



6TH MARUZZA
INTERNATIONAL
CONGRESS
ON PAEDIATRIC PALLIATIVE CARE

ABSTRACT BOOK



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Scientific Committee

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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 lipofuscinosis 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 Huijjer, 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: Miscellaneous 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 Bernadà, 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	Jurriane 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
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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 Perspective 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 Vilarrubi	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 access 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 Stöblein	14.50-15.00
C24	Palliative care for children with neuromuscular diseases (NMD) in Kazakhstan	Yuliya Streletskaia	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

The Challenges of the Pediatrics Palliative Care in Kharkiv

O. Riga¹, J. Marston², R. Marabyan³, A. Penkov⁴, I. Trofimov⁵, N. Konovalova⁶

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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.



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