help Palliative Care Teams Learn From Expected Childhood Deaths?

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Background: There is a statutory requirement for child death review (CDR) in England to improve & save children’s lives. This includes those receiving palliative care, with health care providers expected to participate in reviews. This paper describes care & service tools developed in a UK Region which helped us learn & improve care & support around the time of death for babies, children, young people (BCYP) & their families.
Method: Regional mission & policy evaluation, revision of planned service outcomes & development of care delivery tools.
Results: Regional outcomes: BCYP supported closer to home by core teams with appropriate support, skills & training; BCYP & professionals who care for them have access to specialist advice & support; reduction in avoidable high intensity in-patient stays as BCYP & families are supported to manage care safely in their own homes; BCYP & families are better supported by the health care system as joint working is developed; BCYP & families have choice, control & involvement in their care; BCYP & families access current evidence based care through strategic leadership, influencing research, education & change. **Tools identified to support learning**: categorized to support personal, service or organisational learning. **Personal:** Multidisciplinary team (MDT) meeting, commemorative debrief, journal club, clinical supervision. **Service:** Regional MDT meeting, end of life checklist, advance care plan, symptom management plan, on call handover plan, teaching sessions. **Organisational:** mortality & morbidity meeting, patient stories, CDR meeting.
Discussion: Unifying regional practice around end-of-life care & providing consistency with evidence informed tools builds confidence & competence among professionals, enhances safer & more effective care & promotes BCYP & family experiences. Underpinning factors for optimising learning are the pivotal role of the MDT & clear lines of communication between all individuals, services & organisations.

Tracheostomy Decision-Making in Pediatric Palliative Care: Systematic Review of Qualitative Research

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Background and aims: Decision to place a tracheostomy in pediatric palliative care (PPC) patients has been reported to be stressful by families and care teams and requires a careful benefit-risk assessment. The perceptions of family and healthcare providers around this important decision have been repeatedly analyzed in literature. The aims is conduct a systematic review and meta-summary of qualitative research (QR) studies regarding the motivations that lead to decide whether or not place a tracheostomy.

Methods: Systematic review and meta-summary of QR according to PRISMA flow diagram guideline. We searched articles following this strategy: (“Tracheostomy”[Mesh] OR tracheostom*) AND (“Decision Making”[Mesh] OR decision making), Filters: Child: birth-18 years. Databases: MEDLINE, EMBASE, Cinahl, Scopus, Web of science.

Results: A total of 669 articles were analyzed following PRISMA guideline. Based on the preset inclusion and exclusion criteria, studies were selected first by title and abstract and then by full text. Seventeen articles were included in the review. Summarizing, for family members, the main themes addressed were strong emotions related to decision making, emotional distress consequent to the decision made, communication with health care providers (barriers/facilitators), difficulties in home health care, benefit-risks consequent to tracheostomy placement, and spirituality. For health care providers, the themes emerged were related to communication within the multidisciplinary team and with family members (barriers/facilitators), benefit-risks of tracheostomy.

Conclusions: The decision to place a tracheostomy in CPP confronts the family and health providers with ethical and spiritual dilemmas. Improving communication between the parties is crucial to reach informed and shared decisions. We hope that this work will be preparatory to the development of tools that help clinicians and families in transition from clinical indications to ethical rationale.

ePROMs for Symptom Assessment in Pediatric Palliative Home Care

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Background: Electronic patient-reported outcome measures (ePROMs) are digital questionnaires in which patients and/or caregivers assess the patient´s state of health. ePROMs may enhance symptom control in palliative care by using tools as the integrated palliative outcome scale (IPOS). To date, no validated outcome scale nor validated symptom categories for ePROMs has been reported for pediatric palliative care. The aim of this study was to implement an extended IPOS version to assess symptom load as ePROMs in pediatric palliative home care (PPHC).

Methods: Relevant symptom categories for PPHC were identified in a mixed method approach consisting of five steps: (1) Questionnaire survey of the three PPHC teams of the German State of Hesse regarding relevant pediatric symptoms. (2) Generation of a preliminary symptom category list based on the survey results. (3) Discussion of preliminary symptom category list in a committee including PPHC physicians and nurses of all PPHC-teams. (4) Revision by the expert committee yielding the final symptom category list. (5) Pilot testing of the symptom categories in all Hessian PPHC teams as ePROMs using a mobile health application.

Results: 37 symptoms were identified, of which 12 are shared with the IPOS and queried in two steps: (1) For initial assessment and in the following a monthly binary digital questionnaire was used to identify all relevant symptoms of a patient. (2) Based on these results relevant patient specific symptoms were assessed weekly using a 7-point Likert scale via ePROMs.

Conclusions: Systematic symptom assessment using ePROMs was successfully implemented. Families may document their symptoms in a feasible, standalone application. PPHC team members get live, color-coded feedback in the patient documentation software regarding symptom severity.

Further research is needed to assess ePROMs clinical impact.

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The Pediatric Day Hospice: A Place for Pediatric Palliative Care

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Introduction and aim Children eligible for pediatric palliative care (PPC) very often present multiple and complex symptoms and needs. To offer a response to the needs of these patients and their families, it is necessary to define not only the level of care need, but also the care setting and the method of providing the most appropriate and functional services for each family unit. The Pediatric Day Hospice (PedDH) intends to act as a service integrated with home-care and residential PPC services. The aim of this work is to describe the PedDH service of an Italian PPC service.

Method An analysis was conducted of the number, type and needs of patients admitted to the PedDH from June 2021 to April 2024. A summary report was then created describing the PedDH's activity.

Results In the 34 months that the service was open, 25 minors were assessed, of which 18 was taken in charge by PPC team. A clinical-diagnostic evaluation space was offered for 14 minors in the care of the CPP service. 13 minors access the service with once-a-week access all year round for educational and rehabilitation courses. 7 benefit from the transport service guaranteed by volunteers. One whole day a month is dedicated to 4 minors to provide relief to their parents and siblings. From the observation of the multidisciplinary paths conducted to date, the following emerge as the main objectives achieved: supporting motor, communicative, sensorial, cognitive, emotional and relational functions, managing pain and disturbing symptoms, encouraging active social participation ina structured context, supporting complex parenting, addressing the issues of illness and acceptance of changes, preventing problems linked to possible complications during bereveement.

Conclusions The PedDH is a space in which responses are given to the complex needs of children in PPC which allows us to maximize the achievement of treatment aim and promote the well-being of the child and family.

Palliative Sedation in Pediatric Patients: Preliminary Data from a Retrospective Study

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Background and aims: Palliative Sedation (PS) lacks official guidelines for pediatric patients: drug types and dosages are deduced from studies involving adult population. Patient’s care setting and clinical characteristics and the availability of routes of administration and devices can influence the management of PS.

The aim of this study is to characterize pharmacological and clinical management of patients undergoing PS in a pediatric hospice (PH) and at home.

Methods: We conducted a monocentric retrospective observational study (currently ongoing). We included patients who received PS and died between April 2019 and March 2024. We collected data from clinical records.

Results and discussion: Preliminary results include 18 patients (11 females and 7 males, median age 7.2 years), of whom 8 died at home and 10 died in a PH. End of life care was provided by pediatric palliative care team. PS was initiated for refractory symptoms including pain (n=6), dyspnea (n=10) and status epilepticus (n=2). Median age was lower in the PH setting compared to home care setting. All patients managed in hospice had stable vascular access, whereas this was present in 30% of patients managed at home. The induction dose of benzodiazepines and opioids resulted higher in hospice than in home setting. There was a significant progressive increase in therapy dosage in both settings.

Although small sample size limits data generalization, preliminary analysis reveals an age difference between the two settings, as well as a difference in the induction dosage of pharmacological therapy, while the dosage increase is comparable in both settings.

Conclusions: Management of PS in pediatric patients is particularly challenging due to the variety and multifactorial nature of refractory symptoms, the pharmacokinetic peculiarities of the pediatric patients, their individual characteristics and the different end-of-life care settings.

Physician Lead Role in the Global Comfort Promise at KHCC

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Background: The Global Comfort Promise (GCP) at King Hussein Cancer Center (KHCC) aims to enhance pediatric oncology care by managing pain during needle-based procedures. Based on the St. Jude Global Packages model, this quality improvement project is led by physicians dedicated to reducing procedural pain and improving patient experiences.

Methods: Physician leads at KHCC integrate clinical expertise with strategic leadership to implement pain management protocols. Innovative approaches include EMLA cream for pain relief, distraction methods, strategic patient positioning, and rewards like small toys or candies. Staff training occurred through regular educational activities during management rounds, MDCs, and nursing meetings.

Results: Our quality metrics show project success and areas needing improvement. Patient satisfaction rates after needlestick procedures consistently achieved a median of 70%. Use of topical anesthesia had a median of 83%, indicating high compliance with GCP protocols. Challenges included securing space, obtaining financial support for supplements, selecting appropriate toys, and navigating lengthy approval processes. Reward systems had a median usage rate of 9.77%, highlighting an area for improvement.

