



TOGETHER, FOR A BETTER TODAY.

ABSTRACT BOOK



3rd CONGRESS ON PAEDIATRIC PALLIATIVE CARE - A GLOBAL GATHERING
Rome, 16th - 19th November 2016

WITH THE ENDORSEMENT OF

The Italian Ministry of Health
With the patronage of the Italian Committee for UNICEF
Istituto Superiore di Sanità



PARTNERS



Scientific Committee

Franca Benini (Chair), Director of Paediatric Palliative Care – Pain Service Consultant in Paediatric Pain and Palliative Care, University of Padua, Italy

Ann Goldman (Honorary President), Paediatrician, Editor Oxford Textbook of Palliative Care for Children, (retired) Consultant in Paediatric Palliative Care, Great Ormond Street Hospital for Children, London, UK

Ross Drake (Co-chair), Clinical Director PPC and Complex Pain Services Starship Children's Hospital and Starship Children's Hospital, Auckland, New Zealand

Margaret Al-Sayer, Managing Director of Bayt Abdullah Children's Hospice in Kuwait City, Kuwait

Myra Bluebond-Langner, Professor and True Colours Chair in Palliative Care for Children and Young People, Louis Dundas Centre for Children's Palliative Care, UCL-Institute for Child Health, London England and Board of Governors Professor Anthropology, Rutgers University, Camden NJ, UK

Lizzie Chambers, Deputy Chief Executive, Together for Short Lives Bristol, UK

Julia Downing, Honorary Professor at Makerere University, Kampala, Vice Chair of the Scientific Committee for ICPCN, Honorary Research Fellow, Department of Palliative Care, Policy and Rehabilitation, King's College London, UK

Rut Kiman, Head Pediatric Palliative Care Team, Hospital Nacional "Prof. A. Posadas". Buenos Aires, ICPCN Board member representing Latin America, Argentina

Malin Lövgren, Karolinska Institutet, Dept of Women's and Children's Health, Stockholm, Sweden

Danai Papadatou, Professor of Clinical Psychology, Faculty of Nursing, University of Athens, Greece

Joanne Wolfe, Director Paediatric Palliative Care Children's Hospital Boston Division Chief, Paediatric Palliative Care Service Department of Psychosocial Oncology and Palliative Care Dana-Farber Cancer Institute Boston, Massachusetts, USA

Boris Zernikow, Director, Vodafone Foundation Institute of Children's Pain Therapy and Paediatric Palliative Care, Datteln and Chair of Paediatric Pain Medicine and Palliative Care, Witten/Herdecke University, Germany

Scientific Programme

WEDNESDAY 16TH NOVEMBER 2016

18.00 - 19.30 **Opening Ceremony**

Greetings

Keynote Lecture: The Significance of Integrated Care

Joanne Wolfe

Presentation of *No Pain for Children Prizes* for the Best Young Researchers' Abstracts

Keynote Lecture: "Religions of the World Charter" for Children's Palliative Care

Richard Hain

Presentation of *Vittorio Ventafridda Award*

THURSDAY

17TH NOVEMBER 2016

08.30 - 09.00 **Gaining insights:** Nourishing the senses

Massimiliano Alajmo - Defendente Mauro Febbrari

introduced by *Momcilo Jankovic*

09.00 - 10.30 **Plenary session**

Symptom Management: The Benefits of Integrated Care

Moderators: *Mercedes Bernad , Joanne Wolfe*

- Nausea and Vomiting - *Ren e McCulloch*
- Challenging Pain Syndromes - *Elliot J. Krane*
- Sleep Problems - *Ross Drake*

11.00 - 12.00 **Oral presentation session (3 in parallel):**

Working session I: Parents, Siblings and Family

Moderators: *Margaret Al-Sayer, Myra Bluebond-Langner*

- The Emotional Worlds of Parents of Children with Life-limiting Conditions
Bryony Beresford
- Parent Perspectives after Receiving an Early Palliative and End-of-Life Care Communication Intervention
Joan Haase
- A Model on Parenting and Parental Caregiving in Pediatric Palliative Care: A Qualitative Study
Marijke C. Kars
- Use of a Newborn's Diary in a Neonatal Intensive Unit (NICU): Parents Perceptions
Ana Lacerda
- Closing remarks

Working session II: Neurological Problems

Moderators: *Rut Kiman, Elliot J. Krane*

- A Pain Observed: A Phenomenological Study of Maltese Caregivers of Children with Severe to Profound Developmental Disability
Hermione Andrejevic

- Spinal Muscular Atrophy Type 1: Needs and Interventions from Diagnosis to Post-Mortem during a Pediatric Palliative Care Program
Chiara Di Pedè
- Seizure Management in End of Life Care for Children
Nicky Harris
- Spinal Muscle Atrophy: The Spanish Pediatric Palliative Care App
Alvaro Navarro-Mingorance
- Closing remarks

Working session III: Perinatal - Neonatal Problems

Moderators: *Marcello Orzalesi, Chakrapani Vasudevan*

- The Outcome of End of Life Care (EOLC) in a Tertiary Neonatal and Paediatric Intensive Care Unit in the UK
Abigail Callender-Iddon
- Development of a Multidisciplinary Regional Perinatal Palliative Care Pathway
Emily Harrop
- How do Neonatal Units Support Siblings Following Loss? – A National Survey
Reyhana Henderson
- Decision-making on Withholding Treatment and Facilitating Choices in Neonates with Congenital Ultra-short Small Bowel: Clinical and Ethical Considerations
Michelle Koh
- Closing remarks

13.30 - 14.30 **Oral presentation session (3 in parallel):**

Working session IV: Parents, Siblings and Family

Moderators: *Maggie Comac, Ulrika Kreicbergs*

- Communication at Diagnosis and at End-of-Life (EOL) in Complex Congenital Heart Disease (CCHD): Fathers' and Mothers' Perceptions
Francesca Benedetti
- Socioeconomic Needs of Families with a Child with a Life Threatening Disease during the Economic Crisis in Greece
Alexandra Gerardi
- Growing Family Strengths: Parent Views on the Potential Benefits and Acceptability of a Structured Group Programme to Enhance Resilience and Well-being in Parents of Children with Life Limiting Conditions and Complex Health Needs
Sharon McCloskey
- Symptom Prevalence and Parental Distress in Paediatric End-of-Life Care
Karin Zimmermann
- Closing remarks

Working session V: Pain Assessment and Control

Moderators: *Eva Bergsträsser, Lucia De Zen*

- The Use of Rapid Onset Fentanyl in Children and Young People for Breakthrough Cancer Pain
Lucy Coombes
- Suitability, Feasibility, Utilisation and Acceptability of Patient Controlled Analgesia in the Community for Children with Life Limiting Conditions
Ellen M. Henderson

- Effectiveness of Innovative Non-pharmacological Therapy with Puppy Humanoid Robot: A Observational Study
Giovanni Poggi
- Identifying and Treating Pain in Children with Advanced Cancer. A Pediatric Palliative Care Perspective
Manuel Rigal Andrés
- Closing remarks

Working session VI: Adolescents and Young Adults

Moderators: *Justin N. Baker, Luca Manfredini*

- Palliative Care Practices in Health Teams Supporting Young Adults with Non-malignant, Life-limiting Conditions
Bryony Beresford
- The Use from Cyberspace by Adolescents in Palliative Care – Their Social Networks
Camila Amaral Borghi
- Make IT Happen – A Project Supporting Young People with Life-limiting Illness Transition to Adulthood
Michelle Koh
- Are Adolescent and Young Adult Patients More Symptomatic at End of Life?
Victoria Hwei May Wong
- Closing remarks

15.30 - 15.45 Plenary session

No pain for Children Award -1st prize winning abstract

Effectiveness of Paediatric Palliative Homecare in Reducing the Need for Hospital Care
Saba Iordanishvili

15.45 - 17.15 Plenary Session

Managing Distress Across Childhood

Moderators: *Myra Bluebond-Langner, Marcello Orzalesi*

- Neonatal - *Chakrapani Vasudevan*
- Young Child - *Barbara M. Sourkes*
- Adolescent/Young Adult - *Justin N. Baker*

17.30 – 18.30 Networking/Focus Sessions (4 in parallel)

Home-based/Community-based PPC

Coordinator: *Justin N. Baker*

Antenatal care planning and pathways

Coordinator: *Chakrapani Vasudevan*

Children with reverse sleep cycle: discuss options to get back to a normal cycle

Coordinator: *Ross Drake*

Guidance for parents (or other adult family members) about the psychological functioning of their children - both the child who is ill and the healthy siblings

Coordinator: *Barbara M. Sourkes*

POSTER EXHIBITION THURSDAY 17TH NOVEMBER 2016

Ex. N. Title – Name

1	Normalization of Symptoms: A Leading Barrier to Symptom Management in Pediatric Advanced Cancer	Veronica	Dussel
2	Developing Confidence in Pediatric Palliative Care: Building from the Evidence	Deborah	Lafond
3	Open for Business	Lee-Anne	Pedersen
4	Breath Easy	Lee-Anne	Pedersen
5	WhatsApp, Doc? Use of Social Media to Facilitate Palliative Care for Children Residing in Remote Locations	Yuriko	Nakashima-Paniagua
6	Hospitality: A Beginning of Paediatric Palliative Care for Children Affected by Cancer, in LMICs and in Italy	Elisa Nicoletta	Accornero
7	Patient-centered Model of Care: Meeting the Patient's Evolving Needs with a Transversal Team	Manuel	Rigal Andrés
8	Patient-centered Model of Care: Meeting the Patient's Evolving Needs with a Transversal Team. A Case Study	Manuel	Rigal Andrés
9	Integrating Social and Medical Care – The Experience of a Paediatric Oncology Palliative Care Service	Michelle	Koh
10	Helping the Helpers: Focus Groups in Pediatric Hematology/Oncology to Explore Factors Contributing to Burnout	Deborah	Kramer
11	"The Nasty, Unpleasant Stuff": Parents' Experiences of Being Responsible for Carrying out Distressing Healthcare Procedures for their Child	Gemma	Spiers
12	"I Guess we Don't Do it very Often": Health Care Professionals' Views, Attitudes and Experiences Discussing Preferred Place of Death for Children and Young People with Life-limiting and Life-threatening Conditions	Michelle	Hills
13	Palliative Care at a Cardiology Intensive Care Unit for Children: Indications and Interventions	Carolina Vieira	Campos
14	Value of a Pediatric Palliative Care Team: The Parental Perspective	Lisa Myrthe	Verberne
15	How Do French Psychiatrists and Psychologists Stand within Pediatric Palliative Care Team?	Laurine	Zerka
16	Nosological Structure of the Patient Population, Receiving Pediatric Palliative Care in Hospital Setting in Russia	Elena	Polevichenko
17	Understanding the Factors that Influence Parents as they Plan and Manage their Child's End of Life Care	Karen	Brombley
18	Pilot Study of a Paediatric Ambulance Care Directive	Irene	O'Brien
19	The Development of a Physician-led Pediatric Palliative Care Service in a Children's Hospital in Republic of Korea	Min Sun	Kim
20	Pediatric Palliative Care: Evolution of a Pediatric Intensive Care-based Service in a Referral Cancer Center	Regina	Okhuysen-Cawley
21	Changing Referral Patterns to an Evolving Children's Palliative Care Service in Ireland	Elizabeth	O'Donoghue
22	A Review of the Impact of Caring for a Child with a Life Limiting Condition on Both Mothers and Nurses	Cathy	Keighery
23	What to Study Next: Utilizing the Delphi Method to Prioritise Research Topics in Paediatric Palliative Care in Ireland	Claire	Quinn
24	Checking in! The Development of the PaedPAL TASK Tool for Appraising Nursing Skill and Knowledge in Children's Palliative Care Nursing	Claire	Quinn
25	Hidden Part of the Iceberg: Making Paediatric Palliative Care in Belgium Visible	Marie	Friedel
26	Access to Palliative Care for Children in Ukraine – Challenges and Views	Andriy	Penkov
27	Hospital: The Place where Patients with Muscular Dystrophy Meet Palliative Care Services	Mirela Silvia	Iancu
28	Family Survey of 3 PPC Services in New South Wales, Australia	Sharon	Ryan
29	"Living Despite the Pain" – The Perspective from Children and Adolescents in Palliative Care	Camila Amaral	Borghi

30	Submission of Abstract for Consideration to Be Presented at the 3rd Congress on Paediatric Palliative Care in Rome, 16th-19th November 2016 Audit of Emergency Care Plan (ECP) Completion in a Cohort of Children Known to a UK Paediatric Hospice Palliative Care Team	<i>Sinead</i>	<i>Summers</i>
31	Is Palliative Care Being Used for Children and Adolescents Living with Rheumatic Diseases? A Review	<i>Esther Angelica Luiz</i>	<i>Ferreira</i>
32	Non-pharmacological Therapy for the Treatment of Newborn in Pain: An Alternative to Neonatal Palliative Care?	<i>Esther Angelica Luiz</i>	<i>Ferreira</i>
33	Evaluation of Treated Patients in the Pediatric Palliative Care Team in Hamburg, Germany	<i>Maite</i>	<i>Hartwig</i>
34	Early Introduction of Palliative Care for Children with CNS Tumor	<i>Carlota</i>	<i>Moraes</i>
35	End of Life Decision Making in Families Receiving Paediatric Palliative Care at Home: How Much and What Happens?	<i>Hui</i>	<i>Ren</i>
36	«Palliative Care Line»: Work of Help-line for Children and Young People in Need of Palliative Care in Ukraine	<i>Kateryna</i>	<i>Burlak</i>
37	The Paediatric Palliative Care Team: The Case Manager of Integrated Paediatric Care	<i>Giovanna</i>	<i>Visconti</i>
38	A New Danish Regional Outgoing Palliative Care Team for Children Based on Existing Cooperation between Paediatrics and Specialised Palliative Care	<i>Mette Asbjørn</i>	<i>Neergaard</i>
39	Advance Care Planning in the Paediatric Population - Development of the 'Thinking Ahead' Framework	<i>Jenny</i>	<i>Hynson</i>
40	Development of a Telemedicine Platform for Pediatric Home Care Assistance	<i>Lucia</i>	<i>De Zen</i>
41	The Memorial Day	<i>Suzanne</i>	<i>Runesson</i>
42	Development Integrated Pediatric Palliative Care (PPC): A Model for a Local Network that Supports Families with a Child in the Palliative Phase at Home	<i>Stephanie</i>	<i>Vallianatos</i>
43	A Prospective Study on the Characteristics and Subjects of Pediatric Palliative Care Case Management Provided by a Hospital Based Palliative Care Team	<i>Antoinette Yvonne Narda</i>	<i>Schouten-van Meeteren</i>
44	X-linked Adrenoleukodystrophy - A Challenge for a Palliative Approach from Diagnosis	<i>Esteria</i>	<i>Boeriu</i>
45	Flexibly Evolving a Hospice Model of Care to Fit the Needs of Babies, Children and Young People with Palliative and End of Life Care Needs - Is this Necessary?	<i>Patrick</i>	<i>Carragher</i>
46	"Growing up with Ricky at Home" School Action in the Course of Treatment of Serious Pediatric Diseases. A Pilot Project	<i>Marilena</i>	<i>Banfi</i>
47	School and Children Affected by Life-limiting or Life-threatening Conditions: The Experience of Veneto	<i>Alessandra</i>	<i>De Gregorio</i>
48	A Summer Camp with CCHS Patients and their Families: An Experience to Improve Sense of Safety and QOL	<i>Alessandra</i>	<i>De Gregorio</i>
49	Role of Palliative Care in Children with Epidermolysis Bullosa: A Case Report	<i>Felipe Yu</i>	<i>Matsushita</i>
50	Belgian Pediatric Palliative Care: Spreading the Ideas of Pediatric Palliative Care in the Different Fields of Pediatric Medicine	<i>Marleen</i>	<i>Renard</i>
51	The Quality of an Integrated Treatment in an Epidermolysis Bullosa Pediatric Case Assumed by the Palliative Care and the Pediatric Home Care	<i>Francesca</i>	<i>Fantin</i>
52	The Best of the Best for the Baby in the Womb the Urgent Need of Prenatal Palliative Care in Memory of Giampaolo Magnani Born on 5th March 2009 Died on 17th October 2010, at 19 Months	<i>Luisella</i>	<i>Magnani</i>
53	Home Psychologist Assistance: A New Model for Children and Families in Pediatric Palliative Care	<i>Monica</i>	<i>Minetto</i>
54	Pediatric Palliative Care Knowledge and Attitude: A National Survey to Healthcare Professionals	<i>Ana</i>	<i>Lacerda</i>
55	Complicated Grief in Children after Parental Loss: A Longitudinal and Prospective Study	<i>Agnès</i>	<i>Suc</i>
56	Through my Pain	<i>Martín</i>	<i>Mindeguía</i>
57	Care Needs and Referral Patterns of Adolescent and Young Adult Cancer Patients Referred to a Palliative Medicine Service	<i>Janice Jie Er</i>	<i>Soo</i>

FRIDAY 18TH NOVEMBER 2016

- 08.30 - 09.00 **Gaining insights:** Children's Palliative Care Delivery Across The Spectrum of Available Resources
Joan Marston
- 09.00 - 10.30 **Plenary session**
Ensuring Quality Care
Moderators: *Caterina Agosto, Margaret Al-Sayer*
- Does Quality Care Ensure Quality of Life? - *Eva Bergsträsser*
 - Standards to Ensure Quality Care - *Mercedes Bernadà*
 - Outcome Measures to Improve Quality Care - *Maria Laura Chiozza*
- 11.00 - 12.00 **Oral presentation session (3 in parallel):**
Working session VII: Education and Training
Moderators: *Stefan J. Friedrichsdorf, Dilini Rajapakse*
- Improving the Nation-wide Outcomes for Children and Families Supported by Paediatric Palliative Care: Phase 1 Learning Needs and Capability, a National Quality of Care Collaborative
Angela Delaney
 - "It Changed my View of Medicine" - Implementing a Multidisciplinary Undergraduate Course on Pediatric Palliative Care for Medical Students
Ana Lacerda
 - Evaluating the Impact of Ireland's Only Nodule on Children's Palliative Care within an Irish Postgraduate Diploma in Palliative Care
Claire Quinn
 - My Neighborhood: An Innovative Education Tool to Optimize the Opportunity for Palliative Care Patients to Stay at Home
Marsha Smith
 - Closing remarks
- Working session VIII: Epidemiology and Surveys**
Moderators: *Delia Birtar, Daniel Garros*
- Children in Scotland Requiring Palliative Care: Identifying Numbers and Needs (The ChiSP Study)
Lorna Fraser
 - Needs Assessment in Pediatric Palliative Care amongst Nurses and Doctors in the Netherlands
Erna Michiels
 - Introducing Multi Disciplinary Reflective Practice Groups into Paediatric Palliative Care Services: An evaluation
Victoria Montgomery
 - Recupera, a Palliative Care Patient Registry: Results from a Pilot Study in Three Argentinean Public Hospitals
Luciano Gabriel Uzal
 - Closing remarks

Working session IX: *Grief and Bereavement*

Moderators: *Angela Feraco, Danai Papadatou*

- Defining Good Death and Dying Well - What Does the Literature Say
Chris Barton
- Healing the Wounds: Setting up a Grief Centre
Ivan Gomez Garcia
- The Challenges and Ethics of Inviting Bereaved Parents to Participate in Research
Fiona McElligott
- Availability of Debriefing Sessions to Nursing Staff Following their Provision of Paediatric Palliative Care in an NHS Trust
Danielle Lewis
- Closing remarks

13.30 - 14.30 **Oral presentation session (3 in parallel):**

Working session X: *Education and Training*

Moderators: *Caterina Agosto, Ann Goldman*

- Ensuring the Quality of Life of Children with Incurable Diseases: Education for Health Care Providers in Ukraine
Luydmyla Andriyishyn
- Training Pediatric Oncology Providers in Palliative Care Communication: Communication Plan, Early through End-of-Life, version 2 (COMPLETE II)
Joan Haase
- Integrated Learning Supports Integrated High Quality Care: A Regional Model of Neonatal Training and Education for Healthcare Professionals
Alexandra Mancini
- Introducing the Trieste Charter to the Russian Audience
Karina Vartanova
- Closing remarks

Working session XI: *Epidemiology and Surveys*

Moderators: *Lizzie Chambers, Momcilo Jankovic*

- A Retrospective Review of the Timing, Duration and Characteristics of Children Accessing Paediatric Palliative Care in Kuwait
Saima Ali
- Outcomes for Children with Life-limiting Conditions in and after Paediatric Intensive Care Units: A National Data Linkage Study
Lorna Fraser
- The Need of Pediatric End-of-Life Care in the Czech Republic
Lucie Hrdličková
- Using Internet Search-query Analysis to Evaluate Public Awareness of Pediatric Palliative Care
Laura Whitla
- Closing remarks

Working session XII: *Home vs. Hospital CPC*

Moderators: *Maria Laura Chiozza, Manuel Rigal Andrés*

- Place of Death: Report of Patients Receiving Paediatric Palliative Care in Kuwait
Manjiri Dighe

- Children's Palliative Home Care Programme Prevents and Reduces Unnecessary Hospitalizations
Anda Jansone
- Home or Hospital? How Parents Decide about the Site of the Dying Child's Care and Death
Danai Papadatou
- An Analysis of Trends in Place of Death Following Establishment of a Regional Paediatric Palliative Service and Opening of Children's Hospice in the UK
Kate Renton
- Closing remarks

15.30 - 17.00 **Plenary session**

Support for the Child, Adolescent and Family

Moderators: *Justin N. Baker, Danai Papadatou*

- Support for the Child and Adolescent - *Ulrika Kreichbergs*
- Support for the Siblings - *Barbara L. Jones*
- Support for the Parents and Grandparents - *Anna Gorchakova*

17.15 - 18.15 **Networking/Focus Sessions (3 in parallel)**

How to improve quality of life in the hospital setting?

Coordinator: *Eva Bergsträsser*

Place and role of spiritual care in the family. Respect for culture and religious practices when you work with family

Coordinator: *Anna Gorchakova*

Living in the shade of death - how to ease the burden of the seriously ill child?

Coordinator: *Ulrika Kreichbergs*

POSTER EXHIBITION FRIDAY 18TH NOVEMBER 2016

Ex. N. Title – Name

61	Managing Uncertainty in Non-malignant, Life-threatening Conditions: The Experiences of Young Adults and their Parents	Bryony	Beresford
62	Provision of Multi-disciplinary End of Life Care for Children and Young Adults with Cancer: A Nationwide Survey	Caroline	Porter
63	Nutrition and Hydration at the End of Life in Children Referred to a Tertiary Palliative Care Service: A Case Series Review	Rachel	Halpin-Evans
64	Place of Death in Children Discharged from PICU: The Importance of Palliative Care	Lorna	Fraser
65	Pediatric Palliative Care in a Multi-religious Society	Alexander	Tkachenko
66	Pediatric Deaths Attributable to Complex Chronic Conditions in Republic of Korea, 2005-2014	Min Sun	Kim
67	Evaluation and Management of Delirium in Seriously and Terminally-ill Children: A Review of the Literature and Contemporary Best Practices	Regina	Okhuysen-Cawley
68	An Individual Care Plan to Stimulate Advanced Care Planning in Palliative Care for Children	Erik A H	Loeffen
69	Narrative Medicine and Palliative Care: Proposals from a Peripheral Center	Lucia	Calafiore
70	Best Practice of Provider/Parent Interactions when Children Are Seriously Ill	Betty	Davies
71	End-of-Life (EOL) in Children with Congenital Heart Disease (CHD) who Died in Hospital: Parental, Physicians' and Psychologists' Perspectives on Suffering and Quality of Life	Francesca	Benedetti
72	The Development of an Integrated Respiratory-palliative Care Service Supporting Patients Requiring Long Term Tracheostomy-ventilation	Michelle	Koh
73	Complex Symptom Management in Advanced Pelvic Cancer: An Integrated Approach	Michelle	Koh
74	Predictors of Quality of Life in Children with Cancer at the End-of-Life	Katharina	Maaßen
75	Our Living Wall: Art, Fun, Stories and Feeling Connected	Amanda	Mingard
76	Comparing the Prognostic Accuracy of the 'Surprise' Question Across Paediatric Diagnostic Categories	Anna-Karenia	Anderson
77	Pediatric Pain Management Evaluation in Healthcare Providers	Aurora	Madrid Rodriguez
78	Analysis of Out-of-Hours Needs in Patients under Direct Care by a Palliative Pediatric Care Unit. An On-call 24/7 Service	Manuel	Rigal Andrés
79	Improving Nation-wide Outcomes for Children and Families Supported by Paediatric Palliative Care. A National Quality of Care Collaborative	Lee-anne	Pedersen
80	Complementary and Alternative Medicine Usage: A Source of Hope for Asian Families with Children in Palliative Care	Issarang	Nuchprayoon
81	Preventing Acute Hospital Admissions through Specialist Palliative Care Intervention	Claire	Wastakaran
82	A Descriptive Narrative of the Journey to Establish a Fully Comprehensive Paediatric Palliative Care Service	Rasha	Al-Hamad
83	Hospital-based Pediatric Palliative Care Programs – A National Survey	Ana	Lacerda
84	Using the "Surprise Question": Who Could Benefit from a Palliative Care Approach in a Secondary Hospital Paediatric Ward?	Ana	Cardoso
85	Mind-body Approaches Can Facilitate Parental End-of-Life Decision Making and Life Closure Activities	Deborah	Lafond
86	Parental Coping in the Context of Having a Child who is Facing Death: A theoretical Framework	Anne-Sophie	Darlington
87	Ensuring their Voice is Heard: Recruitment Challenges in Children's Palliative Care Research	Claire	Quinn
88	Eleonora's Dream: A Project for Normal Life	Chiara	Di Pede
89	A Small Palliative Care Team for Children in Japan	Myoung-Ja	Park
90	Developing a Resilient Workforce	Arlene	Honeyman
91	Survey on Palliative Care to Primary Care Pediatricians	Aurora	Madrid Rodriguez
92	What Is the Correct Dose?	Silvia	Spolverato
93	Fighting the Threat of Multidrug-resistant Strains: Hygiene Guidelines on a Paediatric Palliative Care Ward	Boris	Zernikow
94	The Challenge of Accurate National Data Requires an Organisation's Strategic Response	Patrick	Carragher

95	Evaluation of Advance Symptom Management Plans (ASMPs) in Paediatric Palliative Care	Pat	Sartori
96	Development of a System for Pain Monitoring and Evaluation at Home by a Platform of Telemedicine	Lucia	De Zen
97	Decision Making for Children with Life-limiting Illnesses: The Different Guises of 'Convincing' and 'Compromising'	Emma	Popejoy
98	A Randomized Trial of Yoga for Children Hospitalized with Sickle Cell Vaso-occlusive Crisis	Karen	Moody
99	Music Therapy and Paediatric Palliative Care: Translating Research into Clinical Practice to Improve the Effect of Music Therapy on Perceived Pain for Children with Life Limiting Conditions and their Families	Angela	Delaney
100	Development and Use of Advance Symptom Management Plans (ASMPs) for Children with Palliative Care Needs	Linda	Maynard
101	Home care and Pediatric Palliative Care: Needs Fulfillment for Families Involved in Pediatric Palliative Care Program and Home Assistance in Pordenone – A Cross-sectional Observational Pilot Study	Anna	Luchini
102	"What Can We Do Better?" Analyzing Responses from Parents of Children Who Died of Complex Congenital Heart Disease (CCHD) in Pediatric Intensive Care Unit (PICU)	Caterina	Agosto
103	Nutrition and Pediatric Palliative Care: Questions and Challenges	Matheus J. Danza	Silva
104	Sharing the Learning from an Innovative Perinatal Hospice Service in the UK- An Integrative Approach Ensuring Quality Palliative Care from inside the Womb	Emma	Bleasdale
105	Evaluation of the Need for a Paediatric Palliative Care Service in the West of Scotland: A Mixed Methods Analysis	Jonathan	Downie
106	First Steps on Development of Pediatric PC in Tajikistan	Zarina	Kurbonbekova
107	Dressing Material in Children and Adolescents with Epidermolysis Bullosa: Experiences of Families	Almut	Hartenstein-Pinter
108	The Importance of Training in the Communication of Bad News to Parents	Esther	Ferreira
109	Treatment of Cancer Pain in Pediatric Palliative and End-of-Life care: A Reflection	Angelica Luiz	Ferreira
110	The Introduction of a Pediatric Palliative Care Service in a Medium-sized City in the Interior of Brazil: A Challenge	Esther	Ferreira
111	Leigh's Syndrome: Simultaneous Palliative Care to Improve Quality of Life	Angelica Luiz	Ferreira
112	Use of Methylphenidate in a Pediatric Oncology Patient with Fatigue	Giovanna	Visconti
113	Born and Raised in the Hospital - A Clinical Case	Jacqueline	Duc
114	Where Is the Line: The Art of Companionship	Mariana	Adrião
115	National Art-project "Oscar and the Lady in Pink": Drawing Attention to Palliative Care for Children in Ukraine	Jiri	Kralovec
116	Uncertainty: A Blessing and a Curse in Progressive Childhood Cancer the Illness Stories of Children, Parents and Physicians	Kseniia	Shapoval-Deinega
		Eva	De Clercq

SATURDAY 19TH NOVEMBER 2016

08.30 - 09.00 **Gaining insights: Music cares about you**
Paolo Petrocelli

09.00 - 10.30 **Plenary session**

Learning from Conflict and Adversity

Moderators: *Stefan J. Friedrichsdorf, Ann Goldman*

- Conflict Within and Between Teams - *Jan Aldridge*
- The Value of Team Supervision - *Daniel Garros*
- Managing Adversity in Times of Economic Hardship - *Danai Papadatou*

11.00 - 12.00 **Roundtable discussion: Leadership of a CPC Service**

Moderators: *Lizzie Chambers, Joan Marston*

Panel of experts:

Margaret Al-Sayer

Justin N. Baker

Rut Kiman

Mary Ann Muckaden

12.00 - 12.30 **Closing Ceremony**

Conclusions - *Ross Drake & Ann Goldman*

Thanks & arrivederci! - *Franca Benini*

Conflict within and between Teams

Aldridge J.

Martin House Hospice Care for Children and Young People and Leeds Teaching Hospitals NHS Trust, Clinical Psychology, Leeds, United Kingdom

Capozzoli noted that, 'Conflict, like fire and water, is neither good nor bad.' Conflict only becomes a problem when people are not able to manage and resolve it effectively. Conflicts and disagreements can be regarded as a natural part of the process of people working together, with a positive, growth function. Many people in the helping professions, however, traditionally view conflict as negative and something to be avoided and a significant percentage of people who have chosen to work in caring roles have had limited opportunities to learn how to deal with conflicts satisfactorily in the work situation. Conflict between and within teams in the work place is not a rare occurrence and there is a considerable relevant literature on the topic. One example is Amason's work on conflict and its role in decision-making. He suggested that there are two types of conflict, cognitive (conflict based upon issues, ideas, processes or principles) and affective (conflict based upon personalities, emotions and values). There is, however, little literature that has explored conflict type, occurrence, impact and resolution in the field of palliative care. In fact, although the important role of staff in paediatric palliative care has been acknowledged (Craft and Killen 2007), relatively little consideration has been paid to the conflicts, challenges and needs of staff working in the area. To work in palliative care, while a privilege and an honour, carries with it costs. Studies have highlighted the limited organisational and emotional support for the work. Conflict is known to be more likely, or exacerbated and particularly challenging, at certain times and in certain situations. One potential risk factor may be when the work is emotionally intense and prolonged. In such situations, for example, teams may inadvertently get drawn in to the dynamics of the client group they are serving and end up 'mirroring' the dynamics of their clients. 'Mirroring' will be explored in relation to clinical examples from children's palliative care and the complexity raised by working closely with 'the child within the family system'. In addition to 'mirroring' other proposed causes of conflict in and between teams working in palliative care will be explored. These will include the use of the psychological mechanisms of 'splitting' and 'projection', with examples being drawn from work in paediatric palliative care. Times when teams are particularly vulnerable to conflict will also be addressed, with change being used as a worked example. Change is a time when predictability breaks down and therefore conflict is more likely. At such times there is the potential for conflict to improve team performances, but only under certain moderating conditions; for example, in a climate of high psychological safety (Bradley et al 2012). Ways of providing this will be explored. Finally the ways in which good team work, morale and quality care are inextricably wound together will be acknowledged.

Managing Distress Across Childhood - Adolescent and Young Adult

Baker J.

St Jude Children's Research Hospital, Quality of Life and Palliative Care, Memphis, United States

Adolescent and young adult (AYA) patients have distinct physical and psychosocial needs that are often inadequately addressed. Recent studies indicate that AYA oncology (AYAO) patients often receive intense medical services at the EOL and experience numerous symptoms, many of which are poorly recognized, understood, or treated. Symptom control in pediatric and young adult patients at the EOL is essential, given the negative impact of symptoms and suffering on patient and family quality of life (QOL).

The primary tenets of palliative care (PC) include the provision of high-quality communication, advance care planning, and the assessment and treatment of physical and psychosocial symptoms in the context of an interdisciplinary team, with the goal of improving support for, and reducing the suffering of, patients and caregivers. PC consultation, symptom control, and advanced care planning has been shown to improve the QOL for both pediatric and adult patients with life-limiting conditions. Pediatric PC has been associated with more and earlier EOL care discussions, longer times between the placement of do-not-resuscitate (DNR) orders and death, and increased hospice enrollment in patients with advanced solid tumor malignancies. For AYAO patients, early PC involvement may be associated with less intensive therapy at the EOL, as well as longer overall survival.

This session will be focused on the specific needs of adolescent and young adult patients and how best to address them through an integrated palliative care approach. Pain and symptom management; social, emotional, cultural and spiritual care; loss and bereavement care; and decision making and communication will all be covered in an interactive lecture format.

Specific objectives include:

- Describe the additional complexities of integrating palliative care in the AYA age group
- Learn practical approaches for communicating with AYA about palliative care issues
- Provide "Clinical Pearls" for working with this complex patient population

A word about the speaker: As a pediatric oncologist, palliative care physician, vice-chair of the ethics committee and patient-reported outcomes and Phase I and end-of-life care clinical investigator at St. Jude Children's Research Hospital, Dr Baker is intimately aware of the distress experienced by children with advanced cancer and the ethical and end-of-life/bereavement issues surrounding their disease progression.

Dr Baker currently serves as the Chief of the Division of Quality of Life and Palliative Care at St. Jude as well as the medical director of our Quality of Life Service - the St. Jude palliative care team. He is also the Director of our Pediatric Hematology/Oncology fellowship program. His research interests include ethical considerations surrounding enrollment in Phase I clinical trials, AYA palliative oncology care, end-of-life decision making, integrating palliative care into the ongoing care of children with cancer as well as patient-reported outcomes and pain and symptom control in the context of pediatric oncology care. He has participated in >30 studies related to pediatric palliative care and have authored numerous manuscripts and book chapters on the topics ethical decision making as well as other palliative care subjects within the context of pediatric oncology.

Does Quality of Care Ensure Quality of Life?

Bergsträsser E.

University Children's Hospital, Paediatric Palliative Care, Zurich, Switzerland

In palliative care, quality of life (QOL) of the child and the family is the primary goal of care. In the particular situation of life-limiting illness and palliative care, QOL may be closely linked to quality of care.

Quality of care has been investigated as early as in the 1920s to define fundamentals of good medical care. Today, the Donabedian Model remains the dominant conceptual model for examining healthcare services and evaluating quality of healthcare. It consists of three main levels; structure, process and outcome. 'Structure' describes the context of care delivery; 'process' includes all actions of healthcare (e.g. treatment, interpersonal aspects of care); and 'outcome' contains all effects of healthcare (e.g. improvement in symptoms). The construct of good quality Paediatric Palliative Care (PPC) is not well operationalised, and no conceptual model has been developed and tested so far. Consequently, validated tools to comprehensively evaluate quality of PPC are lacking. In addition, there is no evidence about the relationship between quality of care and QOL, even though it appears logic and attractive.

This presentation focuses on processes and outcomes of care and particularities within PPC. As such, it will concentrate on questions of how to define and measure outcomes in highly complex situations of a child suffering from severe and life-limiting illness, where success and failure are not absolute. Thus, prolongation of life may be a goal of care (outcome), but cannot be seen isolated. To better understand quality of care in specific population groups - as children with PPC needs - dimensions of care and values attached to them will be explored.

Based on guidelines and concepts of palliative care for adults (National Consensus Project; US), some core elements of palliative care delivery in children have been defined. On a structural level, these include involvement of a specialised PPC team and access to PPC (24/7, admission policy to hospital, home care); and on a procedural level, pain and symptom control, communication, decision making, emotional support and care planning take a central position, besides those closely related to end-of-life care (spiritual and religious aspects of care, bereavement support). These core elements or indicators of care may have great impact on outcome; such as symptom control, activities of daily living and QOL of the affected child and of the family. Patient-reported outcome measures (PROMs) and patient-centred outcome measures (PCOMs) using standardised and validated questionnaires would be helpful to measure outcomes that are important to the individual child and family.

The crucial question, whether QOL in the child suffering from life-limiting illness can be improved by specialised PPC, has been documented in several studies. However, the magic potion how this aim can be reached with highest probability, remains open. Some ingredients will be named and hopefully discussed vividly.

Nevertheless, the multiple barriers to get access to PPC should be kept in mind -; unfortunately, these might still be of even higher urgency as compared to PPC outcomes.

Standards to Ensure Quality of Care

Bernad  M.

Universidad de la Rep blica - School of Medicine, Department of Pediatrics, Montevideo, Uruguay

Objectives:

1. To define "Quality, quality of care and standards of quality care (SQC)"
2. To discuss "SQC for Pediatric Palliative Care" (SQC- PPC) found in the literature
3. To reflect about challenges of "global PPC community" for developing standards to ensure quality care

According to Donabedian, standards of quality care *"describe the care that patients should be offered by health professionals and health care systems for a specific clinical condition or clinical pathway, in line with the current available evidence"*. Standards are useful: for the beginning, to set out new programs; for continuous quality improvement; to measure the quality of care; for qualification and accreditation; for ethical reasons and for teaching.

The following are typical and globally accepted general standards of "quality of health care"; they are valid, independently from the health system model and level of development: effectiveness, efficiency, accessibility, patient-centered care, equity and safety. Particular standards have been published for adult palliative care. Specific SQC for PPC were developed by the following organizations: Canadian Hospice Palliative Care Association (Canada, 2006); International Meeting for Palliative Care in Children (Europe, 2006), National Hospice and Palliative Care Organization (US, 2009), African Palliative Care Association (Africa, 2011), American Academy of Pediatrics (US, 2013); Together for short lives (UK, 2013), National Institute for Health and Care Excellence (UK, 2016). They present some steadily shared PPC-SQC regarding "Structure" and "Processes". "Structure": the need of a trained interdisciplinary team available 24/7, integrated to the national health system and able to deliver services in different settings; "Processes": patient and family centered care; excellent comprehensive symptom management and control; psychological, social and spiritual support; a coordinator of care; compassionate, honest and direct communication with patient, family and primary care team; patient and family support in decision making; PPC team partnering with other health care, social, educational resources; etc. Other SQC were included only by few organizations: transition programs to adult services; adverse events registration; satisfaction surveys from patients and families. Research searching for parents perspective of "quality pediatric palliative care" found that in addition to *"parental desire to plan their child's location of death"*, previously reported, *"access to specialist palliative care team 24/7"*, *"access to a direct admission policy to hospital"* and *"discussion of no CPR order with parents by health care team"* were highlighted.

Some challenges of "global PPC community" for developing standards to ensure quality care:

How to balance the role of SQC in everyday life: *"Stick to the script vs. spontaneity"*?

Are SQC coming from developed countries applicable to underdeveloped ones where two out of three children in need of PPC live?

Is it possible to establish an international "Core group of non-negotiable/ fundamental PPC-SQC"?

Would this "global PPC community" be the one leading the effort?/ should other actors participate in it?

Should SQC development work close with "ongoing education" and "recertification" programs?

How to achieve a fair balance that satisfies the perspectives of all the involved actors: patients, families, health care teams, stakeholders and decision makers?

"Systems awareness and systems design are important for health professionals but are not enough. They are enabling mechanisms only. It is the ethical dimension of individuals that is essential to a system's success".
(Avedis Donabedian)

Outcome Measure to Improve Quality Care

Chiozza M.L.

University Hospital of Padua, Department of Staff Services, Padova, Italy

The death of a child is the most difficult experience for a parent. Because it occurs infrequently and represents a considerable emotional burden for families, offering support for parents and relatives through a paediatric palliative care (PPC) approach represents a fundamental issue. PPC for children and young people is an active and total approach to care and begins at the point of diagnosis, throughout the child's life, death and beyond. Palliative care teams include physicians, nurse practitioners, nurses, social workers, chaplains, psychologists, pharmacists, and physician assistants, thus highlighting the need for an effective coordination of all those professionals. Palliative care improves the quality and cost-effectiveness of adult and paediatric patient care, and it decreases unwanted hospitalizations and aggressive care at the end of life. However, there is the need to develop and implement palliative care quality standards and preferred practices to be used for benchmarking by institutions, health care systems, and accrediting bodies. Defining the goals of care and developing appropriate and feasible quality indicators are essential steps in improving the quality of the end-life care and in convincing institutions of the necessity of PPC. Quality indicators are explicitly defined and measurable standards referring to outcomes, processes, and structures of care that are required for a particular type of patients or clinical circumstances. Currently, health care is shifting focus from the volume of services delivered to the value created for patients, with "value" defined at the outcomes achieved relative to the costs. In fact, process measurement has had limited effect on value. Such measures receive little attention from patients, who are interested in results. What generally matters to patients and relatives are outcomes that encompass the whole cycle of care- including health status achieved (e.g. survival, functional status, quality of life); the time, complications, end suffering involved in getting care; and the sustainability of benefits achieved. Unfortunately, there are few studies describing the standards of care in PPC and those reported in the literature are mostly descriptive and qualitative. In particular, outcome measurements are rarely carried out and no "ideal" outcome assessment measure for care in PPC is available.

In fact, the domains of generic health-related quality of life (HRQOL) measures are not relevant to all children receiving palliative care and some domains within specific measures are only relevant for the specific population. According to the new developments in the field of Patient-reported experience measures (PREM) and Patient-centred outcome measures (PCOMS), it may be desirable to combine measures of experience with measures of outcome to obtain a global view of the quality of care. This approach to outcome measure has to be recommended not only to improve clinical care but also to audit and evaluate services, for research purposes and to enable policy makers to monitor and improve health care.

Sleep and Children (Sonno e bambini)

Drake R.

Starship Children's Hospital, Paediatric Palliative Care, Auckland, New Zealand

"Each night, when I go to sleep, I die. And the next morning, when I wake up, I am reborn" - Mahatma Gandhi.

The connection of sleep with death and, by inference, sleep being a "temporary death" is reflected in the above quote by Mahatma Gandhi and has been a recurring theme throughout the ages. However, Gandhi's quote also provokes consideration of the rejuvenating effect of sleep and, in so doing, opens the door to ponder what happens during this state of mind and body characterized by altered consciousness, relatively inhibited sensory activity, inhibition of nearly all voluntary muscles, and reduced interactions with surroundings.

This presentation will outline normal adult sleep architecture by way of introduction to the differences seen across the age range of children; neonate to adolescent. The fact that such changes exist in a physiological event such as sleep is not unfamiliar to the paediatric healthcare professional and is clearly exemplified in the US National Sleep Foundation recommendations for sleep needs at different ages:

- Newborns (0-3 months) - 14 to 17 hours
- Infants (4-11 months) - 12 to 15 hours
- Toddlers (1-2 years) - 11 to 14 hours
- Preschoolers (3-4 years) - 10 to 13 hours
- School-age children (5-12 years) - 9 to 11 hours
- Teenagers (13-17 years) - 8 to 10 hours
- Adults (18-64 years) - 7 to 9 hours
- Older Adults (65 years and over) - 7 to 8 hours

Sleep has been divided into stages since different EEG features were discovered in sleeping subjects by Alfred Loomis in 1937. The phases of sleep have been modified over the years to our current understanding as the physiological changes at each phase have become better defined. Sleep proceeds in sequential cycles of non-rapid eye movement (NREM) sleep, which is divided into three stages, and REM sleep. The normal sequence being N1 → N2 → N3 → N2 → REM.

The International Classification of Sleep Disorders (Revised) have broadly classified sleep disorders into:

1. Dyssomnias
 - Intrinsic sleep disorders
 - Extrinsic sleep disorders
 - Circadian rhythm sleep disorders
2. Parasomnias
 - Arousal Disorders
 - Sleep-Wake Transition Disorders
 - Parasomnias Usually Associated with REM Sleep
 - Other Parasomnias
3. Sleep Disorders Associated with Other Disorders
 - Associated with Mental Disorders
 - Associated with Neurologic Disorders
 - Associated with Other Medical Disorders

The presentation will then be able to focus on the prevalence, identification and management of common sleep disorders in the children we commonly care for in palliative care.

This will include providing a practical approach to educating families and others on the basic principles of sleep hygiene for the palliative child. At its simplest this involves establishing a day-time routine where the child is engaged and appropriately active followed by a good evening routine that incorporates a 45 to 60 minute period of brain "quieting" time before settling to sleep. In those situations where children require a rest during the day a "power" nap of no more than 30 minutes duration can be enough to give the necessary energy for the rest of the day but not impact on night time sleeping.

This will not necessarily be enough for the child with a significant neurological disorder so time will be devoted at the extra session to discuss approaches that can minimise the considerable impact disordered sleep can have on the child and their family.

Support for the Parents and Grandparents

Garchakova A.

'Belarusian Children's Hospice' Charity NGO, Borovliany, Belarus

Interests of the child are the heart of everything that can be called palliative care complex. Interests of child are a decision criterion at the acceptance of any decisions related to organization and direct providing of palliative care. Interests of the parents is in second place after the interests of the child when deciding on the organization and the direct provision of palliative care for children. With birth in a family a child demanding palliative care, parents face a set of problems of material and psychological character and need rendering medical, psychological, social, spiritual and financial support.

Not knowing how to care for the child, how to help him, and not being able to get professional help, they will be forced to simply watch it daily suffering. Traditionally, in the lives of children are involved grandparents, who in a situation of having a child requiring palliative care, also need help. The parents of a sick child, and especially grandparents are faced with the fact of the proximity of their own death. They feel restrictions on freedom, which is due to feelings of guilt, fear, grief, helplessness, loneliness, inability to establish relationships with other people. Parents and grandparents have to endure the loss of their hopes and dreams for the child as a "source of pride", "successor of the family", and of himself as a "successful" parents and grandparents. Especially often it occurs, if it is the first or only child, and they are "stuck" in this grief "parental failure." Parents and relatives of the sick child may be in a great psycho-emotional stress, their resources are being depleted. To cope with their condition, they can take care with this situation, only if they are trust specialist. Helping parents and relatives must be voluntary, the family intervention implemented unobtrusively, taking into account the cultural, social, personal and other factors.

