ENDORSED BY
The Italian Ministry of Health
Società Italiana di Cure Palliative - SICP
Patrocino SICP n. 7 del 31.01.2018

With the patronage of
FMPI - Italian Federation of Pediatricians

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Ulrika Kreicbergs, Professor, Head of the research group, The child and Family in Palliative Care, at Ersta Sköndal Bräcke University College/Karolinska Institutet, Stockholm, Sweden

Joan Marston, Children’s Palliative Care Development Consultant and Global Ambassador for ICPCN Chief, South Africa

Michelle Adrienne Meiring, Healthcare Practitioner, Specialising as a Paediatrician, in Pinelands, Cape Town, Western Cape, South Africa

Mary Ann Muckaden, Professor (Former Head), Department of Palliative Medicine, Tata Memorial Hospital, Mumbai, India. Past President, International Children's Palliative Care Network. President Indian Association of Palliative Care
Scientific Programme

WEDNESDAY
24th OCTOBER 2018

Opening Ceremony
17.30 - 19.45 Welcomes of participants and presentation of Guest of Honour
Franca Benini, Silvia Lefebvre D'Ovidio

Guest of Honour: Her Highness Sheikha Jawaher bint Mohammed Bin Sultan Al Qasimi

Double interview: ‘The Importance/Meaning Of Time’
Interviewer: Ross Drake, Interviewees: Caterina Albertini, Stefano Spigler
Presentation of Vittorio Ventafredda Award

Keynote Lecture: ‘Children's Palliative Care - a Game Changer for Paediatrics?’ - Joanne Wolfe

Launch of a WHO Guide for Health Care Planners, Implementers and Managers "Integrating Palliative Care and Symptom Relief into Paediatrics" - Marie-Charlotte Bouesseau

Presentation of No Pain for Children Awards for the Best Abstracts
Projection of No Pain for Children Award for the Best Video
Children's Hospice – Firefly World
Nino Kiknadze

20.00 - 21.30 Icebreaker - Welcome cocktail and buffet

THURSDAY
25th OCTOBER 2018

08.30 - 09.00 Gaining insights: Galenic Medicine and Traditional Remedies Used in PPC
David Steinhorn

09.00 - 10.30 Plenary session
Next Generation Approaches
Moderators: Ross Drake, Joanne Wolfe
- Innovative Methods to providing PPC - Stephen R. Connor
- New drugs, routes and approaches in PPC - Satbir Singh Jassal
- Medical Technology in PPC: an aid or a limit? - Julie Hauer

11.00 - 12.00 Oral presentation session (3 in parallel):
Working session I - Rainbow Session: Tools
Moderators: Sokhna Ndiaye, Danai Papadatou
- EMDR integration of non-pharmacological techniques for anxiety and trauma prevention in paediatric sedoanalgesia
Isabella Lucia Chiara Mariani Wigley
- "Informed decision-making is a valuable notion but a faulty tool"- pediatric health care providers perspectives on adolescent and young adult advance care planning in bone marrow transplant
Jennifer Needle
- Validation of the Spanish Version for Argentina of the Memorial Symptom Assessment Scale (MSAS) in Children from 2 to 20 years with cancer treated at two public hospitals in Buenos Aires city, Argentina
Maria Silvina Bevilacqua
- Digital tool for better communication in Children's Palliative Care (CPC)
Stephanie Vallianatos

Scientific Programme
• Closing remarks

**Working session II - Surveys and Systematic Reviews**
Moderators: Michelle Adrienne Meiring, Lori Wiener
- Bereavement support for parents of children who have died: A systematic review
  Tom Ainscough
- The prevalence and incidence of anxiety and depression in children and young people (CYP) with life-limiting conditions (LLC): A Systematic Review and Meta-Analysis
  Mary Barker
- Parental Preferences in Decisional Autonomy and Values-Guided Approaches in Tracheostomy Decisions
  Ken Pituch
- Parents’ awareness and perspectives on the pediatric palliative care in South Korea
  In Gyu Song
- Closing remarks

**Working session III - End of Life Care**
Moderators: Ana Lacerda, Mary Ann Muckaden
- Autonomy of competent children about end-of-life decisions: attitudes of Italian healthcare professionals
  Emanuele Castagno
- Palliative sedation in the end of life: Standard based evaluation of practice in a paediatric palliative care service
  Iñigo de Noriega Echevarría
- Where children die, a regional analysis of Child Death Overview Panel (CDOP) data
  Davina Hartley
- A workshop on how to recognise a dying child: Uncovering the complexities and professionals’ fears whilst helping to increase understanding
  Michelle Hills
- Closing remarks

13.30 - 14.30

**Oral presentation session (3 in parallel):**

**Working session IV - No Pain for Children Awards**
Moderators: Stephen R. Connor, Stefan J. Friedrichsdorf
- Parents’ experiences and wishes on information provision and decision-making in the care for their child with spinal muscular atrophy: A population survey
  Kim Beernaert
- Perinatal comfort care: implications for decision-making and perinatal outcomes in pregnant patients with complex fetal anomalies
  Valentina Giardini
- “Adding days to a life, or life to the days left”. Parents’ and physicians perspectives on decision-making in a Dutch interview study
  Marije A. Brouwer
- Bereaved parents are more likely to report that the health care did everything to support their child than non-bereaved - A two countries study of parents of children with severe SMA
  Elin Hjorth
- Closing remarks

**Working session V - Rainbow Session: Meeting Needs**
Moderators: Lucia De Zen, Daniel Garros
- Networking to increase access to Children’s Palliative Care: the ICPCN Experience
  Julia Downing
- Pediatric Palliative Care in Sub-Saharan Africa. What “knowledge” to transmit and how?
  Christine Edan
- Building a Paediatric Hospice in the Home (The Lego Project): How one health care region in Ireland co-ordinated existing child and family community services to ensure seamless, cost neutral community palliative care at the end of a child’s life
  Siobhan Gallagher
- Meeting expectations: student feedback from Irelands first Masters Programme for Children’s Palliative and Complex Care Nurses
  Claire Quinn
- Closing remarks

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**Scientific Programme**
Working session VI - Parents and Siblings
Moderators: Finella Craig, Federico Pellegatta
- Parents’ experiences of requests for organ and tissue donation: the value of asking
  Anne Sophie Darlington
- An exploration of the experience of caring for a child with a non-malignant life-limiting condition from the perspective of parents
  Fiona Hurley
- Anxiety and depression in bereaved parents after losing a child due to life-limiting diagnoses
  Camilla Lykke
- An analysis of use of ‘cool rooms’ in two children’s hospices in the UK
  Kate Renton
- Closing remarks

15.30 - 15.45  No pain for Children Award - 1st prize winning abstract
Pediatric death attributed to life-limiting conditions in Republic of Korea: exploring the nation-wide pediatric palliative care needs - Cho Hee Kim

15.45 - 17.15  Plenary session
The Needs of Young Adults in PPC and Model Transitions in PPC
Moderators: Mercedes Bernada, Ulrika Kreicbergs
- How needs change - Graziaiella Fava Vizziello
- The weaknesses and strengths of children’s palliative care in the age of transition from childhood to adulthood - Finella Craig
- Care models - Myra Bluebond-Langner

17.30 - 18.30  Networking Sessions (4 in parallel)
Preventing or Reducing Needle Pain for Hospitalized Children
Coordinator: Stefan J. Friedrichsdorf
How to assess and manage the distressed non-verbal child in PPC
Coordinator: Satbir Singh Jassal
Parents’ Time and Space when a Sick Twin Child is Surviving
Coordinator: Graziaiella Fava Vizziello
Intractable Symptoms in Children with Severe Impairment of the Central Nervous System: What Defines Success when Elimination of Symptoms is not Possible?
Coordinator: Julie Hauer
Ex. N. Title – Name

1. Dynamics of quantitative indicators of pediatric palliative care in the russian federation
   Elena Polevichenko

2. Sibling bereavement
   Silvia da Encarnação Barros Ramos

3. Qualitative medical education for children's palliative care in Ukraine. Increasing demand
   Vadym Ludymla Andriishyn

   Ksenia Shapovalov Deinego

5. Sedation at the End Of The Life In a Pediatric Palliative Care Unit
   Maria José Peláez Cantero

6. The role of the pediatric continuity nurse: there is no place like home
   Anarasa Bondioli

7. Defining Palliative Opportunities in Pediatric Patients with Solid Tumors
   Katharine Brock

8. Influenza strikes and ... costs
   Mirela Silvia Iancu

9. Pediatric Pain Profile-Cross Cultural Translation and Adaptation to Italian
   Silvia Soffritti

10. Implementation of a Transition Pathway in Paediatric Palliative Care: a quality improvement approach
    Joanne Balfe

11. Buccal opioid use for pain and dyspnoea for children with palliative care needs during end of life care
    Linda Maynard

12. Quality of Palliative Care for Paediatric Patients in hospital stage in Latvia
    Sofija Tomase

13. Caregiver burden, quality of life and their relationship to healthcare utilization in low-income parents of children with life-limiting conditions
    Andrea Postier

14. Thinking outside the box: A new approach to handle patients with multidrug resistant bacteria on a paediatric palliative care unit
    Pia Schmidt

15. Paediatric Advance Care Planning (pACP) and the Italian law: the outcome for children in a paediatric palliative care (PPC) programme
    Perina Lazzarini

16. Themes from the early days of children’s palliative care
    Joan Marston

17. The utilisation of hospice services following referral from malignancy tertiary team
    Fiona McElligott

18. The experience of childhood cancer survival: reports of adolescents
    Caroline Rossi de Faria Ichikawa

19. Family impact on the diagnosis of autism spectrum disorder
    Caroline Rossi de Faria Ichikawa

20. To provide difficult information to parents when their children have a brain tumour
    Elisabeth Björn

21. Spinal muscular atrophy type 1: An experience at a pediatric hospital
    Rodolfo Verna

22. Cutting to the chase: When do severely ill children's sleep problems require clinical attention?
    Larissa Alice Dreier

23. Continuous professional education in pediatric palliative care from recruitment stage
    Kateryna Burlak

    Liam Robson

25. Stepping up to integrate PPC in an intermediate care facility for children in Cape Town, South Africa
    Alex Daniels

26. Psychological home assistance in the Paediatric Palliative Care: an operative model
    Arianna Pezzotto

27. Medical marijuana use in pediatric oncology patients: single institution experience
    Ruth Ofir

28. Improving Medication Safety in a Children's Hospice; a quality improvement project
    Joanne Balfe

29. Caring for the team, caring for the child: developing a culture of staff support in a children's hospice
    Joanne Balfe

30. Half-hourly buccal medications for end of life symptom management for infants too small for subcutaneous infusion
    Pat Sartori

31. Options for management of pontocerebellar hypoplasia in light of a systematic review and patient cohort analysis
    Marinka Astrid de Groot

32. Sustainable innovations in CPC, based on the real patient story!
    Rachel Carolien Huizinga

33. Care analysis at a Pediatric Palliative Care Unit
    Maria Silvina Bevilacqua

34. Perinatal Palliative Care: a protocol is enough?
    Francesca Rusalen

35. How EPEC-p training changes PPC Ukraine
    Olena Riga

36. Development and implementation of a community-based pediatric palliative care network in the presence of a well rooted adult network
    Marco Bolognani

37. An assessment of the learning needs in Paediatric Palliative Care in Ireland
    Joanne Balfe

38. Adaptation of infusion solutions for symptom relief and sedation for children in palliative care at home
    Marinka Astrid Rachel de Groot

39. Ensuring their voice is heard: parental recruitment challenges in children’s palliative care
    Claire Quinn
Pediatric palliative care service markedly reduce hospital resource use - a Southeast Asian experience

Specialist paediatric palliative care for children and young people with cancer: a mixed methods systematic review

"I didn't knew a newborn could die!" Evaluating the impact of a new course in paediatric palliative care for midwife students in Belgium

A prospective study of preference in the place of death for children with life limiting conditions cared for by a tertiary palliative care service

Anticipating the future in pediatric palliative care by parents and health care professionals: a qualitative study

"Capturing the voice of families". A service review of an Irish Children's Charity on its 20th anniversary
## Scientific Programme

**FRIDAY 26th OCTOBER 2018**

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| 08.30 - 09.00 | Gaining insights: New Methods of Communication: Social Networking and PPC  
Federico Pellegatta                                           |
| 09.00 - 10.30 | Plenary session  
Breaking Walls: PPC and Paediatric Specialties - Part 1  
Moderators: Julie Hauer, Marcello Orzalesi  
- Perinatal/Neonatal PC - Elvira Parravicini  
- PPC in PICU: yes we can! - Daniel Garros  
- Inherited metabolic disease with life-limiting consequences - Carlo Dionisi Vici |
| 11.00 - 12.00 | Oral presentation session (3 in parallel):  
**Working session VII - Neonatal and Perinatal**  
Moderators: Richard Goldstein, Elvira Parravicini  
- Nursing Recommendations to improve Palliative Care in Neonatal Intensive Care - Joana Mendes  
- Outcomes of a High-Risk Cohort of infants with Complex Congenital Heart Disease referred to a Perinatal Palliative Care Service - Regina Okhuyzen-Cawley  
- ‘Juggling and struggling’ - parent and professional experiences of accessing and providing neonatal palliative care within a children's hospice - Jayne Price  
- Challenges of perinatal hospice care in Hungary - Eva Zsak  
- Closing remarks |
| 13.30 - 14.30 | Oral presentation session (3 in parallel):  
**Working session VIII - Rainbow Session: Research**  
Moderators: Jan Aldridge, Holly Spraker-Perlman  
- Nusinersen and Children with Spinal Muscular Atrophy type 1 (SMA 1): do they still need Pediatric Palliative Care (PPC)? - Caterina Agosto  
- Priorities for research on children and young people with life-limiting conditions: a systematic review and consultation exercise - Lorna Fraser  
- How much does a charitable hospice in the UK reduce admissions to NHS acute hospitals? - Michelle Hills  
- Home death for children - does inequality exist? - Mette Asbjoern Neergaard  
- Closing remarks |
|            | **Working session IX - Education and Training**  
Moderators: Myra Bluebond-Langner, Nancy F. Cincotta  
- A Descriptive Study of a Simulation Based Palliative Care Communication Curriculum for Pediatric Critical Care Fellows - Katharine Brock  
- Responding to global need for CPC education: an innovative multi-lingual approach - Alex Daniels  
- Project ECHO: creating a community of practice in children’s palliative care - Sharon McCloskey  
- Continuous professional education of clinicians and raising patients'/families' awareness improves pediatric palliative care services quality - Tetyana Vilchynska  
- Closing remarks |

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**Closing remarks**
Scientific Programme

- Creating a safe environment for children and parents: How the concept of holding, applied to paediatric palliative care (PPC), collides with Belgian child euthanasia procedure
  *Marie Friedel*

- Non-religious arguments to discuss pediatric euthanasia: why should pediatric palliative care use them
  *Joana Mendes*

- Beliefs, luck, and oppression associated with paediatric palliative care in South Korea: implications for a model of anti-oppressive surrogate decision-making
  *Seunghoon Oh*

- Closing remarks

**Working session XI - Research Issues**

Moderators: Ulrika Kreicbergs, Jennifer Snaman

- Longitudinal and systematic screening for depression and anxiety in children and adolescents with cancer
  *Gadi Abebe Campino*

- The importance of cyberspace for adolescents in Palliative Care
  *Camila Amaral Borghi*

- Supporting the Evolution of a Programme of Palliative Care Services for Children: Leadership Lessons Learnt
  *Sharon Foley*

- Regular GP consultations are associated with reduced rates of emergency care for children and young people with life limiting conditions
  *Stuart Jarvis*

- Closing remarks

**Working session XII - Advanced Care Planning**

Moderators: Mercedes Bernadá, Julie Hauer

- Pediatricians' experiences and attitudes regarding Advance Care Planning
  *Jurrianne C Fahner*

- Enduring ambivalence: PREPARE - Development of an advance care planning intervention in pediatric palliative care
  *Monika Führer*

- Training paediatricians to discuss advance care planning with families
  *Hannah Massey*

- Feasibility and acceptability of the Family Advance Care Planning (FACE) intervention for adolescent and young adult bone marrow transplant patients
  *Jennifer Needle*

- Closing remarks

15.30 - 17.00

**Plenary session**

**Breaking Walls: PPC and Paediatric Specialties - Part 2**

Moderators: Finella Craig, Lucia De Zen

- PPC in children without a diagnosis - Richard Goldstein
- Chronic communicable disorders - Michelle Adrienne Meiring
- Oncology - Ana Lacerda

17.15 - 18.15

**Networking Sessions (4 in parallel)**

**Encounters at the Time of Death**

Coordinator: Richard Goldstein

- Prenatal diagnosis of Life-limiting Genetic Condition Complicated with Severe Cardiac Anomalies
  Coordinator: Elvira Parravicini

- Paediatric Palliative Care in Acute Communicable Diseases
  Coordinator: Michelle Adrienne Meiring

- Preparing for the Withdrawal of Life Sustaining Therapy in Paediatric ICU in Diverse Cultural Contexts
  Coordinator: Daniel Garros
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Emilie Leroy

62 Osteosarcoma and severe treatment refractory cardiomyopathy: a case report
Maria Silva Bevilacqua

63 The ethical challenge of providing Palliative Care when a parent refuses potentially curative treatment- a case study
Manjiri Dighe

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Bernard Pierre Messing

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Lucie Hrdlickova

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Aisling Devitt

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Luiseilla Magnani

71 Fetal Echocardiography: What every Paediatric Palliative Care Provider Should know
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Mandira Reuther

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Julia Hackett

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Caroliny Rossi de Faria Ichikawa

75 Motivation of voluntary works in pediatric oncology
Caroliny Rossi de Faria Ichikawa

76 Assessment of the needs for pediatric palliative care in our province
Kata Rocchetti

77 Telephone consultation to improve pediatric palliative care across regions
Marinka Astrid Rachel de Groot

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Hiary Noonan

79 The importance of a family foundation in the global development of Children's Palliative Care
Joan Marston

80 Survey of primary care nurses on pediatric palliative care
Maria Jose Peláez Cantero

81 Poor support to siblings of children with cancer: A Swedish and Finnish parental follow-up
Malin Lövgren

82 Perception of palliative care organizations in Republic of Korea toward providing pediatric palliative care
Yi Ji Moon

83 Mortality in a pediatric palliative care unit: who, how, where and why?
Maria Jose Peláez Cantero

84 Emergency care for patients followed up by a pediatric palliative care unit
Maria Jose Peláez Cantero

85 Tracheostomy Care at Home: Yes we can. Caregivers’ Perceptions and Concerns
Lorenzo Giuntoli

86 Thinking out of the box: non opioid rotation method for management of opioid induced neurotoxicity OIN in pediatric cancer patient Case report
Iman Aldiri

87 The experience of losing a sibling in childhood or adolescence
Silvina da Encarnação Barros Ramos

88 PPC PROGRAMMES AND APPROACHES IN THE BIGGEST REGIONS IN UKRAINE – QUESTIONS OR BARRIERS?
Olena Riga

89 Children with extreme complexity: developing and maintaining nursing competency in a children’s hospice
Joanne Balfe

90 A path to specialized pediatric palliative care. Screening tools for attending pediatricians and members of palliative care teams
Merlin Deckers

91 Predictors of place of death among terminally ill children: A systematic review with meta-analyses
Sanne Wolff

92 Polypharmacy in Children with Life-limiting conditions
Joanne Balfe

93 Initiating discussions with Advanced Care Planning in Children with Severe Neurological Impairment; retrospective review to support quality improvement
Joanne Balfe

94 Models of Pediatric Palliative Oncology Outpatient Care – Benefits, Challenges, and Opportunities
Katherine Brock

95 Behind the Scenes: Care Coordination and Non-Billable Time Associated with Outpatient Pediatric Palliative Oncology
Katherine Brock

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**Scientific Programme**
SATURDAY
27th OCTOBER 2018

08.30 - 09.00  Gaining insights: The Representation of End of Life: Media and PPC
              Matteo Asti

09.00 - 10.30 Plenary session
              From Denial to Palliative: Practical Steps for Developing a PPC Program
              Moderators: Myra Bluebond-Langner, Danai Papadatou
              • Training - Stefan J. Friedrichsdorf
              • Awareness - changing the perception of PPC - Jan Aldridge
              • Working with policymakers to ensure palliative care for children - Joan Marston

              Moderators: Ann Goldman, Justin N. Baker
              • Omar Leone
              • Ross Drake
              • Kevin Kajitani, Akira Fukabori
              • Stefano Bellon
              • Mark Brown

12.45 - 13.15 Closing Ceremony
Care models
Bluebond-Langner M.