Conclusion: The GCP's success is reflected in high compliance rates and significant patient satisfaction. Positive feedback from parents and caregivers, who were involved in satisfaction and auditing reports, was instrumental in shaping these reports. Physician leads continually address practice variations and enhance pain management strategies, maintaining high care standards and fostering continuous quality improvement. Future efforts will focus on standardizing practices across departments and exploring new approaches to reduce procedural pain. This aligns with global pediatric oncology care standards and supports KHCC's commitment to compassionate care, marking a significant step towards achieving the Global Comfort Promise goals

The Human Cost of the COVID-19 Pandemic: Implications for Pediatric Palliative Care Providers

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Background: Initial projections that COVID-19 would be a mild, self-limiting disease in children quickly proved to underestimate disease severity. Reports of a new entity similar to Kawasaki Disease, namely, Multisystem Inflammatory Syndrome - Children (MIS-C) with severe organ failure and death despite aggressive support appeared within a few months of pandemic declaration in March of 2020. Although the global health emergency related to the pandemic has been suspended, infections are still occurring. We are now coming to appreciate sequelae of the infection, and there is ongoing concern about emerging variants.

Methods: COVID-19 related data maintained by the Centers for Disease Control, UNICEF, and Johns Hopkins University were reviewed, in addition to PubMed® pediatric-oriented publications as of May, 2024.

Results: Fatalities have occurred in previously healthy preadolescent children with normal body-mass indices, despite support with extracorporeal membrane oxygenation (ECMO) in high resource countries. Although the estimated pediatric mortality is 0.4%, that number likely grossly underestimates this and other indicators of severe disease, since data was not submitted by many low-to-middle income countries. This also complicates estimates of indirect causes of mortality due to loss of a parent and other supportive family members, missed childhood immunizations, poverty and malnutrition, and missed educational and other opportunities. It is likely that many hospitalized children died alone. Survivors of MIS-C may face life-limiting organ dysfunction.

Conclusions: COVID-19 continues to cause significant health-related and psychosocial suffering, on a global scale. In addition to direct patient care, and. advocating for patient-focused, family centered care during natural disasters, palliative care providers can help combat misinformation and promote sharing of effective vaccines against this and other highly transmissible pathogens, and affordable therapeutics.

Training Caregivers to Care for Italian Children in Pediatric Palliative Care: Single-Centre Study

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Introduction and aim The care of children in pediatric palliative care (PPC) is often characterized by high care complexity and dependence on life support equipment and devices. Every day caregivers of these children carry out at home even complex care procedures independently. The nurse has a fundamental role in training caregivers regarding the use of aids, devices and education in the adoption of behaviors necessary for the clinical well-being of the child. The aim of this work are: [1] to map the clinical-care interventions implemented by the caregivers of children in the care of a PPC service and [2] to investigate the satisfaction and outcomes of the educational and training interventions proposed by the nursing staff.

Methods A single-center cross-sectional study was structured on a convenience sample made up of parents with at least one child in the care of an Italian home-based PPC service. A questionnaire was structured from the clinical-care information collected through the assessment form of complex clinical-care needs in pediatrics (ACCAPED).

Results 48 questionnaires were distributed. After four reminders, 31 completed questionnaires were collected (64.6%). The caregivers reported that they had been trained by the nursing staff of the PPC service to manage the devices in use. On average these are 4 per child. Caregivers perform at least one complex care procedure per day (e.g. tracheal aspiration). Satisfaction with the training programs offered by nurses is high, so much so that it gives caregivers good confidence in managing the daily life of a child suffering from complex conditions.

Conclusions Nursing training programs are essential tools for caregivers of children in PPC program as they help them to put themselves in the optimal conditions to safely and effectively manage the particular needs of these children.

Epidemiological Estimation for Paediatric End-Of-Life and Palliative Care in Greece

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Background and aims: Paediatric palliative care (PPC) is described as the active holistic care for children and their significant others, when life-threatening, life-limiting or life-shortening complex conditions are diagnosed. To define national strategic plans on prevention, health services, healthcare professionals' education and to properly allocate resources, a precise estimation of the PPC burden is required, by assessing the current number of children requiring PPC in Greece.

Methods: The estimation of the need for PPC was conducting by consulting the Hellenic national death registry during the years 2014-2021, the Global Atlas of Palliative Care (2nd edition, 2020) and the Palliative Care Feasibility Study for Greece (2019).

Results: A total number of 3,219 children in Greece require PPC according to the estimation (31 children / 100,000 inhabitants). Yet PPC services are still not available and / or accessible by most children and their families in need (PPC services cover less than 1% of country's need), especially in rural and islanding areas of the country. The ten most prevalent PPC health conditions are as follows: perinatal conditions (38,33%), congenital anomalies, dysplasias and chromosomal abnormalities (23,96%), cancer (12,63%), neurological diseases (7,59%), respiratory system diseases (6,03%), circulatory system diseases (3,27%), endocrine, nutritional and metabolic diseases (2,86%), infectious diseases (2,48%), other rare diseases (1,15%), and blood diseases and immune disorders (0,63%). At the time of death between the period 2014-2021, children were <1 year old (65,32%).

Conclusions: PPC is underdeveloped in Greece and access to quality end-of-life care continues to be minimal. There are a lot of complex health conditions which could benefit from palliative care in pediatric setting. However, epidemiological assessment could act as a road map for stakeholders and PPC development of the country.

Nursing Role in Managing Procedural Pain; KHCC (Global Comfort Promise)

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Background: The Global Comfort Promise Project at King Hussein Cancer Center (KHCC) is dedicated to enhancing patient care through a bundle of interventions targeting needle stick pain.
Methods: The success of the project largely hinges on the pivotal role of the nurse leader. This individual is integral in educating nursing staff, patients, and parents on the pain management bundle, which includes distraction techniques, topical anesthetics, and comfort positioning. Regular workshops, hands-on training, and ongoing educational sessions are conducted to ensure adherence to these practices. The nurse leader also facilitates feedback mechanisms among staff to refine techniques and improve patient outcomes.
Results: Initial assessments from Aug and Sep 2023 showed that 90% of the 94 patients assessed experienced pain, indicating the need for pain management strategies. Since the project's inception in Sep 2023, there has been a substantial reduction in reported pediatric procedural pain, with rates dropping to nearly 40%, approaching the interim goal. This improvement is attributed to the nursing staff’s strict adherence to project protocols and proactive patient care involvement. Strategic Actions Implemented; Focused Educational Programs; Comprehensive training programs developed to ensure a uniform understanding and application of pain alleviation techniques among nursing staff. Multimodal Pain Management Strategies Implemented by nurses; including the use of EMLA creams, distraction techniques, and patient education, to mitigate pain perception during procedures.
Conclusions: The leadership and dedication of the nurse leader at KHCC have been instrumental in the significant progress achieved in reducing procedural pain among pediatric oncology patients. Continued focus on education and the adoption of multimodal pain management strategies are crucial for sustaining these improvements and further enhancing the care experiences of patients and their parents.

Ultrasound Guided Long Peripheral Cannula: A Pain Control Device in Pediatric Patients

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Objectives: Venipuncture is one of the most distressing factors for pediatric patients, in particular for DIVA (Difficult IntraVenous Access) ones. They are often exposed to several blind attempts to get venous access because of their poorly visible and palpable superficial veins. Long peripheral cannula (LPC) when ultrasound guided is successfully in first attempt positioning and has longer dwell time compared to short peripheral cannula (SPC), reducing painful events.

The purpose of our study was to compared the effect by positioning of 70 over the needle LPC with those from SPC and to evaluate the success of the LPC in reducing venipuncture related pain. We also analyze whether variables such as age, weight of patient, therapy, catheter/vein diameter or insertion location have influenced the dwell time of the device and if complications occur.

Methods: This prospective observational study took place from October 2022 to May 2023 enrolling 70 patients aged 0 to 19.

All devices were placed in ultrasound guide, with over the needle and no touch technique, using EMLA as local anesthetic. Student's T-test and $\chi 2$ were used for correlation studies.

Results: In all patients LPCs were inserted on the first attempt with an average time of 134.7 seconds. Three patients were transferred. The other 67: 46 (68.6%) achieved the end of treatment, 21 had minor complications that didn't required therapy: occlusion (16; 23.9%); disfunction (2; 3%) thrombophlebitis (2; 3%), dislocation (1; 1.5%). Dwell time of device was 206 hours (8.5 days an undervalued result due to device forced removal in some cases).

Conclusions: More than two thirds of patients with LPC didn't require other venipuncture, avoiding pain. Major complications didn't occur. There was no correlation between the variables examined and a longer lifespan of the device. Ultrasound guided LPCs could be thus a valid choise for pediatric DIVA patients or whom require therapy for 3-10 days.

PALLIAKID: Comprehensive Paediatric Palliative Care Approach

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Background/aims: As survival rates for children and youth with severe diseases increase, the need for paediatric palliative care (PPC) continues to grow. The PALLIAKID project (EU Horizon Europe, Grant Agreement 101137169) aims to improve the well-being and quality of life for young patients with palliative and end-of-life care needs.