Family help should be available as part of the palliative care team services before and after the child's death, and in the last period of his life, it can be provided in an individual or group basis. Every family should have a fixed employee who provides moral support, coordinate services, helps to care for the child, through which the family is provided with the necessary equipment, the provision of additional services. The Belarusian Children's Hospice that person is a nurse performs an advisory role in the family and a source of information. Families of sick children particularly appreciate the duration of the relationship with the coordinator, but in cases when the interaction is no longer necessary or impossible, for this family can be fixed another nurse, and the family must be mentally prepared for this. However, it noted that the services in support of the dying child's parents and grandparents easily take from experts, with which are formed long and trusting relationship.

For the purpose of restoring physical, psychological, and moral resources in NGO "Belarusian Children's Hospice" such kind of assistance as respite care is available for parents or other relatives who take care for their child. It should be kept in mind that sometimes even a short rest while the child is on respite care for some reason is treated by parents as a display of their own weakness. However, exactly their recovery - is just the thing all the parents of hospice's wards need.

Resource recovery and emotional pressure removal is carried out by NGO "Belarusian Children's Hospice" through parents' teamwork in a therapy group, self-help groups, parent's clubs. The working frame in a therapy group is different from a free-form meetings of the parent's club, where parents can come when they have the opportunity to come, without any obligations and plans. Because at the listed groups psychotherapeutic purposes are decided, it is important to organize the process: meetings are regularly; after the group is formed, it is possible to join it, but not one-time only, but for a longer term of participation; group members meet for several months to manage with their own internal problems under the guidance of a psychologist.

Psychological help is important for parents and grandparents in overcoming the fear of future pregnancies and a betraying feeling in relation to a sick or a gone child. A birth of subsequent children may become a rehabilitation family resource.

Providing all kinds of assistance to parents and grandparents of children with life-limiting illnesses is very important not only for children, their parents and relatives, but also for "public health".

The Value of Team Supervision

Garros D.^{1,2}

¹University of Alberta, Fac of Medicine, Dept of Pediatrics, Pediatric Critical Care, Edmonton, Canada, ²Stollery Children's Hospital, Edmonton, Canada

Background and aims: In the Pediatric Intensive Care Unit (PICU), as well as in the hospital pediatric wards, we work within teams. Health care teams help families to make very difficult decisions about the care of their loved ones. It is long gone the model of a single physician managing the patient and deciding alone what is best.

We aim to demonstrate that team work leads to better clinical results in pediatrics, but also it can generate immense conflict and consequently ruin the work environment. Moral Distress, burn-out and the desire to leave the profession can be consequences of bad team work dynamic, and lack of a good leader within the organization. In the fragmented health care we witness today, where lots of specialists care for a child at the same time, interdisciplinary and intra-team conflicts abound.

Methods: Utilizing the literature and research narratives, we will demonstrate that a dysfunctional team and lack of good leadership can lead to dissatisfaction and conflict between families and health care professionals.

Results: PICUs are high-tech, high-pressure environments in which physicians (intensivists) co-ordinate a multidisciplinary team that includes other physicians (e.g. surgical specialists, transplant specialists, cardiologists, etc.), as well as nurses, respiratory therapists, social workers, dieticians, pharmacists, physical and occupational therapists, psychologists and clergy. It is in this context that team work needs to be effective. Uncertainty and ethical dilemmas are also part of the daily life of a critical care unit.

The literature shows that a good team leader is paramount to achieve the necessary team dynamic and interdisciplinary equilibrium on this environment. How is this possible? A good supervisor or leader is one that allows people to speak out their opinions, demands people's best thinking, push for sound decisions by constructing debate and decision-making opportunities. It gives his team a sense of ownership for each ones' responsibilities, and the results will show it, with better patient care, enhanced professional satisfaction and personal growth.

A leader that multiplies brings good results, rather than the one that pretends to be the smartest in the room, draining intelligence, energy, and capability from the ones around. A smarter team then results, since everyone's brainpower, at all levels, is participating. A good supervisor can effectively recognize and attract high-potentials and make them flourish, without just collecting their talents and then making them become stagnant.

When resources are limited, supervisors are expected to do more with less. That is another frequent cause of moral distress and burn-out, since team members feel that they cannot perform at their best and the quality of care diminishes. That is also the time for good and effective team work, with leaders that nurture and care, protect the team members and listen to them, at the same time that they are fighting for better working conditions.

A supervisor can mobilize his team at the right time, at the moment that a shift in the patient's trajectory has been noticed; he/she can do it by counting on the ability of his team members to sense, and communicate freely their perception. Good communication is crucial on this endeavor, and erroneous reading and lack of continuity of care can hinder patient's outcomes and team performance. Team members will feel that they can speak up, manifest their opinions and ideas - even though they may represent a contrary view. This is especially true when the inability to do so is one of the major causes of moral distress in environments loaded with ethical dilemmas and uncertainties such as the intensive care unit.

Conclusion: Effective leaders use their intelligence to multiply the smarts and capabilities of the people around them. Finally, it is all about the patients and their outcome. Good leader allow teams their teams to achieve such outcomes, leaving on each member a profound sense of pride and professional accomplishment - one that makes them willing to return to work the next day.

Finally Flourishing: Personal Dignity and Value at the End of Life in Paediatric Palliative Care

Hain R.

University of South Wales, Health and Social Sciences, Cardiff, United Kingdom

Paediatric palliative care has a lot to say about spirituality. Spirituality is a domain of care that palliative care models strive to address practically alongside the physical and psychosocial. It describes the search for meaning and the construction of biographical narrative. It is therefore obvious that the spiritual domain is important not only to those who identify themselves explicitly with a religion or other specific belief system, but to everyone one. It encompasses a human experience that is universal. Nevertheless, in most countries of the world, individual faith is an important expression of spirituality for many people. Faith both informs, and is informed by, the way meaningful personal narrative is often constructed by families and children, and even by those caring for them.

And faith, in its turn, has a lot to say about paediatric palliative care. Anyone who has been present at the memorial service for an infant knows that, in practice, people often accord the life of a child a special value. Those caring for children intuitively respond to their patients as though they were particularly precious, and feel an obligation to care for them - that is, to act in their interests - that expresses that value.

How do we account for that sense of value ? Principlism, the dominant paradigm in medical ethics, explains the value of life using both a utilitarian subjectivist account (there is a rational sense in which the individual's continued existence will be in her own interests and/or those of others) and a deontological objective one (there are 'contracts' or 'ties of family' whose nature, other things being equal, expresses an obligation to act in the interests of the individual, independently of any impact on the interests of others).

Both accounts are problematic in children, especially in those who are cognitively impaired. Most apprehend the universe in a way that is meaningful, but probably does not link moral action with outcome. The child therefore values his or her life in the moment, but does not have an interest in continuing existence in the way a subjectivist account of intrinsic value requires. Furthermore, even a well child (and even more a sick one) is by definition not independent, but exists in relationship with others on whom he or she is multiply reliant. Current moral accounts of the value of life therefore rely on two attributes the child who needs palliative care usually lacks: rationality and independence.

By affirming the identity, value and dignity of the most vulnerable, on the other hand, all major faiths offer an account that asserts a special value for children, and a responsibility of individuals and of society to care for a dying child, irrespective of his or her limitations and impairments. In this workshop, I will examine spirituality as meaning-making and its relationship with dignity and value in children's palliative care, with particular reference to the Maruzza Foundation's Religions of the World Charter for Children's Palliative Care.

Support for the Siblings

Jones B.

University of Texas at Austin, School of Social Work, Austin, United States

When a child faces a life threatening condition, their entire family is impacted. Siblings face unique challenges as they struggle to understand the illness as well as the way it has changed their family and their future. Siblings can experience a myriad of feelings including fear, confusion, loss, anxiety, hopefulness, anger, and sadness as they begin to face the new reality of their family. Siblings report feeling isolated and ignored in the face of a brother or sister's illness as their parents attempt to cope with the new devastating reality of childhood illness. Sibling reactions and eventual coping are influenced by many factors including their developmental stage, the severity of their sister or brothers' illness, pre-existing family dynamics, cultural and spiritual beliefs, familial and extra familial support, communication, prognosis and suffering, concurrent stressors, and sources of personal and familial resilience.

Siblings in pediatric palliative care cope with a mixture of feelings such as sadness, fear, anxiety, uncertainty, anger, hurt, abandonment and sometimes guilt. Studies show children who have a brother or sister with a chronic health condition display statistically significant negative experiences and exhibit more internalizing and externalizing behaviors. Higher levels of psychological distress and unmet needs appear among siblings who felt they received low levels of attention from their family members and loved ones. Studies show siblings often encounter emotional intensity, vulnerability, enduring sadness, loss, anger, and chronic intensive worry. Siblings may also experience symptoms of post-traumatic stress including intrusive thoughts, hypervigilance and physiological reactivity.

Significant barriers may exist in getting siblings the psychosocial care they need. The majority of siblings' unmet needs occur during acute phases of the brother or sister's time of diagnosis, during treatment and at relapse or terminal phase. As family members are away from home during times of medical crisis, time spent attending to the needs of siblings diminishes. The amount of uncertainties and lack of control often create psychosocial distress for siblings. Parents may not be present to offer support or answer questions. Psychosocial providers can provide supports to the sibling and the family and may be able to help families identify local or national community organizations that provide free or sliding scale resources for siblings.

When supporting siblings and families, it is important to maintain a strengths perspective and to recognize that each has their own sources of resilience that can help them face the challenges of a brother or sister's life limiting illness. It is the responsibility of the healthcare team to help siblings by offering unrelenting compassion and unconditional support as they move through their own coping and healing. This presentation will identify the needs of siblings and offer practical suggestions for supporting siblings in pediatric palliative care.

Challenging Pain Syndromes

Krane E.

Pediatric Pain Management, Department of Anesthesiology, Perioperative and Pain Medicine, Department of Pediatrics, Stanford University School of Medicine and Stanford Children's Health, Palo Alto, California, USA

Summary: Pain is a common symptom in children with incurable diseases in palliative care. While the evidence base guiding management of pain in pediatric palliative care is poor, collective experience and extrapolation from the evidence base of adult palliative care, and children with chronic pain dictates that pain symptoms be categorized into somatic, visceral or neuropathic syndromes, determined to be continuous versus intermittent versus intermittent upon continuous, and integrated into the entire medical condition of the child.

Scope of Problem: The number of children with incurable or terminal diseases who require palliative care is relatively small, and heavily skewed towards neonates and infants (>50%). In the U.S., there are about 42,000 deaths of children under the age of 18 annually, compared with 2.6 million annual deaths of adults. Further, the adults who die are largely elderly, frail, and experience death more quickly than do children, who may have death prolonged over a long time period. These circumstances lead to a relatively small clinical anecdotal experience; a robust evidence base of therapies is nonexistent.

Approach to the Pediatric Palliative Care Patient with Pain: In order to effectively treat and minimize pain, it is necessary to understand the anatomic and physiologic origin of the pain, and to do this one must categorize pain as follows:

- *somatic* (arising from tissues of the periphery, largely skin, muscle, connective tissues, bone, etc.);
- *visceral* (arising from solid or hollow organs, including ischemia of those organs); and
- *neuropathic* (pain arising from peripheral or central neurons, which may be from genetic origins (such as diseases of the nervous system, physical, toxic or hypoxic injury to the nervous system, or involvement of the nervous system by disease external to it, such as infiltration or compression by tumor, or infection). The treatment of pain in each of these categories may be very distinct.

In addition to these classifications, it is necessary for the clinician to define the chronological pattern of pain: is it continuous and present at all times? waxing and waning? intermittent and between periods of pain-free time? or a combination of these? Understanding the diurnal pattern of pain helps the clinician choose the best combination of medications based upon the known pharmacokinetics and pharmacodynamics of drugs in children.

Finally, and perhaps most difficult is the determination of pain severity, the measurement of pain. This is a very challenging endeavor in the verbal, communicative and intellectually intact palliative care child, but is very much more difficult in the pre-verbal infant, in the young child without developed numerical concepts or descriptive language, and yet still more difficult in the nonverbal child with cognitive impairment or obtundation. We will discuss various pain measurement tools in the lecture, and introduce some promising technology for the measurement of pain.

Management of Pain in Children: Management strategies may be categorized as

- *pharmacological* (administration of drugs by one route or another);
- *non-pharmacological* (psychotherapeutic interventions, physical rehabilitation and restoration of function, lifestyle interventions such as changing sleep/awake patterns, massage and therapeutic touch, and integrative medicine;
- and *interventional* (insertion of needles and drugs into the body at specific anatomic targets, usually to interrupt nerve transmission).

Pharmacologic therapy can be further categorized into opioid analgesics, non-opioid analgesics, and non-conventional drugs (medications for analgesia that are not ordinarily considered to be analgesic

drugs, such as anti-depressants, anti-epileptic drugs, corticosteroids, etc.).

Challenging Pain Syndromes: Finally, we come to the title of this lecture. What are the most challenging clinical conditions in children in palliative care that result in pain?

- Neuropathic pain syndromes, most commonly secondary to chemotherapy induced neuropathy, herpes zoster complicating immunodepressed states, and nerve compression or infiltration by malignancies.
- Bone pain, which may be the consequence of pathologic fractures complicating debilitated states, steroid treatment, or malignancy.
- Proptosis of one or both eyes, most commonly seen in advanced stage neuroblastoma.
- Autonomic instability and agitated behavior seen in children with diffuse brain injury and severe cognitive impairment.

Support for the Child and Adolescent

Kreicbergs U.

Ersta Sköndal University College, Caring Sciences, Stockholm, Sweden

Paediatric palliative care should be a human right. Millions of children are in need of palliative care worldwide. In the best-case scenario the child and family are cared for at their location of preference by a specialised paediatric palliative team. Yet, we all know that the availability of such specialised teams is scarce and not equally distributed worldwide.

The World Health Organization defines palliative care as an approach to improve quality of life of the patients and their families. Palliative care for children is the active total care of the child's body, mind and spirit and also involves giving support to the family. But how much do we actually know about the needs of the child and family members? Do we ask? Who do we ask? Who asks?

Suffering is common in seriously ill children. No questions can be asked as long as the child is in pain, either physical or psychological. Symptom management is not only of critical importance for the child, but also for the long-term psychological health of family members. Parents and siblings report being affected by the child's unrelieved pain and suffering still many years following the loss. It is likely that also friends and health care staff share this experience. It must be emphasized that symptom management is more than alleviation of physical pain. As for the child's psychological suffering it has been reported to be contagious; parents blame themselves when their child suffers from psychological distress. Health care professionals' should be trained to become aware of the child's signals about existential questions and awareness of impending death. Staff needs to respond to the child's thoughts and questions and support parents in their attempts to do so. Not seldom the child initiates the communication about these issues, often inspired by fairy tales, films or music. Books, music and films that may inspire thoughts about death and dying should be available where children are cared for. Children as young as three years of age have expressed awareness of death. Although, this awareness probably is common among seriously ill children, our approach and responses must take into account the maturity of each child.

Beyond the child and family also health professionals become emotionally involved and may need support. The care of severely ill children is often a co-operative task by several disciplines. However, there is not always consensus about clinical conclusions and initiatives. This may cause both moral and psychological distress. Moral distress may arise from ethical dilemmas such as staff doubts about the care being in the child's best interest. An external paediatric palliative care team offering a fresh set of eyes and knowledge may help to reduce staffs distress. Caring of the caregiver is essential to provide support for the child and family. To be able to offer and develop best possible care for all involved, children, families and health professionals we must continue to observe, communicate, ask questions and most importantly listen.

Children's Palliative Care in the Developing World

Marston J.

International Children's Palliative Care Network, Administration, Bloemfontein, South Africa

Background and aims: Palliative care is acknowledged as a human right, and therefore should be available to all children with life-limiting conditions, no matter where they live in the world.

Research by the International Children's Palliative Care Network (ICPCN) shows that there are more than 21 million children who would benefit from palliative care globally. Whilst over 90% live in the developing world, mainly in Africa and South-east Asia, most resources and provision is in high income countries. Children living in developing countries suffer from exposure to poverty and a high burden of disease, often living in countries that lack sufficient health care workers and have poorly-resourced health systems. With a predicted 81 million displaced persons in 2016, there are many children with life-limiting conditions who are not being identified or are lost when moving through different countries. The World Health Organisation (WHO) definition of palliative care for children states that it can be provided even when resources are limited, and there are a number of excellent and innovative programmes in developing countries which prove that children can receive high quality palliative care with limited resources. These programmes are models for development in low and middle-income (LMIC) countries. However while they are effective in providing quality palliative care, most struggle due to uncertain financial sustainability, lack of government support and competing priorities.

Methods: With reference to the Sustainable Development Goal for Health and the World Health Assembly Resolution on Palliative Care 67.19 which calls for integration into health systems, education for all involved in providing care and access to essential palliative care medicines, the presentation will highlight successful programmes providing quality palliative care despite a relative lack of resources and funding, in low and middle-income countries. Results will be shared of projects to further develop children's palliative care through beacon centres, advocacy, education, mentorship and model programmes. Results of a research project by Global Partners in Care and ICPCN to identify key elements of successful programmes in LMIC in Africa will be shared.

Results: The work of the ICPCN as a Global Action Network of individuals and organisations working in collaboration with a number of other international agencies has led to growth and development of children's palliative care in a number of countries. ICPCN E-learning modules accessed by health care workers in 115 countries has expanded knowledge; and programmes such as ELNEC and EPEC paediatrics are effectively increasing the pool of educators and educated professionals essential to the development of children's palliative care. The challenge is to have these educators and professionals in developing countries, also supporting the development of policies and model programmes that can act as mentors for development. A further challenge is to reach children needing palliative care in humanitarian situations and the development of a global palliative care collaborative is moving towards this provision.

A global awareness campaign to reach all children will be shared as a challenge to palliative care providers and professionals

Conclusions: There is much still to be done to reach children with palliative care needs in developing countries. More can be done if palliative care workers living in high-resourced countries are willing to reach out and work to support development in low-resourced countries, to share knowledge and resources and to recognise that where resources are limited, innovative people become very resourceful.

Nausea and Vomiting: The Neglected Symptoms?

McCulloch R^{1,2,3}

¹Consultant in Paediatric Palliative Medicine, The Louis Dundas Centre, Great Ormond Street Hospital, London, England, ²Honorary Senior Lecturer, UCL Great Ormond Street Institute of Child Health, London,

³Consultant in Paediatric Palliative Medicine, Helen and Douglas House Hospice, Oxford

The sensation of nausea is a significant burden that is underestimated in the paediatric population. Nausea is often identified as a precursor to the act of vomiting (emesis) however this association is not a simple relationship. Although nausea and vomiting are thought to exist on a temporal continuum, this is not always the case. Nausea often exists without emesis and, less frequently, emesis can occur without preceding nausea. The symptoms are separate, but related, and can cause misery and distress to sufferers.

In paediatric palliative care practice, nausea and vomiting are often recognised by clinicians but identifying the cause, understanding the complex pathophysiology, and consequently optimising therapeutics and achieving effective symptom management can be challenging. This is particularly so in infants and children who are less able to identify and describe their symptoms, specifically nausea. Most adults report nausea to be more common, more disabling, feel worse and last much longer than vomiting. As such an improvement in vomiting may not reflect resolution of nausea and it is highly likely that persistent nausea may become 'lost' within the multitude of symptoms experienced by infants and children as they get sicker.

There is a relatively clear understanding of the mechanism underlying nausea, most of which is about nausea concomitant with emesis. The complex interplay between the brain and the gastrointestinal tract by central and local neurological mechanisms, hormonal regulation and physical factors offers a wide range of potential therapeutic interventions. Most pharmacological approaches work by blocking specific receptors at various sites, and theoretically, this can support a rational approach to prescribing. However pharmacological control is only one aspect of the management of nausea and vomiting. Recognising and addressing the psychological and emotional factors influencing the experience of these symptoms plays a central role in reducing symptoms. Whilst it is important to have a thorough understanding of receptor pharmacology in relation to anti-emetic medication, it is essential to remember it is only one aspect of a wider approach to a multidimensional symptom experience.

With this in mind, the aim of this presentation is to:

- Update on current scientific knowledge and explore 'new 'vistas' in the basic science of nausea and vomiting
- Review the potential causes of nausea and vomiting in the paediatric palliative care patient population

Managing Adversity in Times of Economic Hardship

Papadatou D.

National and Kapodistrian University of Athens, Nursing, Athens, Greece

According to research evidence, countries which are faced with a major financial crisis, experience increased rates of mortality and a significant rise in health problems, suicides, homicides, sudden and violent deaths. Data is inexistent as to how a country's economic hardship affects the daily life of families with a child suffering from with a life-limiting illness, and of families that grieve the loss of a loved person. Greece, among all european countries, has been faced over the past seven years with the most extreme austerity measures, which engendered multiple losses affecting people's health, standards of living, and quality of life.

In this presentation, I will address the following goals. First, I will briefly describe some psychosocial phenomena that emerge in a population that is faced with crisis-related losses, symbolic losses, and ambiguous losses, which often evoke traumatic responses and disenfranchised grief . Second, I will discuss how the prolonged effects of economic and social hardship affect the families of seriously ill and bereaved children who experience, for the first time in their life, increased levels of poverty, and are concurrently deprived of opportunities for socialization, leisure time, and self-care. Quite ofte, these families are isolated, as relatives who are absorbed by their own crisis-related losses, remain unavailable to provide ongoing support. In response, they turn to professionals who become their unique support system through end of life care and bereavement. Third, I will address the challenges that professionals encounter, when they are faced with similar crisis-related adversities (i.e., salary cuts, underemployment, uncertainty about the long-term survival of their work-setting, and other personal and family losses, changes, and threats), and identify with the families they serve. Finally, I will share some personal reflections on the challenges that pediatric palliative care and bereavement support organizations encounter when their viability is at risk and adversity is ongoing. Drawing on my experience as a member of the board of directors at "Merimna", a Greek non profit organization for the care of children and families facing illness and death, I will highlight the factors which have proved helpful in promoting resilience at an organizational level.

As specialists in palliative and bereavement care, we need to revisit our models of care and explore in greater depth how the effects of poverty, of living with ongoing uncertainty, of having to cope with multiple losses, affect the experience of end of life care and bereavement during times of economic hardship. Research must extend its focus beyond the individual and the family, and explore global phenomena that occur during transitional periods at a social and national level.

Advocating for a *life with dignity for all*, requires the cultivation of "aware" communities in which both those who receive as well as those who provide services in palliative and bereavement care, take the time to reflect, attribute meaning to life's losses, and view self, not as victims of socio-economic hardship, but as agents of personal and social change.

Distress in the Young Child

Sourkes B.

Lucile Packard Children's Hospital, Stanford University, USA

Distress in the young child living with serious illness ranges from transitory discomfort or unhappiness to profound clinical phenomena in physical, emotional and spiritual domains. The concept of distress is of course highly salient throughout the trajectory of a child's illness, regardless of the duration. While much of the focus around distress in pediatric palliative care used to focus on the late stages of the disease, it is clear that issues of quality of life, need for decision-making and symptom management are pervasive throughout.

The concepts of adversity / stress / trauma in relation to a child's coping and resilience underlie any discussion of distress. This presentation will provide an overview of the main foci of distress in the child with emphasis on its identification through the child's behavior, words and drawings. Implications for management and intervention will be incorporated into the discussion.

Addressing Distress in the Neonatal Period – End Of Life Care

Vasudevan C.

Neonatal Unit, Bradford Teaching Hospitals NHS Foundation Trust, Bradford, United Kingdom

End of life care in the neonatal period is being recognized as an area with specific challenges such as the vulnerability of the new-born infants, the difficulties in objectively assessing pain/ discomfort and the relative lack of evidence to support treatment measures (pharmacological and non-pharmacological). Historically, there has been a significant shift in recognizing that neonates (especially preterm neonates) have well developed nociceptive pathways that will enable them to perceive pain and react to them in a way that can be clinically assessed. There are a number of validated pain scores that will help clinicians identify and address pain in neonates. Most of the neonatal deaths occur following elective discontinuation of life sustaining measures. Continuing to provide analgesia and sedation is a key component of their ongoing care in the last few hours before death. Opiates such as morphine and diamorphine are the most commonly used medications and the route of administration depends on the options available. There is enough evidence to suggest that oral / buccal administration is effective and often useful in the absence of intravenous access. Benzodiazepines such as Midazolam especially through the buccal route can be helpful in managing acute distress in a dying neonate. The unintended but recognised side effect of respiratory depression with opiates is accepted in such situations as the primary motive is to provide comfort (doctrine of double effect). Non-opioid analgesics like paracetamol can be used as adjuncts to treat pain in the neonate but are rarely used as sole agents. There is significant variation in the use of neuromuscular blocking agents and there are ethical considerations surrounding their use in end of life care.

In addition to managing pain, other symptoms like excessive secretions and seizures need to be addressed to allay distress and parental anxiety. Discontinuing nutrition, enteral and parenteral – needs careful consideration and depends on the clinical condition of the neonate. Moribund babies receiving intensive care, when compassionately extubated die soon and it is entirely appropriate to withhold fluids / nutrition in this situation. In neonates who are physiologically stable and are expected to live longer (days to weeks), it is important to consider feeds which are often comforting and are not directed towards achieving nutritional goals. The decision to provide continuing nutrition i.e feeds has to be balanced against the need for invasive procedures such as gastrostomy or central venous access in these infants.

Empowering and involving parents through decision making is a major component of neonatal end of life care. Acknowledging parental anxiety and distress, helping them recognise pain in the neonate and enabling them to understand the principles of comfort care are vital steps in formulating an end of life care plan. Sensitive and often repeated discussions with the family, compassionate approach from the staff and parental integration into decision making will enhance the family's experience. One of the major challenges in neonatal intensive care is to overcome the sense of detachment from their infant that the parents perceive, often making it difficult to create memories with their dying infant. Involving siblings and grandparents in the infant's care and memory making helps them through their grieving process and should remain as a major focus in end of life care.

A significant proportion of infants (gestations of borderline viability and serious congenital anomalies) die during labour or very soon after birth. The care for these infants is focussed on helping families comfort them and allow time with their parents. Often, pharmacological agents may not be administered and their use needs to be balanced against lack of easy intravenous access. Buccal or oral medications and comfort feeds may be considered if the infant shows any signs of distress or hunger.

Antenatal care planning in situations where the infants are known to have a serious life limiting condition helps both parents and professionals in managing these infants.

In spite of the recent advances, neonatal end of life care still remains a significant clinical challenge to health professionals in terms of accommodating family perspectives and enhancing memory making. A carefully considered care plan and a compassionate approach are important to the quality of care delivered and will significantly enhance the family's experience in the long term. Future research needs to focus on the safety and effectiveness of some of the pharmacological measures and the usefulness of the other interventions in helping families in the long term.

The Significance of Integrated Care

Wolfe J.

*Director Paediatric Palliative Care Children's Hospital Boston Division Chief, Paediatric Palliative Care Service
Department of Psychosocial Oncology and Palliative Care Dana-Farber Cancer Institute Boston,
Massachusetts, USA*

Background: To integrate means to combine one thing with another so that they become a whole, a fundamental principle of Children's Palliative Care (CPC). This lecture will review three ways in which CPC integration is achieved in the care of seriously ill children and their families:

1. CPC involves *integrated* care directed at the physical, emotional, spiritual and social needs of the child and family
2. CPC involves care delivered by an *integrated* interdisciplinary team
3. CPC is *integrated* early on in an illness, in collaboration with the clinical teams responsible for disease-directed care

Methods/Results: Each integration strategy will be demonstrated using case examples and a review of the scientific literature.

Conclusions: Early and ongoing integration is fundamental to the delivery of high quality Children's Palliative Care.

Effectiveness of Paediatric Palliative Homecare in Reducing the Need for Hospital Care

Jordanishvili S., Uchaneishvili M., Katsitadze N., Kvijinadze T.

'Children's Hospice', Tbilisi, Georgia

Background: The aim of the study was to test the effectiveness of paediatric palliative home care in improving the quality of life for its beneficiaries and their families. One of the most important factors is how often the children need medical care and how many days they spend away from home due to hospitalization.

Methods: A questionnaire was created for 15 patients, who have been enrolled in palliative homecare for at least 3 months. The questions compared how many outpatient visits and hospitalization days have been conducted since joining palliative home care, as opposed to the same length of period before. The data was analyzed with a one-tailed, paired t-test.

Results: There was a significant decrease of outpatient visits since joining the home care; $p=0.049$. Children have needed on average 1.4 visits since joining, as opposed to 4.9 before (in the equal time period).

There have been on average 0.5 occurrences of inpatient hospitalization since joining the home care, which is significantly less than 2.3 visits before; $p=0.024$.

The amount of time spent in hospitalization stays in a 3-month period averaged 2.1 days since joining the home care, which is also significantly less than 13.0 days before; $p=0.037$.

Conclusions: Paediatric palliative home care was suggested as a temporary project before the construction of children's hospice. The analysis shows that the amount of outpatient hospital visits have decreased significantly for children who joined the home care. The average number of days spent in hospitalization stays during a three-month period is also significantly lower since joining. The study concludes that paediatric palliative home care has been effective in reducing the need for medical care for children with palliative diseases, which is very important because the beneficiaries are subjected to less stress and can spend more time with their families. This is a positive contribution to their quality of life as well as that of their families.

The Emotional Worlds of Parents of Children with Life-limiting Conditions

Beresford B.¹, Moran N.²

¹University of York, SPRU, York, United Kingdom, ²University of York, Social Policy and Social Work, York, United Kingdom

Background: A sizeable number of studies have investigated families' accounts of living with a life-limiting condition (LLC). Typically they focus on a particular diagnosis and there has been little attempt to look at the evidence across conditions. This paper reports a systematic review of evidence on the emotional worlds and experiences of parents. It is drawn from a wider project on families' experiences of living with a life-limiting condition.

Methods: MEDLINE, CIAHL and PsycINFO (2009-2014) were searched using the search string 'diagnosis' + 'family member' + 'qualitative research'. Diagnoses were drawn from the list of life-limiting conditions (LLCs) used to create the ICD coding framework. Over 14,000 papers were identified; 54 met the inclusion criteria and together represented over 750 parents. Parents' emotional experience was a dominant theme, with relatively high quality evidence and representing a wide range of LLCs. Relevant data was extracted and a thematic analysis and synthesis completed.

Findings: Key themes emerging from the analysis were:

- living in a permanent state of heightened emotions, interspersed with periods of intense emotion;
- sources of emotional distress ranged from living with uncertainty through to others' reactions;
- the emotional demands associated with responsibility for care/treatment protocols;
- dealings with services as a significant source of distress;
- the possibility of significant levels of emotional distress/fragility;
- threats to physical health/ well-being;
- lack of recognition of the threats to well-being;
- impacts on couples' relationships.

Conclusion: Parents of children with a life-limiting condition can face a number of difficult and challenging experiences, many of which have a significant emotional element. These findings raise implications regarding the level and extent of psychological/emotional care available to parents.

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Parent Perspectives after Receiving an Early Palliative and End-of-Life Care Communication Intervention

Haase J.E.^{1,2}, Hendricks-Ferguson V.L.³

¹Indiana University School of Nursing, Indianapolis, United States, ²Indiana University, Center for Research in Palliative and End-of-Life Communication and Training, Indianapolis, United States, ³St. Louis University School of Nursing, St. Louis, United States

Background: Our study pilot tested an early palliative and end-of-life (PC/EOL) communication intervention, Communication Plan: Early through End-of-Life (COMPLETE) delivered by pediatric oncology physician-nurse dyads to parents of children with a brain tumor. COMPLETE, delivered at diagnosis and 2 subsequent tumor response evaluations, included non-abandonment, hope-generating messages, parent and treatment goals, and advance directives discussions and demonstrated positive outcomes in hope and uncertainty. Here, we describe parent perspectives of COMPLETE obtained from semi-structured interviews.

Methods: A n individual semi-structured audio-recorded interview was done with 10 parent participants from two major pediatric-oncology centers in the USA. The research question guiding interviews was: What are parents' perspectives on the meaningfulness and helpfulness of the intervention for their understanding PC/EOL options for their child? These post-intervention and evaluation interviews occurred 4 weeks after COMPLETE intervention delivery and completion of the study measures. Interview data were analyzed using thematic analysis.

Results: COMPLETE fostered therapeutic alliance with health care providers (e.g. being truly heard); specific benefits of receiving complete intervention (gain tools to help family understand decisions); and, provided suggestions about future implementation of complete (e.g., increase sessions; measures for infants and younger children).

Conclusions: Parent interviews provided additional support that, with minor changes, COMPLETE has potential effectiveness to foster early parent-provider communication to improve parent outcomes during the first six months following the child's diagnosis. A randomized control clinical trial is needed to compare benefits of receiving the COMPLETE intervention in a larger sample of parents of children with high risk cancer in comparison to parents that do not receive the COMPLETE intervention.

A Model on Parenting and Parental Caregiving in Pediatric Palliative Care: A Qualitative Study

Verberne L.M.¹, Schouten-van Meeteren A.Y.M.², Colenbrander D.A.³, Bosman D.K.³, Grootenhuys M.A.^{4,5}, van Delden J.J.M.¹, Kars M.C.⁶

¹University Medical Center Utrecht, Julius Center for Health Sciences and Primary Care, Medical Humanities, Utrecht, Netherlands, ²Emma Children's Hospital, Academic Medical Center, Pediatric Oncology, Amsterdam, Netherlands, ³Emma Children's Hospital, Academic Medical Center, General Pediatrics, Amsterdam, Netherlands, ⁴Emma Children's Hospital, Academic Medical Center, Psychosocial, Amsterdam, Netherlands, ⁵Princess Maxima Center for Pediatric Oncology, Utrecht, Netherlands, ⁶University Medical Center Utrecht, Julius Center for Health Sciences and Primary Care, Medical Humanities/Nursing Science, Utrecht, Netherlands

Background: The number of children with a life limiting disease has been increasing and many of them are mainly cared for at home. Their parents play a major role. Yet studies on parenting and parental caregiving in paediatric palliative care (PPC) are scarce and often narrowly focused. This study was aimed at developing a generic and comprehensive model on parenting and parental caregiving in PPC from the parents' perspective.

Methods: An explorative qualitative study using descriptive thematic analysis. In total 47 single or repeated interviews were conducted with 42 parents (18 fathers, 24 mothers) of 24 children (0-18 yr.) with a malignant or a non-malignant disease receiving palliative care.

Results: Parental caregiving became manifest in four groups of tasks parents feel responsible for: providing basic and complex care, organizing the best treatment and quality care, making sound decisions while managing risks and organizing a good family life. The achievement of these tasks was largely driven by the parents' aims. Three aims were identified that cover the parents' wish to be a good parent for the child and the family: controlling the disease and symptoms, creating a life that is worth living and achieving a family balance. In particular the expected yet unpredictable loss of their child, resulted in strong feelings and perceptions and specific coping strategies, such as enduring by suppressing emotions, living before an imaginary screen and taking direction, which influence their ability to perform the tasks that they strive to achieve. A descriptive model incorporating the aforementioned aspects was developed.

Conclusion: The tasks and the way parents try to achieve them, are not only dictated by the child's illness, but also influenced by the parents' aims, experiences and coping strategies. The model increases our understanding of the parents' caring position and can guide health care professionals in more personalized parent-centred support in PPC.

Use of a Newborn's Diary in a Neonatal Intensive Unit (NICU): Parents Perceptions

Mendes J.^{1,2}, Soares B.¹

¹São Francisco Xavier Hospital, Neonatology, Lisbon, Portugal, ²Taskforces of the Portuguese Society of Pediatrics and Association of Palliative Care, Lisbon, Portugal

Background: Therapeutic writing and narrative medicine are new areas. Few studies explore the importance of the use of diaries in the NICU. Parents' responses to the trauma can cause them to forget day to day events during the hospitalization of their child. A diary can become a precious healing tool, especially if the baby does not survive.

Aim: Identify parents' perceptions of the use of the newborns' diary in NICU

Methods: Exploratory cross-sectional study. Email survey. Families that met 3 criteria: 1) NICU admitted (September 2014-March 2015); 2) Gestational age ≤ 32 weeks or malformations or syndromes or birth asphyxia; 3) Positive oral informed consent. Data collected: December 2015.

Results: Demographics collected reported; 22 family members of the 24 invited completed the survey (response rate 83%). Sample: mothers (20/22) with an average of 33.5years. Newborns: gestational age (24- 40weeks; average 30). All newborns were discharged home.

The diary was introduced to 59% of the families (13/22); mainly in the first week (7/22). All families (22/22) considered the diary important (22/22) and relevant to their well-being during NICU stay (12/22). The majority of families uses the diary (19/22): mother are the main users (11/22), followed by the NICU staff (8/22) and the father (7/22). Use frequency: Every day (6/22), 2/3 times a week (2/22). Methods used: writing (11/22), drawing (6/22) and photographs (5/22). Content: Memory creation, emotion expression, self-awareness and communication with providers.

Conclusion: Results are in line with literature and suggest the importance of a diary in NICU. Parents refer the diary's importance to help coping with stressful information, emotions, and maintaining /reframing hope by creating healing memories. These findings reinforce the use of the diary and motivate professionals to introduce it to parents early in the hospitalization. Need of awareness among the team is needed and further research to optimize this tool.

A Pain Observed: A Phenomenological Study of Maltese Caregivers of Children with Severe to Profound Developmental Disability

Andrejevic H.

Mater dei Hospital, Paediatrics, Msida, Malta

Background: In spite of advances in pain assessment, children with severe to profound developmental disability (SPDD) still remain vulnerable to sub-optimal pain management, because they are unable to communicate pain in the usual vocal way, and have pain behaviours that are diverse to those found in typically developing children.

Purpose: The aim was to explore the lived experiences of Maltese caregivers who face the problem of pain in their children with SPDD.

Methods: Interpretative phenomenological analysis (IPA) underpinned the study and consisted of interviews with seven family units of children with SPDD aged 18 months to 19 years.

Findings: Four main themes emerged: 'a life of pain', 'forever doubting', 'embodied knowledge', and 'overwhelming emotions'.

Conclusions: Maltese parents felt that their children suffer from more pain than their unimpaired peers. Although confident that they can recognise their children's pain behaviours, the feeling of uncertainty is always present. They have learnt to cope alone, developing the skills to assess pain over the years that they have looked after them. The lived experiences of 'a life of pain' have resulted in feelings of helplessness and frustration. They felt that although some doctors show empathy, listen to them and involve them in decisions, many others have not prepared them for the pain problem, have poor communication skills and show lack of empathy. They also felt that they were not being given an active part in decision making. There were also positive feelings in relation to their children's pain journey, including feelings of being able to cope, joy when solving pain dilemmas and love that they feel for the children. Recommendations for practice and research in Malta are suggested.

Keywords: Pain, pain measurement, cognition disorders, developmental disabilities, cerebral palsy, pain experiences, parent-child relations.

Spinal Muscular Atrophy Type 1: Needs and Interventions from Diagnosis to Post-Mortem during a Pediatric Palliative Care Program

Di Pede C., Agosto C., De Tommasi V., De Gregorio A., Benini F.

University of Padua, Padova, Italy

Background: Spinal Muscular Atrophy (SMA) type 1 is an incurable, severe and progressive disease, eligible for pediatric palliative care.

Purposes of the study: To describe the clinical history, needs and interventions of patients with diagnosis of SMA 1 attended by the Veneto Regional Pediatric Palliative Care Center (PPCC), for which parents chose supportive care, from diagnosis to post-mortem..

Materials and methods: We retrospectively analysed 17 patients (April 2006-April 2015).

Results: Seventeen children were attended. Median age at death was 6,80 months. Median age at PPC admission was 3,57 months. Territorial services were coordinated by the Center in 100%; limits on acute care were communicated to emergency services for all children. Scheduled domiciliary visits (mean number 14,35), interviews with the family (mean number 12,88) and phone calls (mean number 27,82) were provided in all cases. The respiratory symptoms onset appeared at a median age of 2,62 months. Airway suction was used in all cases (100%); oxygenotherapy in 7 cases (41,18%). The swallowing symptoms onset appeared at a median age of 2,90 months; all children required nasogastric tube at a median age of 4,23 months. Pain was treated with paraceramol, ibuprofen or paracetamol+codeine in 13 children (76,47%); dyspnea was treated with morphine and/or benzodiazepines (BDZ) in 15 children (88,24%). In end of life deep palliative sedation was required for 15 patients (88,24%). Death occurred in 7 cases (41,18%) in Hospice, in 6 cases (35,29%) at home, in 4 cases (23,53%) in a Peripheral Hospital. In 88,24% death occurred in the place previously planned by parents. Pediatric palliative care team was present at the time of death in 14 cases (82,35%). Post-mortem interviews were performed for 16 couples (94,12%). After the death of the son, 10 couples (58,82%) had pregnancies.

Conclusions: Care needs in SMA 1 require a multi-specialistic and shared action from diagnosis to death and beyond.

Seizure Management in End of Life Care for Children

Harris N.¹, Baba M.², Beringer A.¹, Mellor C.³, Rogers R.³, Taylor K.⁴, Sharples P.³

¹University of the West of England, Faculty of Health and Allied Sciences, Bristol, United Kingdom, ²Children's Hospice South West, Bristol, United Kingdom, ³Bristol Royal Hospital for Children, Bristol, United Kingdom, ⁴Devon Virgin Care, Integrated Children's Services, Devon, United Kingdom

Background: Controlling seizures in children approaching death is often challenging. The evidence base to guide best practice is limited. We aimed to compare our current practice against the guidance for seizure management produced by the Association of Paediatric Palliative Medicine, and the Children's BNF, seeking to improve symptom control in this situation.

Methods: Retrospective case note review of episodes of challenging seizure management in children receiving end-of-life (EOL) care over a ten year period (2006-2015) in the southwest region of England.

Results: We reviewed 18 cases where seizure management in EOL care was difficult. 6 (33%) had a malignancy, 8 (44%) had a progressive neurodegenerative condition, and 4 (22%) had a static neurological condition with associated epilepsy. 13 (72%) died in their local hospice, 4 (22%) at home, 1 (6%) in hospital. 17/18 (94%) involved the use of subcutaneous or intravenous midazolam infusion, for a mean of 11 days (range 3-27). There was a wide range of starting doses of midazolam, and 9/17 (53%) received final doses in excess of current dose recommendations. 6/18 (33%) received subcutaneous phenobarbital infusions, with 4/6 (67%) receiving final doses in excess of current dose recommendations. Plans for adjustments of infusion rates, identification of maximal doses, or alternative approaches should treatment fail were inconsistent. In 17/18 (94%) cases seizures were successfully controlled before the child died, but often this took hours or days. Fear of apnoea or over-sedation was the biggest barrier to prompt symptom control. Staff found the experience of managing seizures at end-of-life challenging and stressful.

Conclusions: Seizure management in end-of-life care is inconsistent. Despite limited evidence, best-practice management guidance should be developed to support improvements in this area of symptom control.

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Spinal Muscle Atrophy: The Spanish Pediatric Palliative Care App

Navarro-Mingorance A.¹, Peláez-Cantero M.J.², Puertas-Marin V.³, Ortiz San Roman L.⁴, Rigal Andres M.⁴, Leyva Carmona M.⁵, Navarro Vilarubi S.⁶, Huidobro B.⁷

¹Hospital Clínico Universitario Virgen de la Arrixaca, Pediatría, Murcia, Spain, ²Hospital Carlos Haya, Málaga, Spain, ³Hospital Niño Jesús, Pediatría- Cuidados Paliativos Pediátricos, Madrid, Spain, ⁴Hospital Niño Jesús, Madrid, Spain, ⁵Hospital Clínico Universitario Virgen de la Arrixaca, Almería, Spain, ⁶Hospital Sant Joan de Deu, Barcelona, Spain, ⁷Hospital de Toledo, Toledo, Spain

Background: SMA is a life threatening condition with complex palliative care needs.

Context: In Spain Pediatric Palliative Care Departments (PPCD) are being developed. Also palliative care for SMA disease is growing for children and their families.

Aim: The aim of this study is to review the palliative approach to SMA in Spain during the last 8 years.

Methods: A multicentric retrospective study was performed reviewing clinical reports of children followed and treated in pediatric palliative care resources in Spain.

Results: 41 children and families were reviewed. Clinical classification found was 2 SMA with respiratory distress (SMARD), 37 patients SMA type 1, 1 SMA type 2 and 1 SMA type 3. 36 patients have died. Median age at diagnose was 3 months (1 d-8m). Median delay between diagnose and first PPCD was 6,2 days (1-258d). Median follow up to date PPCU last for 53 days (1 d-1153 d). Most frequent onset symptom was hypotonia. One patient (2,5%) presented at first symptom severe respiratory failure. Median age at onset was 2,5 months. 37 patients (92,5%) received palliative care not only at the end of life. Advanced enteral nutrition was used in 33 patients. 76% received respiratory physiotherapy. 4 patients got invasive ventilation (2 endotracheal tube, 2 traqueostomy). Night non invasive ventilation (NIV) was used in 8 patients (76%). 100% suffer dyspnea. 80% got opioids, 15 needed benzodiazepines. At end of life 13 received benzodiazepines and opioids (85% subcutaneous). Median age at death was 6,6 months (22 days-172,5 months). Place of death was home in 67%. Bereavement follow up was performed in 28 patients with no pathologic bereavement process.

Conclusions: Managing SMA is still a challenge. Pediatricians send children to PPCD at early stages of illness. Dyspnea was present in all patients in our study and needs an appropriate treatment. Most of the patients need opioids and benzodiazepines to reach comfort at end of life.

The Outcome of End of Life Care (EOLC) in a Tertiary Neonatal and Paediatric Intensive Care Unit in the UK

Callender-Iddon A.¹, Mayer A.²

¹Sheffield Children's Hospital, Embrace, Dodworth, United Kingdom, ²Sheffield Children's Hospital, PICU, Sheffield, United Kingdom

Background: Palliative care embraces a comprehensive and multifaceted approach focused on enhancing the quality of life and support for the family, not simply limited to death or bereavement. These principles underpin published international guidelines on EOLC. We aim to examine the EOLC provided on tertiary neonatal and paediatric intensive care units in the UK.

Methods: A retrospective audit of EOLC was undertaken, using medical notes of neonates (NICU, n=10) and children (PICU, n=10) who died between Aug 2015 and Feb 2016, (52% deaths over this period). Data was assumed non-parametric and unless expressed otherwise is described as a median with interquartile range [IQ1-3].

Results: Age at death for the NICU and PICU groups was 2 days (1-5) and 2.5 years (0.24- 3) respectively. 50% (n=5) of NICU diagnosis was congenital heart disease, the remainder: extreme prematurity and congenital abnormalities. In PICU 40% (n=4) was sepsis, 20% (n=2) cardiac surgery, the remainder accidental. The management of symptoms/hydration was documented for all episodes of EOLC. In PICU limitation of therapy was documented in 70% (n=7), 2 died on admission. 60% of NICU episodes were compassionate extubations. Preferred place of death was discussed equally in both the PICU and NICU patients, 60% (n=12). Information regarding organ donation was given to 50% of PICU patients but none of NICU. 40% (n=4) of PICU families had psychological support (psychological referral). 10% of the NICU families had evidence of support. Spiritual support was offered to 70% (n=7) of PICU and 50% (n=5) of the NICU families. Bereavement follow up was offered to all.