Louis Dundas Centre for Children's Palliative Care, Great Ormond Street Institute of Child Health, University College London, London, England

Advances in care of children with life limiting conditions (LLC) and life threatening illnesses (LTI) have led to ever increasing numbers of these children surviving into adolescence and young adulthood. With that has come increased concern in the palliative care sector not only about preparing adolescents and young adults (AYA), their parents and clinicians for transition to adult services, but also for preparing adult clinicians, institutions and services for their arrival and continued care and treatment. This presentation explores the issues that any good model of transition, regardless of health care system, must address. I approach this with the basic principles of palliative care in mind: reduce suffering, improve quality of life, provide family centred care, support decision making and coordinate services to achieve all of these goals.

Quality of life depends on both physiological and psychosocial factors. Expert pain and symptom control are essential in supporting quality of life at any age and at any stage of disease. Psychosocial factors may be underrated in their importance in supporting quality of life for AYA with LLCs and LTIs. Such factors range from individual and emotional ones (e.g., anxieties), to factors involving action and interaction (e.g., resilience and family relations).

Throughout the course of the illness patients and families respond to the intrusion of a serious illness by pushing back to achieve a new normal. They do so through routinizing the tasks of care, acquiring and managing information and the child and young person’s difference from others as well as through reassessment of priorities and reconceptualization of the future. Their approaches underpin and support the resilience which YP will rely upon in adapting to the new adult care environment.

One of the ways in which children, adolescents and young people acquire and act upon information is through participation in clinical consultations and through conversations on the wards. In recent years research has begun to describe and understand how complex this participation is and how complex and dynamic the AYAs relation to and interaction with parents and clinicians is. Such research supports the view that parents can remain deeply involved in decision making. AYAs often exhibit a robust relational autonomy. This is not dissimilar to adults’ involving a spouse or trusted companion in their decision making. This essential framework needs to be respected and preserved through and following transition. Hence a fundamental requirement for a transition process is that the clinical and non-clinical staff understand YPs support and decision making systems.

Transition frameworks need to be configured to support the adaptations by which AYA and their families protect and preserve quality of life and not to impede them. Transition needs to be designed not around the differences between the local systems of paediatric versus adult care but around needs and reality, the sources of strength, of the young person and the young person’s family or other support system. When we look at these closely we find that they are not so terribly different from those upon which older adults rely as well. Improvements in transition may thus be of benefit for more than AYA.
Innovative Methods to Providing PPC
Connor S.
Worldwide Hospice Palliative Care Alliance, London, United Kingdom

An estimated 21 million infants, children, and adolescents will need palliative care annually including those well before and near the end of life, according to a study that looked at prevalence of conditions requiring palliative care rather than mortality. A staggering 98% of these live in a low or middle income country. The Global Atlas of Palliative Care at the End of Life (2014) estimated that only 1.17 million children annually required palliative care at the end of life; and 2.34 million before end of life. A more recent report from the Lancet Commission on Palliative Care and Pain Relief (2017) estimated a total of 5.3 million children at or before the end of life needing palliative care. Both these official estimates are primarily based on mortality data and have been considered underestimations of the real need.

We know that children are less likely than adults to receive any palliative care and that palliative care service development is lagging for children compared to adults. A child may need palliative care for one day or for 20 years. Most children's palliative care can be found in high income countries. Models and methods of providing children's palliative care in high income countries do not always translate well to countries with limited resources. There are some excellent examples of children's palliative care programs and services in low and middle income countries, some based on high income models and others adapted to limited resource settings.

It is important for global palliative care development that care delivery models emphasize home based care both for children and adults and that programs and services are culturally sensitive and integrate into local health care delivery systems. Indigenous models of palliative care that evolve from existing values and norms are needed. Models range from purely home based, to comprehensive programs with home care - day care - freestanding inpatient - and care integrated with hospitals and clinics. Some inpatient children's palliative care is needed but an approach that supports families to safely care for children at home should be a model for sustainable and expandable palliative care for children.

In this session we will look at the variety of palliative care programs and services for infants, children, and adolescents that are available in both high income and lower income settings. Some of these countries include the UK, South Africa, Belarus, Argentina, New Zealand, Malaysia, Australia, Costa Rica, Malawi, Uganda, Romania, Zimbabwe, Chile, and others. We will examine creative examples of programming and service delivery that need to be expanded to meet the immense need for pediatric palliative care globally. We will examine some of the lessons learned from building children's palliative care with scarce resources and look at some pragmatic policy solutions that can lead to a world where all children that need palliative care can access the services, medications, and care they need.
How needs change
Fava Vizziello G.

The extremely reach clinical literature on pediatric palliative care and the political guidance lines that different States or Scientific research and clinical centers edited ,show the change of the meaning of palliative, (from the latin “palliare “ i.e. to cloack, to enveloppe) in these last 30 years for the organization of attitudes that are not only for people who are supposed to die in a short time. The real revolution of PPC is that sanitary services are supposed to take care not only of the pain and the sickness, but of the state, quality of life of the patient, caregivers and of his surrounding . Which would be important in all the situation with more or less time and necessary training. Protection from unwanted changes of the body, and help for cognitive , cultural , affective , spiritual needs because the patient is primarily a human being as well as the people who are attending at him and they all need to be in a space as desirable as possible for that adolescent, in that moment, like european laws ask, since 50 years, to all the States.

In the years the more difficult situations have been studied particularly from the institutions that are taking care of a certain problem: first of all cancers , neurological problems , street accidents with the enormous problems of therapeutic or natural coma and the waiting time for wakening moment, terminal anorexia nervosa , genetics and not rare sickness. Naturally there are different needs that depend on the moment the pathology started: abruptly in adolescence because of an aggressive sarcoma or in latency for the chronicization of a cancer? Different ages in this very changing technological world create very different problems: in the first situation we are dealing with a millennial that consider the smartphone fundamental in his everyday life. This AYA has an enormous part of his social life and also of answers (right or wrong)to his own big questions in the network community, in the second situation, very likely the adolescent has a smartphone for playing and eventually for sporadic messages with his schollmates, no longer necessarily very interested to chat with him, like frequently we see in school, where the presence of Skipe for the child that is sick, is not accepted by peers who must stay more silent in class.

So, we'll take into consideration what makes so difficult to deal for adolescents with death that is just the opposite of “making planes and dream a future “in different situations”. We partly consider also usual the conflicts that in the past , were so typical of this period of life , but we'll consider the smartphone, competitor of parents. Technological instruments make patients to go back and for in the relationship with their parents and give them and take away from them an important part of confidence and intimacy they would like to have with their children for two reasons:

a. the quantity of informations on sickness the AYA will find in internet that they will trust much more then their parents,

b. because it is difficult to think that in such lack of certitude for their own life , AYA will develop fobo : anxiety for better option then the one they are thinking about, often aroused because of suggestions of the social media, and fomo ,fear of missing something very important. Another aspect is sexual life and especially reproductive possibilities , to day really changed for the new possibilities of conserving gametes for the moment they might be useful for them or for a promise that a partner may have done before the death of the beloved one.
PPC and Paediatric Specialties - Oncology
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Cancer, whose incidence is increasing, remains the leading cause of non-accidental death in Paediatrics. In fact, Paediatric Palliative Care (PPC) owes its establishment to a child dying with cancer, Helen. In developed countries, as 4 in 5 children currently become long-term survivors, the burden of late effects (“the cost of cure”) is also increasing.

In the early days of Paediatric Oncology (PO), mortality was very high. So, it is no surprise that, amidst a complex care process, clinicians have always been attentive to psychosocial issues, albeit focusing especially on end of life (EoL). This is usually marked by aggressive care, although trajectories and experiences differ among haematological, solid, or brain tumours. Grounded on these beginnings, in 1999 the International Society of Pediatric Oncology issued “guidelines on assisting the terminally ill child during the period of transition from curative to palliative care.”

It is increasingly recognized that loss and suffering begin not at EoL or death, but rather at diagnosis and may persist after survival. As one mother put it, there is no “new normal” after your child is diagnosed with cancer. The family’s coping ability is affected by distress, loss of control, and unpredictability.

PO must aim for holistic and continued care focusing on quality of life, enhancing communication, defining realistic goals, and supporting (or redirecting) hope. Fortunately, recent years have seen a growing understanding within Oncology of the need for early integration with PC, offering not only symptom control but also essential coping tools. Still, this requires battling the “they are not ready yet” syndrome.

How can PO and PPC work together? How to overcome the main barriers for integration instead of transition-the view of mutual exclusivity, the patient ownership, the lack of clear referral criteria? How to reconcile this ideal with the growing number of 2nd, 3rd, … nth line treatments, some offering the slightest chance for a cure (often at a hefty price, and not only financially)?

Several models have been proposed, the latest being a combined training program (“Pediatric Palliative Oncology”) aiming for embedded expertise. While this might be an ideal scenario, not all institutions have the resources and/or the need for this full time position (and the additional multidisciplinary team). Indeed, PO units present diversely-from small to huge, from rural to urban, from departments within oncology centers, general hospitals or children’s hospitals to (very rare) stand-alone hospitals, from clinical-based to research-based state of the art facilities...

Although in some (mostly anglo-saxon) countries early integration seems to be well accepted, evidence from diverse settings is needed on professionals’ barriers and on users’ points of view. Therefore, the first step for integration, besides an assessment of the needs and resources, must be an understanding of the local culture (institution and society). Only then may the most appropriate model be identified.

Maybe the best approach is the one suggested by Kaye et al, “normalizing” PPC per institutional culture and standard of care. Education and training in PPC become mandatory for staff in PO, Neuro-Oncology, and BMT units. Every child diagnosed with cancer gets an early evaluation, just like any baseline nutritional assessment. High-risk or complex cases receive specialized consultation. Follow-up is maintained or renewed in critical times (life-threatening event, refractory, relapsed or progressive disease, admission to BMT unit, enrolment in early phase clinical trials, EoL), dynamically shifting the focus of care according to needs.

9. Levine DR et al. Patients’ and parents’ needs, attitudes, and perceptions about early Palliative Care integration in Pediatric Oncology. JAMA Oncol 2017;3:1214.
**Palliative Care in the PICU: Yes, we Can!**

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**Introduction:** According to the WHO, "palliative care" (PC) promotes the quality of life of patients and their families facing life-threatening illnesses through the prevention and relief of suffering, early identification, evaluation and impeccable treatment of pain and other problems of physical, psychosocial and spiritual nature.

About 55% of all Pediatric Intensive care Unit (PICU) patients have complex chronic conditions, with increased risk of mortality and morbidity. Furthermore, the majority of children who die in hospital, do so inside the walls of an ICU. According to the American Academy of Pediatrics, such patients will benefit from "an integrated model of PC that continues throughout the course of the disease regardless of outcome". The main objective of PC is to maximize quality of life, not the quality of death, emphasizing the comfort, general well-being of children and their families experiencing situations that threaten and/or limit life, through comprehensive and holistic approach.

**Objective:** We aim to demonstrate that it is always possible to treat the patient with a life-limiting illness with compassion, respect and dignity so that the quality of their life, even if short, is maximized, despite the model of PC that the PICU has adopted. We will also discuss the possible repercussions for the multidisciplinary team when engaging with patients whose trajectories involve them emotionally.

**Content:** A multi center Canadian study reported that only 5-12% of hospitalized children who could benefit from PC actually receive such dedicated service. There is no prospective study to better determine PC needs in any specific PICU setting. However, the resistance can be great; it maybe due in part to the very name of this type of service. There is a "black cloud", a sinister air, and a stigma that surrounds the name palliative. The team confuses the involvement of PC with the idea of "losing hope", giving up, and what is worse, admitting their impotence in healing the patient. How can we improve care at the course of the hospitalization and optimize end of life care? Studies with physicians and nurses have shown that the greatest barriers to establishing advance directives were the parent’s ‘unrealistic expectations about their children’s illness, misunderstanding of the prognosis between the team and the family, and the fact that “parents are not yet ready to discuss the subject ” in the physicians view. Physicians also have reported more commonly “not knowing the right thing to say”. At the same time, 71% of all doctors believe that this conversation about end of life was actually done too late in the patient´clinical course.

The models that exist for PC in the PICU are:  
A) Integrated Care Model (ICM) of PC integrates "being present" with "doing"; it empowers the team to develop a sensitivity to the children's and families' problems and addresses challenges in the health environment that is familiar to them, such as clinical, moral and ethical issues. This integrative model, however, requires multidisciplinary team education and training in the art of listening, promoting respect for the child and family within the whole organization, encouraging the cultivation of collaborative connections, managing the uncertainty inherent in intensive care, tolerating ambiguity, making peace with the conflicts and commit to the care of the team itself to avoid moral distress, compassion fatigue and burn out.  
B) The PC CONSULTANT SERVICE model, characterized by the existence of a PC team that serves the whole hospital, and can be called to the PICU when it is necessary. Although at least 49% of US independent children’s hospitals have a designated PC service, most programs only offer inpatient services on weekdays. In the model of CP consulting teams, even in rich countries are highly dependent on institutional financial support. Such specialists can educate and support the PICU team with symptom management, decision making in complex scenarios, etc, but never taking over the care or being intrusive, rather complementing the PICU team's role.
Conclusion: Regardless of the model of PC delivery in the PICU, the adoption of general PC principles of care is fundamental to the well being of our patients, especially considering the growing number of children with chronic and life-limiting diseases receiving life-prolonging treatments. Defining well the right balance between the continuation of aggressive curative therapy, and the parallel palliative support, is paramount so that the patient receives the best care in all phases of his illness! Understanding where we want to go makes the path to reach that end much easier. And for this, it is necessary not only to understand the patient’s biology (disease and prognosis), but especially his/her biography, the life values of each patient and their families, so their PICU experience and the care at the most crucial period of their trajectory can be optimized.
Pediatric Palliative Care in Children without a Diagnosis

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There are approximately 7000 rare human diseases and about half of those who suffer from them are children, many dying before their fifth birthday. Undiagnosed diseases are a subcategory of rare diseases, comprised of conditions that either never receive a diagnosis or elude definitive diagnosis for years. In common, these diseases are often misdiagnosed, lack a definitive cause, and typically have no established treatment or cure. Patients and their families experience highly variable and unpredictable disease courses, and can be frustrated by a lack of available expertise. These particular characteristics define an important patient population for palliative care, worthy of their own considerations.

This session will review important elements of undiagnosed diseases and their implications for palliative care. We will review research on elements of medical uncertainty and the inability to structure the meaning of illness-related events, with attention to their relationship to family coping factors; symptom profiles in undiagnosed in comparison to diagnosed diseases, and associations with decision making; and research on meaning-making and its relationship with long term adjustment. Finally, we will focus on Sudden Unexpected Death in Pediatrics as an example of undiagnosed disease with high uncertainty and limited variability in the clinical exposure.

We will present original research on 408 mothers bereaved from SIDS, examining Prolonged Grief Disorder and its components as an outcome to their loss without established cause, with additional attention to self-blame and a parent's inability to make sense of the loss. We found 50% of the mothers met diagnostic criteria for Prolonged Grief Disorder in a period from 2-48 months following the loss, immaterial of social circumstances, and that they exhibited patterns in their grief-related symptom profiles. We will present research on pre-loss personal factors in a subset of the bereaved mothers and their relationship to grief outcomes, including pre-loss depression, anxiety, alcohol use, age, only child and previous losses.

This preliminary data identifies those at greatest risk for more severe grief reactions to use when designing bereavement support programs, since universal approaches to bereavement support have not been found to be effective and available resources are generally limited. Lack of diagnosis is associated with important palliative care outcomes, including decision making and coping.
“Policy maker” is a broad term that covers all the people responsible for formulating or amending policy. This can be at local, regional, national or international level and include a wide range of people in a variety of positions and with different interests and expertise. They may be government employees or political figures. One major challenge is that high-level government officials and politicians often change positions, and advocates may find themselves interacting with a number of different policy-makers in the process of developing or changing policy. Policy makers are people first, and will usually have the best-interest of their constituents at heart, usually open to listening to information that can improve their service and position. They can be approached to collaborate on developing a policy for children’s palliative care on both a professional and personal level. As individuals they may be affected by personal experience or even loss, or influenced by stories of children who require palliative care or who have been helped by palliative care. Often the most effective advocates with policy-makers are parents, close family members or even the child or young adult themselves. The Global Voices campaign established by the Worldwide Hospice Palliative Care Alliance has even reached the Director General of the World Health Organisation and led to a meeting with Lucy Watts, a Global Ambassador for Children’s Palliative Care. While policy-makers may not have expertise in children’s palliative care do they bring to the partnership other essential skills and experience, particularly when it comes to understanding complex issues, assimilating knowledge and taking ideas forward. However, they are approached by many other individuals and interest groups; influenced by budget restrictions, conflicting priorities, national and international crises, political views and public opinion. Children’s palliative care advocates need patience, dedication, excellent communication skills, a clear message and a willingness to collaborate. Policies can take many years to be developed, written and approved; and even when this is completed, without adequate finances these policies cannot be implemented. The global impact of the World Health Assembly Resolution 67:19 of 24 May 2014 “Strengthening of palliative care as a component of comprehensive care throughout the life course” accepted by all member states has influenced policy development in many different countries, such as South Africa. There are an increasing number of successful partnerships that have resulted in policies that have been accepted, such as the policy on children's palliative care in Italy which was an early groundbreaking development; while Malawi is an excellent example of a low-income country that has implemented a national policy that includes children’s palliative care. If children’s palliative care is to have wide and continuing impact, partnerships with policy-makers is essential. This requires effective advocates for children’s palliative care working together with national and global organisations and backed up by model programmes where excellent practice can be demonstrated. Working with policy-makers is an ongoing partnership involving children’s palliative care advocates, policy-makers, practitioners, educators and researchers to provide evidence of the impact of palliative care for children and should be backed up by governments and donors prepared to support the implementation of collaborative policies.
Chronic Communicable Disorders
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**Background and aims:** Historically, non-communicable chronic diseases (NCD´s) such as cancer and neurological conditions provided impetus for the development of paediatric palliative care in the developed world. In the developing world it was HIV/AIDS, a chronic communicable disease, that provided this impetus. Although significant strides have been made in the prevention and treatment of Paediatric HIV globally, the battle is not over especially in war torn countries. Drug resistance is an ongoing problem as is co-infection with TB and also HIV associated malignancies. HIV is also only one of many chronic communicable diseases (CCD´s), some of them forgotten tropical diseases, that could benefit from a palliative care approach.

The aim of this presentation is review the many chronic communicable diseases (some of them forgotten tropical diseases) and to demonstrate how the principles of palliative care are relevant to this population of children in whom morbidity and mortality is high.

**Methods:** This presentation starts with a slide show of common communicable and some forgotten tropical diseases and highlights the total suffering of the child as well as the family. Both pain and non-pain symptoms encountered in this population are enumerated as well the significant burden of care (as well as guilt) that is borne by families and health care workers in developing countries. New and emerging epidemics such as the Zika Virus epidemic and the resurgence of measles in the growing "anti-vaccine era" are highlighted. The talk also reminds the audience of the devastating consequence of persistent measles infection in the CNS, namely Subacute Sclerosing Panencephalitis (SSPE) and the need for palliative care in this awful and progressive disease.

**Results:** There is a significant and unmet need for palliative care in children with chronic communicable diseases across the globe. Although much was written about the need for palliative care in HIV/AIDS especially in the pre-HAART era, there is very little guidance on the role of palliative care in many more chronic communicable diseases still encountered today. In addition to the obvious physical symptoms, sufferers from these diseases experience considerable psychological, social and spiritual distress and some die in isolation because of the risk of transmission to other carers and health care professionals.