PALLIAKID seeks to enhance shared and informed decision-making in PPC by adapting tools tailored for patients, siblings, family caregivers, and healthcare professionals. The project is therefore adapting two pre-existing tools:

1. *Needs Assessment HexCom:* designed for comprehensive needs assessment of adult palliative care patients and family caregivers.
2. *Advance Care Planning (ACP) IMPACT:* aimed at facilitating discussions between parents, paediatric patients and care providers regarding goals and preferences for future medical care.

Methods: The adaptation of the HexCom and IMPACT tools will be two-fold, involving qualitative and quantitative approaches carried out in clinical sites in Spain, Italy, Latvia, Denmark and Finland. First, we will carry out interactive co-creation sessions with patients, siblings, family caregivers, and healthcare professionals to adapt the tools to different paediatric cultural and socio-ethical contexts and to digitilize them.

The developed tools will then be evaluated in a randomised controlled parallel-group trial at the 5 sites in a total of 217 children and families, aiming to verify the tools' feasibility, effectiveness and cost-effectiveness versus the current standard of care.

Results: We foresee that directly engaging different populations involved in PPC in collaborative activities will lead to the development of more effective and tailored solutions that better identify family and patient needs and facilitate the shared decision-making process with healthcare professionals, ultimately resulting in improved quality of care and outcomes.

Conclusions: Results are expected in 2025.

The Plight of Migrant Children with Palliative Care Needs in the Americas

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Background: Significant health-related suffering is experienced by children with palliative care needs and their families in the Americas during forced migration due to poverty, conflict, organized crime, or natural disasters, exacerbated by the COVID Pandemic.

Methods: A scoping review of the literature through May of 2024 was conducted utilizing the PubMed® and SciELO® databases investigating migrants with paediatric palliative care needs.

Results; Although there is literature about palliative care in refugees and humanitarian settings in Asia, the principal reports regarding migrant children in America have been collated by the United Nations and other global organizations. Palliative Care of these children has not been comprehensively described in the medical literature.. Much of what we know is what families share, fearfully at times: resources are limited to non-existent after the pandemic, even in countries like Ecuador, with open border policies; some families actually walk to the United States with children with tumors, congenital heart disease, neurologic disorders, hoping for improvement. Families face mortal dangers while crossing the Darien Gap jungle between Panama and Colombia, while traversing Central American jungles, and the drug cartel-controlled transportation in Mexico.

Families face extorsion only to encounter life-threatening barbed wire and physical barriers which cause drownings. Detained medically-fragile children may deteriorate rapidly and sustain cardiac arrest, or even die due to infections and delays in medical care. Guards may be cruel and deny entry to parents, even when death is near. Families are bewildered by long, expensive admissions, sometimes resulting in technology dependence. Cultural and language barriers, and unmet basic and spiritual needs are common. Death carries significant repatriation expenses.

Conclusions: Research, collaboration, and compassion are needed to inform care of these unforrtunate families.

Towards Appropriate Advance Care Planning in Pediatric Palliative Care: A Medical Record Review

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Background and aim: Advance care planning (ACP) is an essential element of appropriate palliative care for children with life-limiting conditions. However, it has not been evaluated if and to what extent ACP is integrated into care as usual. This study aims to evaluate the use of ACP in current care for children with life-limiting conditions, and how ACP outcomes were shared with other healthcare professionals.

Methods: Electronic medical records were reviewed of all children from a Dutch university children's hospital who deceased in 2023. Neonatal or unexpected deaths were excluded. The following elements of ACP were independently scored by two researchers: goals and preferences for future care and treatment (physical, psychological, social and spiritual domains), preferences for life-sustaining treatment and end-of-life care. The frequency and comprehensiveness of documentation were documented, as well as the timing (stable, progressive or terminal disease phase) in which the conversation took place.

Preliminary results: 102 records were retrieved of children who passed away in 2023. Of these, 79 were excluded due to neonatal or unexpected death, leaving 23 records included. An initial analysis of the first 10 records showed that one or more elements of ACP were present in 5 records. The physical domain was described most frequently and comprehensively. ACP elements were most commonly documented when the patient was in the progressive or terminal palliative phase. In medical letters, elements of ACP were described to a limited extent.

Conclusion: Initial analysis shows variation in documentation of ACP elements, in frequency, comprehensiveness, domains covered, and timing. The outcomes are shared extramural to a limited extent. These findings provide valuable insights for developing strategies to improve ACP, with a focus on transmural communication and implement ACP as a structural part of usual care for all children with life-limiting conditions.

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Comprehensive Well-Being, Wish to Change and Concerns of Children in Palliative Care: Scale qESNA-14

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Background-Aims: The Spanish structured interview for the assessment of the Suffering of Children in palliative care (ESNA) has mixed qualitative-quantitative questions about different sources of suffering. ESNA contains 16 quantitative items that make up the qESNA-16 scale. Our aim was to analyze the psychometric properties of the qESNA-16.

Methods: A total of 58 children completed the qESNA-16 scale in a cross-sectional and longitudinal design along with other scales that evaluated anxiety, depression, emotional alterations, cognitive strategies and psychosocial functioning. The statistical analysis was: Basic description of the data; Exploratory and Confirmatory Factor Analysis; Reliability with Cronbach's alpha; Convergent Validity through Pearson correlation coefficients; and Analysis of specificity and sensitivity. The study was approved by the Ethics Committee.

Results: The characteristics of the sample were 32.8% female with an average age of 15.6 (SD=4.50, Range=8.57-23.96) and 69.0% with oncohematological diseases. 1) The exploratory analysis identified a 14-item scale (qESNA-14) with 3 factors: I. Frustration and wish to change, II. Comprehensive well-being, and III. Concerns. 2) Reliability: Cronbach's alpha was 0.85 (0.80-0.91). 3) The convergent validity was high in the correlation with the risk of depression (-0.69) and anxiety (-0.60) and emotional alterations (-0.59). Table 1 shows the significant correlations with psychological variables and Table 2 shows the T-test of mean difference with sociodemographic and illness variables. 4) ROC curve analysis indicates that a score <81 would be indicative of suffering, presenting a sensitivity of 83.33% and specificity of 93.48%.**Conclusions:** The qESNA-14 scale has a multifactorial structure consistent with multidimensional suffering. It has good psychometric properties, is reliable, easy to administer and provides a total suffering score with different factors that can guide a more individualized multidimensional intervention. More studies are necessary in relation to the influence of age and other sociodemographic variables.

Table 1. Pearson lineal correlations of qESNA-14 scale with psychological variables

	Global		*Factor I: Frustration and wish to change*		*Factor II: Comprehensive well-being*		*Factor III: Concerns*	
	r	*p-value*	*r*	*p-value*	*r*	*p-value*	*r*	*p-value*
Emotional symptoms	-0.59	< 0.001	-0.35	0.007	-0.53	< 0.001	-0.46	< 0.001
Global Functioning	-0.34	0.009	-0.21	0.107	-0.25	0.064	-0.29	0.028
Depression	-0.69	< 0.001	-0.29	0.029	-0.67	< 0.001	-0.53	< 0.001
Anxiety	-0.60	< 0.001	-0.31	0.016	-0.45	< 0.001	-0.57	< 0.001
Rumination	-0.44	0.001	-0.27	0.041	-0.49	< 0.001	-0.24	0.070
Positive reappraisal	0.23	0.083	-0.09	0.480	0.19	0.162	0.31	0.018
Catastrophizing	-0.57	< 0.001	-0.39	0.002	-0.48	< 0.001	-0.49	< 0.001
Emotion Regulation	0.45	< 0.001	0.45	< 0.001	0.46	< 0.001	0.34	0.009

Table 2. T-test of mean difference of qESNA-14 scale with sociodemographic and illness variables

	Global		*Factor I: Frustration and wish to change*		*Factor II: Comprehensive well-being*		*Factor III: Concerns*	
	|t|	*p-value*	*|t|*	*p-value*	*|t|*	*p-value*	*|t|*	*p-value*
Sex Female	1.39	0.177	1.38	0.179	1.42	0.167	0.69	0.496
Age >14	**3.34**	**0.001**	**3.40**	**0.001**	**2.03**	**0.048**	1.40	0.166
Spanish	1.38	0.725	1.21	0.233	1.14	0.259	0.82	0.418
Exacerbated Symptoms	**2.40**	**0.027**	**3.86**	**< 0.001**	1.05	0.310	0.11	0.914

Coordinating Children’s Palliative Care in Municipalities: A Qualitative Study

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Background: Children with palliative care conditions and their families have complex care needs. In Norwegian municipalities, designated coordinators facilitate cooperation between health and social care services to ensure a holistic approach to meeting these needs. However, information is limited concerning how coordinators perform their duties and the factors influencing their work performance.

Aim: To explore the factors influencing coordinators’ motivations and work performance regarding children’s palliative care (CPC) in municipalities.

Methods: Semi-structured interviews were conducted with 11 coordinators for children in palliative care and analysed using a reflexive thematic analysis approach.

Results: Both internal and external factors influenced the coordinator's work performance, and they experienced a range of barriers in their efforts to achieve holistic care. Four themes were generated: ‘random knowledge on children’s palliative care’, ‘the abstract concept of coordination’, ‘striving to unite the fragmented whole’ and ‘aiming for tailored coordination’. A lack of training and experience in CPC is widespread among the coordinators. Additionally, the municipal systems seem inadequately developed to address the needs of children in palliative care and their families.