Conclusion: Information, choice and support surrounding EOLC is paramount in ICU. Satisfactory management of distressing symptoms, artificial hydration and bereavement care occurs. The areas that could be improved upon include psychological support, information regarding organ donation and choice about the preferred place of death if appropriate.

Development of a Multidisciplinary Regional Perinatal Palliative Care Pathway

Harrop E.¹, Brenda K.², Wilknsn D.³

¹Helen & Douglas House / John Radcliffe Hospital, Paediatric Palliative Care, Oxford, United Kingdom, ²John Radcliffe Hospital, High Risk Obstetrics, Oxford, United Kingdom, ³John Radcliffe Hospital, Neonatal Intensive Care Unit, Oxford, United Kingdom

Our children's hospice has always offered out of hospital treatment withdrawal & symptom management to babies. Regional services for high risk obstetrics, tertiary neonatal care, and specialist pediatric palliative care have worked in partnership to develop a unified pathway for women with an antenatal diagnosis of a potentially life limiting condition. The aim is to support couples during diagnosis, delivery, postnatally, and to offer bereavement care. Wherever possible delivery is facilitated close to the family's home with provision of specialist input and advice to support local teams.

Methods: Retrospective review of families supported in the first year pilot project.

Results: 7 cases were referred to the palliative care team for counselling, 2 booked for delivery at the tertiary centre, 4 in local hospitals, 2 families elected for termination, 2 babies were still born, 2 live births delivered, 1 remains in-utero. 1 surviving infant. No admissions to NICU, 1 family used cold bedroom & stayed in the hospice, others offered hospice bereavement support. 1 family mentioned neonatal organ donation.

Conclusions: This represents effective partnership between statutory and charitable services and has been held up as an example of good practice in the True Colours Foundation publication 'Life to the Full'. There was no burden on regional acute services, as good advance planning prevented NICU admissions. User feedback was extremely positive: "The palliative care team gave us so much more than the promise of morphine for N. They stepped in to protect the space that we needed in order to deal with her death. They understood that the value of life is not only in being alive, but also in connecting, and that we will take something of this time with N further with us. They accepted our pain, without looking away. We could lean on them as we all stepped back together, allowing that life can end, sometimes just as it is beginning. And they helped me gain a daughter, even as I lost her."

How do Neonatal Units Support Siblings Following Loss? - A National Survey

Henderson R., Minchella S., Vasudevan C.

Bradford Teaching Hospitals NHS Trust, Neonatal Medicine, Bradford, United Kingdom

Background: Supporting siblings following loss of a newborn is an important aspect of neonatal bereavement support. The grief reactions in siblings are influenced by their cognitive ability and by how the family responds to the loss. They are compounded by the fact that neonates often die in the hospital with limited or no interaction with their siblings. Both the Royal College of Paediatrics and British Association of Perinatal Medicine provide guidance on supporting families but there is great variation in practice across the country.

Aims/objectives: To explore the interventions, support systems and resources available in all the Neonatal Intensive Care Units (NICUs) in England to support siblings following neonatal loss.

Methodology: Structured telephonic survey using a standard proforma of all the 44 NICUs in England, over a period of 6 weeks between May and June 2016.

Results: 44 NICUs (100%) were included. 34% of the units said they provide support for siblings after neonatal death through a combination of counsellors / psychologists / family support nurse. 60% involved external services including hospice or a charity organisation. Only 50% of units had any written materials or resources to support siblings. 10% of the NICUs did not have an identified bereavement support / end of life care team. There were varying levels of senior clinician / nursing involvement with the bereavement support team.

Conclusion: This study identifies significant variation in practice across the NICUs. It reiterates the need for a much more unified approach and sharing resources / good practice models across the units. Partnership working and engaging hospices / voluntary organisations enables neonatal units to support siblings and families in the long term. Sibling support needs to be an integral component of the bereavement support offered by neonatal services and appropriate resources / pathways need to be developed to provide equitable access across the country.

Decision-making on Withholding Treatment and Facilitating Choices in Neonates with Congenital Ultra-short Small Bowel: Clinical and Ethical Considerations

Koh M.

University Hospital Southampton, Paediatric Palliative Care, Southampton, United Kingdom

Background: Literature on children with ultrashort small bowel (USSB) (≤ 20 cm) indicates survival on total parenteral nutrition (TPN) is good despite liver disease and line sepsis. However, the cohort of patients is small and heterogeneous, spanning a large age range and different lengths of bowel. We present two neonates born with USSB. We explore the challenges of decision-making and facilitating choices in these situations of uncertain outcomes.

Methods: The first neonate was born with an antenatal diagnosis of vanishing gastroschisis. At laparotomy, he had < 13 cm jejunum; an enterostomy was placed for decompression. The options of either having TPN with a hope of transplant, or end of life care at home were considered. In view of the morbidity of long-term TPN and the uncertain outcome, palliative care (PC) was recommended. His family agreed and he was discharged home with oral Dioralyte and milk for comfort feeding, accepting the enterostomy losses.

In the following 3 weeks, he remained alert and crying to demand feeds. His family now wished for him to have TPN and the PC team had him re-admitted for stabilization and initiation of TPN. He continues to thrive.

The second baby was born with antenatal bowel obstruction. She had < 1 cm of jejunum. An enterostomy was placed. The same options were considered but her outcome bleaker as she had less gut. Her family was clear that she should not have any treatment that might be burdensome or cause suffering. She was discharged home being breast fed for comfort and with PC support. She required buccal midazolam and morphine and died after 6 days at home.

Conclusion: The clinical and ethical decision-making for life-prolonging treatment when the outcome is uncertain raises questions of:

Just because we can treat, should we treat?

How and who decides if treatment is burdensome?

What mechanisms are there to facilitate changes in goals of care?

How do we interpret heterogeneous literature for individual patients?

Communication at Diagnosis and at End-of-Life (EOL) in Complex Congenital Heart Disease (CCHD): Fathers' and Mothers' Perceptions

Benedetti F.¹, Agosto C.¹, Padalino M.², De Tommasi V.¹, Milanese O.³, Stellin G.², Benini F.¹

¹Azienda Ospedaliera Padova Università di Padova, Pediatric Palliative Care and Pain Service, Department of Woman and Child's Health, Padova, Italy, ²Azienda Ospedaliera Padova Università di Padova, Pediatric and Congenital Cardiac Surgery Unit, Department of Cardiac, Thoracic and Vascular Sciences, Padova, Italy, ³Azienda Ospedaliera Padova Università di Padova, Pediatric Cardiology Unit, Department of Woman and Child's Health, Padova, Italy

Background and aims: Communication to parents is one of the hardest tasks in pediatric clinical practice, especially trying to explain prognosis at diagnosis and in the EOL period. We analyzed the perceptions of bereaved parents (BP) about estimated lifespan, estimated quality of life and quality of communication at time of diagnosis, correlating mothers' (Ms) and fathers' (Fs) results. After that we correlated Ms' and Fs' perceptions of readiness to dying symptoms at the EOL.

Methods: This is a cross-sectional survey of BP of children with CCHD who died in hospital (2009-2012). We measured the perceptions of BP concerning the communication process at diagnosis, and during the last 72 hrs of life, with questionnaires based on close-ended questions (11-point scale).

Results: We interviewed 10 families for a total of 20 parents. In the context of diagnostic communication we correlated: expectations for quality of life and for lifespan (All BP: $R=0,6$; F: $R=0,83$; M: $R=0,4$); the parents' need for additional information and how comfortable they were with the way in which information were given (All BP: $R=-0,26$; F: $R=-0,27$; M: $R=-0,22$). Then we correlated the level of preparedness for symptoms experienced during the EOL period and clarity of information concerning severity (All BP: $R=0,28$; F: $R=0,62$; M: $R=-0,26$).

Conclusion: We identified positive correlation between quality of life expectations and lifespan at diagnosis, strongest in patients' fathers; negative correlation between parents' needs of additional information and the way information was presented. We suppose that in presence of a poor prognosis communication is kind and sensitive in order to provide hope but not completely clear. At EOL we found gender difference: fathers have a positive correlation between readiness for dying symptoms and physicians' communication of severity while mothers don't. Mothers are the "dominant care-giver".

Socioeconomic Needs of Families with a Child with a Life Threatening Disease during the Economic Crisis in Greece

Tsaroucha S., Gerardi A.

Merimna - Society for the Care of Children and Families Facing Illness and Death, Pediatric Palliative Home Care Service, Chalandri, Greece

Background - context - aims: Economic crisis can negatively affect health status, through declines in public spending and household income. In Greece, both have sharply declined, and the effects of the crisis have been reported especially for vulnerable groups such as families with a seriously ill child. Exploring socioeconomic issues in paediatric palliative care has not received much attention and especially in countries under economic crisis has not been studied so far. The aim of the present study was to describe the socioeconomic needs of families with seriously ill children that receive palliative home care services in Greece, during times of economic hardship.

Methods: The sample comprised 35 parents of 19 seriously ill children that receive palliative home care services. A semi-structured questionnaire designed for the purpose of the study, included closed and open - ended questions on five domains: a) demographics data, b) child's clinical condition and ECOG performance status, c) child's care needs, d) family's economic condition and e) family's resources. For the data analysis the statistical package SPSS 17 was used.

Results: All participants reported that their socioeconomic status changed significantly after the diagnosis of their child and was further aggravated by the economic crisis. They used various coping strategies with most commonly reported the reduction of expenses. Parents also reported the decrease of leisure time for family and self, which tends to affect social life, leading to isolation.

Conclusions: Families with a seriously ill child who received palliative home care services experience severe financial problems and have limited sources of social support. The majority underlines the need for more governmental benefits, less bureaucracy and respite home care services. Health care providers should be trained to address socioeconomic issues which may impair the family's quality of life.

Growing Family Strengths: Parent Views on the Potential Benefits and Acceptability of a Structured Group Programme to Enhance Resilience and Well-being in Parents of Children with Life Limiting Conditions and Complex Health Needs

McCloskey S.¹, Taggart L.¹, Cassidy T.²

¹Ulster University, Institute of Nursing and Health Research, Belfast, United Kingdom, ²Ulster University, School of Psychology, Coleraine, United Kingdom

Background: Parents of children with life limiting conditions (LLCs) and complex health needs (CHNs) experience additional demands to other parents. Yet how parents cope varies. Coping well is linked to resilience and research confirms resilience is amenable to intervention. While few group resilience interventions have been evaluated with this population, evidence from related programmes indicates positive impact on well-being.

Aim: To develop an intervention to enhance resilience and well-being in parents of children with LLCs and CHNs.

Methods: This qualitative study, undertaken in a UK region followed the MRC framework for the development and evaluation of complex interventions. The intervention was drafted within a resilience theory framework and informed by existing literature. Interviews, focus groups and workshops were held with parents (n=18) and professionals (n=15) to assess relevance with the target population. Written and audio recorded data was collected and analysed through framework analysis. The intervention was revised taking account of the findings. Face validity assessments were completed with the same sample using the methods above.

Results: Resilience theory is relevant to this population, providing a framework to promote individual and family well-being. A structured group programme was of limited appeal to parents with a range of barriers cited to participation. Professionals recognised their capacity to support parents better but identified a lack of skills. An alternative intervention centred on a professional skills development programme was developed for individual delivery with parents.

Conclusion: Engaging with the target population through the development phase has prevented scarce resources being directed towards a programme with limited reach, thereby reducing the likelihood of research waste. The amended intervention is in line with parent, professional and strategic needs and is well placed to move to feasibility testing.

Symptom Prevalence and Parental Distress in Paediatric End-of-Life Care

Zimmermann K.^{1,2}, Cignacco E.^{1,3}, Bergstraesser E.², PELICAN Consortium

¹University of Basel, Department Public Health (DPH), Nursing Science, Basel, Switzerland, ²University-Children's Hospital Zürich, Paediatric Palliative Care, Zürich, Switzerland, ³University of Applied Sciences, Health Division, Bern, Switzerland

Background-context-aims: Pain and symptom management is a cornerstone of paediatric palliative care (PPC), indicating that a variety of symptoms are present at the end-of-life (EOL) of a child. As part of the Swiss PELICAN study (Paediatric End-of-Life CARE Needs in Switzerland) we compared documented symptom prevalence and distress in parents of children dying due to a cardiological, neurological or oncological disease, or during the neonatal period.

Methods: Retrospective chart review in a Swiss population-based sample of children that died in the years 2011 or 2012, and retrospective questionnaire survey to assess the parental perspectives of their child's EOL care. Parents gave their informed consent to participate in both parts of the study separately. Comparisons between the four diagnostic groups were done descriptively and with binary logistic regression.

Results: An average of 6.42 (SD = 3.14) symptoms were documented in 149 included patients (n = 57 neonatology, n = 37 oncology, n = 36 neurology, and n = 19 cardiology). Documented symptom prevalence was lowest in the neonatology group. Pain was the most common symptom overall, however, the prevalence of other symptoms differed significantly between the four diagnostic groups. For parents, their child's breathing problems were most stressful, followed by pain.

Conclusion: Paediatric EOL care is characterised by a high symptom prevalence and burden which differ significantly, dependent on the dying child's diagnosis. Symptom presence and distress are important quality outcomes of PPC and intensive symptom management is indicated. Systematic symptom assessment, as part of the management process, however, is limited by validated measures.

The Use of Rapid Onset Fentanyl in Children and Young People for Breakthrough Cancer Pain

Coombes L., Burke K., Anderson A.-K.

Royal Marsden NHS Foundation Trust, Sutton, United Kingdom

Background: No studies have looked at the use of rapid onset fentanyl in children. The aim of this study was to assess correlation between effective dose of fentanyl and background oral morphine equivalent in children. Secondary objectives included looking at correlation between effective dose of rapid onset fentanyl and age, weight and breakthrough opioid dose as well as reviewing reported side effects.

Method: Retrospective case note review of all children < 18 years who received rapid onset fentanyl in a tertiary paediatric oncology centre in England from 2009 - 2016. Data was analysed using Spearman's correlation as data was non-parametric.

Results: 26 children (5-17yrs; 13-100kg) were identified; 11 used buccal tablets, 17 lozenge, 1 nasal spray (3 used 2 formulations). A significant correlation was found between effective dose of fentanyl lozenge and weight ($r=0.81$, $p<0.001$). There was no correlation between fentanyl and age, background or breakthrough opioid doses. Few side effects were reported but included nausea and sleepiness.

Discussion: This study demonstrates that there is no relationship between background or breakthrough opioid dose and effective dose of rapid onset fentanyl in children. There was a strong positive correlation between effective dose of fentanyl lozenge and weight. Clinicians may be more inclined to increase fentanyl lozenge doses as the child is in control of when they have had enough. Buccal tablets are absorbed quickly and the child always receives the full dose, making clinicians more reluctant to titrate doses, despite weight.

Conclusion: Fentanyl preparations seem well tolerated with few side effects reported. Children as young as 5 were able to use the lozenge. The results of this study suggest that children should start on the lowest available dose of rapid onset fentanyl and that doses should be titrated according to response. Clinicians should be aware that doses are more likely to need increasing in those with higher body weight.

Suitability, Feasibility, Utilisation and Acceptability of Patient Controlled Analgesia in the Community for Children with Life Limiting Conditions

Henderson E.M.¹, Rajapakse D.², Kelly P.^{1,2}, Boggs T.², Bluebond-Langner M.^{1,3}

¹University College London, Institute of Child Health, Louis Dundas Centre for Children's Palliative Care, London, United Kingdom, ²Great Ormond Street Children's Hospital, Louis Dundas Centre for Children's Palliative Care, London, United Kingdom, ³Rutgers, The State University of New Jersey, Department of Sociology, Anthropology and Criminal Justice, Camden, United States

Background and aims: PCA has been found to deliver pain relief in a safe, acceptable and efficacious way in a hospital setting, for acute pain. Recent studies would suggest it can provide similar results in other settings. This project describes suitability, feasibility, utilisation and acceptability of PCA (both at service and patient level) in children with life limiting conditions (LLC) followed by a tertiary palliative care team.

Methods: A mixed-methods processual evaluation to assess suitability, feasibility, utilisation and acceptability of PCA in the community including: accounts of suitability reported in MDTs, observations of training sessions for community teams, daily evaluations of pain, evaluations of other symptoms and monitoring of opioid toxicity of patients.

Results: 40 patients were assessed for PCA by the palliative care team over 16 months. 29/40 patients were considered ineligible by the team for the following reasons: pain not the primary symptom (n=10), pain well controlled by other means (n=8) and lack of community nursing support for PCA in the home (n=8). 11/40 patients were considered suitable and offered PCA, 4 declined and 7 received PCA.

The 7 patients who received PCA ranged in age from 6-17 years and had PCA for a range of 3 hours-5 weeks. 2 patients had it removed for convenience. 2 other patients experienced technical failures with their pump, 1 of which also experienced delays in syringe changes but both chose to continue. Daily pain scores were not associated with bolus use or increases in analgesia by the palliative care team.

Conclusions: This project suggests that PCA has a place in the care of children with LLC with pain in the community. Warranting further study are the technology for delivery of PCA, mode of delivery, pain scoring and resources in the community to provide rapid, responsive service for prescription, care provision and clinical evaluation.

Effectiveness of Innovative Non-pharmacological Therapy with Puppy Humanoid Robot: A Observational Study

Poggi G.¹, De Tommasi V.¹, Mancin R.², Cimolato A.³, Basso G.⁴, Benini F.¹

¹Azienda Ospedaliera di Padova, Paediatric Palliative Care and Pain Management Service, Department of Women's and Children's Health Padova University, Padova, Italy, ²Azienda Ospedaliera di Padova, Technical Area, Scientific-Technical and Data Processing, Department of Women's and Children's Health Padova University, Padova, Italy, ³University of Padova, Department of Information Engineering, Padova, Italy, ⁴Azienda Ospedaliera di Padova, Pediatric Oncology and Hematology Clinic, Department of Women's and Children's Health Padova University, Padova, Italy

Background and aims: During the hospital cares, a child incurs diagnostic and therapeutic procedures that can involve suffering and discomfort. The procedural similar-sedation has the purpose to allow the medical procedures to be carried out with the pediatric patient feeling no pain. Before the procedures, the child is usually affected from anxiety, that can develop in a real psychological trauma, if not prevented. It is possible to integrate drug therapies with Non-Pharmacological Therapies (NPT) to prevent this eventuality.

In the procedures of the Azienda Ospedaliera di Padova (AOP), it has been added to the NPT the NAO puppy robot, programmed to distract the child.

Methods: The observational study carried out at the pediatric procedures service of the AOP has assessed and quantified the effectiveness of this NPT. In the study were involved 20 children, ranging from 4 to 16 years old, without any severe cognitive retardation or neurological deficits.

The ad-hoc questionnaire is in heteroevaluation and analyze the following area: evaluation of pre-procedural anxiety and fear; perception and appreciation of the experienced state of anxiety; personal observations from both parents and patient. The study is comprehensive of typology and quantity of the employed drug for the subsequent anesthesia.

Results: The data show a high acceptance by the pediatric patient (12 Male - 8 Female, age 8,78+/-3,68 y.o.). There is a significant abatement of the negative emotional states coefficient of 20% and an increment of the positive emotional states coefficient of 26%, respect before and after the interaction with the Nao puppy robot.

Conclusions: The results confirm the hypothesis of effectiveness of this innovative NPT within painful procedures. It emerges the possibility of having at disposition a new and innovative approach for children assistance. Pediatric patients are now able to experience these unpleasant events by preventing the development of profound psychological trauma.

Identifying and Treating Pain in Children with Advanced Cancer. A Pediatric Palliative Care Perspective

Rigal Andrés M.¹, Parra Plantagenet-Whyte F.¹, Ortiz San Román L.¹, Quiroga Cantero E.², Martino Alba R.¹

¹Hospital Niño Jesus, Pediatric Palliative Care, Madrid, Spain, ²Hospital Virgen del Rocío, Pediatric Oncology, Sevilla, Spain

Background and aims: Pain is a salient concern for children with an incurable cancer. Nevertheless, specific data on pain in Pediatric cancer patients is scarce, with only a few large case series published. The aim of this report is to describe a current case series in order to encourage professionals to reflect on the pain treatment these children may need.

Methods: This is a descriptive study conducted within the caseload of the Pediatric Palliative Care Team from Madrid, Spain. This team offers hospital and home care for children with life-limiting conditions. We retrospectively reviewed the clinical notes of those patients with incurable cancer that were referred from February 2008 to June 2015.

Results: During this period, a total of 445 patients were referred. Of those, 121 had cancer, but 8 were lost during follow-up. The remaining **113 patients were studied**, with a median follow-up of 44 days until death. **93.8% suffered from pain.**

A total of **130 pain episodes** here described (24 patients had two different causes of pain), being 89.9% due to direct effect of tumor and 6 episodes caused by treatment. **96.9% were persistent or progressive in time.** On its pathogenesis we found: 41.1% mixed pain cases, 40.3% nociceptive, 17.7% visceral and 2.4% pure neuropathic pain.

87.7% of pain episodes were severe in intensity, needing opioids in their treatment. Up to **63.8% were treated with an adjuvant analgesic**, and 8 patients underwent analgesic procedures. The 103 patients needing opioids received them for a median of 43 days. 71 needed parenteral analgesia, but only a median of 5 days before death.

Conclusions: Pain is a very frequent and notable symptom in the disease trajectory of a child with incurable cancer. Oncological pain is intense and complex in pathogenesis. It needs treatment both with opioids and adequate adjuvants. In spite of this, most of the patients can be adequately managed with oral analgesia until only a few days before their death.

Palliative Care Practices in Health Teams Supporting Young Adults with Non-malignant, Life-limiting Conditions

Beresford B., Maddison J.

University of York, SPRU, York, United Kingdom

Background: Compared to young adults with cancer, little is known about addressing the palliative care needs of young adults with non-malignant conditions. This paper reports a study of practitioners' experiences of caring for this particular population. It sought to identify practice issues and challenges, and to describe solutions developed by adult health care teams, including the involvement of specialist palliative care.

Methods: Case study design with four non-malignant conditions (Duchenne muscular dystrophy, renal disease, cystic fibrosis, complex cerebral palsy) and secondary and tertiary NHS settings represented. Semi-structured interviews with adult health care team staff (n=23) explored practices around advance care planning, end of life care and links with specialist palliative care providers. Interviews were audio-recorded, transcribed and subject to thematic analysis.

Findings: Conditions labelled as life-limiting in paediatrics did not necessarily carry that label into adult health. In these situations, advance care planning and the involvement of palliative care services were not seen as relevant. Where services recognised the potentially life-shortening nature of their young adult patients' condition, planning for deterioration was formalised into routine processes. Practice around advance care planning was, in contrast, highly individualised. The involvement of specialist palliative care providers by adult health care teams was variable. When it occurred, their contribution to supporting conversations about end of life and providing options in terms of place of death were greatly valued.

Conclusions: The transfer from paediatrics to adult health care for young adults with non-malignant conditions can raise challenges. However, there is evidence that systems and practices can be implemented, and working in partnership with specialist palliative care providers may be a useful approach.

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The Use from Cyberspace by Adolescents in Palliative Care - Their Social Networks

Borghi C.A., Szylit R., Baliza M.F., NIPPEL

University of São Paulo, School of Nurse, São Paulo, Brazil

Background: While work with adolescent in Pediatric Palliative Care we need to notice their development (psycossocial and cultural). The adolescence it is characterized by social questions, where the adolescent need to belong to some group and their friends are very important. The technological growth changed the adolescent communication, nowadays, within the cyberspace, the adolescents can use the social networks and instant messaging platforms for communication with their friends, so they can keep connected constantly with, regardless of where they are or what are they doing and promote a sense of belonging to a group of friends.

Aim: The aim of this study was to explore the use and the content of social networks by adolescents in palliative care with life limiting conditions and life treatment.

Methods: This is a qualitative study that used the virtual ethnography and the content analysis. In a period of six months, six social networks profiles of adolescents aged 12 - 18 years old were observed. All of posts, photos and comments were decoded for content analysis. The six adolescents have some life limiting disease (as epidermolysis bulhosa, osteogenesis imperfecta and leukaemia).

Results: It was possible to identify themes that includes: "Living a normal life despite my disease"; "Having a lot of friends"; "Teaching the others about my condition"; Having my beliefs" and "Receiving support by my virtual friends".

Conclusion: The social networks are an important tool to promote care for adolescents with life limiting disease, because the social network encourage the users for the communication with their friends and family, besides of being a space for the adolescents can share their experiences and learn with others. The health care professionals need to work with adolescents and families who are in Palliative Care using those tools to interact with them and promote more care and support.

Make IT Happen - A Project Supporting Young People with Life-limiting Illness Transition to Adulthood

Astall J.¹, Wilkins S.¹, Koh M.²

¹Naomi House Children's Hospice, Family Support Team, Winchester, United Kingdom, ²Naomi House Children's Hospice, Winchester, United Kingdom

Background: Medical advances mean that increasingly, young people with life-limiting illness are surviving into adulthood. It is crucial that they are supported to develop their potential & life-skills and as much independence as possible. Whilst there is guidance on transitioning from paediatric to adult healthcare services, there is less information on programmes empowering patients to make life choices for their future.

Method: Make IT Happen is a project developed in 2016 by a hospice for teenagers. It is aimed at patients aged 14-18 years and their families. It consists 4 one-day workshops exploring social opportunities including sexual & relationship issues, further education & employment, developing skills & aspirations. A workshop for siblings looked at their priorities & future hopes and understanding the transition process for their affected sibling.

Participants were asked to complete an Outcomes Wheel - a self-reporting scale of their confidence and knowledge on their personal and social skills - before and after the workshops.

Results: The first workshop was attended by 8 patients and 10 parents. The young people reported:

- Feeling more confident about talking to parents & professionals about their future aspirations and taking control of their condition;
- Having the knowledge & information needed to make decisions and choices about their education and career options;
- Having clearer goals about what they would like to achieve for their future.

Conclusions: With the diagnosis of a life-limiting illness, the future for the patient and family becomes uncertain. The challenges of living in the present and planning for the uncertain future are compounded by the physical, intellectual and emotional impact of the illness.

A targeted programme in a supportive environment with appropriate resources and expertise can empower them to take control of their healthcare decisions and gain the confidence to express themselves and live the life they want.

Are Adolescent and Young Adult Patients More Symptomatic at End of Life?

Wong V.H.M.¹, Soo J.J.E.², Toh Y.P.¹, Lee G.Z.³, Neo P.S.H.¹

¹National Cancer Centre Singapore, Singapore, Singapore, ²National University of Singapore, Singapore, Singapore, ³Singapore General Hospital, Singapore, Singapore

Background: Adolescent and young adult (AYA) patients face a multitude of complex problems and challenges at the end of life. Previous studies have shown that AYA cancer patients have late access to palliative care. There is currently little information available on the symptom burden, treatment received or other characteristics that may influence the time of referral to a palliative care team.

Aim: This study aims to explore the characteristics and symptom severity in AYA patients compared to non-AYA patients.

Method: Retrospective case notes review was performed for all cancer patients who died in a large tertiary hospital under the care of a palliative care service between July 2012-June 2014. AYA patients (aged 16-39) were compared against a computer generated random sample of non-AYA patients (aged > 39). Baseline characteristics, Palliative Care Outcome Collaboration (PCOC) scores and treatment received 30 days prior to death were obtained. Data was analysed using t-test.

Results: A total of 93 AYA patients were compared with 172 non-AYA patients. AYA patients were referred to palliative care service on average about 83 days earlier than non-AYA patients ($p < 0.005$). They were also admitted significantly longer than non-AYA patients. The number of severe pain event counts were significantly more in the AYA patients ($p = 0.006$). Other symptoms that were significantly more severe include cough ($p < 0.001$) and constipation ($p < 0.001$). In AYA patients, 2.0% had chemo within the last 2 weeks prior to death and 14.3% within a month prior to death compared to 1.0% and 10.5% respectively in the non-AYA patients.

Conclusion: AYA patients have longer hospital admissions which may be related to higher symptom and treatment burden as compared to non-AYA patients. In contrast to previous studies, AYA patients had earlier access to palliative care.

Improving the Nation-wide Outcomes for Children and Families Supported by Paediatric Palliative Care: Phase 1 Learning Needs and Capability, a National Quality of Care Collaborative

Herbert A., Baggio S., Slater P., Delaney A., Pedersen L.-A., Quality of Care Collaborative (QuoCCA) for Paediatric Palliative Care

Lady Cilento Children's Hospital, Paediatric Palliative Care Service, Level 12, South Brisbane, Australia

The overarching aim of this National collaborative study is to promote high quality palliative care (PC) provided to children in close proximity to their home through education initiatives, evaluation and research. This poster represents **Phase 1 Baseline learning needs/capability** of the study and aims to determine health clinicians' learning needs specific to paediatric PC, including allied health, medical and nursing professionals in regional, rural and remote settings. An earlier study completed by Chong, Hamsah and Goh (2015) performed a similar learning needs analysis (LNA). This project modelled the LNA survey with author permission. A Paediatric Palliative Care capability tool (PPC-CT) was also developed and released. The PPC-CT was modelled on another tool with author permission. 152 participants completed the LNA to date, 62% live in metropolitan, 24.5% in regional and 13.25% in rural areas. The majority of respondents were allied health professionals (45%) followed by nursing (37%) and medical professionals (16%). Preliminary results show the national learning needs are different from the previous study. Top 3 learning needs are: preparing families for the death of their child (4.21 weighted average), management of the dying child (4.18), communication skills (4.19). These findings are indicative of the larger and diverse participant group. The PPC-CT results show many capabilities requiring further assistance in the supportive and end of life phases. The majority of clinicians report adequate+ capability at the initial phases of PC. The LNA and PPC-CT results will influence areas for further development regarding education modules and supervisory supports. Access to the on-line surveys from a remote setting may be limited. These findings will also inform the project legacy including the website and a mobile app. Funding from the Department of Health (Commonwealth) for nurse, allied health educators and medical fellows enabled these national initiatives.

"It Changed my View of Medicine" - Implementing a Multidisciplinary Undergraduate Course on Pediatric Palliative Care for Medical Students

Lacerda A.^{1,2}, Mendes J.³, Moura M.J.⁴, Calado E.⁵, Ramos S.⁵, Paiva M.¹, Ribeiro D.¹, Miranda M.¹

¹Portuguese Institute of Oncology, Pediatrics, Lisboa, Portugal, ²Nova Medical School, Pediatrics, Lisbon, Portugal, ³Hospital São Francisco Xavier, Neonatology, Lisboa, Portugal, ⁴Portuguese Institute of Oncology, Psychology, Lisboa, Portugal, ⁵Hospital Dona Estefania, Neurology, Lisboa, Portugal

Background: The European Association for Palliative Care (EAPC) established core competencies on pediatric palliative care (PPC) education and the need for universal level 1 education for undergraduate healthcare providers. We aim to reflect on the development and to evaluate the impact of the first multidisciplinary undergraduate course on PPC for medical students in a European country where no activity was recognized until 2013.

Methods: Email survey (5 open-ended questions, June'16) to the 10 students (5th year medical school) who attended this optional course (response rate 8/10).

Results: The one-semester course had a contact time of 48 hours (weekly sessions), with content program in line with EAPC recommendations for PPC level 1. The multidisciplinary teaching panel (physicians, nurses, psychologist, social worker, teachers, volunteers) had different backgrounds (hospital, primary care, homecare, charities). Educational strategies included lectures, tutorials and interaction with children & families. Course was selected for personal motivation (7/8), unfamiliarity with content (3/8) and novelty (2/8). Half the students expect to become pediatricians / general practitioners. For assessment, each two students presented a holistic reflection on a case they explored; this was considered innovative and much appreciated by the group, who valued interaction with families. They also acknowledged personal growth and becoming more considerate of suffering and the true goal of medicine - care oriented by needs and preferences, not only by diagnosis.

Conclusions: Although more evidence is needed, our experience suggests that undergraduate PPC education is welcomed and praised by medical students. The multidisciplinary teaching was deemed essential to realize the complexity of a holistic approach and the need for interdisciplinary respect and collaboration. Communication with the child & family was one of the most appreciated contents.

Evaluating the Impact of Ireland's Only Nodule on Children's Palliative Care within an Irish Postgraduate Diploma in Palliative Care

Quinn C.

National University of Ireland Galway, School of Nursing and Midwifery, Galway, Ireland

Research aims: Educators in palliative care need to provide programs which respond to the requirements of students and service providers, reflecting national and international recommendations.

The Postgraduate Diploma (PGD) in Nursing (Palliative Care) has been in Ireland since 1997 and initially this programme did not specifically include components on children's palliative care (CPC). Around the time of the first Irish Needs Assessment for CPC there appeared to be a growing realisation by palliative care providers of the increase in child referrals and the subsequent preparation of staff.

In 2007, a palliative care nursing programme, run in a university in the west of Ireland, responded to the emerging requirements of service providers by designing the first Irish module on CPC to be taught as a mandatory component of the PGD (Palliative Care).

The aim of this current evaluation is to assess the contribution of Ireland's only CPC module to the clinical practice requirements of practitioners. On successful completion of the CPC module students were asked to rate the value of the programme content as applicable to clinical practice in palliative care.

Study design: An online questionnaire was developed for 24 students who recently completed the PGD. Students represented clinical sites throughout Ireland. Data were analysed using electronic software.

Results: Results showed a high level of satisfaction with the inclusion of a children's module within the PGD. Nurses who undertook the module rated it as helpful to their clinical practice and described themselves as feeling more confident when caring for a child and family with a life limiting illness. Nurses (88%) also expressed a wish to undertake further education in the specialty.

Conclusion: This module was recently evaluated by 24 PGD students who rated it as contributing positively to their clinical practice and preparedness for the palliative child scenario.

My Neighborhood: An Innovative Education Tool to Optimize the Opportunity for Palliative Care Patients to Stay at Home

Smith M.¹, Lafond D.², Hinds P.³

¹Children's National Health System, PANDA Palliative Care/Clinical Resource Management, Washington, United States, ²Children's National Health System, PANDA Palliative Care, Washington, United States,

³Children's National Health System, PANDA Palliative Care/Department of Nursing Research and Quality Outcomes, Washington, United States

Background: Families of children and adolescents with serious illness experience emergent hospitalizations and interventions. Family caregivers must have adequate knowledge and skills to care for their ill child at home. Effective nurse-led teaching beginning at admission prepares families to safely provide this care. The objective of our two-part performance improvement (PI) initiative was to increase family and nurse satisfaction with new diagnosis education and discharge planning.

Methods: In part 1, we documented stakeholder opinions about current education and discharge processes; based on best practices, we designed and implemented a comprehensive program called *The Road to Home*®. This program includes formal education content and a visual map that depicts the advances made by the families, of a newly diagnosed child with serious illness, towards a safe discharge. With the goal of prevention and relief of suffering to maintain the best quality of life, consistent with the family's values, we created part 2 of the program. This program, called *My Neighborhood*®, focuses on optimizing educational resources to help keep patients with complex, potentially life-limiting illnesses, safely at home without hospital readmission when possible, by teaching strategies for aggressive pain and symptom management at home and optimizing quality of life through supportive community and hospital resources.

Results: Over 300 families have participated in the first part of the program, with a greater than 15% average increase in families rating "very good" on satisfaction questions r/t discharge education. Overall nursing satisfaction with discharge education has increased by 58%.

Conclusions: This innovative educational program uses a visual map to guide families in caring for their seriously ill child at home. By leveraging education, children can more often stay at home, where they most want to be, and families feel better prepared to keep them there.

Children in Scotland Requiring Palliative Care: Identifying Numbers and Needs (The ChiSP Study)

Fraser L.¹, Jarvis S.¹, Carragher P.², Beresford B.³, Parslow R.⁴

¹University of York, Department of Health Sciences, York, United Kingdom, ²Children's Hospice Association Scotland, Edinburgh, United Kingdom, ³University of York, Social Policy Research Unit, York, United Kingdom,

⁴University of Leeds, Division of Epidemiology & Biostatistics, Leeds, United Kingdom

Background-context-aims: To identify the number of children and young people (CYP) with life-limiting or life-threatening conditions (LLC) in Scotland and their stage of condition.

Methods: Secondary analysis of linked routinely collected data was undertaken. Two prevalence figures were calculated. 'Hospital-based prevalence' in which individuals who had an inpatient hospital episode during that year were included. 'Complete prevalence' estimates included all children with a LLC known to be alive and resident in Scotland.

Four stages of condition were defined based on use of healthcare services: stable, unstable, deteriorating and dying. Status was analysed by financial year, with the most severe stage of condition being recorded.

The percentage of CYP with a LLC in each category per year was calculated overall, by age group, diagnostic group and deprivation category.

Results: The prevalence of CYP with a LLC in Scotland has risen markedly (41.4 per 10000 in 2013/14 (95%CI 40.9-41.9). The highest prevalence was in the under 1 age group, CYP from a South Asian background and those from deprived areas.

Each year 14-19% (~2200) of these CYP with a LLC were unstable (12-15%), deteriorating (1.6-2.2%) or dying (1.1-1.6%).

Conclusions: Five high level recommendations were made :

More children and young people of ALL AGES in Scotland with life-limiting conditions should have input from palliative care services.

Children under 1 year of age should be seen as a priority group for input from palliative care services.

Age specific palliative care services for young people (aged 16-25 years) with a life-limiting condition in Scotland should be developed.

Palliative care services should be able to provide culturally competent care to children and young people from ALL ethnic groups.

Future development of palliative care services in Scotland should ensure that access to services for children and young people from areas of high deprivation is prioritised.

Needs Assessment in Pediatric Palliative Care amongst Nurses and Doctors in the Netherlands

Michiels E.¹, Ball L.², Plasschaert S.³, Bindels-de Heus K.⁴, van Walraven A.M.⁵

¹*Sophia Children's Hospital-ErasmusMC, Pediatric Oncology/Haematology, Rotterdam, Netherlands,* ²*Willem Alexander Children's Hospital, Leiden, Netherlands,* ³*Princess Maxima Center for Pediatric Oncology, Utrecht, Netherlands,* ⁴*Sophia Children's Hospital-ErasmusMC, Pediatrics, Rotterdam, Netherlands,* ⁵*Stichting PAL, Pediatric Palliative Expertise, Utrecht, Netherlands*

Background: In 3 pediatric academic medical hospitals in the Netherlands, pediatric palliative care teams (PPCT) are being developed. The tasks of such PPCT are multiple, and priorities have to be set which tasks are most important and urgent.

Methods: To explore the needs of the future users of the PPCT, we developed a questionnaire that was sent to all doctors and nurses of the 3 pediatric academic hospitals, asking on which subjects in PPC they needed education and what they considered to be the primary tasks of the PPCT.

Results: A total number of 197 questionnaires were completed, of which 119 by nurses and 78 by doctors.

Amongst nurses of 2 of the 3 hospitals, needs in education were primarily focused on communication skills, ethical discussions in palliative care, assessment and treatment of pain and management of the family with a child in palliative care. In one of the hospitals, nurses wanted to focus education also on terminal dyspnea.

Doctors had comparable priorities concerning education, but the difference with the nurses was that pain assessment and treatment had the highest priority according to the doctors, and management of the family with a child in palliative care was not a priority for them.

Concerning the tasks of the PPCT, 2 tasks were mentioned by nurses of the 3 hospitals: a. acting as a casemanager for the family and b. helping with all the necessary arrangements if a terminal patient is discharged from the hospital. Doctors were more consistent in their idea on the tasks of a PPCT: they all ranked the task of casemanager, the logistics of discharging a terminal patient and being available for consultation in case of difficult symptom management as the main priorities for the PPCT.

Conclusion: This needs assessment will help the newly developed PPCT to focus on educational subjects and tasks that are really important to the people that will be working with the PPCT, and thus will help to ensure the sustainable success of the PPCT.

Introducing Multi Disciplinary Reflective Practice Groups into Paediatric Palliative Care Services: An evaluation

Montgomery V., Maynard L.

East Anglia's Children's Hospices, Cambridge, United Kingdom

Background: Effective clinical supervision benefits patient care by:

- Enabling staff to challenge practice in a confidential environment and reflect on feedback.
- Enhancing staff wellbeing through enabling exploration and management of the personal impact and professional demands of working in palliative care.

Aims: To introduce multi-disciplinary reflective practice groups (MRPGs) into three children's hospice services.

Method: Sessions followed a structured nine-step process, led by an experienced facilitator. Groups had open membership, ran with 4-10 participants and there was mandatory minimum attendance. Group membership included care assistants, nurses, counsellors, art and music therapists and play specialists but excluded care managers. Participants brought a clinical work related dilemma to share, with one dilemma chosen and discussed per session.

Post every session, participants rated the reflection and identified learning by giving an example of "One thing I am going to take away from today's session is...."

Results: Between 11/2015 and 04/2016, 31 MRPGs took place, with 156 participants, totaling 106 different staff.

97% of responses agreed or strongly agreed that MRPGs were useful.

In 8 out of 31 groups, > 75% of participants strongly agreed that MRPGs were useful. All eight of these groups discussed a clinical nursing related dilemma. Key themes in analysis included 'normalising and validating'; 'improving practice/ skills in work with families'; 'reflection' and 'taking action'.

Conclusions: Contrary to staff expectations MRPGs were perceived useful by staff themselves. Key learning areas reported were a good fit with background reasons for introducing the sessions. Our next steps are to:

- Collect examples of perceived impact on the quality of clinical work with children and families across the different disciplines
- Widen participation to include bank staff, volunteers and hospice employees not providing direct clinical work.

Recuppera, a Palliative Care Patient Registry: Results from a Pilot Study in Three Argentinean Public Hospitals

Uzal L.G.¹, Gomez K.², Chacón S.³, Verna R.⁴, Dussel V.¹

¹Institute for Clinical Effectiveness and Health Policy (IECS), Center of Investigación & Implementation of Palliative Care (CII-CP), CABA, Argentina, ²Hospital General de Niños Pedro de Elizalde, CABA, Argentina, ³Hospital Provincial Neuquén - Dr. Eduardo Castro Rendón, Neuquén, Argentina, ⁴Hospital de Pediatría Dr. Juan P. Garrahan, CABA, Argentina

Background: Patient registries allow monitoring quality of care and benchmark setting. We developed a digital Patient Registry System (Spanish acronym: *Recuppera*) for Pediatric Palliative Care Teams (PPCT) to characterize the patient population served and clinical practices used.

Aim: To evaluate *Recuppera's* feasibility, acceptability and reliability.

Design: Mixed-methods longitudinal pilot study.

Population: Purposive sample: 3 public hospital's PPCT selected to represent a range of patient volume, team composition, and care settings.

Methods: PPCT registered incident cases and their follow-up consults. We analyzed

- a) Minimal Data Set (MDS, 25 fields including identifying, diagnostic, consult, and death-related data), completion rate goal >90%;
- b) error logs and user suggestions;
- c) audits of medical charts, or usual registry system looking for missing data and inconsistencies (10% of patients);
- d) field notes;
- e) In-Depth Interviews.

Feasibility was evaluated with a), b), d) and e); acceptability with e); and reliability a), c) and e)

Results: Over an average 295 days, a total of 295 patients and 1469 consults were registered.

Feasibility: no significant system bugs or errors occurred. Median time for loading a consult on *Recuppera* was < 2 min. Most MDS fields had completion rates >90%. Only 4 fields were < 90% (but >85%). Use of *Recuppera* varied depending on patient volume and team characteristics.

Acceptability: All PPCT found *Recuppera* useful, incorporated *Recuppera* notes into medical charts, and decided to continue using it after the pilot. Consult reasons need improvements to better reflect clinical practices.

Reliability: Consistency of *Recuppera's* MDS was very high: 100% for identifying and diagnostic data and 97% for consult data (1.5% inconsistencies; 1.5% missing).

Conclusions: *Recuppera* proved to be feasible, highly accepted, and reliable in different types of institutions. Suggested changes will be incorporated before implementing at a larger scale.

Defining Good Death and Dying Well - What Does the Literature Say

Barton C.

Alder Hey Childrens Hospital, Liverpool, United Kingdom

Background: Living well and dying well aims to encourage individuals, communities and populations to adopt the philosophy that in death we deserve the same standards we demand and strive for in life. Why should those who are dying accept any less than they when they weren't? National schemes and campaigns are currently working towards changing societies perceptions. Child death and dying remains a difficult subject for many to discuss and consider. The aim of this research was to explore published literature and the wide media from recent years to explore widely accepted and used definitions of the terms 'a good death' and 'dying well'.

Methods: The NHS Evidence Portal was used to explore healthcare databases including EMBASE, CINAHL, PUBMED and PsychINFO, with the use of a child health filter to limit results to the paediatric population. Leading palliative care journals were search using publisher and index websites using key terms. Where relevant, search terms were matched to MESH and encyclopaedia results. A manual search using several internet search engines including Google, DuckDuckGo and Yippy.

Results: Journal abstracts, websites, internet hits and miscellaneous results (e.g. forums, blogs, book extracts) were compiled and limited to a 5 year period from the search date (March 2016). Qualitative data relating to dying children and bereaved parents were collated using a pre-defined grid and taken forward to a themed analysis. Traditional concepts such as alleviation of pain and place of death were indentified. Novel themes included being able to represent the child openly through concepts such as social media, and access to legal advice to support medical and parental decision making.

Conclusion: Defining the concept of a good death and dying well is essential to understand not only what children and parents feel, but to consider the prevailing climate and society within which they make their decisions, and understand their influences and peer considerations.

Healing the Wounds: Setting up a Grief Centre

Gomez Garcia I.¹, Jasenkova M.²

¹PLAMIENOK n.o., Grief Centre, Bratislava, Slovakia, ²PLAMIENOK n.o., Bratislava, Slovakia

Background-context-aims: We shall share the experience of setting up a Grief Centre for bereaved children and families and how this project has evolved along five years of existence. This Centre is part of a children's hospice. Our clinical findings and practical and organizational tips could be helpful to those thinking of creating a coherent plan to support bereaved families. Currently we offer the following services: individual and group counseling, therapeutic weekends and summer camps. The number of families who has benefited from our work has steadily increased since we open in 2011. We will analyse how many families, children and adults have attended each activity and the number of sessions. Finally, we will illustrate with a video how children can freely talk about death when they feel secured and supported.

Methods: Grief counseling, gestalt therapy, art-therapy.

Results: Annual data shows that the number of families who used our services in 2011 (10 families, 13 visits), doubled each year until 2014 (87, 614 visits). Written feedback from parents and video recorded interviews with children and adolescents indicate that the activities were beneficial for them increasing their capacity to enjoy life in spite of the loss.

Conclusions: The existence of a Grief Centre as a part of a children's hospice offers an answer to cover the emotional needs of bereaved siblings and families who need support to deal with their grief. A creative and well trained team can offer new ways to healthy acceptance and self-growth.