**Conclusion:** There is an urgent need to both research and provide guidance on the integration of palliative care in to the treatment of children with Chronic Communicable Diseases across the globe. Although palliative care should not stand in the way of the development of new drugs to treat these infections, infectious disease specialists should also not forget about the need to mitigate suffering from not only the diseases themselves but also their treatments. Palliative Care and Infectious Disease specialists need to partner together so that as per the WHO definition, we can provide palliative care alongside active and cure focused treatment directed at the underlying disease. Pharmacists need to advise on the significant numbers of drug interactions encountered in many of these children whose pill burden is considerable and novel ways need to be found to meet the psycho-social and spiritual needs of children nursed in isolation wards.
Perinatal/Neonatal Palliative Care
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When prolonging a patient's life is not an achievable goal a proper plan of care focused on the infant's comfort is essential. Although managing end-of-life care is a fundamental part of neonatology, medical professionals struggle with the challenges of caring for infants affected by life-threatening conditions because of a lack of guidelines or differences in level of care provided or barriers with implementation or limited formal end-of-life education.

One of the most challenging elements of perinatal and neonatal palliative care is that different clinical scenarios require very individualized plans of action. Although most infants born with a prenatal diagnosis of a life-limiting condition have a short life, some of these babies can go on to live for days, weeks, months or years, depending on the primary diagnosis, other associated anomalies and potential medical interventions. In these cases, short and long-term plans of care are necessary to allow these infants to live their natural life in a state of comfort by meeting their basic needs.

Another challenging scenario is an infant who has been admitted to the Neonatal Intensive Care Unit (NICU), often for weeks or months due to severe or chronic conditions, who does not respond to treatment and displays no progress towards healing. For these infants, who face a burden of care and little hope for long-term survival, an adjunctive plan focused on 'quality of life' needs to be added to their concomitant intensive care. A multipronged plan is necessary to allow these babies to gain some comfort and facilitate conversations with their families to explore options and alternatives to intensive care.

When a baby enters the end-of-life stage, that is, a state of imminent/impending death, whether he/she is a newborn with a diagnosis of a life-limiting condition or becomes terminally ill after a course of intensive care, the goal of palliative care remains the same, to achieve a state of comfort. However, the tools utilized to provide comfort at birth can be quite different than those needed for infants still treated with intensive care.

Recommendations for palliative care management of infants affected with life-threatening conditions have been published in recent literature. While several studies highlight the complexity of medical and non-medical needs of infants whose disease is not responsive to curative treatment, the achievement of comfort in these patients is mainly measured through pain assessment. However, 'comfort' for a newborn is not just 'lack of pain' but is better defined as a state in which the patient's basic physiologic and psychosocial needs are fulfilled.

Thus, the lack and/or limitations of professional guidelines regarding the goals of perinatal and neonatal palliative care must be addressed. An essential element of care includes the identification of the baby's basic needs such as bonding, maintenance of body temperature, relief of hunger/thirst, and alleviation of pain/discomfort are met.

Perinatal and Neonatal Palliative care also focuses on the support of the family, starting during pregnancy with prenatal counseling and preparation of the birthing plan, through delivery and beyond. Indeed, the needs, hopes, concerns and expectations of the family are an integral part of the care of any critically ill infant in the NICU.

This lecture reviews 10-year experience of the Neonatal Comfort Care Program, a service of perinatal and neonatal palliative care at Columbia University Medical Center, New York, NY, USA.
This lecture's objectives include:
1. List strategies for a successful perinatal journey when the baby to be born has a diagnosis of a life-limiting condition.
2. The NICU palliative consult: explore parental prognostic awareness, hopes and concerns.
3. Explain how *comfort* is a state in which the baby's basic needs are met.
4. Describe strategies that help to achieve a state of comfort in babies with life-limiting, life-threatening or terminal conditions.
Pediatric Death Attributed to Life-limiting Conditions in Republic of Korea: Exploring the Nation-wide Pediatric Palliative Care Needs

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Background-context-aims: Pediatric palliative care (PPC) is emphasized as a standard care for children with Life-limiting conditions (LLC) to improve symptom control and quality of life for patients and their families. However, the lack of information of children dying with LLC hinders the development of PPC in Korea. The aim of this study was to report population-based statistics of children dying with LLC and its impact on our society.

Methods: The data of National Health Insurance Corporation between 1 Jan 2013 and 31 Dec 2015 were obtained. Children aged under 25 who died with LLC were identified based on a customized list of LLC ICD-10 codes. The number of deaths by demographic characteristics, diagnostic groups and the mortality rate per 100,000 population was calculated. Also the pattern of healthcare utilization and expenditures in the last year of life was explored.

Results: The number of deaths was approximately 1,300 which showed constancy over time. In 2015, there were 1,302 deaths (9.89 deaths per 100,000) and 58.4% were male. The annual numbers of deaths and mortality rate varied with age; largest number in 10- to 19-year-olds (27.6%, 6.2 deaths per 100,000), highest rate in under 1 age group (26.8%, 82.7 deaths per 100,000). Cancer was the most common diagnostic group (35.2%), followed by neurologic and neuromuscular conditions (29.6%). In the last year of life, 91.8% of children with LLCs were hospitalized and mean length of stay was 101.2 days. Average annual healthcare expenditure per person was $46,066.3 of which children under 1-year had the highest spending ($52,395.8). Relative to children with cancer ($36,575.0), children with non-cancer disease ($64,683.2) had higher health care expenditures per person.

Conclusions: This first study across Korea will help to raise awareness of the children died with LLC as well as their healthcare utilization and expenditures. The results may facilitate the development and implementation of PPC in Korea.
EMDR Integration of Non-pharmacological Techniques for Anxiety and Trauma Prevention in Paediatric Sedo-analgesia

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Non-pharmacological techniques (TNF) have been suggested as efficient and safe means in reducing stress and anxiety that exacerbates the experience of pain during invasive medical procedures. Due to the anxious and potentially traumatic nature of these procedures we decided to integrate an Eye Movement Desensitization and Reprocessing (EMDR) session in the pre-procedure TNF. EMDR is an integrative psychotherapy approach that has been extensively investigated and proven effective for the treatment of trauma. The main purpose of this study is to evaluate the efficacy of one session of EMDR in addition to the routine non-pharmacological interventions.

Forty-nine patients from 8 to 18 years (M=25; F=24) undergoing painful and invasive medical procedures (arthrocentesis, bronchoscopy, gastroscopy, renal biopsy) were randomised to receive standard pre-procedural care (N=25) or a session of EMDR in addition to the standard non-pharmacological interventions (N=24). At first, patients were asked to complete SAFA’s A (anxiety) and D (depression) scales and to rate their anxiety on 0-10 scale (NRS). When in the procedure room, patients were asked to rate their anxiety again with NRS just before anaesthesia induction.

There was a significant difference in the level of anxiety expressed before the procedure between the TNF group and the TNF+EMDR group (p=.038). Efficacy of EMDR is correlated with the SAFA-A scores (r=.445 p=.029), especially with social anxiety (r=.689 p=.001), and SAFA-D scores (p=.020), particularly for anhedonia (p=.010).

These results are the first data on the efficacy of EMDR as a technique to prevent anxiety in paediatric sedo-analgesia. Clinical implications of EMDR are important in the long term, because this therapy allows an intervention on situations at risk of future morbidity and the prevention of severe disorders.
"Informed Decision-making is a Valuable Notion but a Faulty Tool" - Pediatric Health Care Providers Perspectives on Adolescent and Young Adult Advance Care Planning in Bone Marrow Transplant

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Background: Advance care planning (ACP) is a process to determine goals, values, and preferences for future medical care. Research involving pediatric health care providers related to ACP and the inclusion of adolescents in end-of-life discussions is sparse. As part of a larger study, we sought to explore the perspectives of pediatric intensive care and bone marrow transplant providers about pediatric ACP.

Methods: As part of a larger study of adolescent and young adult ACP, we conducted focus groups with 14 pediatric intensive care and bone marrow transplant physicians at a single academic medical center. Two questions were asked: can patients and families make informed decisions regarding the future use of life-sustaining technology and does ACP impact informed decision-making? Content analysis was used for thematic analysis.

Results: Pediatricians were supportive of the concept of ACP but were uncertain about the timing and personnel to conduct these conversations. The following themes were identified:
1) providers believe that the trajectory of illness and timing of ACP conversation impact the validity of decisions,
2) patients and families lack experiential knowledge to understand the sequelae of decisions, and
3) communication about the use of life-sustaining technology should occur early in the disease process and should be tailored to the patients' trajectory of illness.

Conclusions: The focus groups demonstrated support for the concept of ACP but raise some limitations. ACP is not a single conversation and requires ongoing communication and decision-making support by multiple providers that is tailored to the patients' trajectory of illness. Intensive care providers struggle between the desire for primary providers to initiate end-of-life discussions during a period of good health and the understanding that changing clinical conditions render them responsible for these difficult discussions.
Validation of the Spanish Version for Argentina of the Memorial Symptom Assessment Scale (MSAS) in Children from 2 to 20 Years with Cancer Treated at two Public Hospitals in Buenos Aires City, Argentina

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Introduction: No validated Spanish symptom assessment tools exist for children.

Aim: To validate the 3 pediatric-MSAS versions in Spanish (Argentina): MSAS-7-12, MSAS-Teens, and MSAS-Caregivers (that evaluate 9, 31, and 33 symptoms).

Methods: Cross-sectional study. We recruited a purposive sample of 151 children and teens (C&T), 2-20 yo, with cancer, treated in 2 public hospitals in Buenos Aires, and a caregiver. All caregivers and C&T ≥7 yo completed 3 tools: MSAS, PedsQL 4.0 (quality of life), and a VAS wellbeing question (WB). We evaluated feasibility, comprehensibility, and acceptability of all MSAS versions, and explored construct validity by testing 4 hypotheses (H).

Results: We recruited 99 dyads of C&T ≥7 yo and 49 caregivers of children < 7yo. Most families lived below the poverty line (62%). Over 80% of C&T >7 yo (n=74) and caregivers (n=127) could self-administer all three versions of MSAS, and most did it with one round of instructions. The inverse correlation between MSAS and: i) PedsQL scores (H1) was strong for MSAS-Caregivers (r=-0.58, CI95%: -0.67,-0.47) and MSAS-Teens (r=-0.66, CI95%: -0.79,-0.46), and moderate for MSAS-7-12 (r=-0.46, CI95%: -0.61,-0.29); ii) VAS-WB (H2) was strong for MSAS-Caregivers (r=-0.62, CI95%: -0.71,-0.61) and MSAS-Teens (r=-0.68, CI95%: -0.81,-0.49), and moderate MSAS-7-12 (r=-0.41, CI95%: -0.56,-0.23). The caregiver-child correlation (H3) was strong for MSAS-Teens (r=0.77, CI95%: 0.63,0.87) and weak for young children (r=0.29, CI95%: 0.02,0.52). With regards to discriminant validity (H4), only MSAS-Caregivers and MSAS-Teens scores allowed the distinction of 3 groups of patients: (i) moderate to intense treatments > (ii) mild intensity treatments/active disease without treatment > (iii) >6 months in remission and off-treatment.

Discussion: MSAS was feasible, understood and accepted. This study contributes to the construct validity of MSAS-Teens and MSAS-Caregivers Spanish versions. More work is needed to understand how young children use MSAS.
Digital Tool for Better Communication in Children’s Palliative Care (CPC)

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Background: To improve the care for children with a life-limiting or life-threatening disease and their families, a nationwide structure for integrated CPC is created. This structure consists of seven regional networks and seven CPC teams in the academic children's hospitals which focus on organising integrated care from hospital to home. Many improvements have been made for quality CPC, but communication is still a problem. Families and professionals indicate the need for better communication between all involved in order to improve CPC and support the families.

Aim: We aim to create a digital community around families, for better communication between the family and all professionals involved.

Design, methods and approach taken: Together with a CPC-team and an experienced designer, we developed the CPC-net. The CPC-net is a web-based program and offers a digital community around a child and family with a communication and information module in a secured environment. The communication module offers functionalities as texting and video calling. In the information module, both documents and videos can be added. The family determines who is part of the community. After a process of design, testing, and redesign, CPC-net will be available for all CPC teams and networks.

Results: At the time of submission, the CPC-net is being piloted by two CPC-teams. Parents will provide their experience and feedback on improvements. We expect to report the results and officially present the CPC-net at this congress.

Conclusions: Digital development is a complex process. Our ultimate goal is better communication to support the families. The nationwide structure offers a platform for feedback and further development to reach our goal. Also, from the CPC-teams and -networks the urgency for better communication was confirmed and future users are included in the development. The Dutch Centre of Expertise for CPC will provide a basis for ongoing improvements and updates to the CPC-net.
Bereavement Support for Parents of Children Who Have Died: A Systematic Review

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Background-context-aims: The loss of a child is an incredibly painful experience, with demonstrable negative effects on parental mental and physical health. Little is currently known of the effectiveness of bereavement support interventions (BSIs). Despite this, both the World Health Organisation and the National Health Service make recommendations for parents' care. The aim of this systematic review was to investigate the effectiveness of BSIs for parents of children who have died.

Methods: A systematic search of MEDLINE, PsycINFO, Embase and CINAHL was performed to identify studies investigating BSIs for the parents of children who died between the ages of 24 weeks gestation and 30 years old. Studies meeting inclusion criteria were quality assessed using the Cochrane Collaboration's tool for assessing risk of bias. Due to significant clinical and methodological heterogeneity between studies, a narrative synthesis was performed.

Results: 15,572 studies were returned by the search, with 27 eligible for inclusion; eight were effectiveness studies (analysed here). Interventions tested included: support groups (N=3), self-help groups (N=1), individual/personalised therapies (N=3) and a support DVD (N=1). Outcomes measured included mental distress, posttraumatic stress, loss accommodation, physical health, marital strain/satisfaction, grief, received support, psychiatric disorder/disturbance, mental distress, loss accommodation, anxiety and depression, coping response, psychosocial adjustment, social functioning, and attitudes. All studies showed substantial risk of bias. Overall, all studies tested complex interventions but made little reference to development and implementation. Similarly, little rationale is provided for study methodology, particularly outcomes measured.

Conclusions: There is a need for greater consensus as to what bereavement support interventions are intended to achieve and the outcomes that should be measured in order to ascertain efficacy.
The Prevalence and Incidence of Anxiety and Depression in Children and Young People (CYP) with Life-limiting Conditions (LLC): A Systematic Review and Meta-analysis

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Background and aims: Mental health problems such as anxiety and depression among children and young people (CYP) represent a significant and growing public health issue in the UK. CYP with a life-limiting condition (LLC) have been found to be especially vulnerable to mental health problems, such as anxiety and depression. However, the results of these studies have not been pooled and therefore it has not been possible to analyse the prevalence or incidence of anxiety and depression across the LLC patient population. The aim of this systematic review and meta-analysis was to assess the prevalence and/or incidence of anxiety and depression in CYP (aged 5-25 years) with a range of LLCs.

Methods: MEDLINE, EMBASE and PsychINFO were searched for studies published between 2000-January 2018 which met the eligibility criteria. Random effects meta-analyses were conducted to generate separate pooled prevalence estimates for anxiety and depression among CYP with LLCs.

Results: 33 studies, with a total of 6,600 participants, met the eligibility criteria for the anxiety meta-analysis, generating a pooled anxiety prevalence estimate of 27.7% (95% CI: 22.3%-33.8%). Sub-group analysis identified DiGeorge Syndrome, a very rare genetic condition, to have the highest pooled anxiety prevalence estimate, 46.77% (95% CI: 38.5%-55.0%). From the 44 studies, with a total of 7,956 participants, reporting depression prevalence, the pooled estimate was 14.1% (95% CI: 11.2%-17.6%). HIV was found to be the LLC category with the highest pooled depression prevalence estimate, 22.7% (95% CI: 13.3%-36.0%).

Conclusions: The findings suggest a high prevalence of anxiety and depression among CYP with LLCs. Further research is required to identify risk factors for anxiety and depression in this patient population in order for the effective targeting of psychological interventions.
Parental Preferences in Decisional Autonomy and Values-Guided Approaches in Tracheostomy Decisions

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Background: In critical situations, professionals often limit communication with parents to providing medical information. Failure to identify parents' desired degree of decisional autonomy or to consider their personal values can lead to decisional conflict and regret. We investigated the impact of varying presentations of a high-stakes decision on parents' attitudes and choices in a simulated pediatric scenario.

Methods: 593 parents, recruited via Amazon Mechanical Turk, completed a Qualtrics survey regarding their choice to pursue a tracheostomy for their ventilator dependent child. Each participant was randomly shown one of six framings of the simulated scenario, divided into information-based or values-guided approaches, with each approach paired with either a recommendation for or against tracheostomy, or no recommendation at all.

Results: Participants were more decisive in values-guided approaches (p=0.037), and indicated a preference for them over information-based approaches (p=< .0001). Decisional autonomy (M=8.47) and receiving recommendations (M=8.18) were preferred to joint decisions (M=6.24) or having physicians decide (M=2.30). Framings in which physicians bore decision burden were ranked most unfavorably. Framings allowing parental autonomy were preferred to those involving shared decisions (p< .0001). Attitudes regarding tracheostomy were non-neutral as many participants reported tracheostomy as personally undesirable (M=2.65), and indicated quality of life (M=7.94) as more important than quantity of life (M=4.75).

Conclusions: Parental autonomy was preferred in high-stakes decisions for children, and values-guided approaches increased decisiveness. Further research on shared decision-making strategies in clinical care, as well as how varying communication approaches influence parents' choices and decision acceptance is warranted.
Parents’ Awareness and Perspectives on the Pediatric Palliative Care in South Korea

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Background-context-aims: Pediatric palliative care (PPC) is known for an essential care for children with Life threatening diseases (LTD) with improving symptom management and quality of life for patients and their families. However, PPC is unfamiliar medical service in South Korea and researches were rarely performed on parents of pediatric LTD patients. This study aimed to investigate awareness and opinions of parents with LTD patients in South Korea about PPC and end-of-life (EOL) care.

Methods: A survey was conducted among 300 caregivers of LTD patients under 18 years at three tertiary hospitals in South Korea. During the survey, awareness of the term 'pediatric palliative care' was asked. If respondents did not know the term, we showed the explanation of PPC and asked willingness to use. In addition, appropriate timing of conversations about prognosis and EOL care were surveyed.

Results: Among respondents, 53.3% were caregivers of cancer patients. Albeit 11.0% were aware of PPC, 90% of care-givers revealed their willingness to use PPC after they got information about PPC. The most prevalent reason why they wanted was “It would be helpful for patient's psychological stability.” Over half of respondents (51.7%) answered that the appropriate age of a patient to have conversation about their poor prognosis was over 12 years. For the question about timing of discussing EOL care, 32.3% of caregivers chose “when death is expected despite all medical efforts” and “when death is expected in several days or weeks despite all medical efforts” followed with 20.3%. About 14% of caregivers did not want to discuss EOL care.

Conclusions: In this study, few respondents were aware of PPC but most of them wanted to use it. A national pilot program for PPC will start from this July in South Korea. In order to successful implementation of the program, promotion of the concept to patients and their family and developing a culturally appropriate guideline is required.
Autonomy of Competent Children about End-of-Life Decisions: Attitudes of Italian Healthcare Professionals

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Background: Few studies investigated end-of-life (EoL) care of children between neonatal and adolescent age. We aimed to explore the attitudes of healthcare professionals (HPs) towards competent children's autonomy about EoL decisions.

Methods: Between May and July 2016, we surveyed the physicians of the local Medical Association, physicians and nurses of the Italian Association for Pediatric Hematology and Oncology, members of the Italian Federation of Pediatricians, pediatricians and nurses of 6 Pediatric Institutions, and a class of nursing students at the last day of course. Ad hoc survey was made of 18 multiple-choice questions about children's autonomy at the EoL; 12 more questions explored social and demographic features. The survey return through GoogleForm® was anonymous and constituted the consent to participate. Descriptive analysis was performed.

Results: Out of 592 HPs, 326 (55.1%) completed the survey (167 nurses (51.2%), 118 physicians (36.2%), 38 nursing students (11.7%), 3 (0.9%) unclassified); 261 (80.1%) were females, 240 (73.6%) were catholic. Overall, 283 (86.8%) thought that competent terminal children should be involved in EoL decisions; 202 of them (71.4%) thought that their will should be binding: this answer was significantly associated with HPs' young age ($p=0.02$) and previous bioethical studies ($p<0.001$), but not with their religion ($p=0.74$). When asked if a competent terminal child could refuse to be resuscitated, 189 (58.0%) said "yes regardless of age"; nurses were more favorable than physicians ($p=0.008$). Overall 289 HPs (88.7%) asked for a law on euthanasia and 260 (79.8%) thought it should include competent children.