Conclusion: The coordinators face challenges due to a lack of initial training and articulated work instructions, procedures and routines. Strengthening coordination in municipalities for children in palliative care and their families requires that coordinators receive systematic training in CPC and further development of their support systems.

Every Moment Matters

I. Plechatá[1]
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We see a world where families with seriously ill children will have top-notch care and the opportunity to experience moments of joy.
Our goal is to make the Czech Republic a world leader in providing pediatrics palliative care by 2031.
The Vlček Family Foundation (Nadace rodiny Vlčkových) was established in March 2021 by Katarína and Ondřej Vlček. At the outset, they invested 40% of their considerable family fortune in the Foundation. The vast majority of it serves as the endowment principal, which is being invested by financial experts.
"We founded the Foundation to develop children's palliative care in the Czech Republic and build a network of services that reflect the needs of families caring for a child with a serious ilness."
Foundation focusses energy and resources on increasing the capacity and accessibility of care for families with seriously ill children in all regions of the Czech Republic; ensuring a coherent system for financing care; promoting high standards of care; and advancing systemic change where appropriate.
Main current activities include data analysis; ensuring continuity of care and eliminating regional disparities. The Foundation contributes to the training of current professionals and educates future professionals, while promoting discussion of relevant ehitcal issues.
One of the goals is to open a Pediatric Palliative Care Centre with an inpatient hospice in Prague. The dilapidated historical Cibulka farmstead is being rebuilt into a respite, social and health care facility where specialists will care for sick children so that parents can take a break from demanding long-term care.
The foundation is building international partnerships and encouraging international collaboration in the field of pediatrics palliative care. It takes an inspiration from abroad and facilitates information about best practices to local professionals. It also supports students and brings international experience to the Czech Republic.
Get in touch with us!

Palliative Care in Children: Italian Translation and Validation of a Questionnaire

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Background and aims: New technologies, medical advances, and overall improvements in care have led to a gradual increase in the survival of infants, children, and adolescents with incurable diseases or severe disability. Physicians and nurses sometimes differ in their perception of the limit of care. End-of-life dilemmas can range from always sustaining life regardless of the prospect of severe morbidity (sanctity) to limiting intensive care (quality).

Methods: Translation, adaptation, and validation into Italian of the "Pediatric Resident Perception and Participation in End-of-Life Care" questionnaire by Niehaus et al. With the author's permission, forward and back translations were carried out by dual operators, and a panel of experts evaluated the content validity.

Results: 100 questionnaires analyzed (15 physicians, 85 nurses), majority women (n=84), Catholic religion (n=74, atheists 21, non-Catholic Christian n=5), total experience >5 years (n=91), CPP experience (n=81) not always extensive (zero assisted families n=17, one-two families n=21). CVI-I and CVI-S were satisfactory according to literature criteria; Cronbach's alpha was 793. Perception of inadequate training received (n=61), failure to inform families of CPP options (n=31), insufficient involvement of CPP team (n=45), discomfort with opioid administration (n=18), discussion of goals with family (n=35), dissatisfaction with team's ability to discuss goals with family (n=54) and poor post-mortem debriefing opportunities (n=34) emerged. Communication skills regarding bad news were a primary educational need (Me=5[4-5]) with no distinction between physicians and nurses (p=0.349) or PPC experience (p=0.701).

Conclusions: The Italian version appears adequate to detect different perceptions of the limit of care during EoL pediatric care between physicians and nurses. The questionnaire identified the gap in training in specific areas of PPCs as a priority area for implementing particular interventions.

Current Models of Providing Perinatal Palliative Care in 4 Perinatal Centres in the Czech Republic

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Background and Aims: Perinatal palliative care in the Czech Republic has received increasing attention in recent years, but models of its implementation in hospitals have not yet been described. The aim of the project was to describe the specific experiences of health care providers working in tertiary perinatal centers in the country and to identify models of care used for implementation and formation of perinatal palliative care teams.

Methods: This project was conducted in January 2024 by a working group composed of leaders of hospital-based pediatric and perinatal palliative care teams, with support from professional societies. Data were collected using online focus groups and questionnaire survey method. In total, 4 focus groups were conducted with the aim to identify common and different elements of provided hospital-based perinatal palliative care and describe the advantages/disadvantages of care provision across different settings.

Results: Representatives from 4 perinatal centers with a developing perinatal palliative care program were included. Based on the data collected, 3 basic models of perinatal palliative care delivery were identified describing the organizational structure of teams, forms of interdisciplinary collaboration, and other specifics of care. The models of care were defined as "specialized", "integrated" and "combined".

Conclusions: Although the study was conducted with a selected sample of the tertiary perinatology centers operating in the country, the finding brings a novel insight into the models of perinatal palliative care delivered within a specific cultural context. The presented advantages and pitfalls of the identified models of care offer inspiration for other centers, help to advocate for the integration of perinatal palliative care into current development of palliative care and strengthen cooperation between palliative care providers.

The work did not have external funding; participants were involved without remuneration.

End of Life Care Utilization in Pediatric Oncology Patients in Latvia: An Observational Study

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Background and aims: Palliative care (PC) aims to improve quality of life for patients and their families. For better PC integration in paediatric oncology patients in Latvia, we must recognize the complex determinants of PC utilization in these patients and their main disease characteristics.

Methods We conducted a retrospective descriptive study with a national-wide active search for all pediatric oncology patients treated at Palliative Care Centre (PCC) between January 2019 to November 2023. Data collected included demographics, disease characteristics and PC support, specifically documenting existence of treatments prescribed by PCC.

Results During study period 2019-2023, median 43.8 children per year were diagnosed with hemato-ongological disease, additionally 10 cases of CNS tumour yearly (children population in Latvia – 361 000 in 2023). During five-year study period total 20 pediatric oncology patients were identified receiving palliative and end of life care in Latvia. Most common oncological conditions were CNS tumour in 11/20 (55%) patients, Ewing sarcoma 3/20 (15%) and osteosarcoma in 2/20 (10%). Four patients died at hospital, however 16/20 patients had home-based death care. The most common PC treatment included pain and nausea relief.CC.

ConclusionsThe evidence presented affords great insight into the current situation in Latvia for pediatric palliative care involvement, current utilization of palliative care services in the care of children with cancer and their families. These include managing symptoms, providing psychological support and facilitating discharge from the hospital for children nearing end-of-life.

The Impact of the War in Ukraine on Pediatric Palliative Care: A Study from our Center

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Background and aims: to assess the impact of the war on the opportunities of families with children with disabilities.

Methods: evaluations were conducted with 110 families using the SF-36 questionnaire before the war, at the onset of the war, and after the return and adaptation of evacuated families.

Results: anxiety testing prior to the war revealed the following outcomes from the pre-war assessment using the SF-36 questionnaire: 56.67% of parents attained an average quality of life rating, while 49% scored lower on the quality of life assessment. Only 3% of parents received a low quality of life rating. Results of testing after 2 years of war: 29.17% of parents scored an average quality of life, 45.83% of parents had a diminished quality of life score, 25% were nearing a low quality of life rating. Evacuation of families at the beginning of the war: Out of 110 families, 36.36% evacuated. After 1.5 years since the start of the war, 16.67% of families returned. The lowest scores quality of life were predominantly observed in the vitality and mental health scales. According to the Hamilton Anxiety Rating Scale (HAM-A), it was found that 15% of parents are at potential risk of anxiety disorder, 69% experience mild anxiety, and 11% experience moderate anxiety.

Conclusions: factors affecting parents' well-being: financial instability directly impacts their ability to support their child's life. There is anxiety about power outages as many devices crucial to children's well-being rely on electricity. Fear of losing loved ones who are involved in the war. During wartime, levels of anxiety and depression notably escalate, particularly among those caring for children with disability. These findings highlight a significant adverse effect of war on the mental and physical health of parents tending to severely ill children. Therefore, providing support and counseling services to parents is imperative.

Bridging Intensive snd/or Palliative Care in SMA Type 1? a Case Report

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Background and aims: Notwithstanding the new therapies, type I spinal muscular atrophy (SMA1) is still characterized by a high clinical-care complexity and is potentially life-threatening, eligible for pediatric palliative care (PPC) since diagnosis. Multidisciplinary management is needed to address complications and improve quality of life.

Methods: The story was described of E., 3-month-old Albanian baby born to term and brought to the pediatric emergency department by his parents for severe hypotonia and respiratory distress. He was admitted to the Neonatal Intensive Care Unit (NICU) and diagnosed with SMA1.

Results: The neurological evaluation showed a serious situation (CHOP Inted 2/64). Risdiplam therapy was started. For intercurrent infectious conditions, non-invasive ventilation (NIV) was used up to 24h/d, showing difficult weaning. The easy fatigability of spontaneous oral motor skills required enteral feeding by nasogastric tube. The language barrier and difficult acceptance of the disease have complicated parents' awareness. The slow improvement in the child's clinical conditions, the issue of the appropriateness of choices and the presence of factors of social fragility in the family unit led the staff to activate the PPC team. It was decided to activate simultaneous care focused on the appropriateness of choices and admission. E. was transferred to a pediatric hospice for continuity of care and a home-care network organization. He underwent respiratory, neuromotor and speech therapy rehabilitation activities daily. The training of parents was continued. The family was supported from a social and psychological point of view. E. was discharged after 45 days in NIV 12h/d., with enteral feeding by mouth and gastric tube and neuromotor improvement (CHOP Inted 29/64).