Originality of research: An opportunity to share the growth of a Grief Centre on his creative adventure to heal the wounds of children and families with losses.

Relevance to paediatric palliative care: Hospices and paediatric palliative care services can find inspiration to create new programmes that will help to face the challenge of supporting bereaved children and families extending their services beyond the death of the child.

The Challenges and Ethics of Inviting Bereaved Parents to Participate in Research

McElligott E.¹, Smith O.^{2,3,4}

¹Yorkshire and Humber Deanery, Yorkshire, United Kingdom, ²Professor of Paediatrics, School of Medicine, University College Dublin and Director, Cancer Clinical Academic Directorate Ireland East Hospital Group, Dublin, Ireland, ³Haematology Department, Our Lady's Children's Hospital, Crumlin, Dublin, Ireland, ⁴Regius Professor of Physic [1637], and Professor of Haematology [2002], Trinity College Dublin, Dublin, Ireland

Background: It is widely agreed amongst paediatric palliative care practitioners that there is a lack of evidence for decisions in some aspects of care. One reason is that physicians and research ethics committees, perhaps feel protective towards patients and parents, believing them to be already overburdened by their loss. This particularly affects research that seeks the reflections of bereaved parents, on the time when their child was unwell or dying. We seek to explore the evidence to support whether, on balance, such invitations cause benefit or harm, and if bereaved parent's views are documented in this area.

Methods: A literature search was conducted to consider the current evidence base, using the search engines Medline via Ovid, CINAHL and Embase. Search terms included 'bereaved parent', 'research', 'harm', and 'damage'. Abstracts were screened and relevant literature retrieved.

Results: Parents reported positive experiences in contributing to the 'future' and also to 'helping others' who might find themselves in similar situations. The published literature did not substantially document the reasons for parents declining to participate.

Conclusions: There is a paucity of evidence to support a theory that contacting parents after the death of their child causes harm. Furthermore, parents reported a perceived benefit from interview process, finding an element of catharsis in the experience. We acknowledge this may reflect a bias in reporting as the literature, for the most part, documents the opinions and findings in parents who have chosen to participate.

Availability of Debriefing Sessions to Nursing Staff Following their Provision of Paediatric Palliative Care in an NHS Trust

McElligott F.¹, Lewis D.², Storton H.², Minchella S.², Vasudevan C.², Catriona M.²

¹Yorkshire and Humber Deanery, Yorkshire, United Kingdom, ²Bradford Teaching Hospitals NHS Trust, Bradford, United Kingdom

Background: Bradford district has the highest prevalence (42.4 per 10,000) of children living with life limiting conditions in Yorkshire and Humber¹. Bereavement debriefing sessions are documented as beneficial². We surveyed paediatric, midwifery and neonatal nurses working in Bradford Teaching Hospitals Trust. We report on the section regarding debriefing sessions following the delivery of palliative care investigating availability and uptake of formal debriefing, use of informal debriefing, perceived benefit of debriefing and experience of hosting or facilitating a debriefing.

Methods: The survey was constructed using the web-based programme surveymonkey.com[®]. Survey's were approved by department managers and distributed in hard or soft copy depending on area preference. All data was returned in soft copy and data was manually entered into the programme.

Results: 70 surveys were returned from paediatric wards, neonatal unit, children's community, midwifery and neonatal outreach nurses. 37 (of 63) respondents reported being offered debriefing, with 15 (of 29) reporting that they had participated in formal debriefing sessions. 48 (of 58) respondents reported debriefing informally and 48 (of 50) reported benefit from the debriefing. Only 3 (of 67) respondents had ever 'hosted' a debriefing session.

Conclusion: The work of Fraser et al. highlighted the unusually high prevalence of children with palliative care needs. This survey informs us of the current availability, and styles, of debriefing.

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Ensuring the Quality of Life of Children with Incurable Diseases: Education for Health Care Providers in Ukraine

Andriyishyn L.¹, Shapoval-Deinaga K.², Bratsyun O.³, Melnyk R.⁴

¹Ivano-Frankivsk Regional Clinical Palliative Care Centre, UA, Ivano-Frankivsk, Ukraine, ²International Renaissance Foundation, UA, Kyiv, Ukraine, ³National Medical Academy of Post Graduate Education, Kyiv, Ukraine, ⁴Ivano-Frankivsk National Medical University, UA, Ivano-Frankivsk, Ukraine

Comprehensive palliative care for children can improve the quality of life for young patients and their families throughout the disease. This approach should be applied to patients no matter where they are. Palliative care in Ukraine has just started to develop. Regulations on pediatric palliative care do not yet exist, only one inpatient children's hospice in Ivano-Frankivsk and 4 home care teams for children exists.

Purpose: We would like to emphasize the importance of training on palliative care for children for specialists regardless of their profile; show the role of training for everyone who works with seriously ill children regardless of their place of treatment or stay to ensure the quality of life of these children.

Methods: Ivano-Frankivsk Training Center for Palliative Care supported by the International Renaissance Foundation conducted 2 phases of the research. 1. training of trainers was carried out in the Belarusian children's hospice; WHO Guidelines on treatment resistant pain in children with medical conditions were translated and approved by the MOH as the source document for National Protocol for pain management (June 2016). 2. carried out in 2014-2016 staff of Nadvirna children's hospice (20 pl), 4 multidisciplinary Home care team (25 pl), medical and social workers of 2 boarding houses (90 pl) children's oncologists (3 specialists) and neurologists (6 specialists), pediatricians and family doctors from Ivano-Frankivsk, Zaporizhya, Kharkiv', Ternopil' oblasties, Kyiv city (84 specialists) were trained.

Results: 224 specialists received special knowledge on provision of palliative care to children. We plan extension of educational processes and lobbying for legislative amendments in the sphere of children's palliative care.

Conclusion: Quality of life for children with incurable and serious diseases can and must be achieved not only in specialized palliative care institutions, but also in any other places of residence or treatment.

Training Pediatric Oncology Providers in Palliative Care Communication: Communication Plan, Early through End-of-Life, version 2 (COMPLETE II)

Haase J.¹, Moody K.², Graffis R.², Hendricks-Ferguson V.³, Fetting L.⁴, Newton E.⁴, Shih C.-S.², Pradhan K.²

¹Indiana University School of Nursing, Indianapolis, United States, ²Indiana University School of Medicine, Pediatrics, Indianapolis, United States, ³St. Louis University School of Nursing, St. Louis, United States,

⁴Indiana University School of Medicine, General Internal Medicine, Indianapolis, United States

Background: For optimal palliative and end of life (PC/EOL) care, pediatric oncology providers need training in communication and interprofessional collaboration (IPC). In our previous work, parents of children with brain tumors experienced increased hope and decreased decision regret and uncertainty after receiving a PC/EOL communication intervention (COMPLETE I) delivered by trained MD/RN pairs. Based on provider feedback and audio-recordings, we further revised training to improve MD/RN empathic statement use and IPC. This abstract describes the impact of our revised training on provider level outcomes before, during, and after delivery of COMPLETE II in a sample of parents of newly diagnosed children with cancer.

Methods: COMPLETE II training includes a goals-of-care roadmap for conversations, VitalTalk communication skills training via role play with simulated patients, and interprofessional education. RN/MD dyads deliver COMPLETE II with 12 parents at 3 time points including diagnosis. Provider level outcomes include measures of communication self-efficacy, personal accomplishment, and collaboration. COMPLETE I and II provider empathic statements and collaboration are compared from audio recordings.

Results: Three pediatric oncology RN/MD dyads completed the revised training. To date, 3 patient sessions are completed. Compared with baseline, the providers' mean communication self-efficacy scores were significantly improved after training ($p < .0001$). At baseline, 2/3 of providers scored moderate to high on personal accomplishment. Both MDs and RNs report that they had frequent interprofessional collaboration.

Conclusions: COMPLETE II training improved provider communication self-efficacy. Interprofessional collaboration, personal accomplishment, and empathy will be examined and compared with baseline scores and with COMPLETE I results. A future randomized trial is planned to examine the effects of COMPLETE II in a larger sample of parents of children with cancer.

Integrated Learning Supports Integrated High Quality Care: A Regional Model of Neonatal Training and Education for Healthcare Professionals

Mancini A.^{1,2}

¹*Chelsea and Westminster Hospital, Neonatal, London, United Kingdom,* ²*The True Colours Trust, London, United Kingdom*

Current evidence indicates neonatal palliative care is an emerging specialty and recent studies report that neonatal staff have limited training and lack of knowledge and confidence in delivering care and support. Professionals delivering neonatal palliative care strive to deliver consistent high quality care to infants and their families. In order to do so effectively, it is imperative that they access regular training which is accessible and specific to their field of practice.

A regional model of neonatal palliative care training was developed to empower staff by facilitating improved knowledge and awareness of specialist palliative care services for infants.

Over a 12 month period, over 600 healthcare professionals diverse professional groups attended a 4 hour training workshop at one of the 30 neonatal units in a central region in England. The majority of participants were neonatal nurses, medical staff including Consultants, and maternity and paediatric staff, ensuring benefits of integrated learning.

A senior nurse coordinated the programme by inviting speakers from palliative care services local to each neonatal unit, highlighting services they offer families of infants with complex and palliative care needs. The sessions were tailored to each unit's local needs and resources and delivered free of charge.

Each training session was evaluated with a pre and post training questionnaire and collating referral information to services. Participants received a certificate of attendance, confirming four hours of professional development.

This training initiative is the first of its kind, a model of delivering education, with clearly evaluated benefits of integrated learning amongst diverse professional groups, ensuring an integrated approach to delivering high quality neonatal palliative care. This model can be developed to reflect the needs of local population and is transferable to other regions in nationally and internationally.

Introducing the Trieste Charter to the Russian Audience

Vartanova K.¹, Polevichenko E.²

¹*Russian Children's Palliative Care Foundation, Moscow, Russian Federation,* ²*Pirogov Russian National Research Medical University (RNRMU), Moscow, Russian Federation*

Being recognized as a separate type of health care only in 2011, pediatric palliative care in Russia is still in the very early stage of development. Lack of clearly defined and agreed bioethical principles related to working with the dying child is one of the crucial barriers in building a quality system of PPC in the country.

Given the situation when the foundation of PPC are laid down, introducing the principles of the Trieste Charter, or the Charter of the Rights of the Dying Child, to the Russian audience has been considered as a high-priority task in promoting the best interests of “invisible” dying children.

The Trieste Charter project has been implemented by the Russian Children's Palliative Care Foundation in 2015-2016 in Moscow, Russia and included the following steps: translation of the Charter from English into Russian; establishing the expert group of doctors, nurses, parents, health care administrators, scientists, philosophers, priests. In order to make the Charter a practical and relevant tool, each right's description has been provided with a set of special comments and notes linking universal ethical norms and standards to the current practices.

The Charter published in Russian in May 2016 and presented on the eve of Children's Day with the purpose to attract widest possible attention to the rights of a child approaching the end-of-life - the issue never touched before in Russia.

The publication is widely covered in the media, available on many Internet sites, and disseminated in more than 20 Russian regions. It is planned to incorporate the Charter principles into medical training programs of basic and postgraduate education.

The Charter, as a first and unique bioethical document in Russian focusing on the rights of the dying child, is extremely important not only for development and strengthening of the PPC system, but also for making health care in general more child- and family-oriented.

A Retrospective Review of the Timing, Duration and Characteristics of Children Accessing Paediatric Palliative Care in Kuwait

Ali S., Dighe M., Al-Hamad R.

Bayt Abdullah Children's Hospice, Sulaibikat, Kuwait

Background: Children with life-limiting and life-threatening conditions often experience symptom burden and suffering throughout their illness trajectory. Early integration of paediatric palliative care can improve symptoms and quality of life outcomes for patients and caregivers. Our hospice represents the largest purpose built free-standing service for children's palliative care in the Middle East. However little is known in regards to the details of service use and characteristics of the children accessing this service.

Aim: To describe the characteristics of patients and the timing and duration of paediatric palliative care services in order to plan future research and service development.

Methodology: A retrospective chart review study was conducted using routinely collected electronic data for all children receiving paediatric palliative care services at hospital, home or in hospice settings between the start of the service in June 2013 until May 2016.

Results: 58 patients (34 female and 24 male) received paediatric palliative care services. Children were aged between 1 -20 years (\bar{x} 10 years). 43% of patients were Kuwaiti, 26% had no official Nationality and 31% came from expatriate families (10 Nationalities). The majority of diagnoses were cancer related (85%) of which brain tumours were the most common (49%). The average time between diagnosis and first contact with palliative services was 1101 days (range 43-4158 days). 38 children had died. The average time between first contact with paediatric palliative care services and death was 119 days (range 2-533 days).

Conclusion: Children accessing palliative care in Kuwait represent a diverse group, however timely access to paediatric palliative care appears to be slow. Further research is needed to investigate barriers to referral and methods to encourage earlier implementation of palliative care and the extent to which the service can improve outcomes for children and families.

Internally funded

Outcomes for Children with Life-limiting Conditions in and after Paediatric Intensive Care Units: A National Data Linkage Study

Fraser L.¹, Fleming S.², Parslow R.²

¹University of York, Department of Health Sciences, York, United Kingdom, ²University of Leeds, Division of Epidemiology & Biostatistics, Leeds, United Kingdom

Background: To identify children with a Life-Limiting Condition (LLC) who have had an admission to a Paediatric Intensive Care Unit (PICU) and their outcomes.

Methods: Data for all children with a PICU admission in the UK between 1st Jan 2004 and 31st March 2015 were identified from the PICANet dataset.

Linkage to inpatient Hospital Episode Statistics (HES) data and ONS death certificate data was undertaken by the NHS Health and Social Care Information Centre for all children who had been resident in England.

Although the data quality is high in the PICANet dataset, comorbidities are variably coded therefore identifying whether a child has a LLC or not is not possible. A previously developed ICD10 coding framework was used to identify individuals with one or more of these LLC codes in the inpatient HES dataset.

Results: 199,548 PICU admissions in the UK for 135,759 individuals occurred during the time period of the study. Data for 43,565 admissions (32,025 individuals) were excluded due to not having been resident in England or poor quality demographic data.

Data on 103,734 individuals (155,983 admissions) were sent for linkage. Successful linkage occurred in 102,722 individuals (99.4%).

51.0% of these children had a LLC and these children accounted for 62.7% of the PICU admissions.

The crude PICU death rate in the children with a LLC was 5.0% (n=4826) compared to 3.1% (n=1786) in those without a LLC. The OR of death in a model adjusted for diagnostic group, sex, age, and expected risk of mortality for children with a LLC was 2.11 (95%CI 1.97-2.27).

5040 children died after discharge from PICU, 91% of these children had a LLC.

Conclusions: Children with a LLC account for a large proportion of all PICU admissions and deaths in PICU in England. Although only 5% of these children died in PICU, another 5% died after discharge from PICU. More integration of specialist palliative care with PICU services may allow more choice for children and families.

The Need of Pediatric End-of-Life Care in the Czech Republic

Hrdličková L.^{1,2,3}, Zavadová I.^{2,3,4}, Mojžíšová M.^{2,3,5}, Sláma O.^{2,6}, Dušek L.⁷

¹University Hospital Motol Prague, Pediatric Hematology and Oncology, Prague, Czech Republic, ²Czech Society of Palliative Medicine, Prague, Czech Republic, ³Czech Pediatric Palliative Care Working Group, Prague, Czech Republic, ⁴Home Care Hospice Cesta Domů, Prague, Czech Republic, ⁵Hořovice Hospital, Pediatric, Hořovice, Czech Republic, ⁶Masaryk Memorial Cancer Institute, Brno, Czech Republic, ⁷Institute of Health Information and Statistics of the Czech Republic, Prague, Czech Republic

Background: The Czech Pediatric Palliative Care Working Group was established in November 2015 with the aim to set up standards of palliative care for children in the Czech Republic. However, no valid data regarding the need of palliative and end-of-life care in children in our country are available. This paper evaluates the expected number of children who shall profit from the end-of-life care in the Czech Republic.

Methods: We examined pediatric mortality among infants (< 1 year), younger children (aged 1 - 5 years), older children (aged 5 - 9 years) and adolescents (aged 10 - 19 years) between 2012 and 2014 using statistics registry data. We focused on the type of diagnosis and the leading causes of death among pediatric patients. We used the collected data to assess the need of pediatric end-of-life care in our country.

Results: 1836 children died in the Czech Republic within 2012 and 2014. 10,9%, 8,3% and 36,5% of deaths occurred in the younger children, older children and adolescents, respectively. 44,3% of deaths occurred within the first year of age mainly due to perinatal complications (53%) and chromosomal and congenital abnormalities (20%). The leading cause of death were injuries among younger children (20,4%) and adolescents (58,5%). Cancer was the leading cause of death in older children (28,3%). Life-limiting and life-threatening illness was the leading cause of death in 498 children within 2012 and 2014. Most frequent were chromosomal and congenital abnormalities (46%), cancer (28%) and severe cerebral palsy (7%). No significant difference in mortality rates and in the leading causes of death among children between the year 2012, 2013 and 2014 was observed.

Conclusion: Approximately 150 to 170 children per year may profit from the pediatric end-of-life care in the Czech Republic regarding the collected data. These are preliminary data which are for the first time analyzed as basis of systematic development of pediatric palliative care in Czech Republic.

Using Internet Search-query Analysis to Evaluate Public Awareness of Palliative Care

Whitla L.¹, Lennon P.², McLean S.³

¹Our Lady's Children's Hospital, Crumlin, Paediatrics, Dublin, Ireland, ²St. James's Hospital Dublin, Dublin, Ireland, ³St. Francis Hospice, Raheny, Palliative Care, Dublin, Ireland

Background: Palliative care (PC) is a rapidly growing specialty. A recent study used Internet search-query analysis to demonstrate that public awareness of PC has greatly increased in the US. There is robust empirical evidence for the benefit of pediatric palliative care (PPC) for children with life-threatening conditions, uncontrolled symptoms, and complex psycho-social needs, and a concomitant growth in service provision. The aim of our study was to use Internet search-query analysis to evaluate trends in public awareness of PPC in the United States, and to assess whether or not these mirrored the trend seen in PC.

Methods: Google Trends provides a referenced score for the relative popularity of a search-term, for defined time periods. The popularity of the search-term 'pediatric palliative care' was measured between 01/07/2005 and 30/06/2016 in the US, and analyzed using independent t-tests and Joinpoint analysis.

Results: The mean popularity of the search-term decreased significantly between 2005-2006 ($p=0.0004$), 2006-2007 ($p=0.0009$), and between 2010-2011 ($p=0.0015$). Joinpoint analysis was used to evaluate the monthly percentage change (MPC). The MPC decreased significantly by 1.31% ($p<0.0001$) from July 2005 to December 2011, whilst the MPC to the end of the study was not significant ($-0.23\%/month$, $p=0.225$). Over the entire time period the MPC was found to be -0.91% ($p<0.0001$).

Conclusions: Although public awareness of PC has increased rapidly over the past ten years, the relative popularity of the internet search term 'pediatric palliative care' has fallen over the same time period. Public awareness campaigns have helped boost the profile of PC, and increased knowledge and understanding have been shown to increase the likelihood of patients considering PC for themselves or their family. This study indicates a need to increase public awareness, in order to ensure that all children who may benefit from PPC receive appropriate and timely care.

Place of Death: Report of Patients Receiving Paediatric Palliative Care in Kuwait

Dighe M.¹, Nabil Z.², Al Hamad R.², Al Khabaz E.², Saima A.²

¹Bayt Abdullah Children's Hospice, Palliative Care, Kuwait, Kuwait, ²Bayt Abdullah Children's Hospice, Kuwait, Kuwait

Background: Our centre is the first Paediatric hospice and the only provider of Paediatric Palliative Care (PPC) in the country.

Methods: A multi disciplinary hospice based team provides PPC across outpatient, daycare, respite, home settings as well as limited inpatient care. The team also delivers outreach PPC for patients in tertiary hospitals.

Electronic records of all referred patients who died between June 2013 and May 2016 were reviewed. Data were extracted regarding demographic details, diagnosis, and place of death. Any textual information about choices of place of death was reviewed.

Results: 38 patients died. 17 were male. Ages ranged between 1 and 20 years, the mean age was 9.8 years. 16 were Kuwaiti; 22 belonged to other nationalities. Majority had cancer (n=34). 23 patients died in hospital wards, 3 in hospice, 2 at home, 5 in the Intensive Care Unit (ICU). 5 patients died abroad where they were receiving further disease modifying treatment.

Discussion: 60% patients died in hospital. The possible reasons for this trend are- complex symptom management needs, parental preference and ongoing disease modifying therapy. The commonest reason for ICU deaths was families "wanting to do everything". In contrast, families of children who died at home or hospice had clearly opted for palliative care only.

At present, the significant barriers to home deaths are- legal restrictions precluding administration of parenteral medications (e.g. opioids) at home and physicians' professional obligation to provide acute treatment and resuscitation (irrespective of natural disease outcomes) if requested by families. Regulations mandating 24-hour physician on site presence and limited hospice staff capacity may have limited access to children dying here.

Conclusion: Further research is needed to investigate the barriers to and the feasibility of End of Life Care in different settings.

Children's Palliative Home Care Programme Prevents and Reduces Unnecessary Hospitalizations

Jansone A.^{1,2,3}, Fridrihsone D.^{1,3}, Krumina V.^{1,3}, Misurenko J.⁴, Voitoviča I.^{1,3}, Gigele I.^{1,3}

¹Children's University Hospital, Palliative Care Department, Riga, Latvia, ²Riga Stradiņš University, Riga, Latvia,

³Children's Palliative Care Society, Riga, Latvia, ⁴Children's University Hospital, Riga, Latvia

Background and aims: Hospital based children's palliative home-care (CPHC) service is developed to meet the physical, psychological, spiritual needs of the patients with life-limiting and life-threatening diseases at home. CPHC team is intended to improve symptom control and quality of life, to enable patients to stay at home, and to avoid unnecessary hospitalizations. The aim of this study was to assess the effectiveness of appropriate CPHC services in reducing hospitalizations and the number of days spent in hospital due to acute illness.

This study is important to substantiate the benefits and efficiency of CPHC services and promote the development of political decisions in health care by the governmental institutions and non-governmental organizations, by developing and improving children's palliative care in our country because it is not available for all children.

Methods: Data about CPHC patients' hospitalization and length of treatment during acute illness during the time period of 2013-2015 at the Children's hospital was collected, compiled and analyzed, using the electronic data system and the ambulatory medical records of the Children's hospital. Unified data base was created.

Results: In 2013, out of 157 palliative home-care patients 32 % were hospitalized due to acute illness. In comparison with 2013, the number of palliative home-care patients has increased by 13%, the number of hospitalized patients has decreased by 28%, and the length of stay in the hospital has decreased by 25% in 2014 and by 19% in 2015. The number of episodes of acute illness has decreased by 46% in 2014 and by 15% in 2015. The most common reason of hospitalization is acute respiratory tract infections (30% of cases).

Conclusion: Our study confirms the effectiveness of CPHC in enabling supporting during the long periods of illness at home and in averting unnecessary hospitalization. The services of a CPHC reduced the consumption of hospital resources.

Home or Hospital? How Parents Decide about the Site of the Dying Child's Care and Death

Papadatou D.^{1,2}, Kalliani V.¹, Liakopoulou P.¹, Karakosta E.¹, Bluebond-Langner M.^{3,4}

¹Merimna - Society for the Care of Children and Families Facing Illness and Death, Athens, Greece, ²National and Kapodistrian University of Athens, Nursing, Athens, Greece, ³UCL-Institute of Child Health, London, United Kingdom, ⁴Louis Dundas Centre for Children's Palliative Care, London, United Kingdom

Background, context-aims: No gold standard exists as to where seriously ill children should die. While several studies explore “what” families want or do at the end of life, knowledge is limited as to “how” they form a desire, reach a decision, and develop a plan of care in different cultures. The presentation, which is part of a larger study, explores how parents decide about the site of end of life care and death.

Methods: The sample comprised 36 parents of 22 children who died at home or hospital. Those who consented (81% response rate) participated in a semi-structured interview. Data analysis was performed according to the principles of grounded theory and credibility of findings was ensured through researcher triangulation.

Results: Data analysis revealed three core categories:

- (a) the *decision-making process* involving distinct patterns of interaction among spouses and professionals which led to decisions by consensus, by accommodation, by imposition or by exclusion;
- (b) *factors affecting decisions* about the child's location of care and site of death; and
- (c) *types of decisions* comprising clear-cut, conditional or no decision.

The options of hospital and home were desirable to different families or even to the same family, their choice being affected by a combination of factors. Hospital was most likely chosen when symptoms were perceived uncontrollable, parents had no confidence in their caregiving efficacy, and felt that time was limited to acquire new skills. Decision for home care was affected by the awareness of the terminal condition, respect of the child's desire to be at home, and striving for quality of life.

Conclusions: Decision-making at the end of life emerged as a dynamic, evolving process, influenced by a nexus of interrelated factors. Results can help professionals to facilitate decision-making by gaining deeper insight into personal, interpersonal, familial and sociocultural factors affecting decisions at the end of life.

An Analysis of Trends in Place of Death Following Establishment of a Regional Paediatric Palliative Service and Opening of Children's Hospice in the UK

Renton K.^{1,2}, Mayer A.^{1,2}, Alison L.³, Byrne R.⁴, Yeomanson D⁵

¹Paediatric Palliative Medicine, Sheffield Children's Hospital NHS Foundation Trust, United Kingdom, ²Bluebell Wood Children's Hospice, Sheffield, United Kingdom, ³Safeguarding, Sheffield Children's Hospital NHS Foundation Trust, United Kingdom, ⁴Sheffield Safeguarding Children Board, United Kingdom, ⁵Paediatric Oncology, Sheffield Children's Hospital NHS Foundation Trust, United Kingdom

Background: In 2008 the establishment of a regional Paediatric Palliative Medicine (PPM) service (including hospice opening) coincided with the establishment of a national reporting mechanism for all deaths in childhood (Child Death Overview Panel, CDOP). CDOP data contributes to strategic planning, including directing local health promotion priorities. CDOP includes information regarding "expectedness" and place of death, allowing us to describe trends in place of death for all children dying over the time the regional PPM service was being established.

Methods: Retrospective cohort study from 2008-2015 using anonymised data from five databases; four local CDOPs and local children's hospice. Data for >700 deaths subjected to descriptive statistical analysis. Information includes; year of death, age, gender, ethnicity, home suburb, location of death, and category of death (expected/not expected).

Results: For deaths outside the neonatal period (n=369), 27% (n=99) occurred at home. 11% (n=42) died in the hospice, which compares with 4.2% nationally. Analysis demonstrates an increased proportion of "expected" deaths occurring in hospice over period studied (3%, n=2 in 2008-09; 15%, n=9 in 2014-15). This coincides with a decrease in the proportion of 'expected' deaths occurring at home (17%, n=11 in 2008-09; 8%, n=5 in 2014-15).

Conclusions: This exploratory work describing patterns in place of death during a period of substantial expansion and evolution in local PPM provision challenges the oft quoted, but poorly evidenced view that home is the preferred place of death for children with life limiting illnesses. The possibility that historical preference for home death may have been due to lack of alternatives is given further weight by the above average proportion of deaths now occurring in the hospice, reflecting increased accessibility and capability of PPM in the region.

P001

Normalization of Symptoms: A Leading Barrier to Symptom Management in Pediatric Advanced Cancer

Dussel V.^{1,2}, Bilodeau M.³, Uzal L.², Orellana L.⁴, Requena M.L.², Wolfe J.³

¹Boston Children's Hospital, Palliative Care, Boston, United States, ²Institute for Clinical Effectiveness and Health Policy (IECS), Center for Research and Implementation in Palliative Care, Buenos Aires, Argentina, ³Dana-Farber Cancer Institute, Psychosocial Oncology and Palliative Care, Boston, United States, ⁴Deakin University, Faculty of Health, Burwood, Australia

Background: A better understanding of symptom management (SM) processes is necessary to reduce burden in child cancer.

Aim: To identify barriers to effective SM in pediatric advanced cancer.

Design: Qualitative approach that included focus groups (FG), in-depth interviews (INT), and a multiple comparative case study (MCCS) as part of formative research for an early palliative care (PC) intervention at a large US pediatric cancer center.

Population: We held 1 physician (n=7) and 1 nurse/psychosocial clinician (n=8) FG and 7 INT of patients (n=2) and parents (n=5). For the MCCS, we enrolled a purposive sample of 41 children ≥2 years with cancer that progressed beyond initial treatment, their parents and providers.

Methods: Provider/families' views on SM processes were probed in FG/INT. In the MCCS, children or parents reported weekly (for 16 weeks) on child symptoms using the Memorial Symptom Assessment Scale (MSAS) via an electronic patient-reported outcomes system, PediQUEST. When MSAS scores >33 were reported we studied SM using observation, INT of staff/family members, chart abstraction, field notes and provider email correspondence. Data were coded and analyzed using grounded theory and NVivo software.

Results: The main theme that emerged was that symptom distress was seen as an unavoidable result of cancer treatment. As a consequence, SM was not highly prioritized; families accepted high levels of distress. We found that non-pharmacological strategies were rarely used and the hospital PC team was seldom used as a resource. In no case when a patient reported a severe symptom (MSAS>75) during the study, had oncologists initiated a consultation with the hospital PC team.

Conclusions: Among children with advanced cancer, "normalization" of symptoms appears to be a major barrier to adequate SM. PC teams, as SM experts, are uniquely positioned to change these attitudes through education, role modeling and implementation of family and provider activation strategies.

P002

Developing Confidence in Pediatric Palliative Care: Building from the Evidence

Lafond D.¹, Reggio C.², Hinds P.³

¹Children's National Health System, PANDA Palliative Care Team, Washington DC, United States, ²Children's National Health System, Division of Blood and Bone Marrow Transplantation, Washington DC, United States,

³Children's National Health System, Department of Nursing Research and Quality Outcomes, Washington DC, United States

Background: Palliative care (PC) improves patient/family satisfaction, symptom distress, quality of life, and burdens felt by parents and health care teams. Innovative models may increase access to PC services across the spectrum of care, and support bedside clinicians providing primary PC care with support of subspecialty PC teams.

Methods: We investigated acceptability and outcomes of early PC consultation for children undergoing hematopoietic stem cell transplant (HSCT). Interventions included pain and symptom management, psychosocial support and integrative therapies. Clinicians expressed inadequacies in end-of-life (EOL) care facing escalating symptoms or psychosocial crises. An educational program and primary PC resource teams were implemented to improve access to PC and support bedside and hospice clinicians.

Results: We achieved 100% referral and recruitment of eligible families. Families and providers reported high satisfaction. Outcomes included improvement or no significant change in comfort across the trajectory of HSCT. Early integration of PC is feasible and acceptable, and is now standard for HSCT. Nurses (N=80) report high satisfaction and improved confidence in: integrating PC at diagnosis ($p=.031$), during treatment ($p=.02$), at EOL ($p=.028$), and in anticipatory guidance ($p=.017$). Nurses state when providing PC they feel more prepared, less stressed and that they are making a difference for patients and families. Primary PC resource teams have initiated 14 quality improvement projects. Subspecialty PC consults increased by 30%. Education of community hospice partners has resulted in the subspecialty PC team participating in hospice team meetings, increased home visits, partnership as medical directors, and increased visibility in the community.

Conclusions: Education and mentoring are key components to developing confidence in PC through knowledge, skills and attitudes. Use of evidence from each program garnered support for PC initiatives.

P003

Open for Business

Pedersen L.-A.

Lady Cilento Children's Hospital (LCCH), Paediatric Palliative Care Service (PPCS), Brisbane, Australia

Aim: The challenges of opening a new children's hospice - a clinical perspective.

Background: The state now has its very own children's hospice - one of only three in the whole country. The opening of this new service has presented a number of challenges and a number of surprising positive outcomes. The hospice team has worked closely with the well established state wide paediatric palliative care service (PPCS) and the tertiary children's hospital to ensure common approaches and excellent clinical care.

The referral processes and intake has been divided into three phases as described by the patients clinical care needs and their degree of complexity. Each phase will be introduced as the hospice staff develops confidence and competence. Phase one included intake of those children the less complex clinical needs, and is well underway. Phase two will include referral of children with central venous access devices and home parental nutrition. Phase three will include those with non invasive ventilation needs and tracheotomies. It hoped that this staged approach will result in confidence by the families as the hospice begins provide short break care, day therapies and end of life care.

Method: This paper will illustrate some of the learning's from the establishment of the clinical services of the new hospice. The qualitative and quantitative data collected from this first phase will include parent's feedback as some of the first families through; staff feedback regarding their learning needs as the children come into their care; data from the executive team as the families and staff come together in these first phase of care; and input from some of the volunteers working in the hospice as it welcomes families.

Summary: It is hoped that by sharing these experiences that other paediatric palliative care teams can learn from the challenges and rewards as they are constructing teams, clinics, or even a hospice.

P004

Breath Easy

Pedersen L.-A.

Lady Cilento Children's Hospital (LCCH), Paediatric Palliative Care Service (PPCS), Brisbane, Australia

Aim: Address the challenges of working with rarer conditions seen in paediatric palliative care and sharing care with multiple teams.

Background: This paediatric palliative care service (PPCS) is providing care to an entire state, for children age 0- 18 years with life limiting conditions. In the greater paediatric palliative care arena of more affluent countries, with access to transplant programs, it is rare to have a child with cystic fibrosis referred to a PPCS for end of life care. The success of more intensive, tailored management of these children from birth in combination with progress of transplant care, has resulted in cystic fibrosis patients living into their forth decade.

Methods: This paper will examine the experience of this PPCS as the team cared for two teenagers with cystic fibrosis, who died within days of each other but with different clinical histories. The first teen had undergone a double lung transplant with complications and hope for a second transplant. She was supported by adult services and the PPCS. The second was not eligible for a lung transplant but was supported with non invasive ventilation at home. He was managed by paediatric respiratory services and the PPCS. Both families have other siblings affected by cystic fibrosis.

There were marked differences in the families' approaches and earlier symptom burden. Both teens were well connected to the PPCS team and died peacefully in their own homes. The PPCS wants to share the strategies that improved working relationships with both the paediatric respiratory team and adult transplant teams to help meet the clinical and psychosocial needs of the teenagers and their families. The PPCS team also learnt how to negotiate hope of a second transplant, and the care of surviving cystic fibrosis affected siblings. It is hoped by sharing these experiences; it will improve care for others.

P005

WhatsApp, Doc? Use of Social Media to Facilitate Palliative Care for Children Residing in Remote Locations

Nuno I.A.¹, Nakashima-Paniagua Y.¹, Okhuysen-Cawley R.²

¹Universidad de Guadalajara, Pediatrics, Guadalajara, Mexico, ²Baylor College of Medicine, Texas Children's Hospital, Houston, United States

Background: Pediatric Palliative Care is in early stages of development in our country. Very few tertiary pediatric facilities can provide around-the-clock palliative support. Our hospital has a nine-state referral base primarily serving poor, medically-indigent patients. Many of these families reside in remote villages with limited transport options. Since adequate symptom control is the cornerstone of palliative care, we have increasingly relied upon the use of social media for symptom control, the care of the imminently dying, and bereavement support after discharge from our referral center.

Methods: This is a descriptive, retrospective, observational review of the database and communication logs maintained by our interdisciplinary team during a 13-month period encompassing January 2015 through January of 2016.

Results: A total of 476 patients were seen. 308 hospitalized children and 168 outpatients were referred by institution-based maternal/fetal, surgical and pediatric subspecialists. 48 families whose children needed close follow-up due to a significant symptom burden accepted media-based support upon discharge from the hospital. A pediatric palliative care attending physician and her team collaborated closely to provide this service. Primary symptoms addressed remotely utilizing the WhatsApp platform included pain, gastrointestinal complaints (nausea, vomiting, constipation), dyspnea, bleeding, and seizures. One boy developed status epilepticus, managed successfully at home by his parents. Approximately one half of the families maintained contact with the interdisciplinary team after the child's death, using WhatsApp or telephone conversations.

Conclusions : A wide variety of symptoms was effectively palliated using WhatsApp, suggesting that the appropriate use of social media may facilitate palliative care for children in resource-limited settings. Our team was able to provide practical and bereavement support which would have been impossible otherwise.

P006

Hospitality: A Beginning of Paediatric Palliative Care for Children Affected by Cancer, in LMICs and in Italy

Accornero E.N.¹, Rizzi D.², Bergami E.³, Mina T.³, Rubert L.³, Tolva A.³, Carpino L.⁴, Zecca M.³

¹IRCCS Policlinico San Matteo, Oncoematologia Pediatrica, Pavia, Italy, ²Soleterre ONG, Opera, Italy, ³IRCCS Policlinico San Matteo, Pavia, Italy, ⁴Soleterre ONG, Oncoematologia Pediatrica, Opera, Italy

The purpose of the study is to analyse how paediatric palliative care is provided in low and middle income countries (LMICs), compared to Italy, investigating among 5 Departments of Paediatric Oncology. The hypothesis is to study semantic, lexical and pragmatic level of the concept of "Hospitality" (sharing linguistic root with "hospice") in a view of beginning of palliative care, in an attempt to respond to an increasingly emerging need within the Italian context where it is necessary to give psychological support and palliative care in a multicultural social context.

Methods: PHASE A Study about "Hospitality in Paediatric Oncology" literature in 11 specific texts, 64 scientific articles, 2 studies by AIEOP, 4 IPOS studies and 4 AIRTUM studies.

PHASE B Research in 5 paediatric cancer hospitals in Ivory Coast, India, Italy, Morocco and Ukraine. Involved 150 parents of children.

Data Collection by semi-structured questionnaire (17 questions) with a purposive validated sampling. Statistical analysis by cluster analysis. Ethical considerations: how to make palliative care available to cancer patients in LMICs.

Results: The data show a clear disparity in perception of problems concerning palliative care among LMICs and Italy. In addition to the impossibility of regular access to pain medication, lack of blood donors (17% Ukraine), lack of proper nutrition (14.3% Ukraine), financial difficulties also during regular care

(92% Ivory Coast), lack of information (24% India and 50% Morocco). These results are very far from the perceived problems in Italy concerning a request of improvement and better organization (64%).

Conclusions: In LMICs countries, in the absence of access to pain medication, we can invest in including parents of patients in a therapeutic alliance where palliative care is essentially linked to psychological therapy. We must implement international cooperation projects to make palliative care a right for all paediatric cancer patients.

P007

Patient-centered Model of Care: Meeting the Patient's Evolving Needs with a Transversal Team

Martino Alba R., Rigal Andrés M., González Blanco, C., Fillol Cuadrado A., del Rincón Fernández C.

Hospital Niño Jesus, Pediatric Palliative Care, Madrid, Spain

Background and aim: On its journey towards ill health, a patient with a life-limiting condition will have changing care needs, usually met by different professionals and institutions. But health care transitions are a recognized source of distress. In order to minimize this impact we propose a patient-centered model of care and describe the activity of a team adopting this model.

Method: The Pediatric Palliative Care Team from Madrid organizes assistance in 3 different levels of care, designed to meet the needs of patients in different stages of their illness.

Level	Place of care	Orientation	24/7 care
1	Outpatient clinics	Patient needing PPC input, but mostly general pediatrics care.	Professional support
2	Home or hospital as consultants	Patient needing PPC input and complex care needs, but still benefits from other specialists care during aggravations.	Telephonic
3	3a.Home 3b.Hospital	Patient needing only direct PPC as illness aggravates.	Telephonic and presential

[Organizational levels of care]

No matter at what level child is met, its treatment plan is designed and executed by all the members of the team due to rotation, regular team meetings and out-of-hours assistance.

Results: This team started its activity in 2008. 553 patients have been attended, of which 203 are currently active. An average of 61 cases were referred per year, outnumbering those who died (av. 36/year) so there has been constant increase in the caseload.

Patients went through an average of 2,4 transitions. 52% received direct PPC care (Lv. 3), 39% at home and 13% in hospital. Although in the first years most patients were met at Lv. 3, this tendency is shifting towards a greater use of outpatient clinics (Lv. 1). Still, direct care at home consumes most of team's working hours.

Conclusion: PPC organization must direct resources where they are needed most. For an individual patient's need change with time. A same team can efficiently meet these needs in different settings, favoring a coherent treatment plan and smooth transitions along the way.

P008

Patient-centered Model of Care: Meeting the Patient's Evolving Needs with a Transversal Team. A Case Study

Rigal Andrés M., Chocarro González L., Ortiz San Román L., González Peña A., Mangudo Paredes A.
Hospital Niño Jesus, Pediatric Palliative Care, Madrid, Spain

Background and aim: This communication complements a parallel work presented in this congress with similar title. By presenting a case, we seek to exemplify the implications of this model for a particular patient.

Method: The Pediatric Palliative Care Team from Madrid adopts a care model such as the one previously described. Here, we describe a recent case that was chosen because it supposed a dense example of care transitions in changing health conditions.

Results: Myriam was an 11 year old girl affected by a Severe Cerebral Palsy. She was first met by the team in May 2014 while hospitalized due to dystonia and pain. Symptoms were controlled and she was then followed in a Home Care program. After 9 months of stability, she was met in outpatient's clinics.

In November 2015 she underwent orthopedic surgery because of hip pain. Due to uncontrollable postoperative pain the team took charge of her treatment in hospital. Initial nociceptive pain evolved to a difficult neuropathic pain. Acknowledging the burden of prolonged hospitalization, she was discharged to continue same treatment at home. Pain control was poor, so an anesthetic technique was sought, requiring again hospital admission. Not achieving proper pain control either way, she went home under team's care. She died in May 2016 while at home, accompanied by her family and the team. Visits for bereavement support were held.

Follow up time was 746 days, of which she spent 93 hospitalized in 4 separate episodes. She received 68 interventions as outpatient (70% at home, 23% in outpatient clinics and 6% at school).

Conclusion: Myriam's case was dramatic for its clinical evolution. On her last 2 years, the same team of professionals guided her care no matter the setting. This favored team and family engagement and trust in difficult times. It also permitted her to stay at home as much as possible while promptly receiving hospital interventions when needed, with swift transitions between different settings.

P009

Integrating Social and Medical Care - The Experience of a Paediatric Oncology Palliative Care Service

Koh M.¹, Williams R.², Martin T.²

¹University Hospital Southampton, Paediatric Palliative Care, Southampton, United Kingdom, ²University Hospital Southampton, Paediatric Oncology, Southampton, United Kingdom

Background: Dying and bereaved people experience changes and trauma which leave them vulnerable. We need to integrate this aspect of patient care into our practice. We explore the role of a specialist paediatric oncology social worker in the management of patients with cancer, in particular patients with incurable disease. In the UK, these roles are typically funded by cancer charities rather than the state and often not available to non-cancer palliative care patients who have similar needs.

Methods: Literature review and retrospective review of the roles and streams of support provided by the social work team to paediatric oncology patients in a tertiary centre in the UK.

Results: The social worker's role provides continuity from diagnosis, through treatment and into bereavement. In this centre, the social work team consists of 4 members, meeting 100-110 families each year and they supported 20 deaths in 2015.

They provide care which focuses on accompanying the patient, containing suffering whilst promoting growth, acknowledging need, facilitating reflection and affirming bonds.

This supports patients in difficult decision-making, enables resilience during transitions from health, to illness, to death and bereavement.

They assist with practical issues and challenges by promoting patient control and self-esteem.

The reassurance of ongoing care after bereavement is valued by the patient and family.

They also provide valuable support for their colleagues in the oncology palliative care team.

Conclusions: Social workers address the wider holistic needs of the whole family, not just the patient's medical and nursing needs. They work in settings important to the patient: home, school, hospital.

Currently, such roles are funded by charities. We highlight the importance of integrating this care into our practice to help secure this crucial service and to advocate its expansion to patients with non-cancer illnesses.

No funding to declare

P010

Helping the Helpers: Focus Groups in Pediatric Hematology/Oncology to Explore Factors Contributing to Burnout

Kramer D.¹, Moody K.², Graffis R.², Karnieli-Miller O.³, Roth M.⁴, Stein J.⁵

¹College of Mount Saint Vincent, Bronx, United States, ²Indiana University / Riley Hospital for Children at IU Health, Pediatrics, Indianapolis, United States, ³Tel Aviv University, Kiriat Tivon, Israel, ⁴Albert Einstein College of Medicine / The Children's Hospital at Montefiore, Bronx, United States, ⁵Schneider Children's Medical Center of Israel, Petach Tikva, Israel

Context: 40-80% of healthcare providers (HCPs) caring for children with cancer report at least moderate burnout (defined as emotional exhaustion, depersonalization, and diminished feelings of personal accomplishment). In 2012, a randomized-control trial was conducted to assess the effects of a Mindfulness Based Stress Reduction (MBSR) course on staff burnout in Pediatric Hematology/Oncology (H/O) HCPs. Nearly 100% of all subjects met criteria for high levels of burnout at all timepoints; however, MBSR did not objectively impact these scores (previously published). This study aims to unpack the factors contributing to burnout by conducting focus groups in order to better develop interventions that could improve the quality of HCPs' experience working with pediatric H/O patients.

Methods: The first round of focus groups were conducted at a hospital in Israel, and will be followed by additional groups to be held in August 2016 in Bronx, NY. In Israel, all pediatric H/O staff were divided into three discipline-specific sessions (8-12 HCPs/group, ~1 hr) and asked questions regarding work-life balance, administration, environment, support systems, satisfaction, relationships with colleagues and patients, world view, and more. Interviews were analyzed for recurrent themes and patterns contributing to burnout.

Results: The themes that emerged from this first round of focus groups as impacting the incidence of burnout were work-life balance, atmosphere in the department (support or criticism), dealing with death and dying, satisfaction, hospital bureaucracy, and world view.

Conclusion: These qualitative data will lead to a better understanding of how staff is impacted by caring for families of children with cancer and the deaths of children in their care. Ultimately, this could lead to more effective, multi-pronged interventions aimed at reducing burnout in this population of healthcare providers.

P011

“The Nasty, Unpleasant Stuff”: Parents' Experiences of Being Responsible for Carrying out Distressing Healthcare Procedures for their Child

Spiers G., Beresford B., Clarke S.

University of York, Social Policy Research Unit, York, United Kingdom

Background: Children with life-limiting/threatening conditions may have complex health needs at some stage of their illness. To enable their child to remain home, parents can become responsible for administering procedures that cause their child distress (e.g. giving injections, inserting naso-gastric tubes). This is an under-researched area. This paper reports findings from a study of parents' experiences.

Methods: A qualitative study design was used. A purposive sample representing a range of circumstances, families and procedures ensured we explored this topic in depth. Data from 24 UK parents were collected through depth-interviews, and analysed thematically. Ethical approval was obtained.

Results: Carrying out distressing procedures meant parents faced 'added' challenges. Many reported that these were not addressed when being trained in a procedure. Minimising their child's distress was a significant issue. Some were confident about this, but others wanted or valued professional guidance. Managing physical resistance could be challenging, especially when parents carried out procedures alone. The child's observable distress meant parents also had to manage the presence and reactions of siblings. Parents reported varying degrees of emotional discomfort, including conflict and guilt, which they tried to control in the moment of carrying out the procedure. Typically, they adjusted to these challenges over time, but for some there was still a support need for the emotional aspects of this role. Training, supervision and reassurance from the community nursing team were highly valued.