Conclusions: Italian HPs declare respect of competent children's autonomy about EoL decisions. Age and profession, but not religion, play a key role driving personal believes; bioethical studies should be implemented to achieve higher awareness and constructive debate.
Palliative Sedation in the End of Life: Standard Based Evaluation of Practice in a Paediatric Palliative Care Service

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Background: Palliative sedation (PS) is a procedure used to avoid suffering due to refractory symptoms. The aim of this study was to analyse the practice of PS during end-of-Life (EoL) of patients assisted by a Regional Paediatric Palliative Care Unit (PPCU), compared to an elaborated quality standard.

Methods: A PS practice standard was defined based on literature review and practice guidelines recommendations. The following requisites were considered standard:
1. Indication: Adequate symptom treatment + refractoriness
2. Informed consent: Evaluation of patient´s competence + participation

A descriptive retrospective study of deaths attended by the PPCU between Jan 2013-Dec 2017 was conducted, studying the adjustment to this standard.

Results: Of 202 demise reports, 39 were excluded due to missing data. Amongst the 163 analysed, 20 (12.3%) received PS, 17 performed by the PPCU. 10 patients had cancer and 7 neurological conditions.

- Proper indication-58% met standard: 10 cases had refractoriness identified. All patients had adequate previous treatment.
- Informed consent-17% met standard: 2 patients were considered suitable for consent. Only in one case patient´s explicit decision was registered. On the 15 non-competent patients, discussion with the family was registered in 2 cases.
- Sedation application-64% met standard: In 16 patients the drug chosen was adequate, not being registered in the last one. In 11, the starting dose was adequate, in 2 it was non-sedative and 4 had missing data. All patients had motorization either by symptom control alone (100%) or by sedation level (41%). No motorization scales were used.

Conclusions: Only 12.3% patients attended by PPCU received PS in EoL. In the 17 cases, only in 3 the standard was completely met. The most frequent failure concerned registration of informed consent. The use of a quality standard may be useful in finding areas of improvement in PS.
Where Children Die, a Regional Analysis of Child Death Overview Panel (CDOP) Data

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Background: All child deaths in England are reviewed by a local Child Death Overview Panel (CDOP) to identify modifiable factors. This is a statutory requirement (since April 2008) independent of Coronial processes. The aim of this study is to collate and evaluate child death data from all CDOP's within the Yorkshire and Humber region to inform future strategic planning, justify funding, and improve the care provided to children.

Methods: Retrospective cohort study, service evaluation. Data analysed from all 14 CDOPs in the region. Descriptive analysis performed using SPSS. Dataset: 3 full years of CDOP data (2013 - 2016), all child deaths (expected and unexpected), age (0-17 inclusive), gender, ethnicity, partial postcode, place of death and category of death following review. Patient identifiable data not requested. Ethical approval not required. Missing data excluded from analysis on a pairwise basis.

Results: Over the study period total 1221 deaths, with an average mortality rate 407 deaths per year (total child population = 1.1 million, 3.5 deaths/10000 children). The major causes of death were peri/neonatal events, and chromosomal, genetic and congenital anomalies; Combined these account for 60% (n=712/1183). 'Expected' deaths accounted for 64% (n=730/1149) of all child deaths. Place of death for expected deaths = Hospital deaths: 77% (n=564) Home: 9% (n=67), Hospice: 13% (n=91). A greater proportion of white British children (n=201) died at home (16%, n=33) or within a hospice (23%, n=47) than did Asian children (Home: 12%, n=14; Hospice: 9%, n=10); Chi-squared 15.07, p=0.002.

Conclusions: Place of Death (POD) is a key quality indicator in EOL care. Home is the preferred POD in adults, limited evidence of preferred POD in children. Ethnicity appears to affect POD. Hospital remains the POD for majority. Limitations include inconsistent data collection and no collection of preferred POD. Robust and in depth data set to inform service delivery and development.
A Workshop on How to Recognise a Dying Child: Uncovering the Complexities and Professionals' Fears Whilst Helping to Increase Understanding

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Background/context/aims: Multidisciplinary staff at a UK NHS hospital requested teaching about the recognition of a dying child. The author devised a workshop to help multidisciplinary staff explore their own beliefs and experience of why they need to recognise a dying child, how they recognise a dying child, what stops them admitting a child is dying and what makes them think a child is not dying. The workshop was evaluated to assess its value and the themes which emerged.

Methods:
1) Literature review
2) Thematic review of flipchart sheets and feedback forms from workshop attended by approx 150 multidisciplinary UK children's professionals from an NHS hospital and the local community services and hospices over three years
3) Pre and post-course questionnaire from 23 attendees from last workshop

Results: A literature review provided evidence for signs to recognise dying in the oncology population however the evidence was less clear for other patient groups.

Workshop attendees felt it was important to recognise dying to prepare families and plan for a good death in their preferred place, with medical, social and spiritual support available and to prevent inappropriate interventions. Workshop attendees admitted they often recognise dying only when physical observations deteriorate or if another professional or family member states it. Attendees explained they recognise dying late, as dying feels like a failure, they are scared of getting it wrong, do not want to take away hope and always feel there is more they could do.

The workshop helped increase people’s understanding of the importance and ways to recognise dying from 6.43 to 8.33 using a scale 1-9 where 9 was complete understanding and 1 was complete lack of understanding.

Conclusions: A workshop where professionals acknowledged the shared difficulties and fears of recognising dying helped attendees gain understanding in why and how they can recognise dying.
Parents' Experiences and Wishes on Information Provision and Decision-making in the Care for their Child with Spinal Muscular Atrophy: A Population Survey

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Importance: Parents and clinicians caring for children with spinal muscular atrophy (SMA) are and will often be confronted with difficult care decisions. Therefore, insights on experience and wishes from parents of a child with SMA is paramount.

Objective: To explore the experiences and wishes of parents of children with SMA about information provision and decision-making regarding diagnosis, treatment and end-of-life care.

Design, setting and participants: A full population survey, conducted in 2015, in parents of children with SMA who were born in Denmark between the 1st of January 2003 and 31 December 2013. Among the 47 parents that were identified, 34 parents of 21 children participated. Eleven of them were non-bereaved and 23 were bereaved parents.

Measures: We used a questionnaire with items about the experience and wishes about information provision regarding diagnosis, treatment and end-of-life care.

Results: All parents stated that health care staff did not take any decisions without informing the parents. Some parents reported that they were not informed about what SMA entails (32%), about possible treatment options (18%), and about the fact that their child would have short life (26%) or dead was imminent (57%). Most (xx/xx) of the bereaved parents' who had wishes concerning how and where their child would pass away were fulfilled.

Conclusion and relevance: The results showed that all parents reported that they were informed about treatment decisions. However, it was also found some points of improvement for information provision about what SMA entails, about treatment options and prognosis. Possibilities with palliative care and advance care planning should be investigated for these parents, their child and health care providers.
Perinatal Comfort Care: Implications for Decision-making and Perinatal Outcomes in Pregnant Patients with Complex Fetal Anomalies

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Background-context-aim: Several studies have shown that medical staff plays a significant role in influencing the decision-making process of parents after a diagnosis of severe fetal anomaly. Palliative care -“Comfort Care” (CC) - is an innovative and compassionate model of support for parents who choose to continue their pregnancies following a prenatal diagnosis (PD) of a life-limiting condition. Some parents could opt for termination of pregnancy because the CC option has not been proposed. The aim of this study is to investigate the effect on the parental decision and fetal outcome of a perinatal CC option.

Methods: A retrospective study of pregnancies complicated by ultrasound-detected fetal plurimalformative syndrome at FMBBM/S.Gerardo Hospital Monza (Italy) between 2010 and 2016 was performed. All women received a personalized antenatal care multispecialist consultation.

Results: During the study period, out of the 93 fetuses with multiple anomalies, 50 cases (54%) had limited life expectancy. Of those, 36% of the women (n=18) interrupted the pregnancy, 62% (n=31) continued pregnancy and one case (2%) was lost to follow-up (FU). Out of 31 women who decided to continue pregnancy, 87% (n=27) accepted the option CC, 10% (n=3) opted for intensive care; one case (3%) was lost to FU. The most frequent diagnoses in the CC group were chromosomal abnormalities (74%, n=20). In 93% (n=25) there was a poor outcome: 13 fetal deaths, 4 stillbirths, 8 neonatal deaths. 2 babies (1 Trisomy 18 and 1 Trisomy 13) are still alive (8 and 3 years old).

Conclusion: Early diagnosis, multiple abnormalities identification, and an assessment of the fetal prognosis are important factors to enable parents’ best participation in decision-making on the conduct of pregnancy and neonatal care. CC was welcomed by many parents (87%) after a potential life-limiting PD, to respect your baby’s life and to avoid the therapeutic obstinacy. Therefore PD services should offer to parents the CC option.
"Adding Days to a Life, or Life to the Days Left" Parents´ and Physicians Perspectives on Decision-making in a Dutch Interview Study

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In 2016, the Dutch Ministry of Healthcare requested research to answer the question how care and decisions for children(1-12) in the palliative phase can be improved. As part of this study, we investigated how parents and physicians make crucial decisions in the palliative phase, and what their needs are with regard to the decision-making process.

In this nationwide, large-scale qualitative study, we interview parents and physicians from the following groups:
- Children (1-12) with a life-threatening condition, and
- Deceased children (1-12) who died after a medical trajectory (< 5 years)

Sampling is done by maximum variety. The in-depth interviews are recorded, transcribed, and coded. Subsequently interviews are thematically analyzed using DIPEx-methodology.¹

So far, parents and physicians of 43 children have been interviewed. Preliminary results show that crucial decisions for children with a life-threatening condition often involve considerations about proportionality of treatment. The narratives give insight in how decisions between “adding days to their child’s life, or [quality of] life to the days that are left” are made, and what the underlying arguments are.

It also sheds light on the positions that both parents and physicians take in the decision-making process. While some physicians evaluate the decision as primarily a medical decision about futility of treatment to be made by physicians, many physicians report to be uncomfortable with deciding on such a personal matter, and take a step back, leaving the decision to parents.

The question ‘should everything that can be done, also be done?’ is seen throughout Dutch pediatric palliative care. Our findings could have an important impact on palliative care, where physicians often feel uncomfortable with such conversations, and parents feel ‘left alone’ in the decision-making process.

(1) DIPEx International Quality Control Manual, Available at:
http://www.dipexinternational.org/research/research-amethodologies/
Bereaved Parents Are More Likely to Report that the Health Care Did Everything to Support their Child than Non-bereaved: A Two Countries Study of Parents of Children with Severe SMA

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Background and aims: Children with severe spinal muscular atrophy (SMA) have complex care needs due to progressive muscle weakness, eventually leading to respiratory failure. Rapid development of treatment of genetic diseases, including SMA, enriches and complicates palliative efforts. Increased knowledge about parents' experience of palliative rehabilitation is therefore needed. The aims of this study were to explore parents' reports of:

1) if care has taken every opportunity to help the child feel as good as possible,
2) satisfaction with various care settings and
3) satisfaction with coordination between settings.

Methods: Data derives from Swedish and Danish nationwide surveys based on bereaved and non-bereaved parents to children with severe SMA born between 2000-2010 in Sweden and 2003-2013 in Denmark (N=95, response-rate=84%). Descriptive statistics and content analysis were used.

Results: A majority of the parents reported that care had taken every opportunity to help the child feel as good as possible. However, a third of the parents reported the opposite. Bereaved parents were significantly more satisfied with care compared to non-bereaved. The different care settings were rated high by the parents, even though the children received care at many different locations. Not all parents reported care coordination as satisfying, describing problems with lack of knowledge and communication among staff, and that they as parents had to take initiatives for care managements.

Conclusions: This study highlights the importance of increased professional disease-specific competence and inter-professional communication and knowledge exchange. To achieve good quality of care for these children and families, further emphasis should be put on involving parents in dialogue on care and for staff to be more proactive and take initiatives of managements.
Networking to Increase Access to Children's Palliative Care: The ICPCN Experience

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Background: With more than 21 million children globally needing palliative care (8 million needing specialist care) & only an estimated 10% accessing palliative care, the challenge is there for us to address the need & increase access globally. Yet in each country, culture, & setting, needs vary, along with the emphasis put on children's palliative care (CPC), with some places not recognizing its importance.

Methods: An international network was set up in 2005, to address the gap & bring together those interested in CPC to learn from each other, share experiences, provide a strong voice for CPC & strive towards access to CPC for all. Work focused around 5 areas: Communication; Advocacy; Research; Education & Strategic Development.

Results: Communication is an essential component of any network. It has been important to address new forms of strategic communication e.g. Instagram, Facebook Lives, Tweet Chats etc. & these, alongside traditional methods of communication such as emails, newsletters, the website, have strengthened the communication capacity of the network & impacted access to care. Advocacy cuts across all the work of the network & has included working at the Global level with the WHO, Multilateral Agencies & Donors, along with implementing, supporting & disseminating research on CPC. The provision of CPC education is challenging, thus a variety of forms of education programs have been supported by the network, with over 3,000 people having taken their e-learning programs in the past six years ago. Strategic development is cross cutting both in terms of supporting others & developing the network. The review of the previous strategic plan demonstrates impact of the network along with identifying innovative ways of moving forward.

Conclusion: Networking, sharing, learning from each other is pivotal to the ongoing development of CPC globally. The network is in a great position to drive ongoing changes & is addressing innovative ways to move forward in advancing CPC.
Pediatric Palliative Care in Sub-Saharan Africa. What "Knowledge" to Transmit and How?

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If a palliative approach in pediatrics is justified by mortality rates, it is obviously needed in Africa, especially in the sub-Saharan area where these rates are the highest in the world. Nevertheless, if the conditions for establishing a palliative care program in developing countries have been clearly stated their implementation on the ground can be very difficult. This abstract aims to report this experience: thanks to the grant of the My Child Matters program (Sanofi espoir foundation), a three-year training program has been launched in April 2016, aiming to integrate a palliative dimension in the offer proposed by the Franco-African Group of Paediatric Oncology (GFAOP). Since, 2000, GFAOP has demonstrated that children with certain types of cancers in Africa can be cured. We thus bet that blending palliative care with curative treatment could be beneficial in providing children and family with the most complete medical care possible.

The main objectives of the training were to enhance routine patient assessment, especially pain management, and to reinforce the multidisciplinary exchanges. 65 multidisciplinary trainees from 18 oncology pilot units (PU) of 15 French-speaking African countries, have participated into this program and received a first step course on PPC theoretical and operational basics. An interim evaluation in 15 out of the 18 PUs showed that 7 sites were not able to integrate them. We will list the identified obstacles, and we will say how the continuation of the teaching program took into account these results.

But on-site visits also raised ethical questions: Are we sure to be benevolent, and furthermore not to be maleficent for the trainees enrolled? The concern for ethics, raising the question of the legitimacy of our action, may not be appreciated regularly. But if we ignore it, our actions will be ineffective or counter-productive, carrying a risk of mistrust and withdrawal, to the detriment of children in care.
Building a Paediatric Hospice in the Home (The Lego Project): How One Health Care Region in Ireland Co-ordinated Existing Child and Family Community Services to Ensure Seamless, Cost Neutral Community Palliative Care at the End of a Childs Life

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Research aims: This evaluation reports on the first successful state and charitable partnership model for a paediatric Hospice at Home.

Study design: The project funded by the Irish Hospice Foundation and one regional (adult) Hospice examines the existing end of life care services provided to children and their families incorporating the opinions of families and stakeholders. A qualitative exploratory and descriptive design was adopted. Data was collected via in-depth semi-structured interviews using an interview guide specifically developed for the project. Data was managed electronically to generate themes.

Results: The evaluation demonstrated that this unique programme of co-ordination and leadership furthered the vision of one of the key 2010 Irish policy recommendations by facilitating cost neutral improvements in the co-ordination of service provision for children at the end of life. Findings include: ensuring the availability of skilled professionals, Enhancing communication between professionals, parents and other service providers, Ensuring consistent links to acute paediatric services as required, Facilitating co-ordinated out of hours support, Providing hands on care, Cost-neutral co-ordination and Bereavement support. Participants also reported challenges and supports for the effective delivery of any repeat project and suggested areas for improvement. This finite project commissioned at national level (albeit only in one health care region), had a direct effect on local paediatric palliative care service delivery and included recommendations for consideration which will shape the next phase of Irish policy.

Conclusion: This study evaluated a 'one off' project established in one geographical health care region to enhance care provision. Findings demonstrate that through partnership and leadership and at no extra costs to services, optimal co-ordination can contribute to the provision of responsive paediatric end of life care in the community setting.
Meeting expectations: Student feedback from Irelands First Masters Programme for Children’s Palliative and Complex Care Nurses

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The evaluation sought to examine the views of students who were undertaking the first Irish MSc in children's palliative and complex care run collaboratively between two major Universities in Ireland. Uniquely, this evaluation captures early thoughts of postgraduate students' mid-way through the 3 year pilot. This evaluation includes data gathered from online questionnaires. The evaluation demonstrates that this unique and dynamic program is already meeting the needs of both nurses and employers who wish to learn more about children's palliative and complex care and importantly respond more competently and confidently to the needs of children and families' in a variety of settings. Results indicated 5 important outcomes of the pilot including: Nurses gained a deeper understanding and knowledge of the philosophy and unique speciality of paediatric palliative care, Nurses reported high quality clinical exposure in a variety of co-ordinated specialist settings where palliative and complex care for children is provided, core competencies in paediatric palliative and complex care are achieved during the duration of the programme, Nurses are eligible to apply for specialist or advanced practice roles in children' palliative/ complex care. 8 nurses have already availed of opportunities for promotional posts meeting the demands of the health service. Parental and stakeholder involvement in curriculum design and module delivery ensures a robust and reflective programme. This 3 year pilot programme commissioned at national level, has already had a direct impact on the clinical settings (home, hospice and hospital) and on standards of local paediatric palliative care service delivery. Recommendations have been included for consideration at national policy level which will shape the next phase of policy implementations. Findings support the consideration of the permanent implementation of this dynamic and effective programme at national level.
Parents' Experiences of Requests for Organ and Tissue Donation: The Value of Asking

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Background: A proportion of children die, making them potentially eligible to be organ and/or tissue donors. Parents' experiences around considering donating their children's organs/tissues have been investigated. However, to date the focus has been on parents who have been approached about donation. We know that a significant number of families are not approached. This study aimed to investigate to what extent organ and tissue donation is discussed as part of paediatric end-of-life care and to explore parents' and health care professionals' (HCPs) experiences.

Methods: Bereaved parents, parents of a child with a long-term condition (LTC) and HCPs were interviewed to investigate their experiences of discussions about organ and tissue donation; recruited through two neonatal intensive care units (ITU), two Paediatric ITUs, a Cardiac ITU and a children's hospice.

Results: 24 parents of 20 children were interviewed: 21 bereaved parents and 3 parents of a child with a LTC. Seven parents were asked about donation (13 not asked), 4 agreed, 2 donated. 41 HCPs were interviewed. Themes: complexity of donation process, quality of staff, parents' assumptions about health of organs (when donation is not discussed). HCPs indicated that they felt donation discussions are important, but reported that raising the topic of donation was difficult and that often these discussions were not held.

Conclusion: The findings add new knowledge to our understanding of parents' assumptions about the value of their child's organs when discussions about organ donation are not raised and that HCPs don't routinely ask, are sometimes hesitant to ask in fear of damaging relationships, and the reality of the complexity of the donation process. Our study suggests that given the current levels of awareness around organ and tissue donation that the topic should be raised, as parents can derive comfort from the thought that their child was considered for organ and tissue donation.
An Exploration of the Experience of Caring for a Child with a Non-malignant Life-limiting Condition from the Perspective of Parents

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Background: Children with NMLLCs constitute the largest proportion of children requiring palliative care (ACT, 2009; Siden, 2018). This is partly due to technological advances, resulting in growing numbers of these children experiencing improved survival (Fraser et al., 2012). Their care is provided in most cases at home by the family over long periods, sometimes over many years (IHF/LLH, 2013). It is imperative to understand the experience of caring for a child with a NMLLC from the perspective of parents in order to support their care needs.

Aim: Provide an in-depth understanding of the unique experiences of parents caring for a child with a NMLLC.

Methods: Semi-structured interviews were used to collect data from parents regarding their experience of caring for their child. A total of twenty-three parents (eighteen mothers and five fathers) participated.

Results: Three dominant themes emerged, charting parents' journeys and unique experiences of caring for a child with a NMLLC.