Conclusions: Early collaboration between the NICU, neurology, and PPC proved to be a winning strategy to ensure adequate care, appropriate therapeutic-care choices and better quality of life.

School Inclusion of Children and Youth in Pediatric Palliative Care: A Retrospective Study

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Background and aims: The school is a crucial environment for children and is one of the network nodes coordinated by the pediatric palliative care (PPC) service; it is the environment where clinical, psychological and social needs intersect. Education is a fundamental children's right but most studies focus on children with physical or mental disabilities, while there is little research on the school experience of those in PPC. This study aims to analyse the school placement of children in palliative care in an Italian region.

Methods: The retrospective study involved 190 children and young people with life-limiting and life-threatening diseases, followed by a PPC network. Researchers collected data through medical records and telephone calls to caregivers. Two items of the International Classification of Functioning, Disability and Health, Children & Youth V. were used to assess mental and psychosocial functions.

Results: 30.9% of school-age patients do not attend school. Clinical severity (48%) and parental decision (25%) are the main reasons. Most have severe intellectual and psychosocial impairments (75% and 63.5%). 69.1% of patients attend school, average attendance is 75.6% of school hours. School support includes school assistants (59.4%) and support teachers (69.02%). School attendance decreases with the severity of impairment. Patients with mild or no cognitive impairment have higher care coverage (76.08% and 69.57% of school hours). The presence of feeding and ventilation aids is associated with lower school attendance.

Conclusion: Because of the complexity of care for out-of-school patients, the families bear the burden of care. Patients who attend school are mainly enrolled in high school; few autonomy and independence projects are available. School inclusion is not homogenous; further studies are needed to understand how to give personalized responses to patients' needs.

Barriers & Opportunities for Perinatal Palliative Care: A Nation-wide Mixed-Method Study

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Background: The importance of perinatal palliative care (PPC) is paramount in pediatric palliative care due to the numbers of affected families. The aim of this study was to map the current state of PPC in the Czech Republic, including the scope of existing services, expectations, and collaboration with staff at perinatological centers, as well as to identify barriers to further development in this field.

Methods: The project consisted of 3 interrelated studies employing different methods. A total of 26 perinatal centers for intermediate and intensive care participated. The first study utilized publicly available statistics to define the target population. The second study used semi-structured interviews with 38 healthcare professionals from perinatal centers. The third part surveyed 590 staff to gauge understanding and expectations of PPC through a comprehensive survey.

Results: The findings indicate challenges in defining the exact number of children and families who could benefit from PPC due to unclear indication criteria and inconsistent data. Results of interviews and the survey recognized the importance of PPC, including the cases of medical termination of pregnancy and stillborn care. Experience varied across centers, with intermediate care staff reporting fewer PPC cases. Significant barriers included lack of personnel, inadequate education, insufficient space, and emotional burden. Notably, differences were observed among specialties, with neonatologists reporting higher levels of palliative care education and awareness compared to gynecologists and pediatricians.

Conclusions: Despite institutional support for PPC, practical implementation is hindered by negative attitudes towards palliative care, lack of professional support, and resource constraints. To improve PPC, it is essential to address educational needs, enhance interdisciplinary collaboration, and ensure the availability of specialist teams and resources.

Funding: Vlček Family Foundation.

Methodology of System Integration of Palliative Care in Pediatric Patients with High-Grade Gliomas

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Background and aims: Pediatric CNS tumors are the most common solid tumors in pediatric oncology. Unfortunately, they are also associated with the highest morbidity and mortality rates in the field. Pediatric high-grade gliomas (HGG) account for approximately 10% of these tumors and are associated with a devastating prognosis of long-term survival < 10%. Early and systematic integration of pediatric palliative care (PPC) for these patients and their families should be an integral part of their primary oncology care with the aim of ensuring the highest possible quality of life in the course of this catastrophic disease.

Methods: The Centre for Pediatric Neurooncology at the Motol University Hospital in Prague centralizes the care of most patients with HGG in the Czech Republic. There are in average 10 such patients in our centre every year. Pediatric Supportive Care Team (PSCT) cooperates with primary neurooncological team from the moment of diagnosis.

Results: Based on the Model of Routine Tiered Palliative Care Integration in Hematopoietic Cell Transplantation at St. Jude Children's Research Hospital published by Levine et al. in 2022 we developed a model of the PPC integration in the primary neurooncological care of patients with HGG. Predefined time points in the patient's treatment trajectory were identified for the PSCT to meet with the treating neurooncologist and the family (diagnosis, radiotherapy, MRI evaluation, clinical deterioration etc.). This model allows for optimal patient symptom management, appropriate navigation of care goals, including end-of-life care.

Conclusions: Early integration of PPC is crucial to ensure the highest possible quality of life for patients with HGG and their families. We are setting up a new model of palliative care integration for these patients and collecting initial data on its effectiveness. Further research is needed to assess the feasibility of implementation this new model.

Supported by Vlček Family Foundation

The Realities of Children's Hospice in Ukraine with Challenges and Opportunities

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Background and Aims: This study aimed to foster collaboration with parents of children with disabilities by assessing parental needs, gauging societal support, and identifying areas for societal development in understanding disabilities.

Methods: An online survey was conducted using Google Forms within a mobile hospice's internal parents' group. The survey included both multiple-choice and open-ended questions to evaluate public awareness and support for families with children with disabilities. Ethical considerations were observed. Data collection took place over a specified period, and statistical analysis was employed to identify trends and group characteristics.

Results: The survey found that 62.9% of respondents were only partially informed about their rights, with 17.1% receiving no assistance and only 20% satisfied with the support. A significant majority (82.9%) expressed a need for medical assistance, while 45% emphasized financial, social, and psychological support. Inclusive education was negatively viewed by only 2.9%. Only 14.3% rated cooperation in educational institutions positively. Attitudes towards children with disabilities included prejudice (54.3%), lack of observation (37.1%), and 8.6% not noticing it. Avoidance of meetings with families of children with disabilities was reported by 77.1% due to fear of misunderstanding, 48.6% due to lack of information, and 8.6% due to fear of physical violence. Societal attitudes towards individuals with disabilities ranged from empathy (57.1%) to acceptance (42.9%), indifference (11.4%), and negative emotions (<10%).

Conclusions: The study underscores the need for better public education on disabilities to alleviate difficulties for parents of children with disabilities. These parents require strong support from their communities, healthcare providers, and the government. Inadequate public awareness and limited support for mobile hospice patients were apparent, highlighting gaps in assistance.

Which Minors are Eligible for Palliative Care? a Tool for the Training of Healthcare Professional

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Introduction and aim The timely introduction of palliative care can significantly improve the quality of life of minors suffering from an incurable pathological condition and/or serious disability, and of their families. However, even today we are witnessing a lack of response to the required need with a strong delay in the implementation of what has been described at a legislative level. In the Italian reality, only 15-18% eligible minors have access to pediatric palliative care (PCC) services. One of the main causes of this situation is the significant lack of training of healthcare workers regarding PPC. The aim of the work is to develop a tool for training health workers regarding the early identification of children eligible for PPC.

Methods An observational study was carried out on cases of minors suffering from incurable pathologies admitted to an Italian pediatric hospice in the period September-December 2023. Five different clinical histories were identified on the basis of the eligibility criteria reported in the international standards for PPC and the scores of the assessment form of complex clinical care needs in pediatrics (ACCAPED), a tool validated in Italian for the identification of the need for palliative care in the pediatric field.

Results Five different narratives were drawn up for the analysis of the cases, each referring to a minor in the care of the PPC service. For each case, the eligibility condition, the pathological condition and the green lights for the eligibility of the pediatric subject for PPC were described. Finally, the ACCA PED score was calculated, from which the level of care complexity was derived.

Conclusion Training tool allows healthcare professionals to learn new skills and an assessment method that allows for early identification of children eligible for PPC.

KoCoN: A New Horizon for Children with Chronic Complex Neurological Conditions

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Children with complex chronic neurological conditions often depend on medical assistance, including home ventilation. Thanks to advances in medical care and drug therapy, the number of these patients is growing steadily. Their care is extremely demanding and complex. In Germany, there is a lack of integrated, interdisciplinary, and multi-professional care structures that address the needs of these young people and their families. This is where "KoCoN" comes in.

KoCoN is an inpatient care pathway designed specifically for children with complex chronic neurological conditions and their families. It aims to improve symptoms and disease management, enhance quality of life, and empower patients and their families. KoCoN provides interdisciplinary and interprofessional treatment decisions that are family- and patient-centered, following the “choose wisely” approach. The main components of KoCoN are: i) a comprehensive assessment of the patient, ii) single-sourced coordinated interdisciplinary management of diagnostics and treatment iii) multi-professional case management iv) early integration of advanced care planning, and v) intersectoral use of digital health applications.