Conclusions: Carrying out these procedures is not simply a clinical process for parents: there are added issues to contend with because such procedures cause their child distress. In the home setting, these issues may not always be visible to nursing and palliative care teams. This presents implications for the training and support of parents with this responsibility.

P012

"I Guess we Don't Do it very Often": Health Care Professionals' Views, Attitudes and Experiences Discussing Preferred Place of Death for Children and Young People with Life-limiting and Life-threatening Conditions

Hills M.¹, Baillie J.², Bluebond-Langner M.³, Nelson A.⁴

¹Martin House Hospice Care for Children and Young People and Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom, ²Cardiff University, School of Healthcare Sciences, Cardiff, United Kingdom, ³UCL, Louis Dundas Centre for Children's Palliative Care, London, United Kingdom, ⁴Cardiff University, Marie Curie Palliative Care Research Centre, Division of Population Medicine, School of Medicine, Cardiff, United Kingdom

Background: Significant numbers of children and young people (CYP) have life-limiting conditions (LLC). Advance care planning is recommended to prepare patients and families for what they wish to happen. Preferred place of death (PPD) is one aspect. Having opportunities to plan PPD is considered a better proxy for quality of care than the actual location of death.

Aim: To gain understanding of healthcare professionals' (HCP) views, attitudes and experiences discussing PPD for CYP with LLC.

Methods: Doctors and nurses (n=9) with experience of caring for CYP with LLC in various specialties were sampled purposively from two UK hospitals. Semi-structured interviews were audio-recorded, transcribed verbatim and analysed using Framework analysis.

Results: Five themes emerged: 'why', 'when' and 'how' discussions occur, 'who' with and whether the CYP's 'voice' is lost. HCPs believe discussions are important to give families control and should be undertaken as soon as appropriate. In practice, discussions often happen closer to death. HCPs feel they need experience and knowledge to undertake such conversations, and that recognition, declaration and subsequent parental acceptance that a child is dying is necessary to be able to initiate them. Fear, taking away hope and feeling that choices are unrealistic were perceived as barriers. Palliative care professionals were acknowledged to have more engagement and confidence in discussions than other specialists. Despite CYP's choices being mentioned in HCPs' definitions of PPD, overwhelmingly parental discussions and preferences take precedence. The CYP are rarely involved in the process and their voice is often lost.

Conclusions: This research confirms and deepens our understanding of the challenges in engaging in discussions about PPD but also identifies areas to be addressed in palliative care education and training.

P013

Palliative Care at a Cardiology Intensive Care Unit for Children: Indications and Interventions

Campos C.V.¹, Gaiolla P.V.¹, Barbosa S.M.M.², Zoboli I.², Miana L.A.¹, Shimoda M.S.¹, Gustavo F.¹, Ikari N.M.¹

¹Universtiy of Sao Paulo, Heart Institute, Sao Paulo, Brazil, ²University of Sao Paulo, Children's Hospital, Sao Paulo, Brazil

Introduction: Although there has been great progress in management of children with heart disease (HD), this is still a group with high morbidity and mortality rates. Despite that, few data is available on palliative care (PC) for children with HD. Since 2013, there was established a PC team in our pediatric cardiology unit. We aim to analyzed this initial results.

Methods: We conducted a retrospective analysis of 53 pediatric patients that were admitted in the cardiology intensive care unit between January 2013 and December 2015 and were evaluated by the PC team. The average age was 6 years (3 newborns) and there were 29 girls (54%). Univentricular physiology and heart-transplant were the most frequent diagnosis (24% each).

Results: The main indication for PC evaluation was sedation/analgesia (39%) and absence of therapeutic options (30%). Help in communication and adjustments in sedation/analgesia were the most frequent actions taken (33% each). Twenty-seven (50,9%) patients had an associated extra-cardiologic condition and 62% was already followed at our institution in an outpatient setting prior to admission. The average length-of-stay was 116 days (1-557days). Twenty-four patients (45,3%) died and 9 of them (37,5%) received cardiopulmonary resuscitation. Among deceased patients, fourteen (58%) received at least one intervention during their last 24-hours of life, including central venous access (16%), surgery (16%), orotracheal intubation (12%) and mechanical circulatory support (12%).

Conclusion: Cardiology pediatric patients are difficult to manage, specially those with complex congenital HD and transplanted patients. The length of stay is usually long, so physicians benefit from a conjunct follow-up with a PC team, not only for medication adjustments, but also for help in communication and decisions regarding end of life care, in order to attenuate patient/family suffering and optimize the number of interventions in their last hours of life.

P014

Value of a Pediatric Palliative Care Team: The Parental Perspective

Verberne L.M.¹, Kars M.C.¹, Schouten - van Meeteren A.Y.N.², Bosman D.K.³, Colenbrander D.A.³, Grootenhuys M.A.^{4,5}, van Delden J.J.M.¹

¹University Medical Center Utrecht, Julius Center for Health Sciences and Primary Care, Department of Medical Humanities, Utrecht, Netherlands, ²Academic Medical Center, Emma Children's Hospital, Department of Pediatric Oncology, Amsterdam, Netherlands, ³Academic Medical Center, Emma Children's Hospital, Department of Pediatrics, Amsterdam, Netherlands, ⁴Academic Medical Center, Emma Children's Hospital, Psychosocial Department, Amsterdam, Netherlands, ⁵Princess Maxima Center for Pediatric Oncology, Utrecht, Netherlands

Background: Parents of children with a life limiting disease often feel abandoned and have to rely on themselves at home while adequate pediatric palliative care (PPC) and guidance are lacking. Since children are increasingly cared for at home, well-organized qualified PPC covering hospital and home care situations is needed. Worldwide pediatric palliative care teams (PPCT) are introduced to ensure continuity and quality of PPC and to support the child and the family. Yet little is known about the parents' experience with a PPCT. The objective of this study is to obtain insight in what parents value of a PPCT.

Methods: An interpretative qualitative study using thematic analysis. 47 single or repeated interviews were conducted with 42 parents (18 fathers, 24 mothers) of 24 children with a malignant or non-malignant disease. A multidisciplinary PPCT located at a large children's university hospital was involved to guide these children and their families through the complex care processes.

Results: In advance parents had limited expectations of the PPCT or had difficulty accepting PPC for their child. Once they experienced what the PPCT achieved for their child and family they valued the PPCT's involvement. Valuable tasks of the PPCT were: having experience and expertise in PPC, visiting the child and family at home, being on equal terms with parents, quickly arranging practical matters, being a reliable contact and a sounding board for parents, offering guidance in decision-making, signaling the needs of all family members and creating continuity and coordination of PPC. As point of improvement parents suggested to be more clear about the type of support the PPCT offers.

Conclusion: Parents valued many aspects of care by the PPCT but suggested to offer more information about the concrete support the PPCT can provide to increase the likelihood of acceptance of the PPCT in an early stage. The valuable aspects of the PPCT provide guidance for the design of new PPCTs.

P015

How Do French Psychiatrists and Psychologists Stand within Pediatric Palliative Care Team?

Zerka L.¹, Vignes M.², Timsit P.¹, Raynaud J.-P.², Boulanger C.¹, Cayzac D.¹, Carissan O.¹, Suc A.¹

¹*Equipe Enfant-Do, CHU Purpan, Toulouse, France, ²SUPEA, CHU Purpan, Toulouse, France*

Background and aims: In France, in 2011, 21 Regional Paediatric Palliative Care Teams (ERRSPP) were created in order to integrate palliative approaches in professionals' practice. In these multi-disciplinary teams, psychiatrists and psychologists offer a space allowing children to share their concerns. They also give support to family and professional teams. Beyond the task of coordinating healthcare provided to children and their families, how do they deal with the long-term follow-up? How is the transition with the therapists previously in charge of the child ensured? Are the arrangements for the links with physicians standardised? Do psychiatrists prescribe psychotropic drugs? Do they work with the child, his family, at home or in the hospital? How do they deal with hospital staff, private medical teams or adult colleagues? Are they involved in grief counselling and follow-up?

Methods: We have conducted semi-structured telephone interviews with psychologists and psychiatrists using an interview guide to allow professionals to share personal experiences.

Results: The results of this study dealing with the role of psychiatrists and psychologists within an ERRSPP will be presented, pointing out the specificities of paediatric practices. A focus will be made on common and singular experiences.

Conclusions: Paediatric palliative care is a recent and evolving discipline and it is necessary for the relevant teams to offer quality integrated care. Even though the practice of psychologists is supervised by SFAP's reference table, children are not miniature adults and specific function of psychiatrists and psychologists in paediatrics teams cannot be similar to adult practices. Taking into account the emotional issues of dealing with children's death, it seems essential to better define and assess their role in order to support their absolute necessity.

French Society for Support and Palliative Care: SFAP

P016

Nosological Structure of the Patient Population, Receiving Pediatric Palliative Care in Hospital Setting in Russia

Polevichenko E.¹, Nevzorova D.², Kochetkova L.³

¹Federal Scientific Clinical Center of Pediatric Hematology, Oncology and Immunology, Pediatric Department, Moscow, Russian Federation, ²Hospice №1 named after V.V. Millionschikova, Moscow, Russian Federation,

³National Research University Higher School of Economics, Moscow, Russian Federation

Background: The provision of pediatric palliative care (PPC) is included in the medical legislation of the Russian Federation (RF) in 2015. According to the national government program "Healthcare development", infrastructure of PPC is focused on the availability of hospital beds for providing PPC (up to 2,08 per 100 000 children by 2020). However, the nosological structure of the patient population, receiving PPC in the inpatient settings, varies depending on the local capacities of the regions of the RF.

Aim: To evaluate nosological structure of the contingent of patients, who received PPC in hospital conditions in different regions of RF in 2015.

Materials and methods: A retrospective analysis of annual reported data provided by the government authorities in the field of health protection of the subjects of the Russian Federation in 2015.

Results: In 2015, inpatient PPC in the RF was provided by 7 hospices (including 4 children's hospices) and 84 inpatient departments in 43 regions. The total bed capacity of PPC was 566, that ensured care for 4289 incurable patients (pts). In nosological structure of hospitalized children were predominantly pts with neurological disorders (2387; 55,6%). Inpatient PPC was provided to 553 pts (12,9%) with malignant tumors and to 55 pts (1,3%) with infectious diseases. Other pts (1294; 30,2%) suffered from different genetic diseases, malformations and complications of injuries. Only 29 (34,1%) of 85 subjects of the RF provided inpatient PPC to pts with cancer.

Conclusion: The nosological structure of the patient population, receiving PPC in the inpatient settings in 2015 in Russia, in whole corresponds to international statistics. Taking into account undeveloped network of outpatient PPC and the absence of pediatric non-invasive forms of narcotic analgesics, it is necessary to improve availability of the inpatient PPC for children with cancer in all regions of Russia.

P017

Understanding the Factors that Influence Parents as they Plan and Manage their Child's End of Life Care

Brombley K.

Helen & Douglas House / John Radcliffe Hospital, Outreach Team, Oxford, United Kingdom

Background and aims: There is an almost universal focus on home as place of death as the preferred outcome in paediatric palliative care. By contrast, data suggests that home is rarely achieved. There has been little research into why this discrepancy exists, and whether it matters. There is also a lack of understanding of parents' choices and priorities for end of life care changing over time, and of the different factors (positive and negative) influencing these choices.

Methods: A practice inquiry which critically analysed personal reflective accounts of the end of life care of children known to the practitioner to ascertain the factors influencing parents as they made choices and plans around their child's end of life care.

Results: A multitude of factors were found to influence parental choices. While an initial recognition of the importance of normality (as distinct from the place 'home') influenced the majority of cases, the interplay between all influencing factors highlighted will be demonstrated. An understanding of how all these factors can positively or negatively impact on the families' desire for normality, and a recognition of a hierarchy of significance- eg unmanaged pain will always 'trump' other factors leading parents to move to a location where the pain can be managed. This presentation explores this hierarchy and how enabling families to understanding these competing factors can support parental choices and coping.

Conclusion: In the context of discussions on compassionate care, this presentation will offer a different perspective to inform practitioners as they enable parents to plan for the end of their child's life.

P018

Pilot Study of a Paediatric Ambulance Care Directive

OBrien L.¹, Liane M.², Lonergan D.³, Seaman M.³, Byrne A.³, Finan A.⁴

¹*Our Lady of Lourdes Hospital, Paediatrics, Louth, Ireland,* ²*University Hospital Waterford, Paediatrics, Waterford, Ireland,* ³*National Ambulance Service, Dublin, Ireland,* ⁴*Cavan General Hospital, Paediatrics, Cavan, Ireland*

Background-context-aims: The absence of nationally agreed care directives and communication processes has led, on occasions, to inappropriate resuscitative measures being provided by paramedics to children with Life Limiting Conditions (LLC) at end-of-life. Differences between hospital and ambulance service governance structures prevent the transfer of advance care decisions from the hospital to pre hospital environment. The aim of this project was to design and evaluate the effectiveness of a new Hospital - Ambulance communication pathway and Ambulance Care Directive (ACD).

Methods: The pilot project received approval from the relevant governance groups to proceed in two geographical regions and data was collected from May 2015 to February 2016. A total of 31 ACD's were completed for children with LLC for whom it had been agreed that cardiopulmonary resuscitation would not be in their best interest. Notification of the child's ACD and address details were placed on the national ambulance computer dispatch system and copies of the ACD were held in the home and alternate places of care. An evaluation questionnaire was completed by both parents and ambulance crew to assess the effectiveness of the ACD and communication pathway.

Results: 16 ambulance calls were activated, 2 were for end-of life cases and 14 were acute hospital transfers. 14 out of 16 crews received advance notification of the ACD and all care provision adhered to the child's agreed treatment plan. High levels of satisfaction were reported by parents and ambulance personnel particularly in relation to clarity of care direction and improved communication.

Conclusion: The pilot demonstrated the system to be reliable and dependable. Positive outcomes for children at end of life were evident. Limitations of these findings relate to the two geographical regions selected and duration of the pilot study. Nonetheless, the results would support a proposal for the adoption of this system nationally.

No funding

P019

The Development of a Physician-led Pediatric Palliative Care Service in a Children's Hospital in Republic of Korea

Kim M.S.¹, Moon Y.J.², Song I.G.³, Suh D.I.³, Shin H.I.⁴, Park J.D.³

¹Seoul National University Children's Hospital, Department of Public Health Medical Service, Seoul, Korea, Republic of, ²Seoul National University Children's Hospital, Department of Planning and Coordination, Seoul, Korea, Republic of, ³Seoul National University Children's Hospital, Department of Pediatrics, Seoul, Korea, Republic of, ⁴Seoul National University Children's Hospital, Department of Rehabilitation, Seoul, Korea, Republic of

Background: Despite significant advances in disease diagnosis and treatment, resources for the pediatric palliative care (PPC) of children are limited in Korea. We report the process of creating the first physician-led palliative care consultation service at a large children's hospital in Korea.

Methods: We reviewed the process and strategies of PPC service development in the hospital from June 2013 to June 2016.

Results: During the early phase, we focused on raising awareness among health practitioners of the organization. After securing a budget from philanthropic capitals, we hired a social worker and held serial educational sessions to communicate with hospital staffs. Then, we started volunteer-based respite program for inpatients to counter myths on palliative care and lower barriers to access.

After literature review and pediatric inpatient death analysis, interdisciplinary team members including pediatrician, social worker, adult hospice nurse, art therapist were recruited. Service delivery began with three-month pilot phase, during which checklist for referring physicians, report template, and documentation format were developed. Since official consult was initiated, the team consulted in the care of 84 patients for 14 months. Care involved symptom management, decision making assistance, psychosocial support, dying care, and bereavement support. To advocate PPC in public, we worked with documentary staffs and revealed urgent needs of seriously ill children. After releasing documentary, the Government decided to conduct national needs assessment and pilot project of PPC implementation on several children's hospitals with personnel and operating expense support.

Conclusions: We introduced work flow of PPC development in Korean children's hospital where public and professional recognition is low. The strategies offered here can be extrapolated and adapted to other circumstances, especially with resource-limited setting.

P020

Pediatric Palliative Care: Evolution of a Pediatric Intensive Care-based Service in a Referral Cancer Center

Okhuysen-Cawley R.

Baylor College of Medicine, Pediatrics, Houston, United States

Background: Children with advanced cancer may have a high symptom burden at the time of discharge from pediatric intensive care units (PICU). A PICU-based palliative service, known as the Pediatric Supportive Care Team (PSCT) was created to promote continuity and optimal end-of-life care for these patients. PSCT was activated after 8 months of preparation with experts within and outside the international referral cancer center. A pediatric intensivist and a specialist nurse joined an existing multidisciplinary team consisting of a chaplain, a psychologist, social workers, and Child Life specialists who had been caring for these children for several years with medical oversight by the hospital's adult Supportive Care Team.

Methods: A retrospective review of records maintained by the PSCT was cross-referenced with the database maintained by the chaplain for bereavement care during a 42-month period. All patients seen by the PSCT were classified according to date of consultation, referring service, and outcome.

Results: 110 children were seen, rapidly surpassing design projection. Non-PICU referrals accounted for 77% of consultations, an unanticipated finding. All PICU patients received palliative care and were added to the PSCT roster at the time of transfer if active involvement of the PSCT was warranted for complex symptom management. 52 % of children had solid non-neural tumors, 25% leukemia or lymphoma, 19% brain or spinal tumors, and 4 % had received stem cell therapy. Patients were followed in all inpatient and outpatient locations for up to 3 years. 3 children were seen exclusively in clinic. 14 patients were transported nationally or internationally for end-of-life care. Demand eventually exceeded staffing capability, prompting transition back to a non-PICU based program with a full time pediatrician.

Conclusions: This model can be replicated at hospitals with similar resources. Institutional support is indispensable for program development and sustainability.

P021

Changing Referral Patterns to an Evolving Children's Palliative Care Service in Ireland

O'Donoghue E.¹, Hurley I.², Devins M.¹, O'Reilly M.¹, Twomey M.¹

¹Our Lady's Children's Hospital Crumlin, Palliative Care, Dublin, Ireland, ²Our Lady's Children's Hospital Crumlin, Dublin, Ireland

Background: Paediatric palliative care is an evolving speciality internationally. The first consultant paediatrician with a special interest in paediatric palliative medicine was appointed to a national tertiary paediatric centre in Ireland in May 2011. Prior to this, the children's palliative care service had been led by 2 visiting part time adult palliative medicine physicians. Having a full time palliative medicine paediatrician on site has resulted in an increase in the number of referrals to the service. This study undertakes to compare referral patterns before and after the appointment of the palliative medicine paediatrician.

Methods: The medical records of all children referred to the palliative care service from 01/01/2010 to 31/12/2010 and from 01/01/2015 to 31/12/2015 were reviewed retrospectively. Data collected included the number of referrals, diagnoses, referral sources and reasons for referral.

Results: There were 53 referrals to the children's palliative care service during 2010 and 115 referrals during the same period in 2015. In 2015, referrals were received from teams who had not referred in 2010, namely Antenatal (referred 4 patients). In 2010, 88% of referrals were for symptom control and 12% for end of life care whereas in 2015, 73% of referrals were for symptom control, 21% were for end of life care and 6% were antenatal reviews.

Conclusions: Referrals to the children's palliative care service have increased by 117% since the appointment of the palliative medicine paediatrician. The number of referrals for end of life care has increased. This information highlights the need to further develop the service with an emphasis on increased staffing.

P022

A Review of the Impact of Caring for a Child with a Life Limiting Condition on Both Mothers and Nurses

Keighery C., Moran S., Doyle J., Ni Mhurchu E., Naughton M., Clay C.

Coventry University, Health Sciences, Coventry, United Kingdom

Background-context-aims: The National Policy (2009) in Ireland highlighted a growing need to address the service provision for children with life limiting and palliative care needs. As work commenced to address responsive services to this group, attention to the impact on both mothers and nurses caring for children with life limited conditions appeared limited. This research reviewed available literature to enrich knowledge of their journey taken. This review also examined factors that may influence caregiving and coping such as attachment, burden of care, social isolation, respite and paternalism.

Methodology: A computer based focused systematic literature review method was used. The main databases used were CINAL, MEDLINE, the Cochrane library and PSYINFO. Together for Short Lives library was also accessed to broaden the search for relevant literature.

Results: Three main themes emerged:

1. Emotional resilience displayed by both mothers and nurses while caring for a child with LLC.
2. Attachment and burden of care,
3. Social isolation and respite.

Paternalism was also identified as a variable which impacts on all three themes. This review found that further research is required in this area, especially in regard to parental experience.

Conclusion: This research identifies compassion fatigue as a common, variable which can impact on both mothers and nurses caring for children with LLC. The importance of assisting both mothers and nurses to be resilient practitioners, preventing compassion fatigue and maintaining adequate coping strategies, whilst empowering them to continue caring through an unpredictable disease trajectory, is paramount. The significant need for further education of staff working in the area of children's palliative care is also highlighted. In addition, this review highlighted the increasing need for the provision of an adequate and equitable respite service for all families.

P023

What to Study Next: Utilizing the Delphi Method to Prioritise Research Topics in Paediatric Palliative Care in Ireland

Quinn C.¹, Devins M.², O'Reilly M.², Twomey M.², Ling J.³

¹National University of Ireland Galway, School of Nursing and Midwifery, Galway, Ireland, ²Our Lady's Children's Hospital Crumlin, Dublin, Ireland, ³European Association for Palliative Care, Dublin, Ireland

Aims: Irish paediatric palliative care (PPC) is an evolving speciality. There is a need to develop an evidence-based approach to providing care and in order to do this in a systematic way, identification of the research priorities in children's palliative care is required. The Delphi study has been undertaken in several countries and findings are not usually transferable between countries due to a variety of factors including: different healthcare delivery systems, varying policy initiatives, differences in geographical regions and access to services. Thus there is a need to identify country-specific research priorities.

Study design: The Delphi study is aimed at identifying research priorities in children's palliative care. Originally developed by the RAND Corporation in the 1960s, the Delphi method is a consensus building approach to data collection. Experts were invited to participate to ascertain their opinion. The Delphi technique is an iterative process of data collection that uses 'rounds' in order to achieve consensus. Though classic Delphi studies use four rounds, three is often viewed as sufficient to achieve consensus and avoid participant fatigue (Felicity Hasson, Keeney, & McKenna, 2000). The first 'round' establishes a list of topics or questions which are then put forward in subsequent rounds through the use of questionnaires to seek group consensus relating to the relative importance of each topic. In general, surveys are used during the first round to establish the key areas to be put forward for review in later rounds.

Results: Following a robust 4 round Delphi study, consensus was reached. Needs Assessment (including a database of children with life-limiting conditions, accurate data on the prevalence); Service Development; Policy; Education/ Training and Care Supports.

Conclusion: The wide range of topics emerging from the Delphi process confirms the need for greater evidence within this emerging speciality.

P024

Checking in! The Development of the PaedPAL TASK Tool for Appraising Nursing Skill and Knowledge in Children's Palliative Care Nursing

Quinn C.

National University of Ireland Galway, School of Nursing and Midwifery, Galway, Ireland

Research aims: Caring for children with palliative care requirements places exceptional demands on health professionals. It is essential to understand the development requirements of nurses within this evolving speciality. The literature indicates that there are few formal mechanisms to allow nurses to self-check and appraise their evolving knowledge/ competencies within PPC.

A project team within a new Irish children's hospice designed an appraisal tool (PaedPAL TASK) based on published competencies for children's palliative care nursing. This new Paediatric Palliative Tool for Appraising Skills and Knowledge (PaedPAL TASK) were translated into problem based or service related questions to aid nurses in identifying their practice knowledge strengths and deficits, with the ultimate goal of focussing nurses to plan their own individual professional learning goals. This presentation will provide an overview of the unique tool and share the main findings from the project evaluation.

Study design: The Tool was piloted with 6 nurses. Views on the project were gathered by focus group interviews and by individual questionnaires. Data were analysed thematically.

Results: Participant views were sought about the tool, role of facilitator, standards and the feedback process. All nurses from the pilot project agreed that the tool when utilised with the support of an experienced practitioner, was helpful in revealing personal strengths and key areas for ongoing professional development. Suggestions were also made for process modifications, timing and content of the assessment.

Conclusion: The creation of a dedicated appraisal tool allowed nurses to translate the conceptual requirements for competence in clinical practice into a reflective appraisal document. This unique PaedPAL TASK provides a mechanism to encourage nurses to formally challenge their existing knowledge with a view to documenting and recognising personal requirements for professional development.

P025

Hidden Part of the Iceberg: Making Paediatric Palliative Care in Belgium Visible

Friedel M.^{1,2}, Brichard B.³, Fonteyne C.⁴, Renard M.⁵, Vandecruys E.⁶, Misson J.-P.⁷, Degryse J.-M.¹, Aujoulat I.¹

¹Université Catholique de Louvain (UCL), Institut de Recherche Santé et Société (IRSS), Bruxelles, Belgium,

²Haute Ecole Vinci, Nursing Studies, Bruxelles, Belgium, ³Cliniques Universitaires Saint-Luc, Brussels, Belgium,

⁴Hôpital Universitaire des Enfants Reine Fabiola, Brussels, Belgium, ⁵Universitair Ziekenhuis Leuven, Leuven,

Belgium, ⁶Universitair Ziekenhuis Leuven Gent, Gent, Belgium, ⁷Centre Hospitalier Régional de la Citadelle, Liège, Belgium

Background/Aims: Belgium is mostly known for being the unique country of the world having, under strict conditions, legalized euthanasia for minors without restriction of age. The activities of PPC teams are less visible. Description of (i) the type of activities that have been delivered by the 5 PPC teams over a 5-year period (2010-2014) (ii) the characteristics of the children followed (number, age, disease, location of death).

Methods: Quantitative analysis through descriptive statistics and qualitative thematic analysis were done on database gained by Cancer Plan. Results were discussed with a review panel of representatives of each PPC team.

Results: Six main activities were identified: (i) palliative care embedded within the context of curative care including bereavement care, (ii) coordination of care among all care settings, (iii) education in PPC among the team and outside, (iv) research, (v) communication about the PPC teams' work, and (vi) fundraising. Over a five-year period, 3607 children benefitted from a follow-up (Mean 721 patients/year, min 660-max 770). 47% of them were 1- 10 y old, 25% were younger than 1 y, 25% had between 11 and 20 y, and 3 % were older than 20 y. 50% of them suffered from an oncologic pathology, 27% from a neurological disease and the remaining 23% included diseases affecting systems including cardiac, immunity, gastrointestinal, respiratory, and renal as well as neonatal diseases. Among the 3507 children, 459 died (mean 91, min 80-max 99 per team) with 51% who died at home (mean of 40 home deaths/year), 41 % in hospital, and 8% in respite care services or other institutions. After the child's death, in 2014, 672 contacts with 99 families were recorded by the teams, with an average of 7 contacts per family.

Conclusion: The results demonstrate the smooth integration of PPC ensuring continuity of care, including bereavement care. Additional research on how these specialized care impact on children's quality of life is requested.

P026

Access to Palliative Care for Children in Ukraine - Challenges and Views

Penkov A.¹, Riga O.², Gonchar M.², Marabyan R.³, Shapoval-Deinega K.⁴, Konovalova N.³

¹NGO Ukrainian-German Medical Association, Kharkiv, Ukraine, ²Kharkiv National Medical University, Pediatrics N1 and Neonatology, Kharkiv, Ukraine, ³Kharkiv Regional Specialized Baby Home #1, Kharkiv, Ukraine, ⁴NGO Renaissance, Kiev, Ukraine

Background: Ukraine, a country with a population of 45 million, does not have a national Pediatric Palliative Care (PPC) policy.

Aims:

- (1) To review Ukrainian resources regarding PPC.
- (2) To analyze initial experiences of a mobile palliative care team for families and young children in Kharkiv region (1.4 million people) in 2015.

Methods:

- (1) Review of existing print and online resources.
- (2) After the creation of the first mobile PPC team, we reviewed the visits of 31 families at home to define their clinical and psycho-social-spiritual needs.

Results: In 2016 no PPC regulations, guidelines, or manuals in Ukrainian language exist and no education curriculum for medical students, nurses, physicians, or other clinicians were implemented. No palliative care specialist were listed in the catalog of medical professions.

All 31 children displayed pathologies of CNS: congenital malformation (29%); cerebral palsy (35.4%); genetic disorders (12.9%). Parental and childrens' needs fell into three categories: (A) Medical issues: orthopedic (93.5%), vaccination (93.5%), feeding (80.6%), posture (61.3%), hypersalivation (32.2%), anticonvulsant therapy (16%); (B) Psychological issues: problems with siblings (100%); communication / socialization of children (90.3%); sensory activity (83.8%), parental relationships (74.2%); provision of developmentally appropriate space to play (67.7%); (C) Social issues: need for volunteers' support / social worker (58.1%), poverty (58.1%), connection with local rehabilitation centers (54.8%), need for medical equipment (41.9%).

Conclusions: In spite of high medical, social and psychological needs for children with life-limiting conditions there is currently no PPC infrastructure nor access to PPC for children with life-limiting conditions in Ukraine beyond a model project. Mobile team home visit approach could be the better way to begin building of PPC service in condition of low income and resources of the country.

P027

Hospital: The Place where Patients with Muscular Dystrophy Meet Palliative Care Services

Iancu M.S.¹, Plesca D.A.², Hurduc V.², Dobre O.³

¹'Dr. Victor Gomoiu' Children's Clinical Hospital; St. Margaret's Hospice - Children in Distress Romania, Bucharest, Romania, ²'Dr. Victor Gomoiu' Children's Clinical Hospital, Bucharest, Romania, ³'Carol Davila' Medical University, Bucharest, Romania

Background: Muscular dystrophy (MD) is a life-threatening disease with slow functional decline and well-known need for nursing and palliative care. Hospital is the place where the diagnosis is confirmed, where treatment starts and where child returns for periodic evaluation. It should be the place where family learns about palliative care and where they can find this.

Methods: The medical records of children with MD admitted in our hospital in 2014 were retrospectively reviewed in order to evaluate the palliative care services that child and family received since diagnosis. Where data was not available we asked parents by phone. The study also evaluated characteristics of the group of children with MD.

Results: During this period 24 children with MD were admitted, aged between 5 and 16 years. Most of them came from urban zones across the country (61%). 88% of children were still ambulatory, 80% had deformation of spine and 70% underwent physiotherapy. 71% was the percentage of patients with steroid treatment. One third had ventilation dysfunction but only 1 child benefit from non invasive ventilation. 30% had cardiac involvement but only 3 children were taken Angiotensin converting enzyme inhibitors. Finally, only 1 family benefited from palliative care services.

Conclusions: Most families have never heard about palliative care. This means we have to improve awareness of this kind of services and inform families about them. We decided to use the map of pediatric palliative care centers that are active at this moment along the country. We superpose this map to their locations, find the closer institution and offer contact data. It would be family's decision to use them or not.

P028

Family Survey of 3 PPC Services in New South Wales, Australia

Coombs S.¹, Ryan S.², Shepherd E.³, Mherekumombe M.³, Scully M.², Heaton M.¹, Arnott L.⁴

¹Sydney Children's Hospital Network - Randwick, Paediatric Palliative Care Service, Sydney, Australia, ²John Hunter Children's Hospital, Paediatric Palliative Care Service, Newcastle, Australia, ³Sydney Children's Hospital Network - Westmead, Pain Medicine and Palliative Care, Sydney, Australia, ⁴Bear Cottage, Sydney, Australia

Background and aims: There are 3 tertiary paediatric palliative care services in New South Wales, Australia and these services collaborate as the NSW Paediatric Palliative Care Programme. This Project aimed to determine how well palliative care is provided to children, young people and their families across New South Wales.

Methods: Eligible families/carers were invited to complete either a paper survey or electronic survey. Invitations were sent out to the parents/carers of 146 patients. The survey content included: 1. Demographic information pertaining to the child and family; 2. PPCS evaluation with the option to provide further comments; 3. Other services and resources which the PPCS provides; and 4. details of any areas of unmet need.

Results: 62 responses were received (68% from mothers, 22% from fathers, 3% from foster carers and 7 % other). 95% were either very satisfied or satisfied with care provided by their PPCS. Greater than 90% felt the level of contact was about right, the timing of referral was about right and would recommend the PPCS to other families. There was some variance about offering of other resources and referral to other services. In relation to unmet need, an analysis of themes is being undertaken and will be presented for this conference. A recurrent theme is in relation to primary health care provider (GP) support including after hours support.

Conclusions: This was a unique attempt at assessing family and carer views across three paediatric palliative care services. Whilst each service has a slightly different model of care the survey show that families and carers report a high level of satisfaction with the NSW PPC services.

P029

"Living Despite the Pain" - The Perspective from Children and Adolescents in Palliative Care

Borghi C.A., Rossato L.M., Szylit R., Baliza M.F.

University of Sao Paulo, School of Nurse, São Paulo, Brazil

Background: Pediatric Palliative Care is not limited to the end of life care, sometimes it is necessary since childhood until adulthood. The focus of pediatric palliative care it is to provide the highest quality of life for children, adolescents and their families, while the suffering and pain are minimizing. Pain it is a stressful event for children and adolescents and can have negative consequences even more when it is accompanied by a disease with no possibility of cure. The pain it is quite experienced by children and adolescent in situation of Life limiting and life threatening conditions.

Aims: The aim of this study it is knowing the daily experience of children and adolescents in palliative care.

Methods: Considering the uniqueness of the experience of children and adolescents in palliative care, we chose to develop a qualitative study using the Oral History as a methodological framework.

Results: We interviewed six children and adolescents in palliative care (all of them have chronic diseases). We found three themes: Having pain; using a variety of alternatives for managing symptoms; and being normal despite pain and disease.

Conclusions: We realized that children and adolescents with life limiting and life threatening conditions have a lot to say and teach us, especially with regard to how they deal with pain and their disease in daily lives. Although pain is a limiting factor in the lives of children and adolescents, we found that they faced their daily pain and still had a life beyond pain and illness.

P030

Submission of Abstract for Consideration to Be Presented at the 3rd Congress on Paediatric Palliative Care in Rome, 16th-19th November 2016 Audit of Emergency Care Plan (ECP) Completion in a Cohort of Children Known to a UK Paediatric Hospice Palliative Care Team

Summers S.

Shooting Star Chase Children's Hospice, Guildford, United Kingdom

Background: The use of ECPs allows clinicians to document the wishes of the child and family in regards to elements of care at end of life, including advanced life support interventions. This documentation is considered good practice within palliative care settings.

Aims: To audit whether ECPs were followed in a cohort of children with life limiting conditions known to a hospice-based UK Paediatric Palliative Care Team. To examine whether lack of ECP led to inappropriate attempts to resuscitate.

Methods: All ECPs completed during a 3 year period between 2013 - 2016 were examined. Reasons for not completing an ECP were explored. Individual aspects of care were analysed to see what families wanted for their child. finally, whether the plan was followed at end of life was analysed.

Results: Over the audit period 56 children died. 36 had ECPs. 20 children died with no ECP in place. Of the children with an ECP in place one child received cardiac massage which was contrary to the ECP. Of the children with no ECP in place, one child received cardiopulmonary resuscitation and 2 children died whilst on full ventilator support.

Conclusions: Most children known to the palliative care team did not receive resuscitation. ECPs were followed in the majority of cases. Most children without an ECP did not receive resuscitation; discussions in regards to resuscitation had taken place and were documented in other ways in the majority of these cases. This infers that formal ECP documentation may not be necessary in all cases, thus reducing distress in families. In 2 cases legal advice was sought by the hospital in order to support withdrawal of treatment. One child with no ECP was resuscitated after presenting at Emergency Department with an unusual illness. A limitation of this study is its small size. Due to the nature of the method used information about some children was incomplete therefore they were not included.

P031

Is Palliative Care Being Used for Children and Adolescents Living with Rheumatic Diseases? A Review

Ferreira E.A.L., Gramasco H.H.F., Gonçalves F.P.

Federal University of São Carlos - UFSCar, Medical Department, São Carlos, Brazil

Background: About 25% of rheumatic diseases occur in children under the age of 16. Those conditions can be severe and potentially life threatening besides can leave serious consequences in patients. Among the last years, the profile of pediatrics patients has changed, becoming increasable frequent children living with chronic and life threatening diseases. The Pediatric Palliative Care emerges as the form of full assistance to these children, in the biological, psychological and social dimensions, as well as support their families.

Aims: To evaluate the use of palliative care for children and adolescents living with rheumatic diseases.

Methods: Research was conducted in national and international electronic databases: Virtual Health Library, BVS - which includes Lilacs and Scielo, PubMed, Web of Science and Science Direct (Elsevier database). The consultation was conducted by descriptors: (*Rheumatology OR Rheumatic Diseases OR Rheumatism*) AND (*Palliative Care OR Palliative Medicine OR Palliative Care Medicine*) AND (*Pediatrics*). Articles published in the last 10 years were considered.

Results: No article was found in this search. Some rheumatic diseases cause situations that require integral approaches on its handling, like the approach of palliative care. Dermatomyositis can cause significant calcifications and debilitating pain for the patient, situations with no curative treatment, similar to ischemic pain in patients with Takayasu's Arteritis. Juvenile Idiopathic Arthritis can cause motor sequelae, which benefit from nonmedicamentous therapies. Patients with Systemic Lupus Erythematosus and secondary Antiphospholipid Antibody Syndrome who had stroke can also benefit from palliative care in the management of its comorbidities.

Conclusions: Despite the severity and high morbidity profile associated to childhood rheumatic diseases, the palliative care approach is poorly used for assistance the needs of these patients.

P032

Non-pharmacological Therapy for the Treatment of Newborn in Pain: An Alternative to Neonatal Palliative Care?

Ferreira E.A.L.^{1,2,3}, Campos G.A.P.³, Nassif D.S.¹, Silva M.J.D.¹, Gramasco H.H.F.¹, Baptista F.H.¹, Salustiano P.H.M.¹, Barros G.A.M.²

¹Federal University of São Carlos - UFSCar, Medical Department, São Carlos, Brazil, ²São Paulo State University (UNESP - Univ Estadual Paulista), Botucatu Medical School, Botucatu, Brazil, ³Irmãdade da Santa Casa de Misericórdia de São Carlos - ISCMSC, São Carlos, Brazil

Background: Pain control is an essential part of palliative care, especially in newborns, since they undergo a large number of painful events, such as manipulation and multiple punctures. As pediatric palliative care handles not only terminal patients, but also chronic diseases, pain management is of extreme importance within the neonatal age, either term or pre-term children, because newborns' painful experiences might have relation to his or hers future reaction to new stimuli.

Aim: This study intends to reinforce the relevance of non-pharmacological measures in handling pain in newborn, as a resource group that should help pain control.

Methods: Recent Medical literature review about acute pain treatment with non-pharmacological techniques in newborns, evaluating its methods and results, they were analyzed and faced to authors' experience.

Results: Pain in newborn may be treated with pharmacological therapy, although we must be aware of its mechanisms of action and collateral effects, for an appropriate choice.

Non-pharmacological measures are considered effective e harmless to the child. Ambiental care - such as diminish light and noise levels -, use of non-invasive monitoring and other techniques previously cited, are manners also important to the child's well-being. It was evidenced that non-pharmacological methods can lessen the objective result in pain scale. Kangaroo Care is one of those methods, proving that physic contact between newborn and his mother is essential. Non-nutritive sucking is controversial, as it may have deleterious consequence regarding breast-feeding. Sucrose, glucose and sweetened solutions orally also can be used and, when suitable, show good efficacy and security.

Conclusions: Non-pharmacological therapy is an important tool in pain control in newborn, for its low or none cost, its easy applicability and absence of collateral effects, mostly. Therefore, it can be used as main or complementary treatment in neonatal palliative care.

P033

Evaluation of Treated Patients in the Pediatric Palliative Care Team in Hamburg, Germany

Hartwig M., Mainzer K., Pothmann R.

KinderPaCT Hamburg e.V., Hamburg, Germany

Background: Since the amendment of the Social Law V in Germany in 2007 patients with life-limiting illnesses have the opportunity to be taken care of by special palliative care teams at home. Approximately 30 pediatric palliative care teams have been founded so far in Germany. In Hamburg one pediatric team exists compared to 8 teams for adults. The Hamburg pediatric team started its work in 2011. It now consists of 5 nurses specialist in palliative care, who are involved in daily business, 4 additional nurses for emergency service, 1 coordinator and 7 physicians, 3 involved in daily business and 4 for the emergency service. There are also a psychologist and a music therapist on honorar basis.

Method: Data of treated children and their families over the last 3 years including data from 2013 until 2015 were collected.

Results: 63 patients were treated in 2013, 73 in 2014 and 69 in 2015. Number of deaths were 25 in 2013, 19 in 2014 and 18 in 2015. In 2013 19 patients died at home, in 2014 there were 14 and 10 in 2015. In 2013 35% of our patients had a malignant disease, in 2014 38%, in 2015 20%. The average time of involvement in the families was 5.7 months for children treated up to one year. 14 families were enrolled in the program for over one year. Because of stabilisation of the disease, treatment could be paused in 12 families in 2013, in 28 families in 2014 and in 32 families in 2015.

Conclusion: The number of enrolled patients has been stable over the last 3 years. Whereas some patients are enrolled over a very long time, some are treated only for very few days. Therefore the requirements for the team are very individual for each family. During the last years we could stabilize more and more patients, so a treatment pause in and reenrollment during crises was more and more possible, which also means lower costs for health insurance companies.

P034

Early Introduction of Palliative Care for Children with CNS Tumor

Moraes C.

IOP -GRAACC/ UNIFESP, Pediatric Oncology, Sao Paulo, Brazil

Background: Children with infratentorial brain tumor, located in brain stem has the highest rate of relapsed and mortality among another tumors of the central nervous System.

Children with tumors of the Central nervous system have toxicity related the therapy as radiotherapy and central nervous system tumors mainly located in the brain stem have many side effects that have major impact on quality of life of children and their families and this children have high rate of mortality.

An early introduction of pediatric palliative care for patients with central nervous system tumor what could have a worst prognostic was implemented for this children and their families.

Objective: To assess the impact of early introduction of pediatric palliative care for children and their families , children with diagnose of central nervous system located in brain stem .

Methods: During December ,2012 until june of 2016 , was performed new diagnoses 45 children with brain stem tumor.

Pediatric palliative care were introduced for 42 these children and their families.

The average time of children who were diagnosed and sent to the team of pediatric palliative care was 3 weeks.

The perception of the interventions was assessed among physicians, nurses and psychology.

Results:

45 children with brain stem tumors we diagnosed during the study period

Early pediatric palliative care was offered to 42 children and their families.

42 children out accompanied by the psychology team and the team of motor and respiratory physiotherapy.

35 school-age children were accompanied by teachers

42 children were accompanied by medical and nursing staff of the palliative care team and its symptoms and clinical signs were evaluated and relieved.

Conclusions: Early pediatric palliative care with children with diagnostic brain stem tumors and aggressive tumors facilitates the care of patients and their families, facilitates communication and planning the trajectory of the disease.

P035

End of Life Decision Making in Families Receiving Paediatric Palliative Care at Home: How Much and What Happens?

Ren H., Chong P.H.

HCA Hospice Care, StarPALS, Singapore, Singapore

Objectives: Allowing adolescents to be involved in their own healthcare decision-making, especially at End-of-Life (EOL), acknowledges their burgeoning autonomy and innate rights. Organizations like American Academy of Paediatrics and World Health Organization promote this as good practice. The objectives of this study are firstly, to evaluate how much older children, adolescents & younger adults were involved in EOL decisions while receiving palliative care under our team; and secondly, how individual decisions differ between parents and children.

Methods: Information is extracted from our electronic database that recorded relevant conversations while patients were still alive and during bereavement visits to families after their deaths. For the purpose of this preliminary evaluation that precedes a larger study, we focused on four critical decisions on care near the end of life:

- 1) Participation in Advanced Care Planning (ACP) discussions;
- 2) Enteral feeding options;
- 3) Invasive ventilation and cardiopulmonary resuscitation at sudden collapse;
- 4) Place of death.

A total of 56 patients between ages of 10 to 28 years old (suffering from cancer and a heterogeneous group of non-cancer conditions) who had died in the years 2012-2016 constitute the sample.

Results: Data collection and analyzing are still in progress. In spite of early findings, the full report will be presented in the final poster if shortlisted.

Conclusion: Particularly near the EOL, listening to the voices of our adolescent and young adult patients is pivotal for both parents and healthcare workers to render truly patient centered care. We hope the findings from this study will add to the little evidence available on such an important subject. This project will lead to a bigger study in future by our growing team.

P036

«Palliative Care Line»: Work of Help-line for Children and Young People in Need of Palliative Care in Ukraine

Burlak K.¹, Halushka M.¹, Chekmariova A.², Shapoval-Deinega K.³, Lavrenuk L.¹

¹Charitable Organization Childhood Cancer Foundation "CRAB", Kyiv, Ukraine, ²Ukrainian Specialized Children's Hospital, Kyiv, Ukraine, ³International Renaissance Foundation, UA, Kyiv, Ukraine

Aim: Analyze 55 requests, received by all-Ukrainian Palliative Line (PL) during 6 months and define barriers for receiving high-quality palliative care and pain relief for patients aged 0-19 y.o. Average time of support of patient and his/her family from the time of request till death - 2 months. Out of 55 requests: oncological 92.72%; other 7.27 %. Age disaggregation in %: 0-3:0, 3-6:9, 6-16:72.72, 16-19:8.18. Percentage of ratio of request based on type of experts: anesthesiologist 63.63%, psychologists 7.27%, lawyer 29.09%. N.B. All families asked for consultations from several experts.

Requests to the Line:

100% of patients were notified about diagnosis by health care professional, but the prospects of treatment were not described clearly;

1% of the customers were informed by health care professionals about the possibility to receive palliative care;

95% of customers were informed about the necessity of the relief of pain for a child using opioids, but treatment schedule was not designed;

0% of patients received assessment of pain based on the WHO scale;

100% of patients had been suffering from chronic pain before they addressed PL

50% patients were placed in intensive care units.

After consultation by PL:

- 100% of families received consultations and correct treatment schedule has been assigned to patients, including opioids according WHO scheme;

- 95% of cases, treatment schedule was reconsidered

- 41% of patients were discharged from intensive care units;

- 23% of patients were transferred from the intensive care units to other departments (pediatrics, oncology);

- one patient, a teenager, was placed to an adult hospice.

Conclusions:

- Palliative patients group studied do not have access to high-quality pain relief, including those who live in regional centers and big cities;

- Incorrect clinical trends are observed - weak opioids are often prescribed in the terminal stage of disease as the only analgesic, which does not allow to provide adequate pain relief.

P037

The Paediatric Palliative Care Team: The Case Manager of Integrated Paediatric Care

Visconti G., Carmagnola M.L., Rolla G., Ghironi C., Grossi A., Zecchillo S., Lonati G.C., Rizzi B.