‘Starting out in haziness’ represented the time period from diagnosis or recognition of a life-limiting condition and marked the beginning of an unknown journey filled with emotional turmoil.

‘Managing an unexpected life’ captures the time period after the haziness started to settle in the component of the parents' stories and where they attempted to respond to the resultant emotional and practical impact of their child’s condition on their life and that of their family.

‘The ship is going to go down’ represented the parents' often never verbalised but ever present experience of living with the knowledge and uncertainty that whilst death was inevitable, they did not know when it was likely to occur.

Conclusions: Representing the views of parents is valuable in order to provide an insight into the reality of their lives. Based on their views recommendations are made with regard to supporting parents who are caring for a child with a NMLLC.
Anxiety and Depression in Bereaved Parents after Losing a Child Due to Life-limiting Diagnoses

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Aim: Losing a child is considered extremely burdensome for the parents. The aim of this study was to investigate anxiety and depression in parents after the loss of a child due to life-limiting diagnoses in order to target psychological interventions for specialized pediatric palliative care in Denmark.

Methods: In the period 2012-2014 a register-based study identified death causes of 951 children 0-18 years of age. Potential life-limiting diagnoses were identified by using a “Directory” classification elaborated in Wales. Four-hundred-and-two Danish children were included. In a cross-sectional study a self-administered questionnaire was used to screen for anxiety and depression in bereaved parents. A non-response survey identified reasons for lack of response.

Results: In all, 152 children (38%) were represented by 193 bereaved parents. During the child’s illness 65% of the mothers and 63% of the fathers experienced moderate to severe anxiety; however, 3-5 years after their loss anxiety decreased markedly in both parents. During the child’s illness 32% of the mothers and 44% of the fathers experienced moderate to severe depression, respectively. However, depression did not decrease 3-5 years after the loss. Major depression was significantly associated with lower education and/or being unmarried.

Conclusions: Anxiety seems to be most pronounced in parents during the child’s illness. However, 3-5 years after the loss of a child anxiety decreases, while depression stays at the same level. When targeting future psychological interventions for specialized pediatric palliative care in Denmark, this knowledge must be integrated in the treatment program.

Acknowledgement: The Danish Child Cancer Foundation supported all phases of this study.
An Analysis of Use of 'Cool Rooms' in Two Children's Hospices in the UK
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Background: 'Cool rooms' refer to purpose designed rooms to which deceased people can be moved following death, as an alternative to a mortuary/funeral director. Family can visit their loved one whenever desired. Current practice varies between hospices but some guidance on their use is provided by national authorities. There is some evidence that use improves the bereavement process but research is limited. Increasingly, use is being extended to children not previously known to hospices. The aim of this study is to establish how these rooms are used by two UK hospices.

Methods: A retrospective cohort study based on anonymised demographic data extracted from two UK hospice databases over an eight-year period (2010-2017). Data obtained for >700 deaths: hospice, year of death, age at death, gender, cause of death, place of death, whether known to hospice previously, whether used room and if so for how long. Data subjected to descriptive statistical analysis and grouped for both hospices. All data fully anonymised and only relevant data accessed for study. Missing data excluded pairwise.

Results: Of patients known to the hospice, 47% (n=306/670) of patients were cared for in the cool rooms after death, this didn't change over the years studied. Bereavement suites were most likely to be used by neonates (64%, n=34/53), least likely were those 25-years-old and more (18%, n=6/33). Of those that died in the hospice, 88% (n=191/217) used the rooms; 27% (n=43/158) were transferred to cool room from home; and for those that died in hospital, 26% (n=69/266) used them. Of patients not known to the hospice the cool rooms were predominantly used by under one-year-olds (61%, n=17/28). Mean length of use was 8 days (range 1-24 days).

Conclusions: It is likely that those that die in the hospice continue to be cared for in a cool room and it would be interesting to establish what the reasons are behind this. Analysis would aid future service planning and hospice development.
**Nursing Recommendations to Improve Palliative Care in Neonatal Intensive Care**

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**Context:** The development of Peri and Neonatal Palliative Care (PNPC) in the Neonatal Intensive Care Unit (NICU) is considered a worldwide priority. Literature acknowledge nurses, specially the paediatric specialized nurse, as one of the main keys in this development. Nevertheless, in this western European country, exclusively nursing recommendations for PNPC practices are few, fragmented, with a major and almost exclusive focus on end of life care and bereavement and far from overlapping with World Health Organization (WHO) definition.

**Objectives:** Identity experts perceptions about PNCP in the NICU according to:
1) nursing intervention areas,
2) nursing models /theories in clinical practice and
3) recommendations for nursing PNCP practices.

**Method:** This is a qualitative study using exploratory interviews with content analysis (five specialists).

**Results:** Experts recognised nursing intervention areas according to: nursing care characteristics, levels of professional development and place of clinical practice (hospital/community). They considered nursing models/ theories relevant to advance care planning, identified some authors, but underlined the importance of combine them to meet the newborn and family's palliative needs in daily practice scenarios. Experts made different levels of recommendations addressed to: nursing schools, health professional namely nurses, health care units, board of nursing and central decision-making bodies.

**Conclusion:** To implement WHO definition of palliative care in NICU remains a challenge. Nurses, particularly the pediatric specialized, are fundamental for the development of PNPC in NICU. More research is needed. In this country, nurses are on the lead of PNCP development and should move forward, by identifying nursing quality indicators or developing nursing PNPC pathways, to meet WHO definition and international standards.
Outcomes of a High-risk Cohort of Infants with Complex Congenital Heart Disease Referred to a Perinatal Palliative Care Service

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**Background:** Significant progress has been made in the care of neonates with congenital heart disease (CHD) identified by fetal echocardiography. While the majority of ante-natally identified lesions are amenable to medical intervention and definitive surgical correction, some defects carry a high risk of perinatal death and maternal morbidity, even in resource-sufficient environments.

**Methods:** We queried the Texas Children's Hospital Fetal Cardiology (FC) and Perinatal Pediatric Advanced Care Team (PPACT) databases. Institutional Review Board is not required for retrospective studies at our institution.

**Results:** 6314 comprehensive fetal echocardiograms were interpreted by dedicated pediatric cardiologists during a 36-month period ending in January of 2018 in women who had been referred referred for suspicion of congenital heart disease. 14 fetuses were deemed at high risk for intrauterine or neonatal demise due to the severity of their anatomic defects, or associated extracardiac and/or genetic anomalies. These families were referred to Texas Children's Hospital's Perinatal Pediatric Advanced Care Team (PPACT) for creation of a perinatal care plan. 3 babies died in utero, 2 were stillborn (defined as death at or after 28 weeks gestation), 7 died in the hospital within days of delivery, and 2 who were discharged on hospice care died at home. Seven (50%) babies had trisomy 18 or 13, or significant comorbidities, such as the VACTERL association or congenital high airway obstruction syndrome (CHAOS).

**Conclusions:** Expert teams can accurately identify high-risk cardiac defects, facilitating referral for perinatal palliative support and the individualized care plans these families need. Comprehensive counseling of the expectant family and formulation of a consistent and comprehensive patient-focused, family-centered birth plan, inclusive of medical, psychosocial, spiritual and bereavement care is indispensable. Further research is needed in this emerging area.
'Juggling and Struggling' - Parent and Professional Experiences of Accessing and Providing Neonatal Palliative Care within a Children's Hospice

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**Background:** Advanced technology has led to babies who would not previously survive birth being born with life-limiting conditions. Opinion suggests we are reaching the 'final frontier' in palliative care development where the needs of babies and families shortly after or before birth are recognised as discrete and under-addressed. This study examines parental care experiences and decision making regarding accessing hospice care during the perinatal/neonatal period.

**Methods:** Qualitative approaches explored experiences of parents (n=5) and health and social care professionals caring for them within a children's hospice (n=17). Interviews collected data from parents and focus groups from professionals. Thematic analysis was used. Ethical approval was given.

**Results:** Uncertainty was constant in parents' and professionals' narratives. Professionals talked about the need for flexibility whilst striving to balance between being supportive and not being intrusive. Parents described their struggle to make decisions in the light of such uncertainty. The expertise available in hospice in providing high quality care for the baby and family unit in a home like environment was evident, however recognising and meeting the physical needs of mothers post birth was challenging. Parents highlighted that gaining access to hospice and awareness of services from the neonatal unit was ad-hoc as they juggled competing demands and struggled with uncertainty. Further hospice staff felt there was a struggle between them and neonatal units to ensure timely referrals were made for eligible babies.

**Conclusions:** Findings highlight that children's hospices are a potential option for some babies with life limiting conditions in neonatal units. Such care may be in the antenatal period, end of life, following death or into bereavement. A consistent approach and open dialogue between neonatal units and children's hospices is required. Further research to examine the perspectives of hospital staff is necessary.
Challenges of Perinatal Hospice Care in Hungary
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Context: Losing a child at any age is an immense tragedy. When it happens during the perinatal period its weight is intensified by the illegitimate status of perinatal grief, its surrounding taboo, so the burden it conveys is all the bigger. In Hungary in 2017 91,600 live births were registered, perinatal mortality rate was below 0.5% and cca. 1 in 4 pregnancies ended in some loss. No standardised perinatal bereavement care is provided on an organized level, yet, there are attempts to implement it.

Objective:
(1) Present the applied practices, contrast the guidelines and the available support.
(2) Highlight the main challenges to introduce standardised perinatal bereavement care.

Methods: In-depth interviews and study of the protocol and practices in involved departments (7 PICs, 6 obstetrics and gynaecology departments, 33 interviews - 12 doctors, 7 mid-wives, 10 nurses, 4 psychologists) concerning perinatal death and forms of bereavement care. The focus is on the provided overall support; existing and wanted competencies; personal death and loss attitudes and on experienced difficulties.

Results: Professional and personal requirements of bereavement care presently show that there is a growing need for this care, specific trainings are also necessary, for the personnel is equipped with few tools and competencies to communicate, help families cope with grief and loss, or to cope with their own feelings; all these involving an elevated risk for burn-out and compassion fatigue.

Conclusions: Care guidelines and trainings in the formative processes are to be implemented to improve coping strategies, communication, supporting skills, competencies and self-protecting measures. For proper perinatal hospice care in Hungary a shift of attitude and skills development are needed as much as established cooperation of multidisciplinary groups. It requires new protocols, competency trainings, supportive and psychological measures.
Nusinersen and children with spinal muscular atrophy type 1 (SMA 1): do they still need pediatric palliative care (PPC)?

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**Background-aims:** SMA1 was considered a life-limiting condition eligible for PPC. Nusinersen is the first effective drug approved for SMA (in Italy since October 2017) and has dramatically changed the natural history of the disease. The aim of our study is to evaluate if a curative treatment alters children’s and families’ needs and the indication for enrollment in PPC.

**Methods:** This is a retrospective medical record review of children with SMA1 referred to our Hospital for Nusinersen (October 2017- June 2018). The following data were collected: age, sex, respiratory state, feeding management, functional motor scale, presence of anticipatory plans, admissions in Pediatric Intensive Care Unit (PICU), children’s deaths, parental consent or refusal to therapy with Nusinersen.

**Results:** Of 15 children, 10 were already in the Nusinersen maintenance program because they had been enrolled in phase III trials, 4 received the first loading doses, while the parents of a 3 months old infant with severe SMA1 refused treatments. We didn’t register any child’s death. One family decided to withdraw after the first injection because of respiratory failure. The oldest patient withdrew after the second loading dose for extreme scoliosis and pain. Age at time of referral ranged from 3 months to 15 years, median 1 years 10 months; CHOP-INTENDED above 40/66 in one case. Among 15 children of our cohort, 10 were in non invasive ventilation, 2 had tracheostomy, all 15 needed mechanical secretion clearance, and 10 alternative enteral feeding; 4 children were admitted to PICU and 3 had an anticipatory plans of do not resuscitate; for all children palliative consulting was requested, and for one case also ethical discussion.

**Conclusion:** PPC are still essential for SMA1 even during Nusinersen treatment because of the complex needs (symptoms control, emotional burden, social, spiritual and ethic needs) related to the disease.
Priorities for Research on Children and Young People with Life-limiting Conditions: A Systematic Review and Consultation Exercise

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Background and aims: It is essential that all stakeholders are involved in setting research agendas. This was a first priority for the new Martin House Research Centre, just the second centre in the UK focused on research concerning children and young people with life-limiting conditions, their families and the staff who care for them.

Methods: We conducted a systematic scoping review of existing research prioritisation exercises. We then used the review findings as a basis to consult with stakeholder groups about their research priorities through a workshop attended by young people, clinical and care staff, clinical psychologists, chaplains, heads of services and national strategic leads.

Results: Twenty-four existing research prioritisation exercises relevant to children and young people with life-limiting conditions were identified. These had generated a total of 279 issues or research questions which we organised into 15 topic areas.

The range of stakeholders attending the consultation event was more diverse than had previously been achieved. Many of the issues identified as research priorities aligned with those reported by previous research prioritisation exercises. One new topic area was identified: spiritual needs and care.

Stakeholder groups differed in their views on the most pressing areas for research. Young people prioritised research on spiritual care and pre- and post-bereavement support. Parents' believed the most urgent issues were emotional support to all family members and providing support to families where the condition had an uncertain trajectory. Professionals called for research on decision-making and the best ways to provide palliative and end of life care, including spiritual care.

Conclusions: Findings highlight the need for research across all aspects of children’s palliative care. They are relevant to researchers and those who support or fund research within the sector.
How Much Does a Charitable Hospice in the UK Reduce Admissions to NHS Acute Hospitals?

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Background/context/aims: Children's hospices in the UK are funded predominantly by charitable donations. The aim of this study was to give an estimate of the saving by NHS acute hospitals by children and young people with palliative care needs utilising a charitable hospice.

Methods: Retrospective review of notes for all children and young people staying at one UK Children's Hospice over a 2 month period.

Results: 78 days of care were provided in the hospice which would have otherwise resulted in hospital stays. These children came from geographical areas from 6 clinical commissioning groups (funding regions in the UK) and included emergency symptom control stays, children acutely unwell and sick enough to require hospital admission but who opted not to attend hospitals, end of life stays where the child died and an 'end of life stay' where the child recovered. This is a cautious underestimate as any days where it was felt that families could possibly have stayed at home were discounted and it is likely that some of these would have resulted in hospital stays. The data excludes planned hospice respite stays where the child received significant symptom control management or `stepdown from hospital´ stays where the child could have been deemed medically fit for discharge even though additional training and support was of benefit. In addition, hospice staff provided telephone support to numerous families thus avoiding NHS attendances at General Practice surgeries or Emergency Departments, an additional saving for the NHS which was observed but not formally analysed in this retrospective review.

Conclusions: In addition to hospices providing valuable respite for children with life-limiting conditions and their families, the service reduces bed occupancy in acute NHS hospitals. More research is needed to assess the full impact of savings. This has potential implications for funding for children´s hospices at a time when many hospice charities are struggling.
Home Death for Children - Does Inequality Exist?
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Background: Previous studies indicate that terminally ill children and their families prefer for the child to die at home; yet, in Denmark, as in most countries, the majority of children who die from natural causes die at hospital. Knowledge is needed to determine whether inequality exists in place of death (POD) among children.

Aim: The aim of this study was to examine if inequality exist in POD among children concerning age, gender, diagnose and urbanicity.

Methods: All children referred to The Child & Youth Palliative Care Team in Central Denmark Region (1.3 million inhabitants) since April 1st 2016 were included. Age, gender, diagnose (cancer/non-cancer), urbanicity (hospital in the municipality or not) were retrieved in medical files. Adjusted associations with home death were analysed mutually adjusting for the independent variables. Pearson chi² and logistic regression were assessed in STATA-software.

Results: In total, 40 children were referred. Mean age was 7.8 years (95% CI: 5.9;9.6) and one fifth was under one year of age. 23 children died in the study period with a mean age of 6.3 years (95% CI: 3.7;8.8). Nearly one third of these children were under one year of age. 15 (65.2%) died from cancer, 13 (56.5%) lived in a municipality with a hospital and 13 (56.5%) died at home. No differences in POD were found according to children's age, gender or diagnosis, but living in municipalities without a hospital was found to increase the possibility of dying at home (Adjusted OR: 14.4 (95% CI: 1.2;166.3)).

Conclusion: We found no differences in POD according to age, gender or diagnosis, but children living in municipalities with a hospital had a higher tendency to die at hospital. However, only 23 children were included, and CIs are wide, which means that the results must be interpreted with caution. This study stresses the need for larger, population-based studies with focus on inequality in pediatric palliative care.
A Descriptive Study of a Simulation Based Palliative Care Communication Curriculum for Pediatric Critical Care Fellows

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**Background:** Pediatric palliative care (PC) education is lacking in pediatric critical care medicine (PCCM) fellowships despite the desire of many program directors and fellows to expand their training in difficult conversations. Simulation-based training is an experiential method for practicing challenging communication skills such as breaking bad news, disclosing medical errors, navigating goals of care, and supporting medical decision making.

**Methods:** We describe a simulation-based communication series designed for PCCM fellows, including pre-simulation session, simulation sessions, debriefing, and evaluation methods. From 2011-2017, 18 PCCM fellows participated in a biannual half-day simulation session. Each session included three scenarios (one case over three times points, allowing for participation in up to 18 scenarios over three years. Standardized patients were utilized as the mother. PCCM and pediatric PC faculty facilitated, evaluated, and debriefed the fellows after each scenario. Fellows were evaluated in four communication categories (general skills, breaking bad news, goals of care, and resuscitation) using a 3-point scale. Descriptive analysis is provided.

**Results:** 116 evaluations were completed for 18 PCCM fellows. Median scores for general communication items, breaking bad news, and ranged from 2.0 - 3.0 (interquartile range 0-1) with scores for resuscitation lower at 1.0 (IQR 1.5-2).

**Discussion:** This experiential simulation-based PC communication curriculum teaches PCCM fellows valuable communication techniques, while sharing the preparation, methods, and lessons learned. Since many graduate medical education fellows are rated highly in general communication techniques, teaching should be focused on more nuanced and complex communication tasks.
Responding to Global Need for CPC Education: An Innovative Multi-lingual Approach

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**Background:** Fundamental to the design of a palliative care training programme is that it is accessible, affordable and culturally appropriate for that particular setting. Language is key to accessibility and following a successful pilot in October 2011, the International Children's Palliative Care Network (ICPCN) developed an e-learning programme. Courses are accessible in English, French, Portuguese, Spanish, Russian, Serbian, Czech, Mandarin and Dutch with Hindi and Vietnamese courses soon to be made available.

**Aim:** To demonstrate the range and growing global reach of CPC courses available through the ICPCN e-learning platform.

**Method:** A review of period May 2016 till April 2018 was undertaken utilising 3 data sources:
1) Data from the virtual learning environment (VLE), e.g. demographics, course completion, module and course access and assessments;
2) Data retrieved from Survey Monkey used to evaluate participants’ experience; and,
3) Data obtained during an evaluation of ICPCN's education programmes.

**Results:** Over 3,000 participants have accessed the e-learning from 120+ countries. English is the most prevalent language used with 74% of participants registering for English courses followed by 8.5% for Spanish courses. Upon evaluation of the course: 55% participants accessed the internet from home, 39% from work and 6% from an internet café. In an evaluation of participants views on the e-learning courses: 80% scored it as useful, 61% changed their practice, and 73% increased knowledge, skills and attitudes.

**Discussion:** ICPCN e-learning presents an innovative opportunity to broaden the reach and accelerate the upskilling of health care professionals in areas where it is most needed. Whilst there are numerous educational challenges to overcome, including the issue of increasing internet connectivity, these are necessary advancements to be made in an era of rapid technological advancement.
Project ECHO: Creating a Community of Practice in Children’s Palliative Care
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Background: Project ECHO (Extension for Community Healthcare Outcomes) is a structured telementoring model which aims to increase practitioner knowledge and skills to care for people with chronic conditions. Sessions include an education component providing access to evidence based, best practice guidance from specialists and case based learning opportunities with time for discussion and questions. The first children's palliative care ECHO network (the Network) has been established in a UK region to develop knowledge, skills and understanding in the diverse workforce contributing, in any capacity, to children's palliative care. Through video-conferencing technology, this low cost model builds a community of practice across geographical regions, enabling practitioners to take part in 90 minute sessions from work or home, minimising disruption to their day.