KoCoN is funded by the German Federal Joint Committee (G-BA).

Experiences of Parents Caring for a Child with a Life-Limiting Condition in an Inpatient Setting

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Background and aims: Children with life limiting conditions (LLC) are exposed to frequent hospitalizations with their parents as indispensable supporters, even in inpatient care. Data on the experiences of parents in a hospital setting are scarce. This study aims at identifying the burdens and needs of parents of children with LLC in an inpatient setting to promote family-centered care and thus strengthen parents as effective partners in care.

Methods: Descriptive qualitative interview study with purposeful sampling and analysis according to the coding method of Kuckartz. A total of 10 interviews with parents (7 mothers, 3 fathers) was included in the analysis.

Results: Parents reported three main topics: (1) structural conditions, (2) commitment and competence of health care professionals, and (3) cooperation between parents and professionals. Parents felt that the professionals were overburdened with the complexity of the disease and the fate of the child. They perceived a lack of communication and psychosocial care. Parents want to be recognized as experts for their child and at the same time wish to hand over medical responsibility to professionals and receive expert guidance. They highlighted the importance of specialized inpatient structures, such as pediatric palliative care (PPC) units.

Conclusion: Parents acquire medical expertise during their child's illness. However, their competence is often denied in the inpatient setting. Parents should be supported as equal partners in care to improve the quality of their children's care. Cross-structural competence, open communication, and psychosocial support can help relieve parents. Enhancing PPC competence through teaching and provision of specialized services such as consult teams or dedicated PPC inpatient units may help to strengthen the parents' role and confidence.

Psychosocial Support in Paediatric Palliative Care – A Teamwork

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Background: Based on international standards and definition, in 2021, the first national care program for paediatric palliative care was published in Sweden. The care programme states that children with life-threatening or life-limiting illness, and their families, should have access to psychosocial support alongside care. Previous research, however, show there is a knowledge gap regarding if or when psychosocial support is offered and what the support consists of. Therefore, it is of interest to explore how healthcare professionals perceive psychosocial support and their views of if and when it is offered child and family.

Aim: The aim of this study was to explore how healthcare professionals perceive psychosocial support for children with palliative care needs and their families.

Method: This is a qualitative study where the data material was collected through three focus group interviews and two individual interviews which were analyzed using thematic analysis.

Results: Healthcare professionals viewed psychosocial care as best provided through a team approach: All healthcare professionals can identify and acknowledge psychosocial support needs, offer and implement general psychosocial support in daily care by listening, acknowledging what is being expressed, and being supportive in their daily practice. Specialized psychosocial support, however, is best provided by healthcare counselors, although results show that access to healthcare counselors differs.

Conclusions: This study shows that healthcare professionals value psychosocial support and perceive it as important and best provided when working in interprofessional teams. However, for those in need of specialized psychosocial support, healthcare counselors are needed, although this study implies psychosocial support is not provided on equal terms since access to healthcare couselors is limited.

Creation of an Online GP Referral App for Inhouse Requests within a Children's Hospice

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Background: Children who attend a children's hospice often have complex needs that require frequent medical reviews by a GP and adjustments to their medication regimen. A paper request book was used for jobs to be done by a GP when they were onsite. As GP cover expanded it was not practical for the GPs to share the one physical book and was harder for nursing staff to submit requests or to sign off that a task had been checked after completion.

Aim: To move the system online so multiple staff could access the information at the same time.

Methodology: After the successful implementation of other apps through Microsoft PowerApps, an app was developed to log requests to the GP's. A SharePoint page was designed to support this process. This allows everyone to track the request and its status as, 'in progress', 'completed by GP' and 'signed off by nursing staff'.

Results: The app allows staff to input requests from anywhere onsite, remotely or on community visits. An alerts system was built-in, so the team are notified when follow-ups are required. Reports can be easily generated and filtered by child or medication, and logs the staff involved in requests. Children's names are auto populated, and this reduces any errors with spelling/eligibility.

Conclusion: The app has been a successful innovation that has improved the quality and timeliness of care for the children. Staff can input, track, and sign off requests from anywhere, and has reduced errors and delays. Communication and collaboration between the GP and nursing teams has been enhanced. It has provided useful data for reporting and auditing purposes. The app has been welcomed by staff and is subject to ongoing reviews and feedback. Its success has prompted the exploration of how the app could be extended to other areas of the hospice.

The Challenges of the Pediatrics Palliative Care in Kharkiv

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Background and objectives: to describe the provision of palliative care to children in a front-line city during the war (humanitarian crisis) in Kharkiv.

Methods: description of the "Status Quo" of pediatric palliative care services for children during the military conflict and identification of the problems of providing palliative care in a frontline city.

Results: Before the military aggression, a children's hospice, a regional center for palliative care for children, and mobile services worked in Kharkiv region. During the war, access to palliative care depended on territory controlled by Russia or Ukraine. In the first days, the logistics of providing medical and palliative care, except for III-level hospitals, was destroyed. Many medical staff were refugees, parent organizations were non-functional, and access to medication and transportation was limited. There were a lot of deaths all around... In general, society was not prepared for what to do in times of crisis. In 2022, part of the families and staff of the Regional Center "Hippocrates" were evacuated to Germany. In 2023, the Hippocrates Regional Center began to provide services to children and their parents without a residence, and to those who can safely get to the Center. In 2024, a mobile brigade gradually became operational. Bomb shelters were adjusted. We emphasize what we lack: coordination functions, staffing, telemedicine and other points of contact, information about services in the community, knowledge about palliative care during a humanitarian crisis, proper social care, a patient registry, accessibility to our compatriots in the occupied territories, pain relief (opioids) in individual first-aid kits, bereavement support and end-of-life care and post-funeral support.

Conclusions: the experience of a frontline city in providing palliative care to children can be used for society to prepare for humanitarian crises and improve access to palliative care services.

"Your Presence Matters": A Journey of Pediatric Palliative Care in Nepal

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Background and Aims: Pediatric Palliative Care (PPC) is the total active care of child's body, mind and spirit and supporting their families in their unique journey. Nepal is in the early stages of development of PPC. Palliative care for children with developmental disorders including cerebral palsy, Down's syndrome muscular dystrophy, genetic disorders and autism spectrum disorder (ASD) is an established service at our hospital. The aim is to provide children and family centered holistic care to children with developmental disorders in Pokhara.

Method: A 3 day residential program "LILY KO BAGAICHA" for children with developmental disorders and their families is run by a multidisciplinary team of pediatrician, nurses, physiotherapist, occupational therapist, speech and language pathologist, counselors, patient advocate and day therapy in-charge.

'LILY' symbolizes 'LOVE', 'PURITY' and 'REBIRTH' and 'BAGAICHA' in Nepali is 'A GARDEN'. These children represent Lily and the program, the Garden, where they can be nurtured.

The program includes introduction and sharing of expectations, detailed clinical assessments by each specialist, with social, psychological and spiritual assessments to identify issues, interventions and formulate management plans. Group educational sessions, play therapy, fun activities to explore their areas of interest, and counseling sessions are provided.

Results: From June 2023- June 2024, 5 programs have been completed with the participation of total of 24 children (age 4 to 21 years) and 27 caregivers/parents, where families have highly benefited and expressed gratitude for creating such an environment where they felt welcomed with their children and felt loved and cared for. This has encouraged our team members to be present and available for these families.

Conclusions: Integration of pediatric palliative care in developmental disorder brings hope for children and their families who face isolation from the society and face social stigma.

Palliative Care for Children with Neuromuscular Diseases (NMD) in Kazakhstan

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Background and Aims: Kazakhstan's demographic is represented by large families with diverse ethnic and religious backgrounds. Various factors, including close marriages, lead to the birth of babies with terminal illnesses that require pediatric palliative care (PPC).

Methods: We present our own experience of palliative care for children with NMD. Families with multiple (2 or more) children with NMD were selected as the most challenging population to follow. Current status of 18 families with multiple DMD and 11 families with multiple SMA siblings reported.

Results: We observed 38 children in families with DMD, of whom 16 experienced the loss of ambulation (3 were from the same family) and 24 SMA children, of whom 5 were sitters and 10 nonsitters, that necessitated respiratory support. 15 patients with SMA were treated with Nusinersen. All patients received individual Ambu bags, however there is limited opportunity to provide cough machines and non-invasive ventilation for each child. Therefore, a single device is used in a family with individual circuits, filters, and masks. Children are located in different cities across the country, and it is not possible to examine and adjust the devices in person. We use video communication for the management of care in children, involving doctors who are not PPC specialists. With guidance and instructions, they can provide adequate feedback for proper remote adjustment of the equipment. We also use patient education videos and request video feedback from patients to assess the appropriateness of their actions.

Conclusions: PPC is only being implemented locally, and there is only one center for palliative respiratory support in Kazakhstan. We recognize that this care management model is an ideal one, but it at least deserves access to basic life-supporting care. There are many places around the world where PPC is absent or underdeveloped. We believe that our experience will inform PPC development in resource-limited settings.