Associazione Vidas, Milan, Italy

Good paediatric palliative care (PPC) occurs through the coordination of many professionals and volunteers (V). Italian law 38/2010 granted the right to PPC but the PPC network is establishing itself slowly. In 2010-2014 our palliative care service (PCS) supported 21 children and in January 2015 we established a dedicated PPC team (PPCT).

The analysis of the cases undertaken emphasises 2 aspects: the method which can be used to meet clinical, relational and psychological needs and to support children and their families and the role that the PPCT may take towards improving the patients' quality of life.

Study period: Jan2015-Apr2016. 19 children: 12M,7F (17 home, 2 hospice). Average age 10.9 years (range 1-17); 63.2% with cancer; 68.4% dead. Average duration of care 111.2 days. Teams: PPCT and general practitioner (GP), pediatrician, hospital team, informal support network (families, friends, teachers). Regular meetings. The following professionals have been involved: 19GP; 7 hospital paediatricians with paediatric nurses, social workers (SW) and psychologists (PSY) working for the 6 referring hospitals; PPCT (9 doctors, 13nurses, 5SW, 2 physiotherapists; 4PSY, 1speech therapist, 10 V).

The PPCT began the assistance gradually from an early stage of the disease by visiting patients jointly with the specialist in charge or family paediatricians. Cooperation between the PPCT and the medical centres continued through the duration of the period of assistance: conference calls; phone calls; visits made by the palliative doctor and paediatrician together; weekly meetings. The PPCT acted as the link between medical workers and teachers (by face to face meeting) and other people important to the minor, also during the bereavement phase. This working model has allowed 89.5% of the minors to be assisted by the PPC team at home until the end. The PPCT has always taken the role of case manager in managing the complex dynamics between care, relational and communication needs of the paediatric patient affected by terminal illness.

P038

A New Danish Regional Outgoing Palliative Care Team for Children Based on Existing Cooperation between Paediatrics and Specialised Palliative Care

Neergaard M.A.^{1,2}, Bonderup A.¹, Bording I.C.^{2,3}, Jensen D.M.E.^{1,2}, Jespersen T.W.^{1,2}, Thøgersen K.^{1,2}, Edslev P.W.³, Jespersen B.A.^{1,2}

¹Aarhus University Hospital, The Palliative Care Team, Aarhus, Denmark, ²Aarhus University Hospital, Paediatric Palliative Care Team, Aarhus, Denmark, ³Aarhus University Hospital, Department of Paediatrics, Aarhus, Denmark

Background: Recently, Danish health authorities imposed on all five Danish regions to establish outgoing, specialist paediatric palliative care teams (SPPCT).

In Central Denmark Region (Approx 1.3 million inhabitants) cooperation already existed between Department of Paediatrics (DP) and the palliative specialist team (PST) at Aarhus University Hospital. However, only children with cancer had so far been part of this cooperation.

The aim was to describe the establishment of a SPPCT, and to examine the ability to include terminally ill children regardless of diagnosis to enable them to stay at home during the end-of-life period.

Methods:

Staffing: A multi-disciplinary approach: Two nurses (DP), two doctors (DP and PST), a psychologist (PST), a physiotherapist (PST) and social worker (PST). All were employed in the SPPCT part-time.

Referral criteria: Based on WHO's definition of paediatric palliative care, and specified at a meeting with paediatric consultants: Children up to 18 years of age with a life-threatening condition who have the need for specialised palliative care.

Care provision: A doctor and a nurse from SPPCT attend DP's multidisciplinary conference to plan future care of referred child. Subsequently, they visit child and parents at DP or at home, preferably together with the GP and primary care nurse. Other multidisciplinary team-members are involved when needed.

Evaluation data: Number of children, age, diagnosis, symptomatology, hospitalisation and place of death will be retrieved.

Results: SPPCT was successfully established 1 April 2016 and has so far been involved in five trajectories; one child had a non-malignant diagnosis and two children have died (both at home). Data from the first six months will be presented at the conference.

Conclusion: The study will provide knowledge of whether a SPPCT approach is useful to treat children in need of palliative care regardless of diagnosis to enable these children to stay and die at home.

P039

Advance Care Planning in the Paediatric Population - Development of the 'Thinking Ahead' Framework

Hynson J., Sacks B., Williams M.

The Royal Children's Hospital Melbourne, Palliative Care, Parkville, Australia

Background and aims: Helping a family understand their child's prognosis and planning care in advance is often beneficial but these discussions can be difficult so tend to occur late in the illness course or not at all. This has the potential to leave families unprepared, deny them choices and expose children to avoidable suffering. Effective advance care planning (ACP) is a crucial element of paediatric palliative care. The aim of this study was to review existing models of ACP in the paediatric population, audit the use of an existing ACP tool in a tertiary paediatric hospital, and develop a new framework to assist paediatricians and families to engage in ACP discussions.

Methods: A mixed-methods study comprising:

1. Review of the current literature.
2. Review of existing practice in a tertiary paediatric hospital through:
 - a) Semi-structured interviews with clinicians; and,
 - b) A retrospective file audit.
3. Development of a new ACP framework

Results: A review of the literature confirmed that ACP is generally beneficial for patients and families but presents several barriers for clinicians. An audit of current practice at our institution revealed poor clinician satisfaction with the existing ACP tool and low rates of completion (23% of all patients who died over a 12 month period). The existing tool could not capture discussions/decisions-in-evolution and the tick-box nature of the form was driving tick-box conversations. Paediatricians were often unsure about when to begin ACP and how to approach the discussion.

Conclusion: This study demonstrated a low rate of ACP in our hospital. While several barriers to ACP have been described in the literature, this study indicated that the tool may itself contribute to low rates of documentation as a result of its poor utility. A new framework was developed to capture both decisions made and discussions in progress, and to provide guidance to paediatricians as to when ACP is needed and how to approach the discussion.

P040

Development of a Telemedicine Platform for Pediatric Home Care Assistance

De Zen L., Bagolin A., Minetto M., Canzian C., Lucchini A., Rizzetto M., Dall'Amico R., Sclipa G.

AAS5 - Western Friuli - Pordenone, Pordenone, Italy

Introduction: In recent years it is strongly encouraged and recommended the taking charge in the network of the child suffering from serious illness and his family, integrating many figures, favouring, when possible, home assistance.

This new type of care requires a profound organizational change, including the facilitation of new communication models between operators and between operators and families, guaranteeing a quality of care comparable to the hospital setting.

Aim: The goal of the project is to provide a telematic tool for operators and families that allows easy, fast, safe communications with exchange of documents and images. Furthermore, the possibility of remotely acquiring vital parameters is given, as well as the management and the recording of the home therapy.

Methods: Thanks to a fundraiser, it was possible to acquire the resources to develop the ICT platform, softwares and hardwares (personal computer, tablet, smartphone). A Participatory Design project was developed in the belief that the deep understanding of how people work, live and organize themselves as a group, is a critical step to produce usable and useful technologies. The first phase of the work was devoted to the analysis of cognitive market offers for the software, followed by a formal engagement.

Results: The system is currently tested in a pilot group of patients for a trial period of six months, allowing the team to head the adherence of the software to the needs of both operators and families, in close cooperation with the computer technicians. Three lines of work are developed as

1. to improve communication,
2. to record the assumed therapy and
3. to monitor clinical parameters.

Conclusions: This project will serve as a tool to guarantee a quick and secure communication between operators and operators / families, to follow and monitor the home patients in conditions of safety and quality for both the patients themselves, for their families and for operators.

P041

The Memorial Day

Runesson S.

Lilla Erstagården - barn och ungdomshospice, Nacka, Sweden

Aim: The aim is to create a place for closure and to remember and honor the children and youths who died during the past year.

When we meet at The Memorial day families who have treated their children during the same period get a chance to meet again, and also meet the staff. We want to give every child we lost an individual attention.

Methods: It starts with a short program consisting of speech, music and picture slideshows. Thereafter there is a balloon greeting, each family is given a balloon to decorate by painting and writing message to their child. The balloons then rise together against the sky. The remaining time is spent around the table with coffee, lemonade and all kind of buns and cakes. Here we have the time for meetings and the possibility that in a relaxed environment meet other families and staff from the hospice. One task for the staff is to be the contact person for a single family to insure that all families are well taken care of and that they know who to turn to if they are in need of extra support. When the families arrive it is their personal contact task to greet them. This task may include sitting by the family during parts of the day and bringing the balloon and making sure that the family has the support that they need.

Result: We have high attendance from the families on Memorial day. Annual assessments show that both families and staff find support in this day. A mother's statement: *"I have often felt how I stand alone on stage in this awful to have lost a child. Here on Memorial day, I was also on the scene but not alone ... we were more families on the stage who shared the same experience."*

Conclusion: The Memorial day is a day where families and staff have the opportunity to meet for closure and honor of the children who died during the past year. We wish in this way enable the meeting, create a secure connection with worthy content. Evaluations show that this day fills a major function of both families and staff.

P042

Development Integrated Pediatric Palliative Care (PPC): A Model for a Local Network that Supports Families with a Child in the Palliative Phase at Home

Vallianatos S.¹, Spierenburg M.²

¹*Stichting PAL, Pediatric Palliative Expertise, Utrecht, Netherlands,* ²*Vilans, Center of Expertise for Long-term Care, Utrecht, Netherlands*

Background and aims: Research shows that PPC requires special attention and a coordinated approach to support the child and its entire family. July'14 a project was started in the region around Leiden University Medical Center to develop a multidisciplinary network from medical, psychical, pedagogical, social and spiritual perspective. The aim was to develop a model close to home that supports and relief families with a child with a life-threatening or life-limiting illness from diagnosis to aftercare. A comprehensive approach aimed at integrated care to the highest possible quality of life and the ability for the child to develop.

Methods: Desk research, research into experiences parents, partners to bring together, development learning modules, interventions to set up network, implementation, monitoring and evaluation. We developed a multidisciplinary network of professionals from all organisations in the region around the academic centre who support families with children in the palliative phase. The network stimulates, advises and coordinates the care in collaboration with parents and involved professionals to provide a unique situation for each family.

A development model for integrated care (Minkman 2012) was used as scientific basis and evaluation.

Results: The project has led to a model for integrated PPC in which all components of the monitoring are processed. The model described 10 steps to realize a network PPC. Each step consists of the following ingredients: content, learned lessons, results, reflection and products/tools. We found several dilemmas and solutions in the field.

The problemstatement is visualized with cartoons, as a tool for the awareness and dissemination.

>Focus on everyday life; balance and rest back in the family.

Conclusions: Interventions of the network seem to have an important added value for children and families in the palliative phase. Next step is to scale up to a nationwide network structure based on the model for integrated PPC.

P043

A Prospective Study on the Characteristics and Subjects of Pediatric Palliative Care Case Management Provided by a Hospital Based Palliative Care Team

Jagt C.T.¹, Kars M.C.², Colenbrander D.A.³, Bosman D.³, Caron H.N.⁴, Grootenhuis M.A.⁵, Schouten-van Meeteren A.Y.N.⁶

¹Emma Children's Hospital, Academic Medical Center, Department of Pediatric Oncology, Amsterdam, Netherlands, ²Julius Center for Health Sciences and Primary Care, UMCU, Department of Medical Humanities, Utrecht, Netherlands, ³Emma Children's Hospital, Academic Medical Center, General Pediatrics, Amsterdam, Netherlands, ⁴Emma Children's Hospital, Academic Medical Center, Department of Pediatric Oncology, Amsterdam, Netherlands, ⁵Emma Children's Hospital, Academic Medical Center, Psychosocial Department, Amsterdam, Netherlands, ⁶Emma Children's Hospital, Academic Medical Center, Pediatric Palliative Care Team & Pediatric Oncology, Amstelveen, Netherlands

Background: Case management is an important aspect of pediatric palliative care. Detailed descriptions of the content of this type of case management are lacking.

We aim to obtain insight in the content of pediatric palliative case management with specific focus on the multidisciplinary setting, 24-hour availability, pro-active approach. We hypothesize differences in topics of interest for contacts with parents of patients with malignant disease (MD) compared to those with non-malignant disease (NMD).

Methods: a three-month prospective study, with questionnaires filled in by members of a pediatric palliative care team (PPCT) for each contact with parents. Participants: members of a hospital-based multidisciplinary PPCT.

Results: 455 contacts took place with parents of 70 patients (27MD, 43NMD). 62% of all contacts were with the specialized nurse. The child life specialists, psychologist and social worker were also regularly consulted, the chaplain was not consulted. 95% of all contacts took place between 8am and 6pm during weekdays, a limited number between 6pm and 9pm. 25% of all contacts were proactively initiated by the PPCT, 25% were initiated by parents. In these care characteristics, no differences were seen for MD and NMD patients. Psychosocial topics were addressed most frequently, while MD patients consulted the PPCT more often about school and NMD patients about socio-economic issues.

Conclusions: All different disciplines of the PPCT were regularly consulted, except for the chaplain. With easy accessibility combined with a highly pro-active approach availability from 8am to 9pm seems sufficient to accommodate patient's and parent's needs. More anticipation seems required for socio-economic topics. This insight in pediatric palliative case management can provide guidance in the development of a new PPCT.

P044

X-linked Adrenoleukodystrophy - A Challenge for a Palliative Approach from Diagnosis

Boeriu E., Bour A., Zaica C., Sarau I., Boeriu A., Arghirescu S., Bataneant M.

Spitalul de Urgenta Pentru Copii 'Lous Turcanu', Timisoara, Romania

Introduction: X-linked adrenoleukodystrophy (ADL-X) is a rare entity, but it is the most common peroxisome disease caused by a genetic change, that need a palliative care.

Objectives: We intend to follow a patient with X-ADL from diagnosis until advanced stage from 2012 to 2016 and to analyze the challenges and the need for palliative approaches, starting with the diagnosis.

Methods: To confirm the diagnosis, we have examined the case clinically and para-clinically (i.e. imaging, biological, and genetic). The family was assisted to try the holistic approach because the mother is a heterozygous carrier and the grandmother presented a form of disease with the onset around the age of 45 years old.

Clinical case: The patient C.C. is 7 years old, without significant medical history until this age. The onset was in September 2012 when his mother noticed the first progressive neurological changes gait disturbance. In February 2013, he began speaking unclearly, in March strabismus appeared and in June, his mother noticed skin hyperpigmentation around the mouth, followed by a hearing deficiency in the right ear and almost total loss of hearing in his left ear. The 2012 neurological examination: C.C seems to be clumsy and he performs delayed movements. The diagnosis was established after neurological examination, EEG, and brain MRI, that showed deep demyelination with typical spread for adrenoleukodystrophy. ACTH was performed, and it showed an increased level of **122,6pg / ml** (normal range 7,2-63,3pg/ml). Genetic molecular tests revealed the presence of a "deletion" in ABCD1 gene, which includes exon 2, and they confirmed the diagnosis.

Evolution: The patient presented a gradual degradation up to vegetative state, with hypertonic crisis.

Conclusion: ADL-X is a rare disease but with progressive lethal effect in boys. In this case, the communication and palliative approach were taken from diagnosis and the prognosis was limited.

P045

Flexibly Evolving a Hospice Model of Care to Fit the Needs of Babies, Children and Young People with Palliative and End of Life Care Needs - Is this Necessary?

Carragher P.¹, Boutcher P.²

¹Children's Hospice Association Scotland, Central Services, Edinburgh, United Kingdom, ²Central Services, Robin House, Glasgow, United Kingdom

Background: An accurate knowledge of the number of babies, children and young people (CYP) with palliative care needs in one country has recently been published, as well as defining their underlying conditions, genders, ethnicities and any deprivation factors. The study offered some palliative prioritisation with prevalence considered under the following subgroups: stable, unstable, deteriorating, and dying. 2201 were from the last of three groups out of a total number identified as 15404 in the 0-25 year age group. 73% of deaths were in hospital. A newer model of care is evolving with joint appointments with statutory partners where paediatric consultants are now jointly employed by a national children's hospice organisation and senior nurses are employed by the hospice organisation who work extensively in hospitals.

Method: The hospice organisation is receiving a higher number of requests than previously for 'step down care' from hospital neonatal, critical care and general paediatric units for consideration of both for end of care and rehabilitation. This requires a more flexible booking system for the use of the hospice children's bedrooms, as frequently more than one request is made simultaneously. This presentation will illustrate the numbers of requests for step down admissions over a 12 month period and how these are prioritised against bookings which have previously allocated for short planned breaks.

Results: The study shows that there are already emerging trends particularly with increasing requests from neonatal palliative and paediatric critical care units, but also from oncology and general paediatric units. It also demonstrates that the hospice organisation is working more collaboratively with NHS providers in hospitals, children's homes and in its hospices.

Conclusions: There needs to be continued developments to ensure that the hospice organisation's model of care can evolve to meet the needs of CYP being referred for a step down admission.

P046

"Growing up with Ricky at Home" School Action in the Course of Treatment of Serious Pediatric Diseases. A Pilot Project

Banfi M.¹, Toffoli D.², Fabbrini E.², Rizzo C.², Marrocco N.², Corsi M.³, Fusacchia G.⁴, Ciabrone R.⁴

¹Sapienza, Dipartimento di Neurologia e Psichiatria, Roma, Italy, ²MIUR, Istituto di Istruzione Superiore Einstein - Bachelet", Roma, Italy, ³MIUR, Ufficio Scolastico Regionale, Lazio, Roma, Italy, ⁴MIUR, Direzione Generale per lo Studente, l'Integrazione e la Partecipazione, Roma, Italy

Background-context-aims: Upon communicating a severe diagnosis to families of young patients, illness strike their lives with the same destroying strength and negative effects of a Tsunami. During hospitalization of the boys, school intervention in the hospital. At the end of hospitalization, the school is driven home with the Home Education.

At the age of 13 Ricky underwent the amputation of limbs for a GvHD, after an eterolo transplantation for leukemia that struck him at the age of 7. During hospitalization he was followed by the hospital school teachers, but the duration of home education he could have when he got home was not sufficient for the entire school year in order to carry out the programs of high school. The school worked towards a full realization of a project based on the personal needs of Ricky and carried on with the presence of all his classmates.

Methods: After dividing the class into small groups, active paths of homework were planned. With an alternating commitment, groups were accompanied by a responsible teacher at Richy home.

Each group followed the lecture presented by a classmate in ppt, Ricky prepared a lesson as well and Mario overcoming his "selective mutism". Everybody were enriched by the mutual work, thus completing the objectives proposed and enhancing their value from the educational, psychological and social point of view.

Results: Richy has been integrated in a group class and his companions reported excellent educational results. This confirms an improvement in self-efficacy through peer education, which leads to the development of life skills, both for Ricky and for all his companions.

Conclusions: At the end of the school year, the project has received the recognition of the Secretary of Education, who personally handed the certificates of merit to the boys in the class and Richy, who continues to amaze us every day with his great passion for life , that goes beyond his serious illness.

P047

School and Children Affected by Life-limiting or Life-threatening Conditions: The Experience of Veneto

De Gregorio A., Ometto M., Benini F.

Hospice Pediatrico - A.O. di Padova, Padova, Italy

A lot of children affected by life-limiting or life-threatening conditions cannot reach normal school attendance. These children can present both cognitive and physical defects that interfere with their participation in class activities. These special needs require specific answers: from the cognitive point of view they frequently need support (usually delivered by a dedicated teacher) while the physical limitations are managed with different medical devices that imply the presence at school of a dedicated medical operator. To improve cognitive, emotive and social abilities is very important for these children to be in a safe and cooperative contest.

We decided to investigate these aspects among the children with special needs followed at our Center (108 children with different illnesses, 76 of whom in school-age). We developed a survey to investigate specific school needs (such as the types of medical devices used at school) and the given answer. More specifically we want to evaluate the presence and the level of social support offered at their school (i.e. whether a dedicated operator is present or not, which duties has, how many hours are allocated, ...). The first data show that of the 76 children in school-age, 61 attend school while 15 only attend special centers or didn't have any educational program at all. The data gathering and analysis is currently going on.

P048

A Summer Camp with CCHS Patients and their Families: An Experience to Improve Sense of Safeness and QOL

De Gregorio A.¹, Lazzarin P.¹, Fasson A.¹, Catalano I.¹, Martinolli F.², Brugnaro L.², Ometto M.¹, Benini F.¹

¹Hospice Pediatrico - A.O. di Padova, Padova, Italy, ²A.O. di Padova, Padova, Italy

Congenital central hypoventilation syndrome (CCHS) represents an increasingly recognized group of conditions characterized by respiratory and autonomic nervous system dysregulation (ANS). Though the hallmark of CCHS is alveolar hypoventilation with insensitivity to resultant hypoxemia and hypercarbia, patients also have symptoms of ANSD including temperature dysregulation, transient abrupt asystoles, severe breath holding spells, altered gut motility and severe constipation, pupillary abnormalities, and decreased perception of pain and anxiety. This pathology can be considered a life-threatening condition. As most of life-threatening conditions, CCHS makes holidays a moment of stress and fear. A lot of families decide to not have vacations because they don't feel comfortable and safe. For this reason we decided to offer to families (both parents and siblings) with children affected by CCHS a fully-organized holiday.

During the camp there is a dedicated medical staff composed by clinicians, nurses and a psychologist. This team works together with the local educational staff mixing abilities and knowledge. The first camp took place in a small village in Trentino mountains and lasted 5 days in July. The aims were to increase family sense of safeness and quality of life (QOL) and to promote the creation of a network of families. At the end of the camp the achievement of our goals was evaluated using a survey given to parents and children. The project received a very positive feedback from both families and children and the surveys showed a complete achievement of our aims. Due to this results we decided to propose a second edition of the summer camp.

Our project shows how the QOL of families with children affected by life-threatening conditions can be improved through the sharing of common experiences.

P049

Role of Palliative Care in Children with Epidermolysis Bullosa: A Case Report

Matsushita F.Y., Polastrini R.T.V., Danti G.V., Zoboli I., Barbosa S.M.d.M.

Department of Pediatrics, Hospital das Clínicas, University of São Paulo (HCFMUSP), Unity of Pain and Palliative Care, São Paulo, Brazil

Background and aims: Epidermolysis bullosa (EB) is an incurable progressive genetical disease that causes great suffering, both for the patient and for the family. The aim of this study is to evaluate the total pain in a patient with a non-oncologic chronic life-limiting illness over the years.

Methods: The Department of Pediatrics of Hospital das Clínicas is the reference in the treatment of highly complex diseases in all over Brazil. We collected data from all medical appointments in the last 5 years of a 14-years old boy with Epidermolysis bullosa and analyzed all biopsychosocial factors which comprise the total pain.

Results: In the last 5 years, our patient had 66 medical appointments, used 35 different types of medication, 17 times he had to use antibiotic due to multiple skin infections, passed through 3 esophageal dilatation, received 36 blood transfusions and 9 albumin transfusions. Because of the skin lesions, he needs to use morphine before every bath and suffered great psychological damage. Phrases like: "I am afraid to die", "Children in school don't like me", "The bus driver did not let me in" appeared in our conversation. Almost all organic system of his were injured: Muco-cutaneous, gastro-intestinal, cardiovascular, musculoskeletal and Eye/Ear/Throat.

Conclusions: Although Epidermolysis bullosa is mostly recognized as a dermatological condition, this disease compromise much more than the skin. Not only because affects almost all main systems of the body, but psychological and social part are greatly impaired, causing an unthinkable total pain. We could improve his quality of life for more than 10 years, decreasing his pain sensation, controlling organic problems and giving him psychological support. It is clear that not only patients with EB, but all children with a chronic life-limiting illness, must be followed by an Unit of Pain and Palliative Care, since they end up accumulating an unimaginable total pain over the years.

P050

Belgian Pediatric Palliative Care: Spreading the Ideas of Pediatric Palliative Care in the Different Fields of Pediatric Medicine

Renard M.¹, Brichard B.², Francotte N.³, Fonteyne C.⁴, Misson J.-P.⁵, Faingnaert M.⁶, Mattheeuws K.⁷, Ruysseveldt I.⁸

¹Universitair Ziekenhuis Leuven, Children's Hematology and Oncology - PPC, Leuven, Belgium, ²UCL, Children's Hematology and Oncology - PPC, Brussels, Belgium, ³Centre Hospitalier Chrétien Liege, Children's Hematology and Oncology - PPC, Liège, Belgium, ⁴Hôpital Universitaire des Enfants Reine Fabiola, ICU and Emergencies - PPC, Brussels, Belgium, ⁵Centre Hospitalier Régional de la Citadelle, Neuropediatrician - PPC, Liège, Belgium, ⁶Arémis, Hospitalisation at Home - Pediatric Team, Brussels, Belgium, ⁷Universitair Ziekenhuis Gent, Paediatric Palliative Care and Liaison Team, Gent, Belgium, ⁸Universitair Ziekenhuis Leuven, Paediatric Palliative Care and Liaison Team, Leuven, Belgium

Many care givers in the pediatric field are not aware of the different opportunities PPC can offer in many situations, especially in the care of children with different complex conditions.

In Belgium a structural recognition of the PPC by a Royal Decree in 2010, allows 5 liaison teams to offer high quality and continuity of PPC. The PPC liaison teams, already present since 1990, have a coordinated and supportive role between the caregivers, the patient and his family, both into the hospital and the home care environment. The teams are the corner stone of the PPC in Belgium.

However, the visibility of these teams and the ideas of PPC is not always present in the different settings of the pediatric field.

To introduce the spirit of PPC a "Belgian Pediatric Palliative Care group (BPPC)" is created, started from a group of motivated volunteers and people from the different pediatric care fields. A plenary session, with stakeholders in pediatrics, questioned the needs. A structure of 5 working groups was created to develop guidelines on 5 different topics of PPC:

1. Definition of the pediatric palliative patient;
2. Guidelines concerning pain and symptom control;
3. Decision making (advance care planning),
4. Organization of PPC in Belgium;
5. Ethics in PPC and end of life care.

A board is installed to coordinate and to supervise all the work in progress.

These 5 working groups will analyze the different subjects thoroughly and will write down the current 'evidenced based' knowledge and the current situation concerning different aspects of PPC. Some recommendations will be made. The whole process is supported by the FOD (Federal government health care), especially logistical, not financial.

The ultimate aim of the project is to make more caregivers familiar with PPC through these guidelines, to make PPC more professional and to make the care more and faster accessible for children with complex conditions.

P051

The Quality of an Integrated Treatment in an Epidermolysis Bullosa Pediatric Case Assumed by the Palliative Care and the Pediatric Home Care

Fantin E., De Zen L., Bagolin A., Canzian C., Fabris S., Dall'Amico R., Minetto M.

Azienda Ospedaliera Santa Maria degli Angeli, Pordenone, Italy

Background-context-aims: S. is a 7 year's old child who has been diagnosed with dystrophic epidermolysis bullosa of Hallopeau Siemens. Due to the disease seriousness, complexity and chronicity, it is necessary to guarantee the quality of an integrated care that involves every health worker and relative who surround the child.

The aim is to improve the pain management by planning an integrated and shared intervention protocol that will follow the disease progression and it will be adapted to her development. The objective will be achieved through the following steps:

- Identify the most suitable pain management techniques according to S.
- Learn how to use the pain coping strategy so that she can use it on her own
- Share the method with the health team and the family.

Methods: This non-standard protocol requires a team work:

- Meeting the school educator
- Meeting other pain therapy specialists
- Starting an individual support programme with a psychologist to cope with the little girl's mother distress
- Organising meetings with the child to facilitate the therapeutic alliance and make her experience some relaxing exercises.

The identification of two tools:

- The box of relief, which contains the most suitable distraction tools for S.
- Her personal diary to monitor the pain

Results: An important change occurred while these pain management tools were introduced: the mother was ready to designate her husband to take care of medications. The positive changes of the treatment were:

- Shorter time for medication
- The mother reduced her stress in taking care of S.
- S. happily accepted the introduction of these tools

Conclusions: Managing the pain in a DEB case means to be constantly ready to adapt to any change and to the disease gradual development, considering personality and peculiarity of each child. This allows the family and the health system to tackle the routine medication, in an integrated and shared way, with a greater feeling of effectiveness.

P052

The Best of the Best for the Baby in the Womb the Urgent Need of Prenatal Palliative Care in Memory of Giampaolo Magnani Born on 5th March 2009 Died on 17th October 2010, at 19 Months

Magnani L.

University of Studies of Insubria of Varese, Paediatrics, Varese, Italy

Background: It's necessary and urgent being part of the growing awareness that Babies experience pain, discomfort and neglect before they are born. As mother's womb is not sterile there must be a deep education, learning and knowledge given to future mothers and fathers, to mothers and fathers who wonder why their Baby is affected by a disease.

Methods: Obstetricians, Gynaecologists, Neonatologists, Paediatricians, Oncologists, Anaesthetists, Psychologists and Nurses must teach parents that the Baby is conscious in the womb from the Conception and he must be protected, because he is exposed to and he has reactions to the physical, emotional, experiential and chemical environment of the womb.

Results: Listening and living deeply (2015) the experiences and emotions of 11 couples who chose to continue their pregnancies after receiving a lethal fetal diagnosis (LFD), Intra Uterine Growth Restriction, Down Syndrome, Severe Facial Vascular Malformation, Spina Bifida and Hydrocephalus, Microcephaly and other Genetic diseases, motivated me very urgently to become member of the Association for Prenatal and Perinatal Psychology and Health, Canada, (January 2016), in order to Call-to-Practice 10 behavioural categories for Caregivers and Parents:

1. Taking care of the Baby in the womb;
2. Protecting the Baby from negative environmental influences;
3. Promoting the Baby's personhood;
4. Interacting with the Baby;
5. Creating atmospheres for the Baby;
6. Being with the Baby;
7. Thinking of the Baby;
8. Feeling the Baby;
9. Being the Baby;
10. Loving the Baby.

Conclusions: Interaction, millisecondly, with Babies and their Families, communication with Obstetricians, Gynaecologists, Neonatologists Paediatricians, Oncologists, Anaesthetists, Nurses and Psychologists in order to create-become-and-be Always new spaces and times, New Life instilled in Babies' Life.

P053

Home Psychologist Assistance: A New Model for Children and Families in Pediatric Palliative Care

Minetto M., Bagolin A., Canzian C., Luchini A., Fabris S., Fantin F., Dall'amico R., De Zen L.

AAS5 - Western Friuli - Pordenone, Palliative Care, Pain Therapy and e Pediatric Home Care, Pordenone, Italy

Background: During the course of treatment of a child with a life-limiting or life-threatening disease, it's important that the Hospital creates a network to assist the child in his family's reality. This moves towards health and social care pathways that can guarantee a qualified care at child's home, because it's important for the child to stay in his living environment, especially when health and safety are compromised.

Aim: The result is a pilot project that aims to bring psychological care in the home of a child with a life-limiting or life-threatening condition, as well.

Method: Firstly, there is the taking charge of the child and his family through a multidisciplinary team; then, there is a meeting between pediatric home care's members. Secondly, some psychologist's home visits will be structured, due to gather information about story, organization and relational dynamics of family, and due to verify if there are problems inside the family that could interfere with pediatric home care.

All information collected will be shared with health care's practitioners that are caring the child.

Results: Families benefit greatly from a psychological support at home. Furthermore, this type of support allows the entire team to be constantly informed about family's dynamics and, consequently, that allows to deal with emotional changes.

Conclusions: Creating a unique psychological place for parents allows them to feel and to express their distress in a protected place. A family with a sick child has difficulties that require solutions involving different approaches and all resources must be available; it's important for parents to have a place where they can meet and support each other.

P054

Pediatric Palliative Care Knowledge and Attitude: A National Survey to Healthcare Professionals

Lacerda A.¹, Dinis A.², Mendes J.³, Oliveira G.⁴, Franco T.⁵, Salazar H.⁶, on behalf of the Taskforces of the Portuguese Society of Pediatrics and the Portuguese Palliative Care Association

¹Portuguese Institute of Oncology, Pediatrics, Lisboa, Portugal, ²Hospital Pediátrico de Coimbra, Intensive Care, Coimbra, Portugal, ³Hospital São Francisco Xavier, Neonatology, Lisboa, Portugal, ⁴Hospital de Santa Maria, Neonatology, Lisboa, Portugal, ⁵Hospital de Santa Maria, Pneumology, Lisboa, Portugal, ⁶ACES Arrábida, Palliative care, Setúbal, Portugal

Background: Equitable Pediatric Palliative Care (PPC) delivery to children with life-limiting/threatening conditions (CLL/TC) and families is better met by collaboration between pediatric and adult providers. We aimed to assess current professional knowledge/attitude in a European country where no organized activity was recognized until 2013.

Methods: Email survey (58 questions) to the members of the national Palliative Care Association (PCA, March'16) and of the Pediatrics Society (PS, April'16). Statistical significance 0.05 (t-test).

Results: Responses (RR%): PCA 53(8) / PS 159(9); % female gender 96/83; % age 30-39y 47/42; % pediatric providers 10/100; % nurses 47/-; % residents -/24; % NHS hospital based 54/41; % local PPC provision 15/13; % caring for CLL/TC 53/92; % with PPC education 65/48. Comparison based on caring for CLL/TC - for PCA no difference in knowledge/attitude; for PS differences in "I know what PPC is", "I need support", and several communication, care planning, symptom control, emotional and bereavement support questions. Comparison based on PPC education - for PCA difference in "I know what PPC is"; for PS differences in "I know what PPC is", "integrating PPC is giving up", "only specialists should provide PPC", "I will always be uncomfortable", and several communication, care planning, symptom control, emotional and bereavement support questions. Eight themes were ranked differently, highlighting further disparities: ethics (PCA 1 / PS 3), communication with child/family (2/2), family support (3/5), continuity of care (3/4), bereavement care (5/6), spirituality (6/8), team support (7/7), symptom control (8/1).

Conclusions: Caring for CLL/TC is a pervasive experience amid healthcare. Despite limited by low RR, this survey hints at diverse challenges across settings and stresses the relevance of widespread PPC education and program development. Further research is needed to explore multidisciplinary views not included in this sample.

P055

Complicated Grief in Children after Parental Loss: A Longitudinal and Prospective Study

Suc A.¹, Melioli T.^{2,3}, Raynaud J.-P.⁴, Bui T.H.E.^{5,6}

¹Hôpital des Enfants du Centre Hospitalier Universitaire, Toulouse, France, ²Université de Toulouse II, Toulouse, France, ³Centre Hospitalier Universitaire, Toulouse, France, ⁴Service Universitaire de Psychiatrie de l'Enfant et de l'Adolescent (SUPEA) Hôpital La Grave, Toulouse, France, ⁵Massachusetts General Hospital, Boston, United States, ⁶Harvard Medical School, Boston, United States

Background and aims: About 7% of bereaved individuals will experience complicated grief (CG), a distressing and impairing condition that includes persistent and intense grief-related symptoms. Although several studies have examined risk factors for CG in adults, limited data are available in children and adolescents. Prior results suggest that insecure attachment, behavioral avoidance, peritraumatic reactions, depressive symptoms may be risk factors for CG among children and adolescents. The present study aims to identify risk factors for CG among children and adolescents who lost a parent.

Methods: This study aims to include 119 children aged from 6 to 17 years and their parent. At 3, 9, and 13 months post-loss, participants will be invited to complete questionnaires assessing depressive symptoms, peritraumatic reactions, security attachment, symptoms of CG and symptoms of posttraumatic stress disorder (PTSD).

Results: We hypothesize that increased insecure attachment, peritraumatic reactions, behavioral avoidance and depressive symptoms at baseline will prospectively predict increased CG symptom severity at 9 and 13 months post-loss. Furthermore, the surviving parent's grief symptoms will moderate the relationship between early risk factors and CG symptom severity among children. The study was approved by the local ethics committee, and recruitments are ongoing. To date, N=3 children (mean (SD) age = 15.7 (2.3), 100% boys) and their parent (age = 46) have been enrolled (time since loss = 6 months). Overall, children exhibit moderate levels of CG symptoms severity: mean (SD) inventory of complicated grief = 72.7 (16.3).

Conclusions: This study will be the first to evaluate a range of risk factors for CG among children and adolescents. Findings from this study will help to identify mechanisms involved in CG and will therefore help to develop preventive and treatment strategies.

This research is conducted with the support of: OCIRP and the Ligue contre le Cancer.

P056

Through my Pain

Mindeguía M.

Sanatorio Mater Dei, Buenos Aires, Argentina

Background and aims: Showing the therapeutic implications of the approach to "wall of silence".

Methods: Case report

Results: Child of 10 years old. Healthy twin brother.

Diagnosis: Metastatic Ewing Sarcoma, Paraplegic. Palliative care.

Conspiracy or the pact of silence is often defined as an agreement, implicit or explicit, among relatives, close friends and health professionals to hide or distort information about their - diagnosis situation, treatment and / or prognosis - the patient to avoid suffering to face the end of his life. A barrier is introduced into communication, it can manifest in feelings of loneliness, isolation, and something as important as the feeling of lack of understanding. If the patient feels cheated, he can easily increase their anxiety and depression symptoms, with an important component of fear and anger; this emotional situation also lowers the threshold of perception of pain and other symptoms, and it also hinders the expression of his emotions.

Conclusions: Disarticulate the "wall of silence" make possible the integration of pain and loss, opposed to dissociation or fragmentation, vivid meaning and dignity is provided to the patient's life, thus modifying the painful experience.

P057

Care Needs and Referral Patterns of Adolescent and Young Adult Cancer Patients Referred to a Palliative Medicine Service

Soo J.J.E.¹, Wong V.H.M.², Toh Y.P.², Wong Y.Y.², Cheung Y.B.³, Neo P.S.H.²

¹NUS Yong Loo Lin School of Medicine, Singapore, Singapore, ²National Cancer Centre Singapore, Palliative Medicine, Singapore, Singapore, ³Duke-NUS Medical School, Singapore, Singapore

Background and aims: Studies have shown that AYA patients are less likely to gain access to optimal medical and psychological services compared to other age groups. To address these care needs, organisations like NCCN have published guidelines for integrated AYA programmes. At present, there is paucity of information regarding the care received by AYA cancer patients at end-of-life, which limits the development of a useful integrated AYA model. This study aims to assess the care needs and referral pattern of AYA cancer patients referred to a consultative inpatient palliative care service.

Methods: Retrospective case notes review was performed for all palliative care patients with the primary diagnosis of cancer who died in a tertiary hospital between January 2012 and June 2014. The AYA group, defined as patients aged between 21-39 years, was compared with the non-AYA group, which was a random sample of cancer patients 40 years and above within the same study period. Statistical analysis was performed using paired t test and chi-square test.

Results: Eighty seven AYA patients were compared with 180 non-AYA patients. AYA patients had longer length of stay, more frequent admissions to hospital, increased admissions to intensive/intermediate care settings and increased social work services referrals compared to non-AYA patients. There is however no difference in the eventual place of demise and frequency of social work input. The AYA patients were referred earlier from the date of diagnosis and were referred more for need for symptom control and less for discharge planning compared to non-AYA patients.

Conclusions: AYA cancer patients experience more care needs compared to non-AYA cancer patients. This study provides baseline information for introduction of an alternative service model to improve patient access to palliative care and clinical outcomes.

P061

Managing Uncertainty in Non-malignant, Life-threatening Conditions: The Experiences of Young Adults and their Parents

Beresford B., Maddison J., Stuttard L.

University of York, SPRU, York, United Kingdom

Background: Advance care and end of life plans are key elements of palliative care practice. However, these are part of a continuum of plans which support families living with the uncertainty of a life-limiting illness. This paper reports a study of young adults' and parents' experiences of living with a life-limiting, non-malignant condition, and focuses particularly on the role of plans in supporting them to manage uncertainty.

Methods: In-depth interviews with young adults (n=27) with Duchenne Muscular Dystrophy, renal disease, cystic fibrosis or complex cerebral palsy and their parents (n=19), recruited from NHS clinics in four sites across England. Interviews were audio-recorded, transcribed and subject to thematic analysis. NHS REC approval was obtained.

Results: Having plans in place in event of worrying symptoms, a deterioration and/or medical crisis played a very important role in allowing young adults and parents to 'get on' with life. They prevented families from being stifled by concerns and anxieties which pre-occupy and drain emotional energy. Discussing and planning for these sorts of situations could form the beginnings of a discussion about treatment decisions and end of life. There was evidence that those closest to death were amongst those least willing to acknowledge the life-shortening nature of their condition. A minority had made an end of life plan: they were relieved to have done so and believed it enabled on-going conversations within the family. Receiving difficult information and decision-making are two of the key processes in making plans: interviewees identified a number of principles of 'good practice' in this regard.

Conclusions: This paper argues that, as well as advance care and end-of-life plans, attention also needs to be paid to planning for other situations which generate uncertainty in families' lives. These plans can, in themselves, 'enable' more difficult conversations.

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P062

Provision of Multi-disciplinary End of Life Care for Children and Young Adults with Cancer: A Nationwide Survey

Porter C.¹, Carragher P.², Murphy D.³, Managed Service Network for Children and Young People with Cancer Palliative Care Steering Group

¹Children's Hospice Association Scotland, Robin House Children's Hospice, West Dunbartonshire, United Kingdom, ²Children's Hospice Association Scotland, Central Care Services, Edinburgh, United Kingdom, ³Royal Hospital for Children, Paediatric Oncology, Glasgow, United Kingdom

Background and aims: This survey looked to provide an evidential baseline of end of life care provision for children and young people (CYP) with cancer in one country. This will form the basis of a continuous quality improvement programme through the development of Key Performance Indicators. These have been designed and implemented through the Managed Service Network for Children and Young People with Cancer (MSNCYPC) palliative care steering group, in collaboration with Government.

Methods: Eleven CYP were identified in the six calendar months 01/01/15-30/06/15 as having died from malignancy. Data was gathered from questionnaires on seven key areas of care provision. These included evidence and use of an Anticipatory Care Plan (ACP), evidence and use of resuscitation planning using a Child and Young Persons Acute Deterioration Management (CYPADM) plan, preferred place of death, medications used, multidisciplinary team involvement, information technology/communication and bereavement support. The data was provided by nurses involved in the CYP's care. This information was then analysed using Survey Monkey.

Results: Variation in care delivery was demonstrated across the country and the report provides a comprehensive evaluation of all the collected data. The MSNCYPC palliative care steering group should concentrate on ensuring equitable provision in all aspects of palliative care but with particular focus on the use of ACP's and CYPADM plans, anticipatory prescribing and supply of Just in Case boxes, effective communication processes and bereavement services.

Conclusion: This survey provides baseline evidence, for the first time, which will allow the development of standards of excellence in the delivery of palliative and end of life care. These will be designed and implemented through the MSNCYP palliative care steering group, in collaboration with Government. Future audit will determine the efficacy of standards as part of an on-going quality improvement process.

P063

Nutrition and Hydration at the End of Life in Children Referred to a Tertiary Palliative Care Service: A Case Series Review

Halpin-Evans R.¹, McCulloch R.¹, Bryan G.², Bluebond-Langner M.²

¹Great Ormond Street Children's Hospital, Paediatric Palliative Care, London, United Kingdom, ²Institute for Child Health London / Louis Dundas Centre for Oncology Outreach and Palliative Care Great Ormond Street Hospital, Palliative Care Research, London, United Kingdom

Background: Feeding children at the end of life (EoL) is emotive, with consequences for patient physical and psychological well-being. Aims : Assess current practice and advice given to professionals and families about feeding /hydration at EoL .

Method: Retrospective case-note review of nutrition / hydration at EoL of patients known to a tertiary palliative care service who died over a six month period in 2015/2016. Data included review of symptom management plans (SMPs) and patient records 6 months, 4 weeks, 1 week and 48 hours before EoL.

Results: Seventy five patients died in the study period. Sixteen were excluded due to: involvement of other palliative care team (6), missing records (3), no contact in 24 months (1) child died before being met (3) SMP written by study authors (3) Of the remaining 59, 40 (67.7%) had non- malignant and 19 (32.3%) malignant pathology. Thirty-two patients had SMPs (54.2%). Of these, feeding was documented as discussed in 7 (21.8 %) and hydration in 2 (9.3%). Nutrition and hydration at EoL included normal diet, enteral feed, Total Parenteral Nutrition, intravenous fluid and enteral fluid. Feeds of 15 children (25.4%) were altered at EoL: reduced (by < 50%) in 3 cases (5%), suspended in 8 (13.5%) and stopped in 4 (6.7%). Of those stopped, 2 cases were at parent request and 2 on professional advice. Pain, malabsorption or vomiting were most common causes for cessation or suspension of feeds .Fourteen calls were made to our service about nutrition or hydration. Two were made by parents and the remainder professionals.

Conclusion: This study highlights complexities of decision making about nutrition and hydration at EoL. Both parents and professionals used our service to seek advice on this topic. We are developing a practice development guideline for nutrition and hydration at EoL for use in our team and aim to extend the study across London. Nutrition and hydration should be discussed routinely with families and recorded in SMPs.

P064

Place of Death in Children Discharged from PICU: The Importance of Palliative Care

Fraser L.¹, Fleming S.², Parslow R.²

¹University of York, Department of Health Sciences, York, United Kingdom, ²University of Leeds, Division of Epidemiology & Biostatistics, Leeds, United Kingdom

Background: To assess trends in place of death and identify characteristics of children who died in the community after discharge from paediatric intensive care (PICU).

Methods: All children resident in England and Wales when admitted to a PICU in the United Kingdom (1st Jan 2004 and 31st Dec 2014) were identified in the PICANet dataset. Linkage to the ONS death certificate dataset was undertaken by the Health and Social Care Information Centre using their standard algorithm which uses NHS number, date of birth, sex and postcode. Place of death was categorised as hospital (hospital or PICU) or community (hospice, home or other) for random effects multivariable logistic modelling.

Results: The cohort consisted of 110,328 individuals. 7709 deaths occurred after first discharge from PICU. Deaths in hospital (including PICU) decreased from 83.8% in 2004 to 68.1% in 2014. 852 (0.8%) of children were discharged to palliative care.

Children discharged to palliative care were eight times more likely to die in the community (OR 8.06 (95%CI 6.50-10.01)).

Children from a South Asian background (OR 0.48 (95%CI 0.39-0.58)) and those living in the most deprived fifth were significantly less likely to die outside the hospital (OR 0.63 (95%CI 0.51-0.77)).

Conclusions: The proportion of children dying in hospital is decreasing but a large proportion of children dying after discharge from PICU continue to die in hospital and there is inequity with children from South Asian backgrounds and those from deprived areas more likely to die in hospital. More involvement of palliative care at the point of discharge has the potential to offer choice around place of care and death for these children and families.

P065

Pediatric Palliative Care in a Multi-religious Society

Tkachenko A.

Medical Institution 'Children's Hospice', St. Petersburg, Russian Federation

In the context of a multi-religious society, provision of spiritual support requires interaction between psychologists, healthcare professionals and clergy working with children suffering from life-limiting diseases.

Palliative care specialists often face situations when their religious views differ from the patient's ones. It is necessary to create an environment, in which the support is rendered with consideration, understanding and respect of the patient's beliefs and regardless of religious affiliation of the palliative care specialist.