Aim: To provide an outline of
1) the ECHO model;
2) the network and curricula development process;
3) preliminary evaluation of impact, and
4) factors that have influenced or impeded the Network’s success.

Methods: The Network was established following a successful application to the Health Authority. Information was circulated widely and a planning meeting took place with 26 multi-professional participants to set the learning curricula and Network outcomes in line with the Project ECHO model. Seven monthly sessions have taken place to date and a survey is underway to capture participant views at this early stage.

Results: Survey results are being collated. Session attendance, (a proxy measure) indicates the Network is providing a valued learning and support experience with multi-professional uptake maintained at over 40 per session. It has extended its reach with regular participation from neighbouring countries and regions.

Conclusion: While at an early stage, the Network is demonstrating positive impact for practitioners through building a community of practice and through collaborative problem solving.
Continuous Professional Education of Clinicians and Raising Patients'/Families' Awareness Improves Pediatric Palliative Care Services Quality

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**Background:** Increasing pediatric palliative care (PPC) services quality is a major concern in Ukraine. All-Ukrainian Palliative Care Hotline for support of terminally ill children/ families and professional consultations of clinicians has been in operation since September 2015. The ongoing educational project for improving the service quality by continuous professional education (CPD) of clinicians and raising patients/families awareness, started in 2016.

**Objectives:** To explore how the project of CPD of clinicians and raising patients'/families' awareness on palliative care issues increases efficiency and effectiveness of PPC services.

**Methods:** Retrospective analysis of 587 histories of patients who received Hotline support during September 2015-December 2017 was conducted. The main reasons of patients' requests were quantitatively analyzed with the distribution represented by the 10-points scale chart, and the results per each year dynamically compared.

**Results:** Before the project start in 2015, pain management (65%), nutrition support (20%), psychological and legal issues (15%) were major requests. Significant decrease of pain management (1.5 points), nutrition (2 points), legal support (0.7 points) requests, and 2.3 points increase in psychological support requests was observed in 2017. Decrease of pain management and nutrition requests correlated with increasing number of educational events. Decrease in legal support requests correlated with increasing parents' understanding of their entitlements due to continuous legal assistance. Increased parents' ability to identify own psychological problems due to continuous psychological consultations was the reason for increase in psychological support requests.

**Conclusions:** Ongoing educational project of CPD of clinicians and raising patients'/families' awareness increases efficiency and effectiveness of PPC services. As Hotline provides national level support, the results may be considered valid for all regions of Ukraine.
“I’m Going to Church Anyway”: The Impact of Spirituality on Parental Grief
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Background: Bereaved parents identify significant spiritual needs throughout their bereavement journeys. Spirituality has been identified as a primary means by which bereaved parents can find meaning in their loss. This ability to find meaning is associated with lower maladaptive grief symptoms. The use of spiritual coping strategies has been associated with improved coping and mental health outcomes among bereaved parents.

Objective: To describe the impact of spirituality on bereavement and to evaluate how bereaved parents’ spiritual journeys effect measures of grief, depression, and meaning-making.

Methods: 29 participants whose children died of cancer at a large pediatric cancer center in the United States completed a semi-structured interview about their bereavement experience. Participants were prompted to describe the impact of spirituality on their grief. They also completed questionnaires including the Prolonged Grief Disorder Questionnaire (PG-13), Beck Depression Inventory (BDI-II), and Integration of Stressful Life Experiences Scale (ISLES). Interviews were analyzed using semantic content analysis and broadly categorized as describing positive, negative, or neutral spiritual experiences during bereavement. These groups were utilized in a mixed-methods analysis to identify between-group differences in questionnaire data.

Results: Most participants described positive spiritual experiences through bereavement. Participants who described overall positive experiences with spirituality during bereavement had significantly higher scores on the ISLES, suggesting increased meaning making, and lower scores on the PG-13, suggesting less prolonged grief.

Conclusions: Bereaved parents report a diversity of experiences related to spirituality. Those with positive spiritual experiences are less likely to have symptoms of prolonged grief and more likely to find meaning in their child’s death than participants with negative spiritual experiences.
Creating a Safe Environment for Children and Parents: How the Concept of Holding, Applied to Paediatric Palliative Care (PPC), Collides with Belgian Child Euthanasia Procedure

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Context: PPC aims to promote quality of life in children, taken into account the complex relations among family members. Belgium is the only country of the world which voted in 2014 a law extending self-request euthanasia for competent children, without any restriction of age, when facing unbearable constant physical suffering at end of life. Since 2014, euthanasia was granted for 3 adolescents in Belgium.

Objectives:

i) to present analogies which can be found between the holding concept (developed by Winnicott) and the family-centred holistic approach in PPC, especially in decision-making processes.

ii) to demonstrate how the holding concept collides with the formal procedure included in the Belgian euthanasia law extended to children in 2014.

Results: Stepping back from a paternalistic attitude of overprotecting families and deciding at their place, PPC value decision-making at end of life based on honest conversations, expression of feelings and taken into account children's/adolescents preferences. On the other hand, Belgian euthanasia procedure for children focuses on the individual autonomy of the child, placing on him the burden of taken the ultimate responsibility of death.

Conclusion: Identifying the principal elements of Winnicots concept of holding, transposing them to essential PPC interventions and finally comparing them to the current Belgian procedure of euthanasia highlights the sweeping opposite approaches held.
Non-religious Arguments to Discuss Pediatric Euthanasia: Why Should Pediatric Palliative Care Use them

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Context: Pro euthanasia movements are expanding globally. The debate is sensitive and complex and raises a large spectrum of ethical implications. Although the scope is on adults, Netherlands and Belgium have already extended laws to include pediatric age. Arguments evoked to reject pediatric euthanasia are usually linked as religious convictions. Is this a fact or a myth? How can this perception interfere in the quality of the debate?

Aims: Reflect about:
1) religious/ the non-religious arguments against pediatric euthanasia,
2) consequences of this misunderstood in the quality of the dialogue in a secularized society.

Methods: Ethical approach, based on the principles of Beauchamp & Childress and the doctrine of double effect (Tomas Aquino), used to analyze complex singular situations.

Results: Most Pediatric Palliative Care community rejects euthanasia, by the reasons stated by International Children Palliative Network or the European Association of Palliative Care. Arguments are multidimensional, complex and goes far beyond religious convictions: including ethical, psychological considerations, state of the art or cultural and legal framework. In fact, reducing debate to religious arguments, can discredit PPC or introduce mis concepts. In some very complex situations shaped by the media, involving the principle of double effect, religious convictions can be an important bias. On the stories of Charlie Guard and Alfie Evans, pope's public position about withdrawal of medical interventions can have important consequences on the quality of the information surrounding PPC.

Conclusions: The debate surrounding pediatric euthanasia is inescapable, challenging and emerging worldwide. PPC defenders have to point out solid arguments and not contribute to overlapping with religious convictions. This bias can interfere negatively in the quality of the debate, and not contribute for better practices in end of life care that suits children's best interest.
**Beliefs, Luck, and Oppression Associated with Paediatric Palliative Care in South Korea: Implications for a Model of Anti-oppressive Surrogate Decision-making**

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**Background and aims:** There are complex ethical issues that lie between respect for autonomy and paternalism, while conducting surrogate decision making in South Korea. Hidden moral dilemmas which arise towards near the end of life and associated with beliefs, luck and oppression, connecting among risks, contingencies and the best interests. This research aims to examine how social workers can identify the difficulties in the ethos of surrogate decision-making both with terminally ill children and young people.

**Methods:** The researcher employs critical ethnography. Three main methods of data collection are observation, semi-structured interviews and document analysis. In total, 112 interviews took place. The research underwent full ethical review by the School of Applied Social Science's ethics committee at Durham University and the Institutional Review Boards in Korea gained full approval.

**Results:** The emerging themes were identified and elaborated in the following areas: Oppression were reported by individuals, families, communities, institutions, hospitals, palliative care staff and are linked with political, economic, social and cultural aspects. Paediatric palliative care in neoliberalism might face a vicious cycle as oppressed social workers, reproducing oppression as undervaluing the best interests of children, oppression in space, time and ways of communication, and oppression as strong paternalism in bureaucratic system. The study also found that surrogate decision making is related to beliefs' system linking to religion, attitude, culture, superstition, and stigma. Surrogate decision making and luck can be associated with blaming or praising.

**Conclusions:** The findings suggest the need to address oppression and luck in their cultural and social context, alongside children rights initiatives for pursuing effective anti-oppressive practice within a cross-agency approach.
Longitudinal and Systematic Screening for Depression and Anxiety in Children and Adolescents with Cancer

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Background: Children with cancer suffer from psychosocial distress; however depression and anxiety disorders remain under-diagnosed, as screening of depression and anxiety symptoms was hindered by lack of appropriate and efficient measures designed for this population. Here we present the establishment and validation of a 3-tier process for systematically identifying children with cancer coping with depression and/or anxiety disorders and referring them for treatment.

Methods: A prospective screening of children age 7-21 years with cancer treated at Sheba medical center. Screening for symptoms of depression and anxiety is performed at 4 time points: 1, 4, 7 and 12 months following cancer diagnosis. Patients are screened using the child and parent versions of the PROMIS (Patient-Reported Outcomes Measurement Information System) Depression and Anxiety Scales (first tier) followed by a semi-structured interview using the K-SADS (second tier). The tools for the screening process were translated to Arabic and Hebrew as well. Participants who meets the DSM-5 diagnostic criteria for depression or anxiety disorders are referred to a psychiatric evaluation (third tier).

Preliminary results: So far, 83 participants, 41 boys and 42 girls, age 7-21 years (Mean=13.4 y, SD=3.7) were enrolled. The internal consistency of the PROMIS anxiety and depression scales was high (Cronbach´s alpha-0.86 and 0.87 respectively). 42.8% of participants met the criteria of depression and/or anxiety disorders. Using a ROC analysis, we found that PROMIS depression and anxiety cut points of 12 and 16 have sensitivity of ≥90% and specificity of ≥77% for diagnosing depression and anxiety disorders.

Conclusions: Our preliminary results indicate that the 3-tier screening process for depression and anxiety in children with cancer is feasible and efficient. Implementing a systematic screening based on 3-tier process will improve the psycho-social diagnosis and treatment of children with cancer.
The Importance of Cyberspace for Adolescents in Palliative Care

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Background: The adolescence it is a transition phase from the childhood until the adulthood, it is when the adolescent deal with the development challenges. When adolescents are submitted to a long and complex treatment and life limiting diseases, they must to deal too another transition - a treatment and care - and with changes in their lives and routine.

Aim: The purpose of this study was to know the importance of cyberspace for adolescents in palliative care - based on their relation, meanings, actions and practices.

Methods: This is a qualitative research, approved by an ethics committee, which used an ethnographic approach and the Symbolic Interactionism as references. This study was made in two environments, an offline and online. In the offline's we used a paediatric palliative care outpatient clinic, and for the online's we used social networks. 10 adolescents in palliative care, aged 13 until 19 years old, were interviewed and their social networks profiles were observed. A total of 4 hours of interviews and 8861 posts were decodified for the thematic analysis.

Results: It was identified two main categories, "The cyberspace for me" and "My life online". Each one shows, respectively, the meanings of cyberspace and the actions and practices of adolescents, in palliative care. The relationship created it`s represented by the adolescents interactions with other people, with the environments - online and offline - and with themselves.

Conclusion: This relationship promotes a sense of autonomy, recognition and empowerment of adolescents in palliative care. Furthermore the adolescent, in palliative care, become the protagonists of their lives, being able to maintain control of their diseases and treatment. The cyberspace it´s an important tool for the care of adolescents in palliative care. Health professionals should use it as a resource of information, interaction and care, facilitating the transition of care process from adolescents in palliative care.
Supporting the Evolution of a Programme of Palliative Care Services for Children: Leadership Lessons Learnt

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Research aims: This recent evaluation sought to report the outcomes of the first phase of a national co-funded Children's Palliative Care Programme (CPCP) to enhance children's palliative care in the Republic of Ireland (RoI).

Study design: A mixed methods design was used, involving a rapid review of the literature, self-completion surveys, face-to-face and telephone interviews and focus groups. All data collection instruments were developed taking account of: the aims of the evaluation. An advisory group assisted the evaluation.

Results: The evaluation demonstrated that the programme of investment and leadership, comprising of three elements (education, specialist Consultant & national network of nurses) furthered the strategic aims of the 2010 Irish policy by facilitating key improvements in service provision. Results indicated 4 main outcomes of the programme including:

- Improved quality of life for children and their families;
- Improved co-ordination of services to children with life-limiting conditions;
- An improved children's palliative care sector with improved education in children's palliative care;
- Increased awareness of children's palliative care and of the new service.

Participants also provided feedback on challenges to the effective delivery of the programme and suggested areas for improvement and development. The report includes a set of 20 new recommendations for consideration at national level which will shape the second phase of the CPCP.

Conclusion: This study sought to evaluate an initiative to enhance Irish children's palliative care. Findings demonstrate that the three key elements of the CPCP have been welcomed by all stakeholders and contributed to nationwide improvements in service provision. A number of recommendations were made for the next phase of developments in children's palliative care in the RoI.
Regular GP Consultations Are Associated with Reduced Rates of Emergency Care for Children and Young People with Life Limiting Conditions

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**Background-context-aims:** Children and young people with life limiting conditions (LLC) have complex healthcare needs, visit A&E departments and have emergency inpatient admissions. There is some evidence that they go straight to hospital, bypassing GP care - improving GP care may reduce this. The study aimed to determine whether regularity of GP contact is associated with levels of A&E visits and emergency inpatient admissions for this population.

**Methods:** An extract of GP records from the Clinical Practice Research Datalink with linked Hospital Episode Statistics was requested for 0-25 year olds who had ever had a diagnosis matching either an ICD-10 or Read code framework for LLC. Each year, gaps between GP consultations were recorded for each person and a variability score calculated (the variance divided by the mean gap between consultations). Also each year, numbers of A&E visits and emergency admissions per person were counted. Separate models were developed for A&E visits and emergency inpatient admissions as dependent variables; variability score was the independent variable of interest. Age, ethnic group, main diagnostic group, deprivation category, year and total number of GP consultations per year were also included. Multilevel negative binomial regressions were used as the outcomes were count data clustered by individuals.

**Results:** Greater regularity was associated with a lower rate of A&E visits and emergency inpatient admissions: those with higher variability scores had up to 9% (95%CI 2-16%) more A&E visits and 12% (95%CI 6-19%) more emergency admissions than those with the lowest scores. Age group, diagnostic group, deprivation category and year were also predictive of numbers of A&E visits and emergency admissions.

**Conclusions:** Scheduling and attending regular GP consultations may have the potential to reduce use of emergency care among children and young people with life limiting conditions.

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Pediatricians’ Experiences and Attitudes Regarding Advance Care Planning
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Background: Physicians caring for children with life-limiting or life-threatening diseases are involved in Advance Care Planning (ACP). To understand the implementation of ACP in daily practice this study assesses the experiences and attitudes of Dutch pediatricians regarding ACP.

Methods: Pediatricians working in five academic pediatric care settings and a national pediatric oncology center were invited to complete an online survey regarding their experiences with ACP in their most recent case of a deceased child. In addition they were asked about their attitudes regarding ACP.

Results: One-hundred-seventy responses were analyzed, a response rate of 28%. Eighty-five percent of the pediatricians described a case of a deceased child (n=145). Most of the cases concerned a patient who had died in the past two years (81%). The children had a mean age of 6 years (range 0-18) and most of them had died in hospital (69%). Most commonly discussed topics with parents were diagnosis (91%), life expectancy (90%), goals of care (87%), fears and worries (87%) and code status (86%). With children who were estimated to be mentally competent (n=24,) joy (79%), hope (75%), diagnosis (75%) and fears and worries (71%) were most often discussed. Actual care was perceived by the respondents as concordant with prior discussions and parent’s preferences in 92% and 86% respectively. Insight in concordance of care with the preferences of the child was lacking in most cases (74%). Most physicians (94%) were satisfied with their communication in the reported case. Respondents acknowledged benefits of ACP, but only 22% stated these conversations occur often enough.

Conclusion: Pediatricians discussed topics related to ACP with parents, but less often with children. Although pediatricians are satisfied with their practices regarding ACP, the occurrence rate of ACP conversations and the position of the child in the conversations need attention.
Enduring Ambivalence: PREPARE - Development of an Advance Care Planning Intervention in Pediatric Palliative Care

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**Background-context-aims:** Paediatric advance care planning (pACP) takes place in a setting with unclear prognosis, complex disease courses, developmental changes, extreme emotional burden, and large care networks. The study aims at developing and piloting a structured pACP intervention based on the specific needs in paediatric context.

**Methods:** The study takes place in a Paediatric Palliative Care Centre and consists of a development and a pilot phase. The development phase aims at designing a pACP intervention including a discussion guideline, written materials and a training manual. The intervention was developed in a participatory process with purposefully selected bereaved parents and professional experts. Discussion groups were conducted to explore experiences and needs of the parties involved. Data were analysed by the coding method of Saldaña (2016). Results were used to develop a first draft of the intervention. Documents were revised and validated by participants.

**Results:** Data analysis shows that decision making in pACP is not a rational pondering of alternatives, but rather an emotional struggle oscillating between fight, acceptance, and hope. This ambivalence persists even after the completion of written parental advance directives. Indeed, maintaining the possibility of making further changes to the advance directives was of high importance to the parents. Thus, pACP needs to be conceptualized as a continuous communication process.

Health care professionals criticized the lack of a clear legal framework and tended to diminish the importance of written pACP documents in the absence of a personal exchange with parents and facilitators.

**Conclusions:** Decision making in pACP is an ongoing, iterative communication process characterized by a high degree of ambivalence on all sides. These data will inform the currently ongoing development of a pACP-guideline which will then be tested in the pilot phase of the project.
Training Paediatricians to Discuss Advance Care Planning with Families

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Introduction: Advance care planning (ACP) in adult palliative care is known to improve outcomes for patients and families. Although empirical evidence in children is limited, NICE guidance recommends ACP for all children with life-limiting conditions (LLC)\(^1\). More than just a paper document, ACP is a framework for continuous and open conversations between health professionals and children and their families - as partners - to achieve the best outcomes. Doctors' lack of experience and confidence poses a barrier to effective and timely ACPlanning\(^2\). Parents feel let down by doctors' poor communication skills when discussing ACPs\(^3\). We organised an ACP study day for paediatricians comprising didactic lectures and small-group role-play workshops.

Methods: The morning lectures were open to all health professionals in the East of England deanery. Admission to the afternoon workshops was limited: 17 senior paediatricians and one nurse attended. Participants were asked to complete pre- and post-workshop questionnaires online.

Results: 17 participants completed the pre-workshop questionnaire, 15 the post. 60% were general or community paediatricians. 81% had no formal training in ACPs, including 88% of consultants. Participants rated their confidence in discussing ACPs with children and their families on a 1-10 Likert scale, pre- and post-intervention, demonstrating an increase in self-rated confidence ($t(14)=8.21, p<.0001$). Results shown in Table 2.

Conclusion: Even senior paediatricians lack training and therefore feel ill-equipped to lead ACP discussions. Participation in our course improved professionals' confidence in discussing ACPs. Although, further evaluation is needed to see if this brief and summary self-evaluation result corresponds to improved ACP implementation in practice, focussed education programmes including role-play workshops may be simple, yet effective, ways of ensuring better planning for children with LLC.
Feasibility and Acceptability of the Family Advance Care Planning (FACE) Intervention for Adolescent and Young Adult Bone Marrow Transplant Patients

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Background: Adolescent and young adult advance care planning (ACP) has been shown to be feasible and acceptable in non-hospitalized patients with cancer and HIV. To date, ACP has not been investigated in the inpatient setting or among those undergoing bone marrow transplant (BMT). We sought to evaluate the feasibility and acceptability of an adolescent and young adult ACP intervention among patients hospitalized prior to BMT.

Methods: Adolescents and young adults age 14-26 scheduled to undergo BMT were eligible to participate in a feasibility pilot study of the FACE-BMT (Family Advance Care Planning for BMT patients) intervention. The intervention consisted of 3 sessions with the patient and their surrogate(s):
1) An ACP survey completed prior to admission;
2) a facilitated Respecting Choices Next Steps interview within 48 hours of hospital admission; and
3) review of Session 2 and follow up within 48 hours of session 2. Feasibility was measured by enrollment (goal 75%), retention (goal 80%), and attendance of all three sessions (goal 85%). Acceptability was measured by a satisfaction survey (goal 75% rating as satisfactory/very satisfactory).