Navigating Emotional Turmoil: A Case Study in Paediatric Palliative Care for a Boy with Brain Tumour

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Diffuse intrinsic pontine glioma (DIPG) is a devastating paediatric brain tumour with limited treatment options. Early involvement of palliative care aims to enhance the quality of life through symptom management and family support. This case report explores the complexities of family dynamics and decision-making in paediatric palliative care.

A 10-year-old boy diagnosed with DIPG and his parents were under the care of a paediatric palliative care team from diagnosis. Despite multiple sessions, the father, under significant stress, prohibited documentation of these discussions in the medical records. Both parents agreed to a Do Not Resuscitate (DNR) order. Following radiotherapy, as symptoms worsened, palliative medication was set during hospitalization. Subsequent care transitioned to home hospice.

The boy experienced respiratory distress at home due to aspiration, prompting the parents to call an ambulance. In the high-pressure scenario, the father insisted on life-saving measures, leading to the child’s intubation and transfer to the ICU. Despite intensive care, the boy passed away within 3 days. This situation highlights the difficulty parents, particularly the father, had in accepting the prognosis, resulting in a deviation from the established palliative care plan.

This case underscores challenges in aligning palliative care goals with parental expectations and emotional responses. Despite early and frequent communication, the father’s inability to accept the prognosis led to decisions that temporarily extended the boy's life, potentially providing the parents time to come to terms with the inevitable outcome. Regret and emotional distress significantly influenced the parents' decisions. This case emphasizes that intensive communication and support are crucial, yet acceptance of a child's terminal condition may remain elusive for some parents, impacting adherence to palliative care plans.

Ethnicity and Cultural Diversity in a Children’s Hospice

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Background: Ireland is an increasingly diverse society, 17% are non-Irish with many choosing to have and rear their families here. There is limited data on the ethnicity of children who live with a life-limiting condition or die in childhood. International policy, and our national health provider advocate that existing health data should include an ethnic identifier to address inequality and prevent discrimination. This lack of national data led us to profile the ethnicity of the children we provide care to.

Ethnicity refers to a shared culture and way of life, as reflected in language and religious practice, clothing and food, and music, literature, and art. Providing culturally sensitive care is central to children’s palliative care.

Aim: To review the ethnicities of children availing of palliative care in a children’s hospice to inform future staff training.

Methods: Anonymised data on ethnicity was collected from our electronic database of the active children attending our service.

Results /Discussion: Capturing ethnicity data is optional for families. Of the 452 ‘live’ children, 68 had their ethnicity captured (15%). This includes Irish 72%; Irish Traveller 4.5%; Any other white background 10%; African 1.6%; Black or Black Irish1.6%; Indian/ Pakistani/ Bangladeshi 3.2% or Not specified 3.0, and all others Blank. The low rate of ethnicity capture is multifactorial, staff feeling uncomfortable asking personal information, that it is not relevant and our list of ethnicities do not match the census data, thus families may feel their ethnicity is not relevant and leave this data field blank..

Conclusion: This review of the ethnicity of our children offers us more questions than answers. National policy advocate that we should collect it. Our latest strategy has an increased focus on EDI (Ethnicity, Diversity and Inclusion) but before we design cultural diversity training, we must improve ethnicity data capture on referral / admission?

The Best "Quality of Life" in PPC: from Quality of Life to Quality of Life Relationships

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Background and Aims:"Quality of Life" (QoL) is a key concept in applied ethics. There are many studies on the topic of QoL as a functional parameter with respect to incurability and terminality. It is, therefore, a criteria to be relocated that cannot depend on accidental qualities, but on the value of human life itself. Pediatric Palliative Care (PPC) intervenes to safeguard life until death and represents the context in which hospice is embedded. The study will assess how the patients QoL can be improved in hospice. In particular: 1) Repositioning the QoL criteria in order to focalize on the quality of life relationships, starting with moral values and human virtues (consolation - compassion - hope - time) that define PPC; 2) Highlighting how hospice and PPC are functional in improving QoL through enhancing the quality of life relationships; 3) Establishing that the quality of life relationships can become the new ethical criteria utilized in ethics-clinical consultancy.

Methods: Descriptive, observational study. Twelve-month duration. A questionnaire was drawn up from scratch aimed at understanding the perception of a target population with respect to the phenomenon of interest. The questionnaire was validated through a focus group composed of clinicians and family members and was submitted individually to family members of patients in residential settings.

Results: The data analysis showed that hospice and PPC are functional in improving QoL through enhancing the quality of life relationships and that, the latter, can become a new ethical criteria in ethical-clinical consultancy.

Conclusions: Improved QoL in terminality means enhancing the quality of life relationships. The latter can, therefore, be considered as a new ethical criteria in ethical-clinical consultancy. The challenge is therefore, its inclusion in future medical practice for the well-being of the patient at the end of life so that it becomes a transdisciplinary goal of the palliative care team.

Syringe Driver Usage in Paediatric Oncology Patients at End of Life

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Background and Aims: Syringe drivers are an essential option when managing end of life care in a paediatric population. With escalating symptom complexity, a syringe driver can support the continuous delivery of multiple medication to manage a variety of symptoms. Our study aimed to review all paediatric oncology patients receiving end of life care and use of a syringe driver.

Methods: We retrospectively analysed 48 electronic health records and corresponding death summaries of patients who died between 2022-2023, excluding 10 further records due to incomplete data, from a specialist paediatric palliative care oncology service. Data on patient demographics, clinical diagnoses, symptoms and medication regimens administered via syringe driver were extracted.

Results: 32 patients (66.7%), aged 2-17 years, required syringe drivers at the end of life; 16 (87.5%) solid tumour, 17 (65%) brain tumour and 1 haematology (16.7%). Driver usage ranged from 1-37 days; mean 11.6 days. Drivers contained a range of 2-6 medications; 59% requiring ≥4. More solid tumour patients (64%) received ≥4 multiple drugs in their driver compared to 52% of those with brain tumour. Notably, 3 patients (9%) necessitated 2 syringe drivers. The most commonly combined and used drugs were midazolam (n=35), morphine (n=20) and cyclizine (n=23). In total 15 medications were used in 26 combinations.

Conclusions: Our study highlights the ongoing importance of syringe drivers in managing symptoms at the end of life. The number of medications, their combinations and the second driver use illustrate the need for robust evidence regarding drug compatibility to support clinical practice. It also supports better patient care and service planning such as disease specific anticipatory drug prescribing. Identifying frequently used parenteral medication at end of life also tailors education and training around medication used at end of life for different patient cohorts.

Spiritual Dialogue between Pediatric Neuro-oncologists, Patients, & Caregivers

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Background: Spiritual care is recognized as a vital element of psychosocial support for children with cancer and their families. Pediatric oncologists lack training in navigating spiritual communication. The current landscape of spiritual dialogue during clinical oncology encounters remains understudied.

Methods: U-CHAT is a prospective longitudinal study of serial audio-recorded disease evaluation conversations between pediatric oncologists, patients, and caregivers across 24 months or until the child's death. Rapid qualitative analysis was conducted to identify, summarize, and synthesize religious and spiritual dialogue during disease evaluation conversations for a cohort of patients with poor prognosis brain tumors.

Results: A total of 129 discussions, encompassing 30 patient-parent dyads and 7 oncologists, were audio-recorded, transcribed, and analyzed. Spirituality references were found in 18% of encounters (n=23), including 37% of dyads (n=12) and all oncologists. Patients and caregivers introduced spirituality more often than oncologists (65% vs. 35%). About half of spiritual references were related to "prayer" (12/23 encounters with 8 dyads). "Prayer" language often emerged during dialogue about decisions and uncertainty, particularly related to disease response, progression, or therapy options. "Prayer" language sometimes alluded to spiritual/religious practices; other times, "pray" alluded to "hope." One oncologist prayed with a family at the parent's request. Less common spiritual references included greetings (e.g. "Inshallah"), blessing, miracles, church, fate, and holy objects.

Conclusions: Fewer than one in five disease reevaluation encounters contained spirituality dialogue. When present, "prayer" language was evoked by patients, parents, and oncologists and referred to a range of ideas and practices. Future work will examine when and how "prayer" may open the door for spiritual needs assessment and support for patients and families.

There's Always a Way... to Play. Insight into the Diary of a Child Life Specialist in Palliative Care

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Background: In many countries, child life specialists (CLS) are full members of the hospital staff, but only in some of them are they also an integral part of palliative care teams. They help children and families meet the psychosocial needs during illness and therapy and process loss through “play“. Although multidisciplinary palliative teams are rapidly developing in the Czech Republic, they do not include this profession. The aim is to describe the challenges of integrating CLS into multidisciplinary teams in hospitals, based on first experiences of a CLS from a new organisation dedicated to developing child life work in paediatric palliative care in the country.
Methods: The first challenges were identified during staff meetings and child life interventions with families lead by the CLS in two university hospitals in the Czech Republic. They were captured ethnographically after each session by recording field notes into the specialist's diary from January to May 2024 (total: 30 hospital visits, 30 children + parents, 55 interventions) and then analysed using inductive thematic analysis (conducted by the CLS with an external supervisor).
Results: Five key challenges related to integrating CLS into palliative care were identified: *the enormous variability in the conditions and emotional states of children and families*; *lack of awareness among carers of the purpose of CLS work*; *integration into the structure of hospital care*; *insufficient capacity of one specialist in the hospital to work with all families who wish to do so*; *sense of loneliness in the profession*.
Conclusions: These data show what needs to be focused on when integrating CLS into the multidisciplinary palliative team: *education*, *appropriate training for CLS in palliative care setting*, *anchoring the profession in the palliative care system*, *research*, *awareness-raising activities* and *collaboration with team members* to provide the best quality possible and to reach more families who can benefit from it.