A project was conducted to study approaches to spiritual support for families affiliated with the four most common Russian religions: Christianity, Judaism, Islam and Buddhism. A survey among palliative care professionals was conducted who pointed to religious questions, to which they have difficulties to provide answers in their daily work, and described their problems in the provision of palliative care, taking into account the religious beliefs of patients and their families.

A handbook "The Questions We Do Not Know The Answers To" was prepared giving information and instructions to pediatric palliative care professionals, clergy and volunteers working under conditions of a multi-religious society. Co-authors were leaders of the leading religions of Russia. The manual considers clergy as palliative care specialists, whose support can have a significant impact on improving the life quality of ill children and their families and can facilitate the family's rehabilitation process after the loss of the child. It provides guidance on the correct and simple answers to religious questions by young patients and their families.

The project enabled a dialogue on cooperation between pediatric palliative care specialists and representatives of different religions in favor of children with life-limiting illnesses. The project was presented not only to the professional community, but also to decision-makers at the state level.

P066

Pediatric Deaths Attributable to Complex Chronic Conditions in Republic of Korea, 2005-2014

Kim M.S.¹, Song I.G.², Lee J.Y.³

¹Seoul National University Children's Hospital, Department of Public Health Medical Service, Seoul, Korea, Republic of, ²Seoul National University Children's Hospital, Department of Pediatrics, Seoul, Korea, Republic of, ³Seoul National University Boramae Medical Center, Department of Public Health Medical Service, Seoul, Korea, Republic of

Background: There were 267,692 deaths in Republic of Korea in 2014 and children aged 0-19 years accounted for 1.1% of all deaths. To better inform national pediatric palliative care planning, we sought to determine the numbers of complex chronic condition (CCC) attributed childhood deaths, the proportion and predominant cause of deaths according to age groups.

Methods: A retrospective cohort study was conducted of all deaths that occurred to children aged 0 to 19 years in Republic of Korea from 2005 to 2014 using death certificate data from the Korea National Statistics Office.

Results: One third of the 36,808 child deaths during this period were attributable to a CCC. Among CCC-associated deaths, 57% were males, 45% were < 1 year old, and 45% lived in metropolitan area. The predominant causes of CCC-attributed death likewise varied with age. Cancer CCCs were cited as the cause of 3.3% of infant deaths, 43% of childhood deaths and 56% of adolescent deaths. Infant deaths were attributed to prematurity, cardiovascular, and neurologic CCCs in order. While non-CCC deaths occurred at home in 14%, only 8% of children with a CCC died at home. Age, region, and the underlying cause of the child's death were strongly associated with the occurrence of death at home. Using malignancy-related deaths as a benchmark, deaths as a result of neurologic, cardiovascular, respiratory, metabolic, other congenital conditions were more likely to have occurred at home ($P < 0.001$). Child who lived non-metropolitan area was also more likely to have died at home ($P = 0.005$).

Conclusions: We identified characteristics of Korean children's deaths according to age, disease group, region, and place of death. These findings could provide insight into palliative service implementation for children dying with complex chronic conditions in Korea.

P067

Evaluation and Management of Delirium in Seriously and Terminally-ill Children: A Review of the Literature and Contemporary Best Practices

Okhuysen-Cawley R.

Baylor College of Medicine, Pediatrics, Houston, United States

Background: Delirium and other manifestations of neurocognitive dysfunction are major contributors to morbidity and multi-domain symptom burden in seriously ill children, negatively affecting functional outcomes of survivors. Behavior changes characteristic of delirium, especially during terminal phases, are known to be an important source of family and caregiver distress, contributing to complicated bereavement. Besides being a source of suffering for children and caregivers, improperly managed delirium independently affects healthcare outcomes and contributes to increased resource utilization in a variety of settings, particularly intensive care units.

Methods: A literature review was performed utilizing the catalog and search engines, primarily PubMed, maintained by the National Library of Medicine through July of 2016.

Results: An emerging body of literature highlights the challenges of managing delirium, particularly in very young or non-verbal patients. Multiorgan failure in the context of underlying neurologic dysfunction is a recognized risk factor. Common precipitants include fever, hyponatremia, other electrolyte abnormalities, commonly used medications, notably anticholinergics and sedatives, and disruption of circadian rhythms and sleep. Many of these triggers are amenable to prevention, including systematic evaluation for delirium as part of protocolized care (**A**ssess, **B**reathing, **C**hoice, **D**elirium, **E**xercise, **F**amily (**ABCDEF**) bundles. Minimizing exposure to medications and sleep hygiene strategies are essential. Haloperidol or newer atypical antipsychotics can be safe and effective. Dexmedetomidine or palliative sedation may be appropriate in refractory cases.

Conclusions: Incorporation of patient-focused, family-centered strategies reflecting best clinical practices for management of delirium may be beneficial in Pediatrics. Anticipatory guidance tailored to patient and caregiver needs may improve outcomes while mitigating distress when terminal delirium occurs.

P068

An Individual Care Plan to Stimulate Advanced Care Planning in Palliative Care for Children

Loeffen E.A.H.¹, Tissing W.J.E.¹, Schuiling-Otten M.A.², de Kruiff C.C.³, Kremer L.C.M.⁴, Verhagen A.A.E.⁵

¹Beatrix Children's Hospital, University Medical Center Groningen, University of Groningen, Department of Pediatric Oncology/Hematology, Groningen, Netherlands, ²Stichting PAL, Pediatric Palliative Expertise, Utrecht, Netherlands, ³Emma Children's Hospital, Academic Medical Center, Department of Pediatrics, Amsterdam, Netherlands, ⁴Emma Children's Hospital, Academic Medical Center, Department of Pediatric Oncology, Amsterdam, Netherlands, ⁵Beatrix Children's Hospital, University Medical Center Groningen, University of Groningen, Department of Pediatrics, Groningen, Netherlands

Background and aims: In 2013, the Pediatric Association of the Netherlands launched an evidence-based guideline "Palliative care for children". To promote its implementation in daily practice, we aimed to develop and evaluate an individual care plan (ICP), incorporating advanced care planning and patients' and parents' preferences and desires.

Methods: A Dutch working group (28 individuals) with a strong multidisciplinary character including parents developed the ICP based on the recommendations in the guideline. We piloted the ICP (an editable Microsoft Word form) retro- and prospectively in 5 Dutch academic pediatric hospitals. In the retrospective pilot, ICPs for 3 recently deceased patients were completed as if it was early in the palliative course. We evaluated if items were missing, unclear or unusable, and adjusted the ICP accordingly. Then, prospectively the ICPs for 9 patients, who were recently diagnosed with a life-threatening or life-limiting condition, were completed and evaluated on completeness of data, usability and user-friendliness using a digital user survey.

Results: The final ICP comprised five domains:

- 1) care plan data,
- 2) basics,
- 3) social,
- 4) psychosocial and spiritual, and
- 5) somatic.

Each domain covered various items (32 in total). In both pilots, the ICP was considered a comprehensive document that covered all areas of pediatric palliative care, and was experienced as an improvement to the present situation. However, the current form was regarded to lack user-friendliness.

Conclusion: We developed and evaluated an ICP that covers all areas of palliative care for children, based on the Dutch evidence-based guideline, with great emphasis on advanced care planning and patients' and parents' preferences and desires. Our next step is to improve user-friendliness and facilitate implementation in daily practice.

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P069

Narrative Medicine and Palliative Care: Proposals from a Peripheral Center

Calafiore L.¹, Bena C.², Pistot P.¹, Vaccarone E.¹, Cimadamore N.¹, Pescarmona M.¹, Minellono A.³, Barbara A.¹

¹Paediatric and Neonatology Unit, TO4 Local Health Agency, Spoke Center of the Pediatric Oncology Network of Piedmont and Aosta Valley, Ivrea, Italy, ²Integrated Home Care System, TO4 Local Health Agency, Settimo Torinese, Italy, ³Network of Pediatric Psycho-Oncology of Piedmont and Aosta Valley, Ivrea, Italy

Background: In the era of genomic and target therapy, narrative medicine can be a means for a real evidence - based "medicine of person", approaching patients holistically, particularly in difficult situations like the end of life. Our local network has initiated two projects using storytelling to improve our care of children/adolescents with chronic/oncologic diseases as "experts by experience".

Methods: The first project, started in 2009, aims to introduce narrative medicine in our home care system as part of medical records, with a form that parents' patients can fill in with description of their feelings and needs.

The second, instead, is a collective writing project: invent a fictional story can be a stimulus for pediatric patients, allowing the expression of repressed feelings with symbolic or graphic language. We organized the first meeting for the presentation of the story, and the others to define the mutual interaction of the characters, with the supervision of a psychologist.

Results: As regards the first project, we collected 12 stories written by parents of chronic children, two of which with cancer. The integrated clinical record allows parents to create a real therapeutic alliance with healthcare professionals that, on the other hand, can include in the form their personal comments.

The collective writing project, instead, was entitled THE NIGHT OF LOST MEMORIES and involves 8 cancer patients, in treatment and off therapy. The plot recalls the kind "modern fantasy" and can allow participants to rebuild a new identity in an unthreatening environment. One patient is in palliative care; her clear way to express feelings represents a stimulus for others to take out their emotions.

Conclusions: The proposal is to create a "container" of writings, integrated in medical records or framed in collective writing projects, with a special attention to patients in palliative care. The projects are "in progress", and the goal is to extend them to other centers.

P070

Best Practice of Provider/Parent Interactions when Children Are Seriously Ill

Davies B.^{1,2}, Steele R.³

¹University of Victoria, School of Nursing, Victoria, Canada, ²University of California, Family Health Care Nursing, San Francisco, United States, ³York University, School of Nursing, Faculty of Health, Toronto, Canada

Interactions with health care providers (HCPs) are central to well-being for parents of seriously ill children. A vast professional literature stresses importance of effective communication, yet most reports highlight only problems. In this 3-year prospective grounded theory study, we focused on positive HCP/parent interactions to uncover what characterizes best practice.

With ethics approval, we interviewed 80 HCPs (multi-disciplines) and 34 parents in oncology, neonatal intensive care, and children's hospice settings in Western Canada, and noted HCP/parent interactions during 88 observation periods. We analyzed data concurrently with data collection, using NVivo for data management. Three researchers analyzed interviews separately, then achieved consensus on codes, relationships, and the emerging conceptualization - represented metaphorically by a prairie windmill for purposes of knowledge translation.

Best practice HCP (BPHCP)/parent interactions occurred during every encounter and were rooted in an encompassing worldview, specific values, and commitment to authentic engagement with parents; founded in depth and breadth of knowledge, curiosity, openness/flexibility, and self-awareness; and influenced by past experience, self-care, and contextual factors. The process of exquisitely attuning to particularities of the situation in the present moment was central, resulting in positive outcomes for parents and BPHCPs.

Best practice is possible for HCPs and they are recognized as being the best at what they do. Findings make explicit what has only been previously inferred about HCP/parent interactions and about concepts such as person-centred care and narrative medicine. Even 'simple' interactions are complex, and findings imply that professional education and training should extend beyond focusing solely on acquiring and generally applying a set of specific communication skills.

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P071

End-of-Life (EOL) in Children with Congenital Heart Disease (CHD) who Died in Hospital: Parental, Physicians' and Psychologists' Perspectives on Suffering and Quality of Life

Benedetti F.¹, Agosto C.¹, De Tommasi V.¹, Padalino M.², Milanesi O.³, Stellin G.², Benini F.¹

¹Azienda Ospedaliera di Padova, Università di Padova, Pediatric Palliative Care and Pain Service, Department of Woman and Child's Health, Padova, Italy, ²Azienda Ospedaliera di Padova, Università di Padova, Pediatric and Congenital Cardiac Surgery Unit, Department of Cardiac, Thoracic and Vascular Sciences, Padova, Italy, ³Azienda Ospedaliera di Padova, Università di Padova, Pediatric Cardiology Unit, Department of Woman and Child's Health, Padova, Italy

Background and aims: Few researches have focused on EOL in pediatric cardiology. Despite improvements, children with complex CHD continue to present with consistent mortality. We report our experience speculating about parental and caregivers' perceptions in children who died at our institution.

Methods: This is a retrospective medical record review and a cross-sectional survey of cardiac caregivers (surgeons, cardiologists and psychologists) and bereaved parents of children with CHD who died in hospital (2009-2012). With questionnaires, perceptions were measured of physicians and parents regarding EOL experience. Excluded were patients older than 18 years, absence of consent, comprehension limits and litigations.

Results: Among 32 patients, 28 cases were included and 18 gave consent. Median age at death was 45 days (range 15d to 9m); median length of last hospital stay was 27 days (range, 10-130 d). Only 5 families lived in hospital area while majority lived far from the hospital. Fifty percent of the children had univentricular heart. Sixteen children died in intensive care unit (ICU), 94% were mechanically ventilated, and 72% were on ECMO. Only 33% of parents were present at time of death and 15 parents could never hold their baby.

Seventy-two percent of parents report feeling unprepared for the way their child died, and so caregivers' perception. While 45% of parents realize imminent death only in the last hours, 60% of caregivers were aware of it 3 days before.

Conclusions: These children frequently succumb in ICUs, exposed to highly technical care. Both parents and caregivers perceive suffering at EOL. Caregivers have a precocious perception of death compared to parents, but are not able to prepare parents. This is the first study in Italy and Europe about EOL in CHD. These children are often deprived of the benefits of palliative care and, because of the severity of CHD, simultaneous care must be planned at diagnosis.

P072

The Development of an Integrated Respiratory-palliative Care Service Supporting Patients Requiring Long Term Tracheostomy-ventilation

Brook L., Koh M.

Naomi House Children's Hospice, Winchester, United Kingdom

Background: Long term ventilation and tracheostomy technologies are now commonly offered as treatment options to children with life-limiting conditions. As a children's hospice working closely with a specialist children's hospital, we looked at the numbers and needs of this population to explore the feasibility and need for developing a regional integrated respiratory-palliative service for these children.

Methods: We analysed the hospice and hospital's databases to define the numbers of palliative care children with tracheostomy ventilation support, their length of stay in hospital and barriers to discharge.

Results: Five years ago, the hospice supported 7 children with tracheostomies, 2 of whom required invasive ventilation. This has increased four-fold in 5 years to 29 children with tracheostomies, 9 requiring ventilation.

The specialist children's hospital has had 34 children with tracheostomy ventilation from 2010-2015.

As these children have very complex needs, it takes many months to recruit and train sufficient staff and parents to care for them at home. They can spend up to 9 months in hospital high dependency beds after they are medically fit for discharge. Parents also report that going straight home from this specialist clinical environment can be a very difficult adjustment.

Since 2014, the hospice has been offering short term respite stays for families and the tracheostomy ventilated children who are hospital inpatients awaiting a care package.

Conclusions: This successful co-working and robust care pathway between the hospice and hospital respiratory teams has led to the development of a joint, integrated multi-disciplinary service. This service has established a dedicated 3 bed ventilation unit at the children's hospice, enabling earlier discharge from hospital to a home-from-home setting, quality family time and access to play and education. This will transform the patients' experience at a critical point of their short lives.

P073

Complex Symptom Management in Advanced Pelvic Cancer: An Integrated Approach

Koh M.¹, Ramanujachar R.²

¹University Hospital Southampton, Paediatric Palliative Care, Southampton, United Kingdom, ²University Hospital Southampton, Paediatric Oncology, Southampton, United Kingdom

Background: The management of complex symptoms in patients with advanced pelvic cancer can be difficult, requiring multiple professionals and modalities. These patients may need hospitalisation that could be contrary to their goals and diminish their quality of life.

Methods: We present a 15 year old patient with a late localised pelvic relapse of a metastatic prostatic rhabdomyosarcoma. He had increasingly complex symptoms during his palliative phase lasting 14 months. He required coordinated care from various specialties across different hospitals and at home, to preserve his dignity, achieve a good quality of life and a peaceful death.

Results: The enlarging pelvic tumour caused urinary obstruction, nephropathy, bowel obstruction, lumbar radiculopathy, severe penile tip and scrotal pain. Various modalities of treatment were used to minimize side effects and optimize quality of life. He was able to go on short holidays, go to shops and restaurants and cook at home. He spent just 3 weeks in hospital in the last year of his life. He was able to make his priorities clear and make plans for his death.

Month	Specialty	Intervention
July	Urology	Insertion of JJ stents, bilateral ne prostomies, suprapubic catheter
July, August	Oncology	Palliative chemotherapy
August	Surgery	Formation of colostomy
From August	Palliative Care	Analgesia management: Opioids, Gabapentin, Amitriptyline, Ketamine. Supporting care at home
December	Radiotherapy	Palliative radiotherapy
December, February, March	Anaesthetics	Spinal steroids (Dec, Feb); Spinal phenol (Mar)
June	Neurosurgery	T2/T3 cordotomy
Throughout	Local paediatric team, psychology, social work	Co-ordination of specialty teams, care at home
August		Patient died peacefully at home

[Summary of services and interventions]

Conclusions:

- Symptom management can be challenging; coordinated services can be integrated even across different hospitals and at home to achieve patient goals.
- Recognising that expertise in multiple specialties can benefit our patients and the importance of engaging them in a timely way.
- The importance of keeping the patient's goals and priorities central to management decisions.

P074

Predictors of Quality of Life in Children with Cancer at the End-of-Life

Maaßen K.¹, Seyffert F.², Dr.Schmidt P.¹, Dr. Wager J.¹, Zernikow B.¹

¹German Paediatric Palliative Care Centre / German Paediatric Pain Centre, Datteln / University Witten/Herdecke, Department of Paediatric Pain Therapie and Paediatric Palliative Care, Datteln, Germany,

²University Witten/Herdecke, Department of Paediatric Pain Therapie and Paediatric Palliative Care, Datteln, Germany

Background: Children and adolescents diagnosed with cancer display a restricted quality of life (QoL). Especially, when the cancer will lead to death, a growing number of symptoms and treatments as well as the amount and quality of available care and support can affect QoL. Within this study, predictors of QoL at the end of life of children with cancer are investigated.

Methods: N=121 bereaved parents were interviewed retrospectively after they had lost their child due to cancer. Families were recruited from 18 pediatric oncology departments in North Rhine-Westphalia, Germany. Interviews were conducted by psychologists or members of a pediatric oncological team. The German version of the semi-structured questionnaire developed by Wolfe and colleagues (2000) was used. Within the interviews, e.g. cancer treatment, children's number and severity of symptoms, QoL, demographics as well as the planning of location of death at the end of life were assessed. QoL items included 8 questions regarding the child's mood and emotions as well peer interactions and school participation. So far, QoL items were analysed on a single item level. In this study, we aimed to investigate an underlying factor structure of QoL items.

Results: An exploratory factor analysis revealed that items measuring QoL load on two factors: mood/emotions and children's participation. They display a good internal consistency. A logistic regression to predict high QoL yielded the following results: no significant relationships of e.g. age and gender with high or low QoL, but a trend of cancer treatment and planning of location of death with high and low QoL.

Conclusion: The study confirms the suitability of our QoL scale and provides first indications of predictors of QoL in children who died of cancer.

P075

Our Living Wall: Art, Fun, Stories and Feeling Connected

Schwaebisch S., Mingard A.

Helen & Douglas House, Helen House, Oxford, United Kingdom

Background and aims: Our Living Wall (OLW) is a communal art wall at the heart of a children's hospice. We wanted to see whether a wall like this could impact on the happiness of children who visit. We are acutely aware of the challenges faced by these children (limited chances to play, lack of control, low self-esteem, limited social connection) and wanted to respond to these in a fun and creative way. The intention was for the project to be as inclusive as possible, accessible to all children (0-18) with life limiting conditions, regardless of age, ability, illness or background.

Methods: We created a huge wall made of large removable jigsaw pieces. Children and their families, with staff help, take a piece and make it their own, through paint, stickers, images, etc, before putting it back on the wall. All pieces are photographed; next to the wall and online is a rolling exhibition of past pieces. When the wall is full, the child/family can take their piece home or it can be recycled. Our Living Wall has been up and running since April 2015, with over 100 pieces created so far. We have tested the logistics of OLW, the best ways to create, exhibit and share works, learning a lot about practicalities (materials), as well as processes (photography, storage, consent). We also tested the impact of OLW through a mixed-method qualitative approach, including observation, group reflection, feedback cards and interviews.

Results: Initial findings suggest OLW had a positive impact, enabling children to have fun, build positive relationships, and develop a sense of self and belonging. We also identified a powerful impact on families, including bereaved families.

Conclusions: Through OLW, we have learnt a great deal about happiness (and sadness), and about all kinds of connections. OLW changes all the time, as children take it in new and exciting directions. We feel that OLW is transferrable to other settings.

P076

Comparing the Prognostic Accuracy of the 'Surprise' Question Across Paediatric Diagnostic Categories

Burke K.¹, Anderson A.-K.^{1,2}, Coombes L.¹, Menezes T.²

¹The Royal Marsden NHS Foundation Trust, Paediatrics, London, United Kingdom, ²Shooting Star Chase Children's Hospice, Guildford, United Kingdom

Background: The surprise question (SQ) 'would you be surprised if this patient died in the next 12 months' is widely used as a prognostic tool for identifying adult patients who are nearing the end of life. However, there appear to be no studies which have utilised this tool with a paediatric population. The aim of this study was to compare the prognostic accuracy of the SQ across different paediatric diagnostic categories.

Methods: From 2011 to 2013 a multidisciplinary team (MDT) in a children's hospice in England answered the SQ for patients under review or newly referred to the service.

Results: Children were categorised by their diagnosis using ICD 10 coding and the three most prevalent categories (neurology, oncology and congenital) were selected for analysis. The final sample included 224 children of which 26 died within 12 months of the SQ being asked.

Diagnosis	Sensitivity	Specificity	Positive Predictive Value (PPV)	Negative Predictive Value (NPV)	Accuracy	n
Neurology	87.5%	82.2%	25%	99%	82.5%	126
Oncology	100%	28.6%	54.6%	100%	61.5%	26
Congenital	66.7%	68.2%	16%	95.7%	68.1%	72

[Table 1]

Discussion: The MDT using the SQ showed the highest overall prognostic accuracy for children with neurological conditions. The tool was perfectly sensitive for capturing cancer patients who would die, although the MDT had a tendency to over predict death in patients with solid tumours leading to a low specificity value within this category. Both the sensitivity and specificity were somewhat low for patients with congenital conditions, suggesting this group may have the most unpredictable disease trajectory. The high NPV across all categories demonstrates that few patient deaths were unexpected.

Conclusion: The SQ can be a useful tool for recognising children who are at risk of dying and those who will remain stable over a 12 month period. This tool could facilitate service planning and resource allocation based on patient need and prompt professionals to initiate advance care planning with families.

Funding: Caroline Menez Trust

P077

Pediatric Pain Management Evaluation in Healthcare Providers

Escobosa-Sanchez O., Negrillo R., Amores M., Garcia-Hidalgo L., Gutierrez-Schiaffino G., Madrid Rodriguez A., Acha-Garcia T., Urda-Cardona A.

Hospital Regional Carlos Haya, UGC Pediatría, Málaga, Spain

Background and aims: Pain is a subjective and complex experience, it is the most frequent symptom in many diseases. Appropriate pain assessment and treatment have importance and are a challenge for healthcare providers. The right management of pain depends largely on the knowledge that professionals have about pain evaluation and treatment. The aim of this study is to assess the health professionals' training in a tertiary hospital in relation to child pain management in their daily practice.

Methods: A cross-sectional study was carried out through an anonymous self-administered questionnaire distributed among doctors and nurses from a pediatric hospital.

Results: We collected 133 answered questionnaires, 55.6% were answered by physicians (pediatricians 85.8%) and 44.4% nurses. Most respondents had more than 10 years of pediatric care experience. The most commonly used methods to assess pain were observing child's reactions and behavior or listening to parents explanations; 85.7% considered useful pain assessment scales, and they were used at some time by 60.9%. 66.9% used both pharmacological and no pharmacological treatment in their daily practice. The "WHO pain ladder" is known by 69.2%, however it was daily used only by 45.1% of respondents, being the most commonly used analgesic drug NSAIDs in routine practice (66.1%). Opioids are employed by 23.9% of professionals, 93.2% reported knowledge of its adverse effects, 54.1% considered opioids dangerous in and 80.4% believed that they generate dependency. 77.4% of respondents recognize their need for improving learning in pain management, both in evaluation methods and in the use of analgesics.

Conclusions: Health professionals involved in children's pain treatment have theoretical knowledge about the assessment and management of it, however, in daily clinical practice all diagnostic and therapeutic tools are not used. They consider appropriate continuing expanding their knowledge on this aspect, to improve the welfare of sick children.

P078

Analysis of Out-of-Ours Needs in Patients under Direct Care by a Palliative Pediatric Care Unit. An On-call 24/7 Service

Barceló Escario M., Rigal Andrés M., Moreno Martínez A., Pérez Martín M., Puertas Martín V.

Hospital Niño Jesus, Pediatric Palliative Care, Madrid, Spain

Background: Out-of-hours palliative care provision remains a challenge. Advance care planning (ACP) is a useful tool, but organizational strictures may still generate inconsistencies with the plan. 24 hours on-call specialist input may be an efficient complement. We describe the activity of a team that offers this service.

Methods: The PPC Team from Madrid offers direct care for patients in an advance stage of disease, being hospitalized or at home, under proper ACP. It includes 24/7 on-call assistance by 1 nurse and 1 doctor. When the attending professional considers advisable an out-of-hours visit is organized.

An Out-of-hours call registry was filled in from September 2015 to June 2016 (277 days).

Results: During this period the team offered on-call assistance to 203 patients. Of those 27 patients died, 17 being at home (63%). On average, there were 47.7 patients cared at home and 1.8 inpatients per day.

A total of 1410 out-of-hours telephone consultations occurred (average 5.1 per day). 75% were related to symptom control. Respiratory and neurologic symptoms were the most demanding, followed by pain. Other significant issues were: appointments (9%), posology (8%), medical devices or stomas (7%). 82% consultations were solved by phone indications. Respiratory, neurological and fever related ones were solved with only 1 or 2 calls in more than 75% cases. 13% episodes required an out-of-hours visit and 2% were referred to hospital.

Relating to home cared patients, these episodes generated 170 out-of hours visits, meaning an average of 1 urgent home visit every 1,33 days. Main motives were symptoms (79%), care of medical devices (8%) and death certification (8%).

Conclusion: A small specialist team on-call can efficiently cover the out-of-ours needs of patients with advanced disease, as a complement to ACP. Most consultations can be solved exclusively by phone intervention. Still, some urgencies will demand an out-of-hours visit.

P079

Improving Nation-wide Outcomes for Children and Families Supported by Paediatric Palliative Care. A National Quality of Care Collaborative

Herbert A., Baggio S., Slater P., Pedersen L.-A., Delaney A., Quality of Care Collaborative (QuoCCA) for Paediatric Palliative Care

Lady Cilento Children's Hospital, Paediatric Palliative Care Service, Level 12, South Brisbane, Australia

The overarching aim of this National collaborative is to promote high quality palliative care (PC) provided to children in close proximity to their home through education initiatives, evaluation and research. This is a mixed methodology study with different phases.

1. Baseline learning needs/capability involves an on-line learning needs analysis (LNA) and a Paediatric Palliative Care capability tool (PPC-CT) developed and used to determine a baseline of health clinicians in regional, rural and remote settings. Results from the LNA will develop education modules.

2. Educational initiatives and evaluations (Impacts) includes a 'pop-up' model for case consults and scheduled education sessions developed and reviewed with confidence surveys, using a 5 point Likert scale.

3. Consumer & Health Clinician Engagement (Perspectives) uses the Discovery Interview methodology to better understand parents', clinicians' and educators' perspectives relating to the service and educational initiatives. 152 participants have completed the LNA to date, with different findings from another study. Phase 2 indicates a positive impact on health clinicians' confidence levels. Phase 3 is pending ethics approval. The LNA results are indicative of the larger and diverse participant group. Educational sessions led to improved confidence for knowledge of resources, management of a new referral with PC needs and management of fear/anxiety. The highest average difference in paired pre/post confidence levels was for management of a new referral. Incidental education has led to unexpected networking benefits within acute settings. Given that each state has its own ethics committee, these processes were longer than anticipated. Funding for this project is limited and plans for a legacy are in place such as a website, education modules and mobile app. Funding from the Department of Health (Commonwealth) for nurse, allied health educators and medical fellows enabled these national initiatives.

P080

Complementary and Alternative Medicine Usage: A Source of Hope for Asian Families with Children in Palliative Care

Nuchprayoon I.^{1,2}, Vorapun A.²

¹Chulalongkorn University, Department of Pediatrics, Bangkok, Thailand, ²Wishing Well Foundation, Bangkok, Thailand

Background and aims: Complementary and alternative medicine is common in Asian countries. It is often offered by lay people with claims to cure cancer. We aim to assess the prevalence of CAM usage in children with cancer during palliative care.

Methods: Between January 2011 and December 2015, families of children with relapsed/recurrent cancer who chose palliative care were included for the study. We interviewed them whether they gave their child any form of CAM or nutritional supplement during family meeting and recorded answers. When possible, a sample of CAM was presented to our study team. For families who used CAM, we asked the reason behind the usage, and for the source of the medicine.

Results: Fifty-three families of cancer children were included in the study, 35 (66%) used some form of CAM or nutritional supplement. Essentially every family was offered CAM by one or more friends or relatives. Of the users, 19 (34%) used dry or fresh leaves to prepare hot water extract for daily drinks, 14 (36%) used local commercial preparations, usually capsules, which were marketed as food supplement for their children. Two families transplanted from home to communities where herbal therapy and strict diet plan were provided. Eighteen families denies the use of any form of CAM. For the users, they all reported a hope for cure or miracle from CAM.

Conclusion: Complementary and alternative medicine is very common among Asian cancer children during palliative care. It serve as a source of hope and probably help family accept palliative care.

P081

Preventing Acute Hospital Admissions through Specialist Palliative Care Intervention

Wastakaran C.¹, Mayer A.^{1,2}, Fraser L.³, Lyles L.⁴, Wensley C.⁵

¹Sheffield Childrens Hospital, Sheffield, United Kingdom, ²Bluebell Wood Childrens Hospice, Sheffield, United Kingdom, ³University of York, Department of Health Sciences, York, United Kingdom, ⁴Forget Me Not Childrens Hospice, Huddersfield, United Kingdom, ⁵York District General Hospital, York, United Kingdom

Background: Correctly utilising resources currently allocated for the care of children with palliative care needs may reduce demand on acute medical services and consequently on healthcare resources. This service evaluation aims to further our understanding of how children's palliative care services work to reduce the burden of acute admissions to NHS services. This knowledge will enable organisations to ensure provision is effective, appropriate, accessible and equitable, so guiding development of future services.

Method: In December 2015 prospective data was collected from all telephone contact from specialist paediatric palliative care teams (SPPC) in Yorkshire, UK. This included: caller details, age and diagnosis of the child, reason for call, outcome of call and whether the professional felt that this call had prevented a hospital admission. Patient's choice of place of end of life care and place of death was also explored.

Findings: 223 episodes of patient provider interaction were analysed from 5 service providers over a 3-month period. 94% (n=209/223) of patients were known to the SPPC teams. 32% (n=71/223) of calls were for symptom control advice and 34% (n=75/223) where to request a visit. If the SPPC was unavailable 16% (n=32/205) would have attended the childrens ward, 8% (n=16/205) the GP and 3% (n=6/205) the Emergency Department. The Median length of call was 11.8 minutes and took 30 minutes to complete. 46% (n= 68/147) of patients stated a preference that their end of life care be at home or in the hospice, this was also the preferred place of death for 62% (n=47/76) of patients.

Conclusions: Services potentially contribute to saving hospital admissions and reducing overall NHS healthcare costs by managing calls asking for advice, providing home visits and directly preventing hospital attendances by providing an alternative service. Importantly SPPC teams facilitate patient choice in the way of providing care at home.

P082

A Descriptive Narrative of the Journey to Establish a Fully Comprehensive Paediatric Palliative Care Service

Al-Hamad R., Ali S., Dighe M.

Bayt Abdullah Children's Hospice, Souk Al Dakhili, Kuwait

Background: The first stand-alone purpose built children's hospice in the Middle East. Established as an NGO with a Memorandum of Agreement with the Ministry of Health to offer a fully comprehensive Paediatric Palliative Care in a Region where the needs of children with life-limiting and life-threatening diseases were not recognized.

Aim: To describe how this model of care came about through the identification process of the needs and requirements from an NGO Organization not tied in to any particular model. Allowing us the creativity and flexibility for a set up that completely corresponds to the required needs.

Methods: To give a historical narrative of the process taken to fill the gaps identified incorporating cultural aspects of the Country to offer the best possible service.

Results: The Hospice Building underpins the interdisciplinary model of care to meet the requirements of the children and their families on a clinical, psychosocial and educational level for the best quality of life, reflected in the structure of the building.

Conclusion: The Building and services offered has resulted in a seamless comprehensive model of care affirming children's rights both individually and as part of a community.

P083

Hospital-based Pediatric Palliative Care Programs - A National Survey

Lacerda A.¹, Dinis A.², Mendes J.³, on behalf of the Taskforces of the Portuguese Society of Pediatrics and Association of Palliative Care

¹Portuguese Institute of Oncology, Pediatrics, Lisboa, Portugal, ²Hospital Pediátrico de Coimbra, Intensive Care, Coimbra, Portugal, ³Hospital São Francisco Xavier, Neonatology, Lisboa, Portugal

Background: Establishing hospital pediatric palliative care programs (HPPCP) aims to improve quality of care delivered to children with life-limiting/threatening conditions and their families. We aimed to evaluate its current status in a Western European country where no activity was recognized until 2013.

Methods: Email survey (10 questions, April'16, weekly reminders) to the medical head of national Pediatric Services (PS). Respondents were contacted for elucidations.

Results: Of 50 national PS [42 Pediatric Dept in General Hospitals (H), 4 specialized H (SH) -2 Oncology, 2 Cardiology-, 2 Children's H (CH) and 2 Maternities], 33(66%) replied; total 37 answers (4 separate Pediatrics/Neonatology). Ten teams are in place (6 Pediatrics, 2 Neonatology, 2 mixed), including in the 2 CH and 3 SH (the 4th did not reply); six in the Capital region. The first dates from 2005 (Oncology); most were created >2015. In different groupings, disciplines involved are medicine(10 teams), nursing(10), social service(7), psychology(5), education(2), therapy(2), nutrition(2), chaplain(2). One neonatal team includes an obstetrician, another a bereaved mother; an Oncology team includes volunteers. One team reports 24h coverage; 2 have 24h in-floor coverage. In 4 teams all members have PPC (or related) education; in 5 >50% have it; in 1 nobody has it. Ten professionals have post-graduate courses, 3 an MSc and one a PhD. Reported activities varied, most stating care planning/coordination as major role. Comparing PS w/ and w/o teams, the former are more likely to have a transition ($p=0.026$), a breaking bad news (0.011) or a community protocol (0.014) and homecare (0.031); no significant difference for bereavement care or in-house education. Nine PS are organizing teams (4 Pediatrics, 2 Neonatology, 3 mixed).

Conclusions: In only 3y major advances are recognized in the development of HPPCP, with impact in care provision. However, the need for education, training and guidance is paramount.

P084

Using the “Surprise Question”: Who Could Benefit from a Palliative Care Approach in a Secondary Hospital Paediatric Ward?

Cardoso A., Liz C., Soares S., Machado L., Moreira E., Monteiro C.

Centro Hospitalar do Tâmega e Sousa, Paediatrics, Penafiel, Portugal

Background: Paediatric palliative care (PPC) should begin at diagnosis and continue alongside directed treatment. Therefore, for patients eligible for PPC, a generic PPC approach would be beneficial even during hospital admissions for acute events.

A practical way of identifying the patients who could benefit from a PPC approach is by obtaining an affirmative answer to the “surprise question” (SQ): “would you not be surprised if the patient did not live to adulthood?”

The aim of this study was to characterize the patients who could benefit from a PPC approach in a secondary hospital (SH) paediatric ward.

Methods: A descriptive observational study was conducted. Data was collected from hospital discharge records (HDR) of all admissions to a Portuguese SH paediatric ward in 2015. Based on the information available on the HDR, two of the ward general paediatricians were asked the SQ regarding all admissions. The patients for whom there was an affirmative answer by both of the clinicians were selected. Information regarding length of stay, diagnosis, age and gender of the patients was collected and analyzed.

Results: In 2015, there were 770 admissions to the paediatric ward, from which 28 obtained an affirmative answer to the SQ. The final sample comprised 22 patients (5 had more than one admission), 57% male, ages from zero to 17 years old. The most common main diagnosis were cerebral palsy, epileptic encephalopathy, metabolic and neuromuscular diseases. The most frequent acute diagnosis were respiratory infections (57.1%), urinary tract infections (10.7%) and acute gastroenteritis (10.7%). There was one death. The mean length of stay was 9 days (SD 4.5, 1-21 days).

Discussion: Although not representing the main activity of SH paediatricians, patients with complex serious illnesses correspond to a considerable amount of inpatient admissions. The results reinforce the need for the development of PPC educational strategies for clinicians working in SH paediatric wards.

P085

Mind-body Approaches Can Facilitate Parental End-of-Life Decision Making and Life Closure Activities

Steinhorn D.¹, Din J.², Kemper K.³

¹Children's National Medical Center, PANDA Palliative Care Team, Washington, United States, ²Tao Center for Healing, Sacramento, United States, ³Ohio State University, Center for Integrative Health and Wellness, Columbia, United States

Background: Mindfulness based techniques focus one's attention on the moment, acknowledging feelings, thoughts, and sensations. Indigenous shamans journey (Native American "vision quest") to gain information about illness or life events. Meditation and deep prayer create an inner space in which new wisdom can be gained. Guided imagery provides relaxation, stress and symptom reduction. These mind-body approaches share a common thread of achieving a tranquil inner state in which new insights may 'appear' to patients, parents, or caregivers. An experienced provider (priest, rabbi, shaman, healer) can guide people to a mindful state to discover new insights. This state can aid parents in making difficult decisions for their children with incurable disease, especially in those world cultures which do not easily embrace Western cognitive behavioral therapies.

Methods: We utilized a mind-body method to facilitate a mindful state. Hospitalized children and their parents were offered guided sessions incorporating a shamanic journey guided by an experienced practitioner and physician, utilizing drum or rattle to focus the attention. In the mindful state, journeyers were asked to seek information regarding their (child's) condition.

Results: We conducted mindful journeying with 14 families/patients in the last 3 years. Families report new insights and understanding during the process and achieve new clarity on what decisions parents feel they need to make. There were no adverse reactions nor psychological repercussions. Several children were critically ill, terminally ill or legally brain dead. Families found the experience comforting, reassuring, and largely successful in achieving insights they were not able to achieve with conventional Western approaches.

Conclusion: Guided sessions of journeying to a mindful state can provide parents and children access to information that can help them understand their (child's) illness and facilitate decision making and life closure.

P086

Parental Coping in the Context of Having a Child who is Facing Death: A theoretical Framework

Darlington A.-S.¹, Korones D.², Norton S.³

¹University of Southampton, Southampton, United Kingdom, ²University of Rochester Medical Centre, Rochester, United States, ³University of Rochester, Rochester, United States

Background: While improvements in health care have resulted in many children with complex and life threatening conditions living longer, a proportion of them still die. Losing a child is described as the ultimate loss and can put parents at increased risk for anxiety and depression, and complicated grief.

Aims: Increasing our understanding of coping strategies that parents use under such extreme circumstances will increase our understanding of how to best provide support to families, in turn ensuring improved outcomes before and after the child's death. The aim was to develop a theoretical framework of parental coping.

Methods: Evidence from the literature was used to develop a theoretical framework to describe parental coping in the context of having a child with a life-limiting illness who is declining and eventually facing death. The reasoning and argument consists of three guiding elements: 1) the importance of approach as well as avoidance, as coping strategies, in the context of managing the extreme emotions, 2) the importance of the social aspect of coping within a family, whereby parents cope for others as well as for themselves, and 3) the importance of a flexible and balanced coping profile, with parents using different coping strategies simultaneously.

Results: Central to the proposed framework is that effective coping, in terms of adjustment, is achieved by balancing coping strategies: accessing different coping strategies simultaneously or in parallel with a specific focus on

- 1) approach and avoidance, and
- 2) coping aimed at self and others.

Conclusions: Increased understanding of parental coping strategies is essential for health professionals in order to support parents effectively. We hypothesise that high levels of use of each of the coping strategies will result in higher levels of well-being for parents, whereas higher use of a specific coping strategy and lower use of other coping strategies will result in lower levels of well-being for parents.

P088

Eleonora's Dream: A Project for Normal Life

Di Pede C.¹, De Tommasi V.², Agosto C.², Benini F.²

¹Department of Women's and Children's Health Padova University, Padova, Italy, ²Pediatric Palliative Care and Pain Service, Department of Women's and Children's Health Padova University, Padova, Italy

Background-aims: "Eleonora's dream" is a project dedicated to children with incurable diseases followed by the Veneto Pediatric Palliative Care Center. This project was born from the pain of the loss of a baby suffering from Spinal Muscular Atrophy1.

The dead girl's family offered short stays in their medical hotel to children with special rehabilitative and psychoemotive needs.

Aim: To allow children and their families to share some days all together in a protected environment and enjoy a period of respite from daily life; to offer an individual rehabilitation plan including idrokinesitherapy to all children.

Methods: The project lasted from Oct 2014 to June2016.

A questionnaire was proposed to parents and patients at the end of the stay. The questionnaire investigated the following areas: rehabilitative, psychoemotive, pain, final thoughts.

Results: 32 children were involved:18(57%) neuromuscular diseases, 4(12%) encephalopathies, 4(12%) metabolic disorders, 4(12%) genetic disorders, 1(3,5%) cardiac malformation, 1(3,5%) oncologic disease. Mean duration of stay was 7,15 days. 28 couples and 8 children answered to the questionnaire.

25 couples(78%) judged a positive impact of the stay on the physical abilities of their child. All couples reported a positive impact on the emotional state of their child and on the family harmony.

5 children (18%) complained of pain before starting the stay; 3 out of 5 (60%) reported a significative reduction at the end of the stay.

All children and families reported positive emotions regarding idrokinesytherapy and total satisfaction with the stay.

Conclusions: Family is a fundamental part in any pediatric palliative care program: it is actively involved in providing care and has a big responsibility in child caring; its burden is often too heavy to bear without adequate support; practical proposals for coping with isolation and financial insecurity can play an important part in the global management of this heavy situation.

P089

A Small Palliative Care Team for Children in Japan

Park M.-J.¹, Ishizeki R.²

¹Gunma Children's Medical Center, Department of Hematology/Oncology, Shibukawa, Japan, ²Gunma Children's Medical Center, Department of Nursing, Shibukawa, Japan

Background: Our hospital is a local children's medical center with 150 beds in the eastern part of Japan, and congenital heart surgery is performed on approximately 130 patients per year. Human resources are fewer in our hospital than in other children's hospitals, particularly for the provision of pediatric palliative care.

Method: We started a working group in 2011 and had study meetings on palliative care for children every month. A Palliative Care team was established in 2015, but did not have any full-time workers. In an attempt to deepen our understanding of palliative care for non-cancer patients, we held a lecture on the life and death of patients with congenital heart diseases in 2015. After the lecture, we conducted a survey on palliative care for children.

Results: Ninety-eight individuals attended the lecture and questionnaires were collected from 64. Fifty-four attendees answered that they needed to study palliative care for children, while 31 required assistance with communication in difficult settings. After the lecture, the number of consultations at the Department of Pediatric Cardiology increased. By June 2016, we had consultations on 16 patients as a Palliative Care team: 11 were non-cancer patients, including 7 patients with heart diseases. The contents of the consultations were related to family care, decision making, the introduction of home-based palliative care, and holding a multidisciplinary case conference. After the multidisciplinary case conference, overall evaluations for the Palliative Care team were satisfactory.

Discussion: Although our Palliative Care team is small, we have developed mutual acknowledgment and parallel collaborations with other professionals through extensive study meetings and case conferences. The goal of disease-directed interventions has led to increases in the numbers of consultations on advanced heart diseases.

P090

Developing a Resilient Workforce

Honeyman A.

Rainbow Trust Children's Charity, Chesterfield, United Kingdom

Background: Recent UK epidemiology data confirms that the prevalence of life limiting and life threatening conditions in children and young people is increasing and is significantly higher than previously assumed [Fraser et al 2011, 2013, 2015]. This heightened awareness has occurred in the wake of the worldwide financial crisis. The ensuing austerity measures have impacted upon delivery of the services upon which such families depend [Roberts et al 2012]. This project aimed to identify resilience and reflective practice skills amongst staff and volunteers delivering social palliative care and offer a programme of training and support to enhance resilience and reflective practice, [Goodrich et al 2015].

Method: Staff and volunteers were identified from one organisation and self-selected to answer pre and post course questionnaires designed to gather data about personal and ecological factors of levels of resilience. Training was provided to participants covering different areas that could be used to enhance levels of resilience. Organisational Leadership team support was obtained to promote a culture and processes that enhanced the development of resilience.

Results: Participants demonstrated areas of similarity of development around levels of awareness and motivation to sustain behaviours and attitudes that could promote and sustain their levels of resilience. The Organisational Leadership reviewed the results and supported the establishment of a programme of resilience development with other internal supportive processes.

Conclusions: The data has demonstrated the need to spend time focussing on self-care and the potential for this to remain unattended without support. This programme with other measures has the potential to impact the quality of service that staff and volunteers offer to families affected by life limiting or life threatening illness. Further work is now ongoing to develop a resilient based social model of palliative care for families.

P091

Survey on Palliative Care to Primary Care Pediatricians

Pelaez M.J., Madrid Rodríguez A., Martin M., Ramón M.Y., Corripio A.M., Urda A.L.

Hospital Regional Universitario de Málaga. Materno Infantil, Málaga, Spain

Introduction: Pediatric Palliative Care (PPC) represent an approach addressed to improve the quality of live in patients who suffer life-threatening illnesses, and their families. It acts through the prevention, identification and management of physical, psychological and spiritual problems. An effective PPC should embrace several disciplines, involve patient families and use every resource which is available in the community. It should take place from Tertiary Care to Primary Care (PC) levels, but also and most specially at home in a continuously way. Therefore, it is important that PC pediatricians have the capacity to perform this task. The objective of this survey is to assess the knowledge and involvement on PCC of Primary Care pediatricians.

Methods: Descriptive and cross-sectional analysis using an anonymous self-completed survey which was submitted via e-mail to PC pediatricians between January and February 2015.

Results: Seventy four surveys were fulfilled out of a sample of 157. The average length of service was 11 years. Half of respondents did not have any deceased patients during their years of service. Among the respondents, 62% had never assisted pediatric patients who required palliative care. Nearly 70% of the respondents was open to assist patients at the end of their lives if they were managed by a centralised PCC unit. Ninety two percent had a basic training on PCC, and none of the respondents had been provided an advance learning in this respect. Nearly the totality of the respondents agreed that children should die at home.