Results: To date, ten patient-parent dyads (63% enrollment) have been included. Median patient age was 18, 70% were male, 90% were Caucasian. Retention was 90% and 80% of dyads attended all three sessions. Satisfaction was 100%. Due to their clinical condition, half (50%) of the patients underwent session 2 outside of the protocol timeframe.

Conclusions: Conducting an ACP intervention among adolescent and young adult patients undergoing BMT was feasible but required protocol flexibility due to the patients clinical condition. Patients and their surrogates found the intervention to be helpful in facilitating communication about end-of-life decision-making. This preliminary pilot suggests adolescent and young adult ACP is desired by patients and surrogates and can be conducted among hospitalized patients.
Dynamics Of Quantitative Indicators Of Pediatric Palliative Care In The Russian Federation

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Background. The provision of pediatric palliative care (PPC) is included in the medical legislation of the Russian Federation (RF) in 2015. The accessibility of PPC infrastructure is one of the priorities of national healthcare system. However, the development of the PPC system varies depending on the local capacity of the regions of the RF.

Aim. To evaluate the dynamics of the basic indicators of the infrastructure of palliative care for children in Russian Federation (RF) from 2015 to 2017.

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 RF in 2017.

Results. The children’s population of the RF in 2017 was 29,573,981 children under the age of 18. In 2017, inpatient PPC in the RF was provided by 5 children’s hospices (in 5 different subjects of the RF) and 47 inpatient departments (in 33 subjects of the RF). Outpatient PPC was provided by 81 mobile services (5 times more than in 2015) in 30 subjects of the RF. The total bed capacity of PPC was 719 (increased by 27.3% compared to 2015), that ensured care for 5,272 incurable patients (pts) per year (increased by 22.9% compared to 2015). The number of beds for PPC was 2.4 per 100,000 children. In nosological structure of hospitalized children were predominantly pts with neurological disorders (2801; 53.1%). In 11 regions out 85 there were no outpatient and inpatient forms of PPC. The children’s population of these sparsely populated areas is only 6.9% of the country’s children under the age of 18.

Conclusion. In 2015-2017, Russian Federation was very actively developing the infrastructure of PPC. It is necessary to improve availability of the PPC in sparsely populated areas of the country.
**P002**

**Sibling bereavement**

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**Background and aims:** Loss and grief are part of life, but losing a sibling is a momentous event in someone's life, especially if this happens during childhood or adolescence, and it may impact not only one's mental health but also the parental and fraternal relationships, as well as other spheres which define life. The relationship between siblings is unique and may be the most significant and lasting relationship. The child who loses a brother during his or her childhood or adolescence is naturally the family member who lives the most with this loss.

This work arises from the development of a PHD Nursing Study. As the meaning of this experience when transitioning to adult life is unknown, namely in the attitude towards health, we aimed to describe the experience of losing a sibling in childhood or adolescence, its meaning in adult life and to identify the impact on healthcare provision, namely for nursing.

**Methods:** A phenomenological and interpretative study was made, having as a starting question: Which is the meaning of health to people who lost a sibling during their childhood or adolescence? 21 adults, who had lost a sibling during childhood or adolescence, were interviewed. The information related to feelings, experiences and behaviours of each participant was analysed and discussed in order to obtain an answer to the research question and to describe the consequences of the experience of sibling bereavement process until adolescence.

**Results:** In the situation where there is a child/adolescent with a chronic and complex life-limiting illness, which can be prolonged for some time, and which is understandably the center of care for the whole family, the brother resents himself for not receiving the same attention, he also loses visibility within his own family, sometimes receiving messages from people close to him to restrain his hurt, to be strong by his parents.

**Conclusions:** These behaviors lead the child to feel that the pain of their loss is discredited, devalued, misunderstood, ignored. Pediatric palliative care plays a key role in supporting the child/adolescent with a chronic and complex life-limiting disease, as well as support for the family, including siblings and grandparents, including during the mourning period, also considering that the plan should be individualized, always centered on child-family, holistically designed, proactive, flexible and transversal to all the services and structures involved. In assessing needs and providing care the siblings should not be forgotten as well as all family. The diagnosis or recognition a chronic and complex disease in child/adolescent not only affects each individual element, but has an impact on the family as a unit.

Nurses, through the frequent opportunities of closeness to children and families, are in a privileged position to identify those who suffered a loss and need help and specific interventions. The importance of identifying signs and characteristics of a fraternal loss during childhood or adolescence and of evaluating its impact in family life is recognized, which justify a planned intervention aiming to minimize the effects that may arise in adulthood. The impact of the death of a child in the life of her siblings and other close relatives or friends is identified, as well as a model of intervention that necessarily aims for an holistic support to the grieving family.
P003
Qualitative Medical Education for Children´s Palliative Care in Ukraine: Increasing Demand
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In Ukraine, the syrup form of morphine for children was registered in 2017, when the Ministry of Health made purchase of the first batch of 315 vials(dos.of 2mg/ml for 100 ml in vials). The need for PPC is between 35-200 thous. children. Absent clinical protocol for cchronic pain treatment.
At the Ivano-Frankivsk Center for Palliative Care, with the support of IRF a Training Center for Palliative Care is functioning since 2009, which annually holds training for 500 students (doctors, nurses, social workers, chaplains, volunteers, healthcare administrators ect). From 2014, a series of trainings on PPC is underway. 41 students completed course of PPC in 2014, 121 in 2015, 293 in 2016.
CF "Mother Teresa» in April-May 2018 conducted an anonymous survey of 56 doctors: 35 from Ivano-Frankivsk Oblast Children´s Clinical Hospital and Advisory Clinic and 21 from Ivano-Frankivsk City Children´s Clinical Hospital and City Children´s Clinic. Were asked:
1. Do you know that syrup form of morphine, which can be used for children, has been registered in Ukraine?-3% answered "Yes, I know, but I do not use it in my work" and 27% have not heard about it.
2. Do you know what PPC is?
"I do not know, though I heard that it exists"-9%
"I know that Children's hospice for seriously ill children was opened"-53%
"I understand what it is, but I cannot give a full answer"-38%
3. Who is provided with PPC?
"Children with cancer"-33%
"Children who die from severe illnesses"-41%
"I think that patients with cancer who suffer from severe pain"-26%
4. Where can palliative care for children be provided?
"In hospices"-98%

Conclusions: Education in the field of organization and provision of children´s palliative care is essential; Ministry of Health should implement PPC training courses at diploma level; public and parents should be informed about rights to receive reliable medical information and right to pain relief; should be approve clinical protocol for the children´s pain treatment.
P004
Advocacy for Development of Children’s Palliative Care in Ukraine. Charter of the Rights of the Dying Child
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In 2017, by support of International Renaissance Foundation the Charter of the Rights of the Dying Child was translated and published in Ukrainian. Between 30 and 200 thousand children (0 to 18 yr) require PPC. The theme of child’s death is taboo. Talking about the end of life is difficult for health workers and spiritual advisers. Among the available PC teams there are no medical chaplains. On June 1, 2017 members of the Ukrainian Council of Churches and Religious Organizations (RO), with the Minister of Health, U.Suprun, and the Commissioner of the President of Ukraine for Children’s Rights, M.Kuleba, reviewed and signed the Charter. The council consists of 18 community leaders of Churches and RO. During the discussion members of the Board touched upon a number of issues:
- The role of medical chaplain or spiritual adviser in PC
- Ethical issues of euthanasia
- Use of opioids for children’s pain relief
- Participation of representatives of RO in work of the PC service.

Joint work with RO began at initiative of "Eleos-Ukraine" organization in 2014. In 2016, a conference "The Role of Churches and RO in the Provision of PC. Access to pain relief as necessary component of care" was held. In 2017 an information campaign and series of trainings was held on the rights of palliative patients, skills for communicating with families, support in grief and the prevention of burnout.

Conclusions:
- RO are integral part of social life as they participate in PC
- Learning and understanding principles of PC should be integral part of education of religious leaders
- RO want to receive reliable and honest information on principles of PC for their community members
- Among RO there is large number of negative misconceptions about pain management
- Necessary to create public platforms for communication of medical, social workers as well as members of RO
- RO demonstrate openness to dialogue with the medical community and want recognition of their participation in PC.
Sedation at the End of The Life in a Pediatric Palliative Care Unit
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Introduction: Sedation is often used in the end-of-life (EOL) care. The incidence of sedation at the EOL ranges 15-60%, and although it is used in all environments where patients die, it occurs frequently in hospitals and for cancer patients.

Objectives: Analyzing patients who received EOL sedation in a PPCU and describing characteristics and the environment where it takes places.

Methods: A retrospective descriptive study of patients who have received sedation in EOL in a Pediatric Palliative Care Unit (PPCU) between 2012 and 2017.

Results: There were 50 deaths, 25 (50%) required sedation in EOL. The older children at diagnosis required sedation (median 2.5 years compared to 1 month of life) (p< 0.02) and higher age at admission in PPCU (median 7 years versus 9.5 months) (p< 0.05). They often belonged to group 3 of the ACT 19/25 (p< 0.01). Main diseases were: cancer 16/25 (p< 0.01, 9 CNS tumors) and neurological disorders 10/25. The only symptom with significant difference (p< 0.02) was pain (13/25). Median follow-up time was 3 months (0- 33 months). Median days of sedation were 2 days (1-23 days). Midazolam was used in all cases. Route of administration were: central venous reservoir 13/25, via subcutaneous 6/25 and peripheral 6/25. Patients who required sedation in EOL died with greater frequency in the hospital 20/25 (p< 0.01), than those who didn’t. We found relationship between sedation in EOL and causes of death. Patients who died by progression of the disease 21/25 (p< 0.01) were sedated often than those who died of diseases related to the underlying disease 4/25 (p< 0.01).

Conclusion: Age at diagnosis, belonging to group 3 of the ACT and pain determine a greater need for sedation in EOL, which is shown to condition the place of death. Continued attention in the last days of life by PPCU that enables domiciliary assistance of sedation, as well as an earlier diagnosis, would allow families to take part in decision about place of death.
The Role of the Pediatric Continuity Nurse: There Is No Place Like Home

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Background-context-aims: Bologna Public Healthcare Company (AUSL) built an Integrated Care Pathway (ICP) for “Children suffering from chronic pathology at risk of developing multiple disabilities”, with the collaboration between various departments involved in these children's care, and local family associations. Home nurses and pediatricians are essential players in ensuring continuity of care, taking part in the discharge, activation and supply of devices and drugs, and the emotional and practical caregiver's support.

Methods: Periodic ICP assessments were performed, and some critical issues came out:
- higher load for home nurses (greater number of children with complex disease);
- poor knowledge and training in pediatric matters;
- wide territorial extension;
- incomplete census of children with chronic complex condition (CCC) pathology.

The role of the Pediatric Continuity Nurse (PCN) was created within Pediatric Palliative Care Team (PPCT). Experience in pediatrics home care and training in palliative care are needed. PCNs move throughout the whole AUSL area, working with all the people involved to facilitate the discharge from hospital, to offer support to home nursing staff, to cooperate with all the palliative team, to develop structured school staff training, to update data about children with disabilities living in our area. We re-evaluated ICP performance after PCN introduction.

Results: PCN has been recently introduced; nevertheless, in the last 6 months, we observed a sharply lower mean length of stay in hospital for unplanned admissions in CCC children referring to AUSL hospital, compared with the other pediatric hospital where the PPCT is not strongly consolidated.(8,5 vs 19,8 days).

Conclusions: PCN is a promising tool to improve ICP performances. Further data should be collected prospectively, but this trained and dedicated nurse could play a role in providing better home care for these complex patients, also reducing inappropriate hospitalizations.
P007
Defining Palliative Opportunities in Pediatric Patients with Solid Tumors
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Background: Pediatric patients with solid tumors have many opportunities for increased primary or specialty palliative care (PC). However, how many, when they occur, and if they are correlated with other factors are unknown.

Methods: A priori, 9 palliative opportunity categories were defined (disease progression and relapse, hospital admission for symptoms or social concerns, intensive care or marrow transplant admission, phase 1 trial or hospice enrollment, DNR status). A single-center retrospective review was conducted on patients aged 0-17 years at diagnosis with bone/ soft tissue tumors who died from 1/1/12-11/30/17. Demographic, disease, and treatment data was collected. Descriptive statistics and time-to-event analyses were performed. Timing of opportunities was evaluated over quartiles from diagnosis to death.

Results: Patients (n=60) had a mean of 9 (SD=4) palliative opportunities. Number or type of opportunities did not differ by demographics or diagnosis. PC consulted on 18 patients (30%) a median of 14.0 months (IQR 25.0) after diagnosis, and 2.6 months (IQR 11.5) prior to death. Likelihood of PC consult did not differ by diagnosis or total opportunities. The opportunities that preceded PC consult were progression/relapse (9/18), escalated hospital level of care (4/18), symptom admission (3/18), and end-of-life (EOL) concerns (2/18). Hospice was involved for 72% of patients. The majority of opportunities occurred in the last quartile of the disease course (median 5.0, IQR 5.0).

Conclusions: Patients with solid tumors incur many events warranting psychosocial or palliative support which increase toward the EOL. Mean opportunities is likely a minimum due to stringent collection methods. No palliative opportunity or demographic variable was associated with PC consultation. Additional work is needed to further refine what qualifies as a palliative opportunity, how to fully capture opportunities, and how those may differ across different cancers.
Influenza Strikes and ... Costs

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Background-context-aims: 2017-2018 was a very bad season for the flu. According to CDC influenza activity was as widespread as in 2009 pandemic and children with chronic health conditions were at higher risk for flu complications. This study analyzed the epidemiological context of influenza outbreak at our hospice, where 22 foster children with severe neurological disorders and multiple disabilities were looking after, and emphasized the cost of medical care in this situation.

Methods: The medical records of children cared in our hospice were retrospectively reviewed in order to evaluate diagnosis, treatment and evolution of the infectious disease. Meanwhile, costs of medical care were compared with average monthly medical cost, in order to quantify the burden of this outbreak. Finally, efficiency of vaccination was evaluated.

Results: Although all children and staff from hospice were vaccinated for influenza in October 2017, in February 2018 two children were admitted to the hospital for pneumonia and had positive test for B influenza. In the same period other 11 children presented with mild to moderate influenza-like symptoms and 9 had no influenza signs. The Public Health Department declared influenza outbreak at the hospice and indicated to treat with oseltamivir all symptomatic children and give prophylaxis to the rest of them. The total cost, including sanitary protection, disinfection, vaccination and treatment was about 800 Euros, 35% more than average monthly health care expenses. In terms of efficacy, vaccination offered 40% protection.

Conclusions: Children who need palliative care are at great risk of severe influenza and of developing flu-related complications. Prevention consists of vaccination alongside everyday good hygiene practices. The efficacy of the influenza vaccine varies but nevertheless is better than 0%. So, although the vaccine isn’t perfect, it’s still of value and therefore should be used, no mater of cost.
Pediatric Pain Profile-Cross Cultural Translation and Adaptation to Italian

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Background-context-aims: pain is a complex, highly unpleasant subjective experience, better measured through self-report scale. Children with profound intellectual disability have limited communication skills to report their pain and depend on their caregiver for this. In these patients, we commonly use observational scales that have been validated mostly in English language (NCCP-PV, DESS, INRS) with some limitations: hospital setting, pain assessment linked to the post-operative period, long time of scoring or the excessive individualization.

Methods: in our study we chose Pediatric Pain Profile (PPP) as a reference scale for the shortening time of scoring (2-3 minutes) and the possibility of being used in different settings (hospital and home). The PPP scale was validated in English (Hunt, 2004) to assess pain in these patients through the description of 20 items. The objective of this non-randomized, multi-center interventional study is the validation of the PPP in Italian maintaining psychometric properties. The scale will be used on an equivalent population of 75 patients of both sexes between 1 and 18 years, in hospital or at home, with severe neurological and cognitive impairment, the inclusion in the study is based on the outcome of the evaluation of adaptive behavior (Vineland scale). The internal consistency of the scale will be tested comparing the pain assessments made by the caregiver during a period of maximum pain or well-being. To evaluate the inter-operator reproducibility, the PPP scale will be applied simultaneously by the caregiver and the operator; the two scores must be overlapping. The evaluation of pain before and 30 minutes after the administration of acetaminophen at a dose of 15 mg / kg will be used to assess its sensitivity.

Conclusions: The use of this tool should increase attention and awareness of parents and physicians towards pain in this fragile population.
Implementation of a Transition Pathway in Paediatric Palliative Care: A Quality Improvement Approach

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Background: More children with life-limiting conditions (LLC) are surviving through adolescence into adulthood due to improvements in their management. The transfer of care from paediatric to adult services is complicated by the complex needs of young people with LLCs and requires an extended period of transition. Transition in palliative care is the purposeful, planned movement from child-centred to adult-oriented health care systems.

Method: We have developed a transition pathway based on the Together for Short Lives guidance that starts in early adolescence. It includes concrete steps for preparation, active transition and integration that are individualised, holistic and easily understood by staff, parents and young people. A quality improvement approach is being used to facilitate successful implementation, including process mapping and the use of Plan, Do, Study Act (PDSA) cycles.

Results: The first cycle has been the education of staff to ensure common understanding of the terms transition and its implementation. A total of 83 staff received training between October 2017 and May 2018, all staff groups were represented. A survey was sent to ascertain response to training and to plan further implementation. Response rate was 40%, 97% (32/33) found the training useful and all reported that the content was clear. Knowledge of transition was good or excellent following training. Themes deemed most useful were "Starting Early", "Planning" and "Clear process". Future development will include further PDSA cycles, these multiple iterative changes will be described in detail. The unique needs, wishes and aspirations of each young person and their family will remain a priority.

Conclusion: A growing number of children with life-limiting conditions are surviving into adulthood and should have continuity of palliative care services throughout their life span. Children’s palliative care services must support transition through clear structured pathways.
Buccal Opioid Use for Pain and Dyspnoea for Children with Palliative Care Needs during End of Life Care

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Background: Buccal mucosa is an effective route for medication: it avoids first pass metabolism, ensures rapid absorption & onset of action, is minimally invasive, avoids needle insertion. For children it is convenient, when prescribed & prepared in advance, & easy for parents to manage at home. This study aims to review buccal administration of opioids during end of life care & discuss implications for nursing.

Methods: Retrospective case note review of children receiving end of life care over 12 months in 2017 to elicit effectiveness, advantages & disadvantages of buccal opioid administration for breakthrough pain & dyspnoea.

Results: Records of 26 children, 54% female, aged 8 days - 17 years who received end of life care were reviewed. 53% died at home, 27% in hospice, 20% in hospital. Place of death matched family preference in all but one case. 38% had cancer. 15 children had continuous subcutaneous (SC) or intravenous (IV) infusion for symptom control. 70% used buccal opioid (62% Diamorphine; 8% Oxycodone) for breakthrough pain &/or dyspnoea, effective in all cases except 3. One child received SC bolus via retained SC device. One used buccal benzodiazepine to resolve dyspnoea. One disliked the taste so breakthrough opioid was given IV by parent at home.

Advantages: fast absorption & action, painless, easy & timely administration, parents empowered to treat symptoms, inexpensive.

Disadvantages: unpalatable taste, preparation of small doses, storage of ready prepared doses for just in case use, wastage, benefit reduced if dose accidentally swallowed.

Recommendations for nursing: Buccal route administration of opioids is safe & effective strategy & requires: organisational procedures to guide practice, risk assessment for safe prescription, preparation, storage & disposal in preferred care environment, competency training for staff including teaching parents safe administration & monitoring of effectiveness with appropriate pain/dyspnoea assessment tool.
Quality of Palliative Care for Paediatric Patients in Hospital Stage in Latvia

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Palliative Care (PC) Service at the Children's University Hospital is unique service that provides consultations for patients in different departments in the hospital, outpatient consultations and home care in Latvia. Each year, the number of PC paediatric patients increases in Latvia. In 2017 - 215 patients received palliative home care, and 281 patients and their family members were consulted in different departments of the hospital. In the Children’s University Hospital there is no special PC department. Daily care is been provided by nurses of different units. Objective of the work was to assess and analyse views of nurses in different units, as well as parents on the quality of PC.