Access to 24/7 Telephone Advice from Specialist Paediatric Palliative Care Nurses Improves Choice

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Background: Access to 24/7 specialist palliative care support is identified as a quality standard for end-of-life babies, children, and young people. This paper describes the findings of a pilot project to implement 24/7 specialist nursing support across a region within England with the aim of improving access, quality, and sustainability.

Method: A mix of quantitative and qualitative data has been collected through data collection, feedback forms from families and professionals, focus groups and 1 -1 conversations.

Results: Interim results: n=79 calls 61% within working hours, 7% after midnight, 83% of out of hour calls were at a weekend. 93% of calls responded to within 15 minutes. Further advice needed - on 7 occasions. 6 calls to an advanced clinical practitioner within the team and 1 to child's consultant to confirm change to plan. Outcome of calls - out of 79 calls made to the service 3 needed transfer to hospital. 1 was transferred as this was the action to take in the BCYP escalation plan, 1 BCYP was on holiday out of area and 1 BCYP was admitted and discharged later the same day.

Discussion: The service is making a difference and is providing a choice of place of care to families. The service is having a positive impact by enhancing the quality of end-of-life care for BCYP, avoiding unnecessary contact with hospitals, GPs and out-of-hours services. At least 34 hospital admissions/contact with GP services up to end of March 2024 that have been avoided with one BCYP having a facilitated discharge from hospital to home.

Memory-Making Interventions in Pediatric Palliative and Bereavement Care: A Systematic Review

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Background and aims: Addressing the emotional and psychosocial needs of children in pediatric palliative care and their families is crucial. Memory-making interventions (MMIs) help capture cherished moments, fostering emotional resilience and creating lasting legacies. However, there is limited consensus on the scope of these interventions. This systematic review aims to synthesize evidence on MMIs for children with life-limiting or life-threatening (LLLT) conditions and their families receiving palliative or bereavement care.

Methods: Following PRISMA guidelines, we conducted a systematic search from 1985, to February 27, 2024, across PubMed, EMBASE, CINAHL, PsycINFO, Web of Science, Cochrane Library, and Scopus. Studies included various designs examining MMIs for children (0-19 years) with LLLT conditions. Screening, quality appraisal and data extraction were independently performed.

Result: Eleven studies were identified. MMIs in pediatric palliative care include activities like digital storytelling, videography, art-based(e.g. hand/footprints) interventions and integrating music into the legacy-making process. These interventions show small to moderate effects on psychosocial outcomes, with slight improvements in quality of life, family communication, and coping mechanisms. High parental satisfaction was reported. Families noted significant enhancements in emotional comfort, open communication, and meaningful mementos that aided in grief processing and family bonding.

Conclusions: MMIs are essential for providing emotional support and enhancing resilience. The review highlights the need for tailored, well-supported interventions to maximize therapeutic benefits. Addressing barriers like technological challenges and cultural sensitivities is key for effective implementation. These findings inform future research and intervention design to improve care quality for children with LLLT conditions and their families.

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FamilieFOKUS Psycho-Social Support to Families

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FamilieFOKUS is psychosocial palliative support funded by the Ministry of Health in Denmark.
An interdisciplinary team arranges individually interventions based on the needs of the entire family. The interdisciplinary staff which consist of the following professional groups: occupational therapist, physiotherapist, music therapist, psychologist, special educational consultant and nurse, works with the aim of improving the child's and family's quality of life, coping and well-being by offering physical, psychological, social and spiritual palliative support.
The model for interventions is flexible depending on the needs of the family. The choice of intervention is made in collaboration with the family during a background interview, where the child's and the family's issues are uncovered.
In addition, the families are offered to participate in our network courses. Here, the families can meet other families who are in a comparable situation.
The intervention can be offered in all phases of the child's course of illness - also early on as a preventive measure in relation to psychological consequences for the child and the family. The intervention is a supplement to the child's other treatment and can be used in connection with transitions, in the event of disease progression accompanied by complex palliative issues, as well as in crisis and strain reactions in the family. In FamilieFOKUS, we also provide support to families who have lost a child.

Understanding Sleep and Mental Health Outcomes in Parents of Children With LLCs/LTIs

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Background: Parents of children with life-limiting conditions (LLCs)/life-threatening illnesses (LTIs) experience physical & psychological burdens as a result of care, which could lead to increased risk of developing mental ill-health & sleep disturbance. However, there is limited research on prevalence of mental ill-health, or into the ways that sleep and mental health can affect this group.

Aims: 1) Systematically review prevalence and lived experience of mental health amongst parents; 2) evaluate sleep sensor technologies for use in research with parents; 3) develop a program of research on sleep and mental health for this group.

Methods: A systematic review of prevalence of mental ill-health in these parents was conducted [Prospero #CRD42023485442]. Sleep sensors were appraised using an existing three step framework. A research plan for exploring sleep and mental health together was developed.

Results: 4587 papers were reviewed for inclusion, 42 were eligible (34 quantitative, and 8 qualitative). Most research reports on anxiety (n = 20) and depression (n = 22), with few considering other mental health issues. Of the qualitative papers, three key themes were identified: (1) symptoms of mental ill-health; (2) disruptive effects; (3) how it feels to be a parent in this situation.

A broad range of device requirements were defined, analysed, and ranked. Two devices met the criteria for use in this population and thus may be suitable for further research.

Findings from the systematic review and the sensor appraisal give a clear indication of how to conduct future research on this topic.

Conclusions: Mental health needs of parents are under-recognised in clinical practice and policy. More research is needed to determine prevalence of conditions other than anxiety and depression and to qualitatively explore mental health of parents of children with LLCS/LTIs.

Sleep sensors for use in this population may need modification to account for the unique needs of caregiving.

Shepherding Parents in End-Of-Life Decision-Making for Children with Life-Limiting Conditions

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Background and aims: Decisions about life-prolonging treatments often arise as a child with a life-limiting condition approaches the end of their life. Shared decision-making is accepted as the best approach for making such decisions and both paediatricians and parents find benefit in preparing for this decision-making. However, little detail is known about this preparatory process. This study explores how paediatricians prepare parents for making decisions about life-prolonging treatments for a child with a life-limiting condition.

Methods: Individual semi-structed interviews of paediatricians following participation in a communication simulation with two medical actors playing the role of parents of a child with a life-limiting condition at a time of prognostic uncertainty. Verbatim transcripts were analysed thematically.

Results: Eighteen purposively sampled paediatricians who provide care in acute intensive and long-term outpatient settings were involved. Three key themes in a preparatory process (termed "shepherding") were identified: (1) paediatricians aim to lead parents along a pathway to future decisions about life-prolonging treatments; (2) paediatricians prefer to control the pace of these discussions; and (3) paediatricians recognise they need to have courage to face risk with this preparation. Paediatricians use a variety of shepherding strategies to influence pace, content and framing of discussions, which may help prepare parents to make the best treatment decisions when the time comes.

Conclusions: Shepherding is a newly identified process intended to influence parents in decisions about life-prolonging treatments by guiding their understanding of their child's health and potential suffering in advance of decision-making. Paced reflection, thinking and provision of information are shepherding strategies preferred by paediatricians. Further study about the intention of this influence and parental perception of this communication is needed.

A Project to Develop, Implement and Evaluate a Blended Learning Model in Paediatric Palliative Care

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Background: The number of babies, children and young people with life-limiting and life-threatening conditions has risen whilst the opportunity for paediatric palliative care education and training has remained stationary locally. The development, implementation and evaluation of this blended educational programme enabled trainees to have learning adapted to their needs whilst studying the link between new knowledge and confidence.

Methods: This project had two identified and interconnected workstreams: Workstream 1: Evaluation and Workstream 2: Blended Training Programme. Pre, Post, and delayed training evaluations focusing on confidence in skills were sent to all trainees attending both aspects of the training programme for voluntary completion. The blended training programme consisted of two elements: Element One six online lectures for those health care professionals who occasionally supported B with palliative and end-of-life care needs. Element Two, the face-to-face workshop was developed for specialist/ experienced healthcare professionals.

Results: Sample Size n= 98. Pre-training confidence levels were highest in the tertiary centres compared to the district general hospital. Trainees reported the lowest confidence levels in managing and treating distressing symptoms. Self-reported confidence levels were highest within the delayed evaluation results.

Discussion: The blended education programme improved the care of babies, children and young people with life-limiting and life-threatening conditions due to the increased confidence levels of the trainees. Substantial progress has been made towards filling the gap in children’s palliative and end-of-life education and training without underestimating the continued commitment and investment that is required.

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