Conclusions: Due to their deep knowledge of children and their families, Primary Care pediatricians are the ideal candidates to assist children at home, being managed by a centralised PCC unit. The results of this survey show that most pediatricians are willing to perform this task. Therefore, it is essential that public health authorities could develop an improved training program which is addressed to these Primary Care professionals.

P092

What Is the Correct Dose?

Spolverato S., Mazza A., Martinolli F., De Tommasi V., Divisic A., Catalano I., Agosto C., Benini F.

Azienda Ospedaliera di Padova, Paediatric Palliative Care and Pain Management Service, Department of Women's and Children's Health Padova University, Padova, Italy

Background and aims: Oncologic children undergoing painful procedures require relief of pain and anxiety. Our aim was to evaluate differences (efficacy, adverse events and quality of awakening) in the use of midazolam (MDZ), ketamine, propofol managed by trained pediatricians.

Methods: The prospective observational study was performed in our service for sedation-analgesia. We collected induction and total doses of drugs administered (MDZ, ketamine, propofol) assessment of sedation (UMSS:4-5=adequate), occurrence of adverse events (respiratory, cardiovascular and neurological), recovery time, quality of awakening and parents opinions (by phone interview the day after). All patients received appropriate non-pharmacological therapy.

Results: 50 children were enrolled (39 m-16 f). 55 procedures were performed: 24 unilateral bone marrow aspiration (BMA), 12 bilateral BMA, 19 uni/bilateral BMA+lumbar puncture. The mean induction dose of drugs administered was: MDZ 0,11 mg/kg (0,05-0,18), ketamine 0,94 mg/kg (0,2-2,04), propofol 1,26 mg/kg (0,51-2,33). The mean total dose administered was: MDZ 0,12 mg/kg (0,05-0,29), ketamine 1,04 mg/kg (0,2-3,06), propofol 2,1 mg/kg (0,55-7,14). 33% required just the starting dose. An UMSS ≥ 4 was observed in 98% of the subjects following the induction. Mean recovery time was 103 min (11-328). 1 child had an episode of bronchospasm treated effectively with face mask ventilation and salbutamol. No other severe adverse effects were described. On recovery 25% patients experienced agitation. 1 patient at the onset experienced delirium requiring treatment with MDZ. 98% of parents gave a positive evaluation to the procedure. There was no relationship between the dose of drugs and the quality of awakening. There was no increase in the rate of nightmares on phone follow up the day after.

Conclusions: These data represent the background for a wider study with the aim of conforming the pharmacological approach of a sedoanalgesia team, within safety range.

P093

Fighting the Threat of Multidrug-resistant Strains: Hygiene Guidelines on a Paediatric Palliative Care Ward

Schmidt P.¹, Hasan C.¹, Simon A.², Zernikow B.¹

¹Childrens and Adolescents Hospital Datteln, Witten Herdecke/University, Pediatric Palliative Care Centre, Datteln, Germany, ²Saarland University Medical Centre, Pediatric Oncology and Haematology, Homburg/Saar, Germany

Background: The first German paediatric palliative care ward was established in 2010 in Datteln. Palliative care for children, adolescent and young adults who are suffering from a lifethreatening or fatal disease aims to relieve symptoms like dyspnea or pain and to offer age-based assistance in psychosocial issues. Every fifth child admitted to the pediatric palliative care ward with a lifethreatening disease is colonized with multidrug- resistant bacteria (MDR-bacteria).

Method: To prevent nosocomial transmission (NT) and infection (NI) specific hygiene guidelines - "Hygiene Guidelines - Palliative Care" - were developed for the pediatric palliative care ward. They apply to patients diagnosed with MDR-bacteria and deliberately dispense with single room isolation, thus allowing to comply with regulations for preventing infections while enabling young patients to participate in social and family centred care (e.g. art-therapy, music-therapy). This means aligning infection prophylaxis with an increased quality of life.

Results: The "Hygiene Guidelines - Palliative Care" were introduced to and implemented in the pediatric palliative care ward. This required additional education, training and information of patients and their families as well as the staff on the palliative care ward. The guidelines also needed to be accepted by the entire paediatric hospital.

Conclusion: The "Hygiene Guidelines - Palliative Care" allow compliance with regulations for preventing infections while at the same time enabling young patients to participate in social and family centred care programs. This means aligning infection prophylaxis with an increased quality of life.

P094

The Challenge of Accurate National Data Requires an Organisation's Strategic Response

Carragher P.

Children's Hospice Association Scotland, Central Services, Edinburgh, United Kingdom

Background: The accurate knowledge of the number of babies, children and young people (CYP) with palliative care needs in one whole country has only recently been published. Literature reviews show this to be unique as information about their stage of condition, underlying condition, gender, ethnicity and deprivation factors was also collected. This has necessitated a strategic response from a national children's hospice organisation. This study identified that there were significantly higher numbers than previously estimated, with 15404 in the 0-25 year age group. The report also was able to offer some palliative prioritisation with prevalence considered under the following subgroups: stable, unstable, deteriorating, and dying with 2201 in the last of three groups. 73% of deaths were in hospital, which has is causing the organisation to further explore its model of care.

Method: The organisation is presenting the study results to the Parliament's Cross Party Group for Palliative Care, national networks for children's palliative care and reporting it in the wider media, as well as to health board and joint integrated boards. The report is also being disseminated across the UK and internationally. It has engaged the resources of an academic economic analyst to explore the value of its care, and it will continue to investigate how to provide care to a greater number of CYP, and it will continue to work closely with principal investigators of the study.

Results: The effect of the above is currently being closely monitored, but there are already emerging trends particularly within neonatal palliative medicine, but across all ages, with the number of referrals to the children's hospice organisation already increasing but with a greater range of methods where care is being offered.

Conclusions: The study is already influencing national practice. Further dissemination is being undertaken to ensure its influence is optimal, and this will be reported at the conference.

P095

Evaluation of Advance Symptom Management Plans (ASMPs) in Paediatric Palliative Care

Sartori P.¹, Magrill A.², Maynard L.³

¹Addenbrookes Hospital, Cambridge, United Kingdom, ²University of Cambridge Medical School, Cambridge, United Kingdom, ³East Anglia's Children's Hospices, Cambridge, United Kingdom

Background: Individual ASMPs widely used in UK for end of life & palliative care (PC) but little literature, no published standards

2 part study to evaluate

- How ASMPs are written in UK
- Value of ASMPs for on-call team

Method: Survey Monkey questionnaires to

- Senior nursing/medical staff at children's hospices & other PC providers in UK
- Children's nurses/doctors providing on-call in one region.

Results:

UK practice

25 responders (17 institutions): 21 use ASMPs, 48% use proforma

ASMPs always written for: end of life 56%, unstable/deteriorating symptoms 39%, stable phase with complex symptoms 35%, long-term stable symptoms 9%

Symptoms always included: current 76%, disease specific symptoms not present at time 40%, common end of life symptoms 48%

Commonest symptoms: pain, nausea/vomiting, secretions, dyspnoea, agitation, seizures, acute illness.

Always include specific doses for medication: current 52%, suggested next dose of current 57%, 2nd line for current symptoms 38%, 1st line for anticipated symptoms 62%, 2nd line for anticipated symptoms 38%

Value: support on call team, coordination, communication, information for parents

Challenges: keeping ASMPs up to date; anticipating all symptoms

Regional survey of on-call team

31 responses (hospice nurse 45%, symptom management team 26%, paediatric oncology consultant 10%) all used ASMPs, 69% for more than 10 children

Experience 'always': useful 59%, clear 38%, increase confidence in managing children 59%, easy to use 46%, appropriately updated 24%

How often does plan fail to cover symptoms? often 3%, occasionally 68%, never 29%

Does plan suggest source of advice? always 37%, often 40%

Value: structure/planning

Challenge: updating.

Conclusion: ASMPs widely used. Less than 50% always include suggested medication/doses for anticipated symptoms, only 24% always appropriately updated. Developing standards to increase inclusion of anticipated symptoms would increase value for on-call teams & improve care of children with LL/LTI.

P096

Development of a System for Pain Monitoring and Evaluation at Home by a Platform of Telemedicine

De Zen L., Minetto M., Bagolin A., Lucchini A., Blandino L., Rizzetto M., Dall'Amico R., Scippa G.

AAS5 - Western Friuli - Pordenone, Pordenone, Italy

Introduction: Pain is a prevalent symptom in children with incurable disease and / or severe disability and can greatly affect quality of life . For these children there is a strong indication to encourage , whenever possible , home care assistance, through a network that includes many different operators.

Aim: Objective of the project is to allow the assessment, recording and monitoring of pain and relative treatment, making possible the real-time information sharing between all actors in the network.

Method: As part of the project to implement a telemedicine platform for pediatric home care and pediatric palliative care (PPC) and pain treatment, a software for recording pain symptom and related therapy was developed.

Results: The developed software is able to meet the following requirements:

- 1) ability to assess pain symptoms using a questionnaire consists of a series of multiple choice questions that, in a preordained or on request modality, the parents/ patient may respond by touchscreening (eg. pain or not pain, intensity, location, characteristics, ..);
- 2) ability to record the assumed therapy;
- 3) ability to monitor response to therapy;
- 4) possibility for the operator to remotely change the therapeutic scheme in the event of excessive pain or improvement of pain itself;
- 5) allowing multiple operators to view the progress of the symptom and of any changes made by other colleagues with a constant updating of the regimen.

The software is currently in use in a pilot group of patients for a test period of 6 months.

Conclusions: The project is a response to the welfare needs identified in the care of children eligible for PPC, at home, with a network of professionals which at different times and in different situations may be involved in pain and symptom management with the need of sharing and integration.

P097

Decision Making for Children with Life-limiting Illnesses: The Different Guises of 'Convincing' and 'Compromising'

Popejoy E.^{1,2}, Johnston B.³, Manning J.^{1,2}, Almack K.¹, Pollock K.¹

¹University of Nottingham, School of Health Sciences, Nottingham, United Kingdom, ²Nottingham University Hospitals NHS Trust, Nottingham, United Kingdom, ³University of Glasgow, Glasgow, United Kingdom

The number of children with life-threatening and life-limiting illnesses (LLI) in England has almost doubled in the last decade. Families and professionals caring for such children face difficult care and treatment decisions, however, little is known about the process by which these are made. This research aims to better understand multi-stakeholder decision making for children with LLI.

A longitudinal, qualitative case study approach was employed, involving nine core and two satellite cases, which were centred around a child and their family. Additional participants, important in their decision making, were nominated by the family. Data sources included interviews, observations and medical notes.

This paper explores the roles of 'convincing' and 'compromising' in making decisions for children with LLIs, as these play an important part in the complex negotiations involving multiple stakeholders. 'Convincing' occurs over time, aiming to encourage stakeholders to agree and 'compromising' acts as a stop-gap solution during the process of 'convincing'. These concepts are influenced by risk and stakeholder knowledge. They are also related to power imbalances in the stakeholder relationships and predominantly act in the direction of professional to family, although deviant cases will be explored.

Making decisions for children with LLIs is complex and often requires 'convincing' and 'compromising' for stakeholders to agree. Professionals and parents aim to make decisions which they consider are in the best interests of the child, but may sometimes disagree. As experts on the disease and child respectively, both have unique and essential contributions to making informed decisions about the child's best interests. When professionals and families work together in making best interests decisions, there is greater agreement and less need for 'convincing' and 'compromising', as open communication facilitates an understanding of the other stakeholders' perspective.

P098

A Randomized Trial of Yoga for Children Hospitalized with Sickle Cell Vaso-occlusive Crisis

Moody K.¹, Abrahams B.², Graffis R.¹, Santizo R.², Manwani D.², Carullo V.², Eugenio D.², Carroll A.³

¹Indiana University / Riley Hospital for Children at IU Health, Pediatrics, Indianapolis, United States, ²Albert Einstein College of Medicine / The Children's Hospital at Montefiore, Bronx, United States, ³Indiana University / Center for Pediatric and Adolescent Comparative Effectiveness Research, Pediatrics, Indianapolis, United States

Aims: Sickle cell vaso-occlusive crisis (VOC) remains an important cause of acute pain in pediatrics and the most common complication of sickle cell disease (SCD). Pain management recommendations in SCD include nonpharmacological interventions, such as yoga, however, direct evidence for yoga is lacking in children with VOC. The primary objective of this study was to compare the effectiveness of yoga versus a relaxation control on reducing pain in children with VOC. The secondary objectives were to compare the effectiveness of yoga versus a relaxation control on reducing anxiety, length of stay (LOS), and opioid use in children with VOC.

Methods: Patients were eligible if they had a diagnosis of SCD, were between 5 and 21 years old, were hospitalized for uncomplicated acute VOC, and had an initial pain score \geq 7. Subjects were stratified based on disease severity and randomized to either the yoga or relaxation control group.

Results: Seventy-three subjects were enrolled on the study. There were no significant differences in baseline clinical or demographic factors between the two groups. Compared with the control group, children randomized to yoga had a significantly greater reduction in mean pain score, (-0.6 ± 0.97 v. 0.0 ± 1.37 ; $p=0.027$). Thirteen patients (37%) on the yoga arm had a clinically significant decrease in pain score (≥ 1 point below baseline) versus six (17%) patients on the control arm ($p=0.059$). There were no significant differences in change in anxiety, LOS, or opioid use between the two groups.

Conclusion: This study provides evidence that yoga is an acceptable, feasible, and helpful adjunctive nonpharmacological intervention for hospitalized children with VOC. Future research should consider the study of yoga for children with SCD in the outpatient setting.

P099

Music Therapy and Paediatric Palliative Care: Translating Research into Clinical Practice to Improve the Effect of Music Therapy on Perceived Pain for Children with Life Limiting Conditions and their Families

Delaney A.¹, Herbert A.²

¹Children's Health Qld, Paediatric Palliative Care Service, Brisbane, Australia, ²Children's Health Queensland, Division of Medicine, Brisbane, Australia

Research recommends that children with life-limiting conditions (LLC) receive integrated Palliative and medical care. Music Therapy is a growing modality in medical settings despite a paucity of rigorous research. This presentation will describe innovative music therapy research within a State Wide Paediatric Palliative Care Service.

Due to the nature and sensitivity of paediatric palliative care, the ability to extrapolate data related to pain is limited. Only a small number of qualitative investigations supplement the largely anecdotal literature within PPC and MT. This project uses quantitative data within a mixed methods approach to explore the capacity of music therapy within the paediatric palliative care context. Pain scores and heart rate were obtained pre and post music therapy intervention in children with a LLC. Semi-structured qualitative interviews were also undertaken with parents currently caring for children and bereaved parents of a child with a LLC.

Findings suggest music therapy contributes positively to pain management and positive memory making. The author will explore the findings from this research with the capacity of music therapy providing containment for patients and families within an experience where quality of life is compromised.

It is anticipated findings will increase sustainability and equitable access to MT for PPC children and their families across a variety of settings by quantifying the physiological effects of music therapy (as non-pharmacological symptom support); contribute to the literature base for care provided by PPC services; validating clinical practice through its findings; and deepening the scope and understanding of music therapy professional practice.

P100

Development and Use of Advance Symptom Management Plans (ASMPs) for Children with Palliative Care Needs

Maynard L., Lynn D., Taylor H., Norman C., Moriarty N., Combeer J., Gardiner K.

East Anglia's Children's Hospices (EACH), Cambridge, United Kingdom

Background and aims: Individualised, child specific ASMPs are used in the UK for palliative and end of life care to guide the management of current and anticipated symptoms by professionals and family care givers.

Methods: Focus group with six nurse specialists and one consultant nurse to evaluate the development and use of ASMPs in one regional symptom management service.

Results:

Written ASMPs followed a standard template containing: Patient identifiers; weight; known allergies; overview of condition; resuscitation status and active care intervention plan; family priorities and preferences for place of care; specific, disease anticipated and common end of life symptoms including first and second line medication doses and non pharmacological strategies; and professional contact information for during and outside office hours.

Benefits were acknowledged as: Effective symptom management planning reduced the need for out of hours support; person-centred approach enhanced quality of care; standard template enabled stepped approach; faster access to medicines with anticipatory prescribing and 'just in case' dispensing.

Challenges were identified as: Time consuming to initiate, need for expert knowledge base to maintain high quality standard; identifying a prescriber; whilst prescribing formularies were perceived useful, prescribing guidance for neonatal palliative care patients was limited; nurse prescribing preferences caused occasional confusion; maintaining good information governance procedures when transferring ASMPs between different provider organisations; the need for timely review and ensuring accurate version control.

Conclusions: Knowledge of the child and the wider population which shares the child's diagnosis and knowledge of the science behind symptom management are key aspects of effective care planning and symptom management which are facilitated by the use of nurse written ASMPs which follow a standard template.

P101

Home care and Pediatric Palliative Care: Needs Fulfillment for Families Involved in Pediatric Palliative Care Program and Home Assistance in Pordenone - A Cross-sectional Observational Pilot Study

Luchini A.¹, De Zen L.¹, Bagolin A.¹, Grando R.², Morandin A.², Bidoli E.³

¹Azienda Ospedaliera Santa Maria degli Angeli Pordenone, Pediatric Oncology Ward, Pordenone, Italy,

²University of Udine, Nursing Degree, Pordenone, Italy, ³IRCSS Centro di Riferimento Oncologico Aviano, Epidemiology and Biostatistics Department, Aviano, Italy

Background and aims: The Pediatric Palliative Care (PPC) includes assistance to the child and his/her family from the time of diagnosis throughout the disease. In 2006, the Ministry of Health published "Palliative care addressed to the infant, child and adolescent" (2006), identifying the needs of the child, his/her family and PPC team. Since 2011 the Pediatric Palliative Home Care Service has been active in Pordenone. The Objective is to evaluate the level at which the needs of those families assisted by the Pediatric Palliative Home Care Service (PPHCS) in Pordenone are satisfied.

Methods: The questionnaire was developed considering Ministerial Document and it includes three areas of needs: knowledge, psychological and economical support and work and family organization.

Results: The survey highlighted a great satisfaction both for the information received by the family about their child's disease (92%) and the education received (96%). Also the psychological aspect seems to be largely satisfied (84%). The acceptance of psychic pain recorded a 72% satisfaction. 67% of caregivers expressed a favorable opinion about the respite care and 52% about the support received from the volunteer networks. The study showed a slight drop in satisfaction in the area mainly regarding the social aspects. Results have been observed considering children diseases: parents of children with oncology diseases expressed more satisfaction for the aspect of knowledge, while parents of children with non oncology diseases expressed more satisfaction for the social aspects. Both groups communicate equally satisfaction regarding psychological and economical support.

Conclusions: In general, families are very satisfied (88% very satisfied and 12% satisfied). The PPC service could be considered as a model for other centers of PPC and further studies could describe the factors that determine such satisfactory taking care/assistance.

P102

“What Can We Do Better?” Analyzing Responses from Parents of Children Who Died of Complex Congenital Heart Disease (CCHD) in Pediatric Intensive Care Unit (PICU)

Benedetti F.¹, Agosto C.¹, De Tommasi V.¹, Padalino M.², Milanesi O.³, Stellin G.², Benini F.¹

¹Azienda Ospedaliera Padova Università di Padova, Pediatric Palliative Care and Pain Service, Department of Woman and Child's Health, Padova, Italy, ²Azienda Ospedaliera Padova Università di Padova, Pediatric and Congenital Cardiac Surgery Unit, Department of Cardiac, Thoracic and Vascular Sciences, Padova, Italy, ³Azienda Ospedaliera Padova Università di Padova, Pediatric Cardiology Unit, Department of Woman and Child's Health, Padova, Italy

Background and aims: The death of a child has devastating implications for families and it is distressing for the health-care providers. Most of the deaths associated with CCHD occur in young children and in intensive care setting. Because of the lack of long-term relationships in PICU, physicians receive little feedback as to what had the greatest impact for the parents.

We tried to understand the family's needs in end-of-life (EOL) in order to meet this needs and discuss the implications for clinical care.

Materials and methods: It is a retrospective qualitative study based on parents' responses to 6 open-ended telephone-administered questions. We interviewed bereaved parents whose child died of CCHD in PICU between 2009 and 2012.

Results: We interviewed 18 parents of 18 children. The 1st question (Q) asked which was the child's most stressful experience: 8/18 parents reported lack of parent's love, 8/18 intensity of care. The 2nd Q asked which was the family's most stressful experience: 5/18 reported difficult family management and 7/18 distance from home. The 3rd Q explored the parent's most stressful experience: 3/18 said lack of time for themselves, 7/18 separation from family and 1/18 sense of impotence. The 4th Q was about what sustained them: 8/18 family love and 6/18 faith. The 5th Q asked to suggest an advice for other parents: 12/18 have no suggestions, 1/18 suggested to ask more information to physician, 1/18 suggested always to be focus on the best child's interest even when it could be the death. The 6th Q asked to indicate an advice for physicians: 8/18 advocated a better communication.

Conclusions: Parents' priorities are: “fulfill their role as parents”, “making sure the child doesn't suffer”, “always focus on the child best interest” but above all they asked honest and complete information. In our daily clinical care and policy we have to emphasize the role of communication in EOL in order to support and prepare them to afford the child's death.

P103

Nutrition and Pediatric Palliative Care: Questions and Challenges

Silva M.J.D.¹, Fronza B.L.¹, Manhães G.B.², Mello B.C.S.², Gallucci M.R.², Salustiano P.H.M.¹, Ferreira E.A.L.^{1,2,3}

¹Federal University of São Carlos- UFSCar, Medicine Department, São Carlos, Brazil, ²Irmandade da Santa Casa de Misericórdia de São Carlos - ISCMSC, São Carlos, Brazil, ³São Paulo State University (UNESP - Univ Estadual Paulista), Botucatu, Brazil

Background: In Pediatric Palliative Care, there are questions will rise during the course of the disease, leading the multidisciplinary team to follow up. Nutrition is a component that implies directly in palliative care, improving quality of life, if properly adjusted to the demands.

Aims: To discuss nutritional aspects in pediatric patients in palliative care.

Methods: Medical literature review in the area along with databases, using the descriptors "palliative care" and "nutrition" or "nutrology" and "children" or "pediatric".

Results: The assessment of child's nutritional status is fundamental for their welfare and it's used as a tool to diagnose organic disorders in pediatrics. Children in palliative care can be more susceptible to nutritional changes. Patients with encephalopathies require increased attention on a possible malnutrition. Patients with chronic diseases, using important cumulative dose of corticosteroid must have strict control of D vitamin and calcium. Nutritional planning and dyslipidemia control should be considered due to an increased possibility to develop obesity in those patients. Nutritional obstacles are also faced by oncologyc patients. Cachexia is one of the largest death contributing causes in these patients. In terminal patients, nutrition is individualized. If the patient is able to eat voluntarily, health professionals and relatives must consider their desires as much as possible, paying attention to their limitations. In cases in which the patient lacks the ability to ingest, artificial nutrition and hydration must be provided by staff beside the patient / family.

Conclusions: We conclude that, in pediatric palliative care, patients form heterogenous groups with particular needs. Therefore, nutrition must be individualized according to their particular needs, remembering that it goes beyond therapeutic care, due to a strong cultural meaning.

P104

Sharing the Learning from an Innovative Perinatal Hospice Service in the UK- An Integrative Approach Ensuring Quality Palliative Care from inside the Womb

Bleasdale E., Henry L., Dickins S., Branson P., Burton S., McKeating C., Martland C., Krastins C., Lyles L.
Forget Me Not Children's Hospice, Russell House, Huddersfield, United Kingdom

Due to advances in imaging technology and routine screening many life shortening fetal anomalies are detectable in the early antenatal period.

Whilst this allows families the opportunity to make extremely difficult decisions surrounding the progression of the pregnancy, families report a vast lack of support when deciding to continue the pregnancy in the knowledge that their baby may die before birth, during birth or shortly after.

In March 2014 the hospice was successful in securing funding for a one year Perinatal In-reach project with its initial aim of working more closely with regional neonatal units and facilitating choice for families.

Due to the success of the first years project the hospice saw a considerable increase in referrals and interest in it's services, in particular the support that could be offered for an early detection , in-utero baby with a life shortening anomaly.

In the 12 months prior to the project the hospice received one neonatal referral. In the past 24 months the hospice has supported 24 neonatal families and 29 families in the antenatal period.

As a result of the continuing interest and rise in referrals into our perinatal service the hospice has been fortunate enough to have secured a further three years of funding, enabling further development of our specialist perinatal service.

Offering families the opportunity to access specialist perinatal palliative support from point of diagnosis (whether in the antenatal or neonatal period) has immense benefits to all involved. It allows for an individualised, consistent and integrative approach to care, ensuring that families are offered the choices of place of care, place of death and the services and support they feel most beneficial to them as a family, resulting in a more compassionate and positive experience.

P105

Evaluation of the Need for a Paediatric Palliative Care Service in the West of Scotland: A Mixed Methods Analysis

Downie J.¹, Kidson C.², Gettrick A.², Bland R.M.^{1,3}

¹Royal Hospital for Children, Department of General Paediatrics, Glasgow, United Kingdom, ²Royal Hospital for Children, Paediatric Critical Care Unit, Glasgow, United Kingdom, ³University of Glasgow, Institute of Health and Wellbeing, Glasgow, United Kingdom

Aims: To determine paediatricians' perceptions of the palliative care needs of their patients, how well these are currently met, and to explore their experiences of current services.

Methods: A semi-structured survey, containing 22 questions, was sent by email to all senior paediatric doctors working in NHS Greater Glasgow (GGC) between October 2014 - April 2015 (107 recipients). Data were analysed using a mixed methods approach. Quantitative analysis was performed using Microsoft Excel; qualitative data were reviewed independently by the authors, common themes were identified, and higher order categories created.

Results: 76 (71%) recipients responded; the majority were consultants, (n = 72 , 95%). Most cared for children with palliative care needs (n=74, 98%), and for most (n=54, 71%) this constituted < 5% of their work load. Barriers to palliative care provision included lack of: resources, time, a lead clinician, and coordination of services. The most common palliative needs of patients were immediate end-of-life care (n=58, 91%), family (n=54, 84%), nutritional (n=52, 81%), and social/emotional support (n = 53, 83%). Most (n=67, 88%) considered that GGC would benefit from an in-hospital paediatric palliative care service, including a lead clinician, integration of services, staff education and bereavement counselling. Recipients wished to engage with such a service by: individual consults (n=56, 77%), telephone advice (n= 49, 64%), and shared care of specific patients (n= 49, 64%).

Conclusions: Paediatricians from a range of specialties lack the time, resources and skills to provide the palliative care children need, and would benefit from a dedicated service.

P106

First Steps on Development of Pediatric PC in Tajikistan

Kurbonbekova Z., Abidjonova N.

Open Society Institute - Tajikistan, Public Health Program, Dushanbe, Tajikistan

In Tajikistan it is still practiced that when a child with severe illness released from the hospital, parents will be obliged to give written statement that they are voluntarily take a child home and take over all responsibility for the fate of their child. Form of statistical information on the registration of varieties and forms of the congenital malformations (CM) is not developed and implemented yet, this complicates the design and planning of actions to improve the medical care given contingent of patients. Instructive documents on monitoring of the CM are still not developed. The formation of necessary packages of documents on PC can help children in this case, or at least will begin to solve this problem through drawing attention of the MoHSP to this issue.

To determine the effects and keep a record of children with chronic diseases for organization of PC service with the aim to create an appropriate conditions to improve the quality of life of children with severe chronic illnesses.

- Introduction into AR form of medical statistics the forms and varieties of CM in children
 - Collection of data on the number of the birth of children with CM in Tajikistan.
1. Implemented registration forms and varieties in the CM in the annual report form for Health Statistics
 2. Developed instruction on monitoring and registration of the CM in children.
 3. Developed the package of legal documents on PC
 4. Conducted analysis, developed draft clinical protocol "Prevention and treatment of chronic pain of somatic genesis children» and monitoring card for effectiveness of implementation and usage of CP.
- By the results of this project the issue of development of PC for children included in National plan of action Maternal and child health for the period of 2016 -2020./ Development of PC for children, develop standard and protocol on pediatric PC, capacity building of specialists/.

P107

Dressing Material in Children and Adolescents with Epidermolysis Bullosa: Experiences of Families

Hartenstein-Pinter A., Hübner-Möhler B., Wager J., Zernikow B.

Children's and Adolescents Hospital, Datteln, Witten/Herdecke University, Children's Palliative Care Centre, Datteln, Germany

Background and aims: Epidermolysis bullosa (EB) is an inherited, life-limiting disease with different subtypes, causing continuous blistering and wounds at skin and mucosa and requiring frequent and painful dressing changes. Families with a child suffering from EB use dressing materials on a daily basis. Common wound care products often lack a correct size, a good fit, comfort or atraumatic removal. Guidelines for wound care in EB emphasize the individual familial strategies. However, little is known about the family's experiences with wound care products. The aim of our study is the exploration of individual experiences with dressing material.

Methods: The study is part of a mixed-methods approach including qualitative and quantitative methods. In this first part (qualitative approach), semi-structured interviews will be conducted with 15-20 families to inquire their experiences and needs with respect to dressing materials. Parents' and children's reports will be interpreted using the methods of qualitative content analysis.

Results: Preliminary qualitative results on the family's experiences with dressing material will be presented. These results offer a deeper understanding on the choice of dressing material, the decision making process, individual preferences, material properties, particular requirements of material and suggestions for the improvement of dressing material.

Conclusion: The study addresses the specific needs of children and adolescents with EB and their relatives with respect to dressing material. The results will provide important information to facilitate daily wound care management and, at the best, improve the child's quality of life.

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P108

The Importance of Training in the Communication of Bad News to Parents

Ferreira E.A.L.^{1,2,3}, Manhães G.B.³, Silva M.J.D.¹, Nassif D.S.¹, Graçano D.C.³, Mello B.C.S.³, Gallucci M.R.³, Giusti A.L.^{1,3}

¹Federal University of São Carlos - UFSCar, Medical Department, São Carlos, Brazil, ²São Paulo State University (UNESP - Univ Estadual Paulista), Botucatu Medical School, Botucatu, Brazil, ³Irmãdade da Santa Casa de Misericórdia de São Carlos - ISCMSC, São Carlos, Brazil

Background: Reporting bad news is one an essential part of the formation of the doctor, but there are difficulties. Historically, doctors did not feel comfortable announcing severe illnesses to patients, because they understood that this could be associated with a poor prognosis. After this period, the opposite occurred: the news began to be given no criteria, which also did not bring a good result. In this way, has started education in bad news, with the help of protocols, leaving more secure professionals for these situations.

Objectives: Demonstrate the importance of the training and development of the skills of the professional of health in communicate bad news.

Methods: Analyze the profile of professionals in the area of health, with regard to education in reporting bad news, based on a short story of case.

Results: Newborn born from a mother who, during pregnancy, had a normal prenatal evaluation. After the delivery the firs pediatric examination show apgar, 9 at first minute and 10 after 5 minutes. All in all child visits the child had normal development until the seventh month of life started presenting seizures. Referred to the pediatric neurology who made the diagnosis of Burneville Pringle syndrome. A first professional told the family about the disease, treatment and possible dry, but this was resistant to what had been proposed. Then, a second professional, that was prepared during his graduation in communication of bad news, used them steps of the EPEC (*Education for Physicians on End-of-life Care*), in a new conversation with them parents, what resulted in the accession to the treatment; besides the satisfaction with them clarifications, conclusion of the therapy and in the establishment of an accompaniment medical.

Conclusion: Adherence to treatment after the timely guidance, reinforces the importance of the training of professionals in reporting bad news.

P109

Treatment of Cancer Pain in Pediatric Palliative and End-of-Life care: A Reflection

Ferreira E.A.L.^{1,2,3}, Silva M.J.D.¹, Salustiano P.H.M.¹, Nassif D.S.¹, Graçano D.C.², Campos G.A.P.², Barros G.A.M.³

¹Federal University of São Carlos - UFSCar, Medical Department, São Carlos, Brazil, ²Irmandade da Santa Casa de Misericórdia de São Carlos - ISCMSC, São Carlos, Brazil, ³São Paulo State University (UNESP - Univ Estadual Paulista), Botucatu Medical School, Botucatu, Brazil

Background: The pediatric palliative care can be defined as an active and total approach to care, from the time of diagnosis, encompassing the physical, emotional, spiritual and social for until death and beyond. It has its peculiarity as a portion of the population that has distinct characteristics, with multiple and extensive pathologies, often hereditary and rare, these being divided into diseases that limit the life and potentially fatal illness or that threaten life. Oncological diseases are among these diseases. There are several types of pediatric cancers, with heterogeneous prognosis. Some cancers may lead to end-of-life care and pain control is a very important part of it.

Aims: To discuss the importance of pain control in pediatric palliative care in patients with oncological diseases.

Methods: A search was conducted in the Pubmed database with descriptors "pain" and "pediatric" and "oncologic" or "cancer" and "palliative care" and "end-of-life", between the years 2010 to 2016. The selected articles were reviewed in conjunction with literature in the area to discuss the issue.

Results: Analgesics should be used as the "two-step strategy" of WHO, using the appropriate route of administration. Patient-controlled analgesia (PCA) can help in the control pain. Epidural and peripheral nerve blocks can be used in specific cases. Palliative sedation may be necessary. Benzodiazepines are the most commonly used medications, but propofol may be used in some cases. Oral mucositis affects the quality of life of patients and families. Prevention and treatment are essential. Low-energy laser can be used. Alternative therapies seem to reduce pain, as Reiki therapy and homeopathy. Culture and religion of each patient must be considered.

Conclusions: Pain control is an important part of end-of-life care, especially in children with oncological diseases. Thus different types of treatment should be considered.

P110

The Introduction of a Pediatric Palliative Care Service in a Medium-sized City in the Interior of Brazil: A Challenge

Ferreira E.A.L.^{1,2,3}, Campos G.A.P.², Nassif D.S.¹, Silva M.J.D.¹, Salustiano P.H.M.¹, Baptista F.H.¹, Gramasco H.H.F.¹, Barros G.A.M.³

¹Federal University of São Carlos - UFSCar, Medical Department, São Carlos, Brazil, ²Irmandade da Santa Casa de Misericórdia de São Carlos - ISCMSC, São Carlos, Brazil, ³São Paulo State University (UNESP - Univ Estadual Paulista), Botucatu Medical School, Botucatu, Brazil

Background: São Carlos is a Brazilian city located in the state of São Paulo. It is a city of health reference in the region, but It did not have a pediatric palliative care service. Thus, its implementation was initiated with the establishment of a Pediatric Rheumatology, Children's Palliative Care and Pain in Children Care Clinic with a tertiary hospital of the city (Irmandade da Santa Casa de Misericórdia) and Federal University of São Carlos, in March 2016.

Aim: To demonstrate the creation a pediatric palliative care service, and open a discussion about the difficulties of implementation.

Methods: This reflection was made based on the authors' experience, in addition to the data of initial visits to this clinic, together with medical literature of the field.

Results: The idea of creating a pediatric palliative care service emerged from the demand of patients in the region whose problems were not attended properly, especially those with chronic diseases. At first it was planned to create a Pediatric Rheumatology Clinic and another for Children Pain Care *plus* Pediatric Palliative Care, but the latter startled some health professionals and family members, who did not understand which diseases should be referred to it and neither how palliative care could help patients who are not terminally. Thus, the two clinics have merged into one, which increased demand of patients and helped against the prejudice they suffered. The number of patients is slowly increasing, still with more new cases than returns in each day of service. So far, we have not yet completed the multidisciplinary team, because there are so few people with proper preparation for pediatric palliative care.

Conclusion: There are still many difficulties in the implementation of pediatric palliative care services, ranging from the lack of qualified professionals, to the prejudice of health professionals and patients. The importance of creating strategies for its demystification must be reinforced.

P111

Leigh's Syndrome: Simultaneous Palliative Care to Improve Quality of Life

Visconti G., Pozzi D., Schiocchet E., Meroni A., Moneta L., Tagliabue C., Lonati G., Rizzi B.

Associazione Vidas, Milan, Italy

Leigh's syndrome (LS), subacute necrotizing encephalomyopathy, is a congenital disease caused by mutations in 1 of more than 75 different genes (1 in 36,000 newborns) and it's a severe neurological disorder. Most genes associated with LS are involved in the process of energy production in mitochondria. This condition is characterized by psychomotor regression, failure to thrive, early death. During a 3 month period we cared for 2 children with LS. We analyzed the clinical records of the 2 children to identify some indicators to improve the quality of the care. 2 male patients aged 15 (A) and 9 (C) years. We analyzed the family context, the clinical conditions, the assistential and psycho relational needs and identified some quality indicators of care. The family context: A was born in Italy from Egyptian parents and C was born in east Europe (parents moved to Italy for specialized medical assistance). A has a 12 years old brother. Clinical conditions (and therapy): pilepsy (A: refractory symptom), hyperthermia (A), bones deformities (A), respiratory insufficiency (A), needs NTP and mechanical ventilation (A), quadriplegia (A-C), drooling (A-C), severe cognitive impairment (A-C), spasticity (C), dysphagia (C). Psycho relational needs: cultural mediation for the child and psychological assistance for the parents and the brother. A has been referred to our PPCS for end of life care (term care 26 days). He died at home because of severe neurological deterioration. For C the PPCS has began early and is still active. From case analysis we can assume that a late beginning of PPCS does not translate in optimal relations between the patient-parents, the PPC team and the other medical specialists involved. Because of the clinical severity and the very rapid evolution of the LS, early PPCS is suggested in order to integrate palliative and non palliative paediatric care, to assure the best possible quality of life for the child and the parents and to allow parents to take care of their son with competence and compassion till the dead.

P112

Use of Methylphenidate in a Pediatric Oncology Patient with Fatigue

Duc J., Herbert A., Paediatric Palliative Care Service, Children's Health Queensland

Lady Cilento Children's Hospital (LCCH), Paediatric Palliative Care Service, South Brisbane, Australia

Background: Recent studies have found that many children with advanced cancer suffer from significant symptom burden. Of these symptoms, one of the most troublesome - and most difficult to manage - is that of fatigue.

Psychostimulants like methylphenidate have been shown to subjectively improve symptom scores of fatigue in adult patients at end of life. However very little empiric research has been conducted amongst an equivalent pediatric population.

Methods: Mr A is a 12yo boy with relapsed acute myeloid leukaemia. Mr A's pain has been well controlled with pharmacological and non-pharmacological strategies, yet fatigue remains a significant burden to Mr A's quality of life.

A holistic assessment and approach to addressing Mr A's fatigue was undertaken, with allied health input and maximisation of non-pharmacological therapies. Nevertheless, the impact of fatigue remained a significant source of distress for Mr A, impeding his ability to engage in even short activities with his school friends, siblings and family as he wished.

Mr A's case was discussed with extended members of the paediatric palliative care multidisciplinary team and a trial of low-dose methylphenidate was proposed.

Results: Mr A was commenced on methylphenidate 5mg mane. During this period of time, Mr A continued on his regular dose of slow and immediate release opioid, and adjuvant medication. Within days of commencement, Mr A's family noted significant improvement in his mood and ability to engage in short activities, with reported improvement also seen in Mr A's physical and cognitive function.

Conclusions: Psychostimulants such as methylphenidate may provide positive symptomatic benefits for children with end-stage cancer and burdensome fatigue. Nevertheless, discussion of potential negative side effects, further research, and consideration of placebo-controlled trials are warranted, to elaborate the potential scope, safety, and role of such medications in a pediatric palliative care setting.

P113

Born and Raised in the Hospital - A Clinical Case

Adrião M.^{1,2}, Cancelinha C.^{2,3}, Sousa M.R.^{2,4}, Martinho M.^{2,5}, Guerra P.^{1,2}

¹Centro Hospitalar de São João, Serviço de Pediatria, Porto, Portugal, ²Universidade Católica Portuguesa, Lisboa, Portugal, ³Centro Hospitalar e Universitário de Coimbra, Serviço de Pediatria, Coimbra, Portugal, ⁴Centro Hospitalar do Porto, Serviço de Pediatria, Porto, Portugal, ⁵Santa Casa da Misericórdia de Lisboa, Unidade de Cuidados Continuados e Paliativos, Lisboa, Portugal

Background: The evolution of Medicine has allowed children with otherwise fatal diseases to live for longer periods. The bio-psycho-social and spiritual model of Pediatric Palliative Care (PPC) interferes in both child and family life's quality and tries to ensure their needs and beliefs. This project aim is to analyze the clinical case of a five-year-old girl, M, who is still, the most of time, living in the same hospital she was born. She has short-bowel syndrome and is full-time dependent of parenteral nutrition through central venous catheter, alongside with other medical complications and an adverse social situation. She did not benefit from the support of a PPC team.

Methods: Identification of her clinical problems and the psychological, spiritual and social needs of M and her family. Within each field describe the problems and disclose what has been achieved. Reflection about the benefit of the intervention of a PPC specialized team and its holistic intervention in this particularly complex case.

Results: We acknowledge that there were positive measures implemented throughout M's development. However, there is plenty of room for improvement. With that in mind, we discuss the main interventions that could have been applied as well as the future actions that a PPC team might employ to improve M's and her family quality of life.

Conclusions: After our critical analysis of the case, we believe that the collaboration of a PPC team would highly benefit M's development and improvement of social condition. Any health provider should be able to recognize vulnerability and respect ethical principles such as justice, autonomy, benefit and non-maleficence.

There is evidence that its holistic intervention and the involvement of both child and family are of vital worth to upgrade a child's clinical course. Not only a therapeutic intervention but also the spiritual and the emotional well being of the child should be provided in each stage of the disease.

P114

Where Is the Line: The Art of Companionship

Kralovec J.

Klicek Foundation, Praha, Czech Republic

Based on 25 years of work with families with gravely sick children, our submission focuses on searching the boundary between systematic professional help, and helping as a fellow human being; the line between technique and relationship, between professional enthusiasm and respect for individual freedom and privacy, between obliging and empowering. We want to illustrate this with the example of several stories.

One temptation palliative care should resist can be described as excessive “scientification” and rigid „professionalization” of what should primarily be a service: we shouldn't allow our scientific ambitions - and the need to be perceived and respected as experts - to compromise our ability to help.

One of the specifics of the end-of-life care is that it is dealing with deeply personal, ultimate, existential issues that no professional intervention can solve. Most families don't long for another expert to enter their life, but for a friend, for a companion. What really counts is the relationship.

To be able to offer genuine support (together with the formal one), we need to re-define our understanding of who we are, where we stand, what's expected from us and what we expect from ourselves. And it also requires that we establish specific rapport with the family - it then changes our awareness and understanding of what the family deals with and suffers from - and it also profoundly changes the way families communicate their needs and wishes to us.

In retrospect, we are surprised to see that the families we have been accompanying found help in something we either almost hadn't noticed we were giving, or considered too common and/or insubstantial to even mention.

The outcome of personal interaction with the family - the impression left in the life of the family - may actually be positive and meaningful and healing even if the “professional” intervention delivered through the health-care system failed. And vice versa.

P115

National Art-project “Oscar and the Lady in Pink”: Drawing Attention to Palliative Care for Children in Ukraine

Shapoval-Deinega K.¹, Andriyishyn L.², Zhuravska T.³, Aseeva R.³, Bratsyun O.⁴, Lavrenuk L.⁵

¹International Renaissance Foundation, UA, Kyiv, Ukraine, ²Ivano-Frankivsk Regional Clinical Palliative Care Centre, UA, Ivano-Frankivsk, Ukraine, ³CF 'Mother Tereza', Ivano-Frankivsk, Ukraine, ⁴National Medical Academy of Post Graduate Education, Kyiv, Ukraine, ⁵Charitable Organization Childhood Cancer Foundation “CRAB”, Kyiv, Ukraine

Theatrical art-project “Oscar and the Lady in Pink”, developed due to joint creative efforts of artists from Ivano-Frankivsk and Kyiv, is a first attempt of polyphonic theatre performance of Schmitt's work in Ukraine. It is an effort to reveal different aspects of extraordinary world of little Oscar. The art-project offers syncretism of plastique, animation and drama. Such scenic story is an attempt to reach the most steel hearts through emotional story, full of pain and faith.

The purpose of the project is to draw attention of the society to problem of availability of palliative care for terminally ill Ukrainian children.

In Ukraine there is an urgent need for a system of palliative care for children. As of early 2015 only one children's hospital of palliative care for 20 young patients has been created on the basis of Nadvirne Orphanage in Ivano-Frankivsk region.

Majority of children who need palliative care, stay at home, under the supervision of parents. They faced serious problem, a lack of on-site mobile teams that provide palliative care at home and provide timely pain relief for seriously ill children.

Today, the first step is to recognize the right of hundreds of seriously ill Ukrainian children to receive high quality palliative care. To do this, the Ministry of Healthcare shall approve the development plan for and the standards of high quality of pediatric palliative care, educate health professionals, including family doctors, and ensure the work of in-patient and on-site mobile teams for children.

The premiere performance took place in Ivano-Frankivsk on October 4, 2015. Till June 2016 the play was played 28 times around Ukraine.

More than 40 000 US dollars (about 1 000 000 grivnas) were raised to support home care teams for children and for oncology ill children around Ukraine. Funds were disseminated between volunteers and medical groups from Rivne, Kyiv, Zaporizhzhya, Kirovograd, Poltava, Kharkiv, Lutsk, Ivano-Frankivsk, Odesa.

P116

Uncertainty: A Blessing and a Curse in Progressive Childhood Cancer the Illness Stories of Children, Parents and Physicians

De Clercq E., Elger B.S., Wangmo T.

University of Basel, Institute for Biomedical Ethics, Basel, Switzerland

Background: Although childhood cancer is a rare occurrence, for some families it is a hard reality. In the literature, there is increasing attention for parents' experiences during and after their child's treatment and for the work related stress and grief among nurses and physicians. However, the stories of children are rarely ever studied.

The study aimed to complement the results obtained from a large qualitative study on the attitudes and motives concerning end-of-life decisions in pediatric oncology in Switzerland. Progressive cancer was often cited as a reason to enhance children's role in the decision-making process, but it was also identified as one of the main reasons to exclude them out fear that it would affect their morale. The aim of this second analysis was to explore this contrasting finding.

Methods: The presented data come from 16 open-ended face-to-face interviews with palliative pediatric patients, their parents and treating physicians. In order to explore how participants make sense of their experiences, interviews were analyzed using Arthur Frank's dialogical narrative analysis.

Results: Uncertainty was experienced both as a blessing and a curse: it inhibited families' daily lives and their plans for the future, but it also enabled them to carry on and maintain hope. Likewise, uncertainty offered participants the opportunity to ward-off the idea that the child could die. In all the interviews, death was either ignored or contemplated as a possibility, but then immediately pushed away. Except for one patient, children never directly addressed the topic of death.

Conclusion: The way in which death was presented in the participants' stories raises important questions about how the social discourse on death is framed in terms of choice, autonomy and individuality. This discourse not only constrains the way in which children and adults can relate to the minor's death, it also constitutes an obstacle to children's participation in decision-making.