A non-experimental quantitative and qualitative research carried out in 2017. The survey involved 100 nurses and was carried out through a questionnaire, and later results got analysed. Semi-structured PC-related interviews with five parents with an incurably ill children had been conducted and analysed. The main obstacles from nurses’ perspective in ensuring higher quality of PC for patients are: lack of PC training, discomfort experienced by staff when announcing bad news, staff shortages, unmet spiritual or emotional needs of the patient/family and emotionally draining of the provider. The parents view of quality care obstacles include: insufficient support for child’s siblings, communication problems with medical staff including lack of time to explain and talk about child's care.

The quality of PC is significantly affected by the knowledge and skill level of the hospital nurses. A solution would be the development and introduction of a post-graduate training course programme for hospital nurses in PC.
Caregiver Burden, Quality of Life and their Relationship to Healthcare Utilization in Low-income Parents of Children with Life-limiting Conditions

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Background: Caring for a child with a life-limiting condition (LLC) involves challenges above and beyond typical parenting demands, from complicated medical care-giving at home to providing routine access to specialty medical care. This study explored associations between healthcare service utilization and caregiver burden/questions of life (QOL) in low-income parents of children with LLCs.

Methods: Parents of 1,746 children diagnosed with LLCs, or part of a stratified random sample of healthy children, were invited in 2017 to complete a survey containing the CarerQOL, a measure of informal caregiver burden/QOL. Children were 0-17 years old, enrolled in a US Medicaid (low-income medical assistance) program, and living in the Midwestern US. Relationships between parent burden/QOL and claims-based indicators of health services use in the prior year were analyzed for LLC group respondents. Indicators included number of hospitalizations, length of stay (LOS), number of emergency room (ER) and outpatient visits, and number of prescription fills.

Results: 244 parent-child survey dyads (LLC group) responded. More hospitalizations and longer LOS were each associated with lower caregiver QOL and higher burden. Having to fill more prescriptions was associated with higher caregiver burden only. The strongest correlations were found for caregiver burden and number of prescriptions filled, number of hospitalizations, and LOS. Burden and QOL were not associated with number of ER or outpatient visits.

Conclusion: Higher healthcare utilization was associated with higher caregiver burden and lower QOL in low-income parents of children with LLCs. Findings emphasize the importance of considering the high personal, indirect costs (e.g., lost work time) these parents face in ensuring their child's access to quality care. Routine assessment of informal caregiver burden/QOL should be a core component of family-centered care.
P016
Thinking Outside the Box: A New Approach to Handle Patients with Multidrug Resistant Bacteria on a Paediatric Palliative Care Unit

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Background: Multidrug resistant (MDR) bacteria are an important healthcare issue throughout Europe. Because children and adolescents with life-limiting conditions (LLC) are particularly vulnerable to MDR bacteria and nosocomial infections (NI), much effort must be undertaken to avoid new colonisations with MDR bacteria in these patients. The aim of preventing NIs often competes with social participation, which is one major goal of paediatric palliative care (PPC). At the PPC centre in Datteln, Germany, a new hygiene concept for patients with MDR bacteria called PALLINI has been developed. PALLINI follows risk-adapted hygienic guidelines and at the same time enables the patients to participate in the daily routine of the unit. It entails special procedures of barrier nursing for patients who are colonised with MDR bacteria and allocates the patients to one of the following risk groups: high risk, moderate risk or low risk for MDR bacteria.

The current study aims to evaluate the safety of PALLINI by means of a surveillance.

Methods: Over a period of two years (02/2018 - 01/2020), a surveillance will be conducted. All patients on the PPC unit will be screened for MDR bacteria at admission and discharge. Descriptive statistics will be used to analyse the characteristics of study participants, pathogens at admission, localisation of pathogens, proportion of carriers of MDR bacteria and occurrence of NIs.

Expected results: Results of the first 6 months of data collection will be presented. We expect that the rate of NIs due to MDR bacteria, as well as the proportion of positive MDR screenings in the low risk group will be close to zero.

Conclusions: The outcome of this study will be an evaluated safe and liberal hygiene concept for patients with MDR bacteria, which will be transferable to other settings, e.g., hospice and respite care. The study is funded by the German Federal Ministry of Education and Research (grant number 01GY1713).
Paediatric Advance Care Planning (pACP) and the Italian Law: The Outcome for Children in a Paediatric Palliative Care (PPC) Programme


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Background: pACP aims to ensure end-of-life care conforming to patients and families' choices. pACP is an important part of the care planning and a goal of PPC; the new Italian law highlights sick person's values of self-determination, even if child, in a doctor-patient relationship (“Informed consent and living will act” L.219/2017). The aim of the study is to analyse if the parents and children's wishes, declared in the pACP form, are respected.

Methods: The study was a retrospective medical records review conducted in our centre of specialized PPC in Northern Italy. The study population were children died between January and December 2017 in a PPC programme. All parents of children with life limiting conditions or terminal illness, through several interviews, focalized what was favourite place of death for their loved children in the pACP form. The team who supports the families is composed by paediatric palliative care physician, nurse and psychologist; family doctor, home healthcare operator and spiritual assistant when request.

Results: Since January to December 2017, 29 children died (mean age 9 years, range 10 months-17 years). Causes of death: oncological diseases (n=18, 62%) and non-oncological diseases (n=11, 38%). The wish regarding the place of death was respected in 79% (n=23, 79%). Five families (n=5, 22%) had chosen home as favourite place, 10 families (n=10, 43%) had chosen Paediatric Hospice and 8 (n=8, 35%) the paediatric Hospital closest to their home. Three families didn't express their wishes (n=3, 10%) and for other three the wishes weren't respected (n=3, 10%).

Conclusions: When a child and his family are in a specialized PPC programme, pACP is a relevant part of plane of care: the choice about the favourite place of death are respected. In some cases, to die at home couldn’t be the first choice however, the best place to die is where family and child feel safe and comfortable. The Italian law assure the pACP as a right of the child.
P019
Themes from the Early Days of Children´s Palliative Care
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Aims: Children's palliative care (CPC) began developing in the 1970s and many of the early leaders in this field are able to share their memories and experiences. Little has been written of the history and this study is an attempt to share the history of the early development through their personal narratives; and to learn from and build on their foundation. The study also sought to honour the early visionaries who established this field.

Method: Interviews were carried out with CPC leaders to identify those they believed were pioneers. A comprehensive literature review. Questionnaires were sent to identified pioneers and other CPC leaders. Pioneers were interviewed either personally or through Skype. Different themes and personal connections were identified. The information is to be set up on a “live” website for ease of addition of further information.

Results: Pioneers were linked to different elements of CPC - research, education, model development; international networks; international conferences. Early pioneers were very generous in sharing their memories. Most early development took place in the United States and the United Kingdom. Issues we believe are new concerns for CPC were identified by the early pioneers. Some of the early pioneers remain active in the field; Themes that were further examined included:
· The key role of nurses
· The effective collaboration with the Church
· The importance of including General Practitioners as well as Paediatricians
· Connections between pioneers
· Other professional whose writings and work influenced the pioneers to develop CPC

Conclusions: While history itself is of the past, the impact of history is on the present and the future. When we examine the work, writings and wisdom of our early pioneers we discover that they had a vision greater than the original programmes they developed. Together they have nurtured children's palliative care today.
P020
The Utilisation of Hospice Services Following Referral from Malignancy Tertiary Team

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Introduction: Hospice services have traditionally been associated with patients with malignancies, despite upwards of 80% of hospice utilisation for respite involves patients with non-malignant conditions.

Aim: To determine the referral and uptake patterns in children referred from local tertiary malignancy services to the local children’s hospice.

Methods: The hospice/hospital databases were searched for referrals between January 1st 2012 and July 24th 2017 (5 years, 204 days) from Oncology or Malignant Haematology services. Demographics and diagnostics were retrieved from the database, referral letters and discharge letters.

Results: 47 patients were referred (45 accepted, 1 deferred, 1 awaiting decision). 32 of these patients had died at the time of data collection. During this timeframe, 91 children died under the ongoing care of the malignancy services in Sheffield Children’s Hospital (61 oncology, 30 malignant haematology). The scope of this work could not accurately determine how many of those were unexpected deaths. The average age of referral was 10.52 years (0.5-21.58 years). The average time from diagnosis to death was 1103 days (127-3736 days) and the average time from referral to death was 132 days (9-512 days). 19 families used the temperature controlled room in the bereavement suite for care of the body after death, including 3 of 16 who had died outside of the hospice (11 home, 3 hospital, 2 other/unknown). All families were offered bereavement and sibling support.

Limitations: Data was not available on the provision of care in the home from the hospice team and the paediatric oncology outreach nurses.

Conclusion: The hospice provides additional choice to families for place of care, place of death, care of the body after death, sibling support and parental bereavement support. Provision of this service from the voluntary sector affords a resource intense holistic service, and alternative environment, in addition to hospital based services.
P021
The Experience of Childhood Cancer Survival: Reports of Adolescents
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Background: The increase of the number of cancer survivors has altered the concern of health care professionals to give continuity to the follow-up of the survivors. For this to occur, it is necessary to establish a long-term relationship between health care professionals and patients. It is necessary that the health care providers were involved in the care of the children, they must be attentive and able to identify in the long term specific problems, with the objective of detecting the chronic conditions aiming at the quality of life of the survivor and his family. This study aims to know the survival experience of childhood cancer for the adolescent survivor.

Methodology: This is a qualitative research supported by a Symbolic Interactionism as a theoretical reference, and thematic analysis as a methodological reference. The participants were 4 adolescent survivors of childhood cancer. They still accompanied the care at a special outpatient clinic in the city of São Paulo. This study was submitted to the Ethics Committee of the University of São Paulo.

Results: We found that cancer survivors considered their normal lives, they manage to maintain a health routine in their normal activities, besides annual visits to the cancer treatment outpatient clinic, even after the cure, to maintain health surveillance.

Conclusion: Cancer survival requires a family re-adaptation to the child’s chronic condition. There is a need for continuity in the health care of these survivors and their families even after the end of the treatment. Knowing the experience lived by these adolescents, it becomes possible to contribute with interventions that allow the strengthening of these survivors and the family to this condition.
Family Impact on the Diagnosis of Autism Spectrum Disorder
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Introduction: Autism spectrum disorder (ASD), also known as Autism, the condition is prevalence in early childhood where the first signs occur around the age of three. However, this process is long and exhausting until diagnosis, generating doubts and anxiety in the family.

Objective: Identifying the family impact in the diagnosis of Autism Spectrum Disorder and detecting the main changes in the family routine after receiving the diagnosis.

Method: This is a qualitative exploratory descriptive study, carried out through semi-structured interviews. A sample of 10 family members of school-age children diagnosed with ASD were enrolled in a project that attends children with special needs in Mogi das Cruzes-SP, Brazil.

Results and exploration: Through the thematic analysis of the data it was possible to find four central categories: the previous distrust of the diagnosis; difficulty in accepting diagnosis; the search for knowledge to understand better the diagnosis and changes in the family social life.

Conclusion: The family impact caused by the diagnosis results in permanent changes in the family routine and life style, which leads the involved people around to seek for restructuring in order to support it´s child and seek a better adaptation to the new reality of this family.
P023
To Provide Difficult Information to Parents When their Children Have a Brain Tumour
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Background: When a child has got a brain tumour the entire family is affected. The majority are cured, but approximately 30% relapses and 20% dies. Palliative care aims to reduce suffering and achieve good quality of life for both child and family. During these months or years the family receives various types of difficulty information. Studies show that the ability to understand the information depends on the knowledge about communication among healthcare professional (HCP).

Objectives and aim: The aim of this study was to examine how HCP communicate difficulty information to parents when their child has got a brain tumour and how parents think it should be communicated.

Method: In this, both quantitative and qualitative study Swedish parents who, during 1992-1997 lost a child due to brain tumour, answered a questionnaire. Questions concerning how difficulty information was provided were included in this study.

Results and conclusion: Of the 157 participating parents the majority was biological parents, had joint custody and lived with the diseased child. Most difficulty information was provided by a physician, on medical appointments in the presence of both parents and occasionally to one parent alone or by telephone or mail. The worse the information, the more common it was given without the child. Most parents thought that information should be provided to the family as soon as possible by a well-known person. Difficulty information shall be given in an honest respectful, empathetic and humane manner while conveying hope. There is a lack of routines for when and how difficulty information should be given to parents to children with brain tumours and interventions are needed to increase the knowledge among HCP. Parents appreciate forward and honest communication and for them to be able to capture difficult information experienced HCP is required, as well as plenty of time.
Spinal Muscular Atrophy Type 1: An Experience at a Pediatric Hospital

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Background: Spinal muscular atrophy Type 1 (SMA1) is a rare genetic disease that causes progressive muscle weakness. Main cause of death is respiratory distress and most patients die within the first year of life. Management options include focusing on symptom control while others use minimally invasive or invasive interventions. The Neuromuscular Disease Group at the Hospital Garrahan has implemented open communication with families by sharing the evaluation of the available options. Our aim was to describe clinical features, survival, and interventions in patients with SMA1 followed at our hospital.

Methods: A retrospective, descriptive study was conducted using the hospital's electronic records and the Working Group Database. Children born between 2013-2017 with molecular confirmation were considered.

Results: We included 25 patients. The median age at first visit was 5 months (1-39). Overall, 60% (15) were diagnosed at the hospital. Median age at diagnosis was 4 months. Median time between clinical diagnosis and molecular confirmation was 13 days (1-33). Sixteen patients died, 87% within the first year of life at a median age of 9 months (2-56) and 75% were at the hospital. The main cause of death was respiratory complications (81%). Two patients were on Mechanical Ventilation (MV) at the time of death. Among those who died, none required gastrostomy (GTT), and 73% were fed by nasogastric tube (NGT). Seventy-five percent of the patients were seen at the Palliative Care Unit to discuss the expectations of the family and to explain prognosis and treatment options. Of the patients who are still alive, 3 are fed by GTT and 2 by NGT. Five patients need respiratory support; 4 are on MV and 1 receives non-invasive ventilation.

Conclusion: In this series, most patients died due to respiratory complications. The main aim of the working group is to accompany the patient and their family evaluating the options that arise at the moment of severe respiratory insufficiency.
Cutting to the Chase: When Do Severely Ill Children's Sleep Problems Require Clinical Attention?

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Background: Children with life-limiting conditions commonly suffer from sleep problems. The "Sleep questionnaire for children with severe psychomotor impairment (SNAKE)" identifies sleep problems according to its five scales “disturbances going to sleep” (1), “disturbances remaining asleep” (2), “arousal and breathing disorders” (3), “daytime sleepiness” (4) and “daytime behavior disorders” (5). The SNAKE relies on proxy ratings of the children's parents.

Aims: Cut-Off-values for the five SNAKE scales will be defined, enabling identification of clinically relevant sleep problems.

Methods: Parents complete the SNAKE at the time of admission to the pediatric palliative care unit. Additionally, for each child a team of palliative care experts assesses whether clinically relevant sleep problems are present (gold standard). SNAKE scores of children with clinically relevant sleep problems are compared to those of children without sleep problems (Mann-Whitney-U test). Additionally, cut-off-values are identified through ROC analysis.

Preliminary results: N=61 children were included in preliminary analyses (female: n=38; male: n=23; age: M=10.9 years). Experts rated n=27 children as having sleep problems. For scales (2) (U=-2.02, p<.05) and (4) (U=-2.48, p<.05) children that were rated as having sleep problems yielded significantly higher scale values than children who were not rated as having such problems. For these two scales, preliminary cut-off-values can further be defined by means of ROC analysis (2: AUC=.68; sensitivity=.66, specificity=.60, cut-off: 15.5; 4: AUC=.80; sensitivity=.85, specificity=.72, cut-off: 10.5). For none of the other scales clear cut-off-values emerge.

Conclusions: The preliminary analysis shows that the chosen study design seems appropriate for identifying the SNAKE's cut-off-values. A clearer assertion can expectedly be made with increased sample size (09/2018). The project is funded through Witten/Herdecke University.
Continuous Professional Education in Pediatric Palliative Care from Recruitment Stage

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Background: In April-September 2017, the project of pediatric palliative care advocacy among health care professionals of Kyiv was realized with support of European Union and Kyiv State City Council. The project goal was continuous professional education (CPD) of family doctors and pediatricians in pediatric palliative care, with objectives to recruit health care professionals for work in the second Kyiv multidisciplinary team(MDT) providing outpatient visits to the children requiring palliative care.

Methods: The project was implemented by series of lectures on various topics (basics of pediatric palliative care, pain management, care and nutrition, legal, psychological and spiritual support), and a seminar with international speakers' presentations. Each lecture was followed by a participants' survey on availability of children requiring palliative care, in their clinical practice (question 1), and willingness to work in pediatric palliative care (question 2)

Results: 273 health care professionals (doctors, nurses, occupational therapists and medical students) participated in the project. The affirmative answers to question 1 equaled to 2, 6,10,11,35 % after each lecture correspondingly, and 35% after the seminar. The affirmative answers to question 2 equaled to 95, 80,60,35,10 % after each lecture correspondingly, and 5% after the seminar. Based on the answers and awareness of health care professionals, recruitment to MDT was made.

Conclusions: CPD of health care professionals contributed to the recruitment of staff fully aware of scope of work and major issues in palliative care field, as well as psychologically prepared to work in MDT. This allowed reducing staff turnover and professional burnout, decreased costs and increased effectiveness of MDT work due to professional staff recruitment, as well as contributed to provision of seamless palliative care to Kyiv children.
A Systematic Review of the Impact of Psychosocial Interventions for Siblings of Children with Life-limiting Conditions

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Background: Siblings of children with life-limiting conditions (LLCs) have shown to be at risk of developing psychological, emotional, social and behavioural difficulties due to the stressors of living with their severely ill brother or sister. Psychosocial interventions aim to improve negative and positive outcomes for siblings through a diverse range of methods. No recent studies have yet synthesised the evidence on the impact of psychosocial interventions on mental health, social wellbeing and quality of life, specifically for siblings of children with LLCs.

Methods: In this systematic review, electronic databases and additional online resources were used to search for studies of psychosocial interventions for siblings of children living with LLCs. 10 eligible articles representing 9 studies were included. A narrative synthesis is currently being conducted to pool results by outcome and conceptually map intervention impact. Effectiveness is determined by the difference in mean outcome scores between baseline and post-intervention assessment or between intervention and control groups.

Results: Preliminary results for mental health outcomes show that hospital-based group interventions and respite camps are effective at significantly reducing anxiety in siblings of children with cancer. A group intervention, utilising cancer-specific information, discussion of family contexts and problem-solving strategies, was also effective at significantly reducing sibling depression.

Conclusion: Peer interaction appears to be effective at reducing anxiety and depression in siblings of children with cancer. However, the evidence for this finding is limited to pre-/post-intervention studies and needs to be confirmed in RCTs. There is also a lack of evidence on the impact of peer interaction on the mental health of siblings of children with non-cancer LLCs.

Funding: Martin House Research Centre provided financial support to the primary reviewer’s PhD studentship.
P029
Stepping up to integrate PPC in an intermediate care facility for children in Cape Town, South Africa

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Background: The need to access paediatric palliative care at intermediate / step down level within the public health structure had been identified as a gap in care. Through development of a provincial government policy, children living with life limiting and life threatening conditions and their families were afforded an opportunity to access appropriate care and support.

Aim: To describe the population of children admitted to the hospital, determine caregiver’s experiences and to describe the experiences of health care professionals providing care. To evaluate the capacity of the Intermediate Care Policy Framework to meet the needs of children with life-limiting conditions.

Methods: A mixed method longitudinal prospective study was conducted over a six month period at Sarah Fox Convalescent Children’s Hospital. Data retrieved from case report forms described the patient population and their needs. Data retrieved from a questionnaire described primary caregiver’s demographic data and their experiences. Focus group discussions were conducted to obtain data from health care professionals.

Results: Of 25 patients reviewed most patients were admitted for transitional care (n=12), followed by terminal care (n=7) and the most prevalent symptoms managed were pain (n=11) and secretion management (n=9). In terms of caregiver response: 21 felt that caring for their affected child drew the family closer and 24 derived meaning from the experience. Whilst health care professionals valued strong teamwork, they expressed regret that management and health authorities seemed to not appreciate the value of integrating a palliative care approach.

Evaluation: Provincial health policy had created an opportunity for integrating palliative care into a government supported step-down facility. In order for a service of this nature to be successful a committed trained team, adequate resources and buy in from management and health authorities is essential.
Psychological Home Assistance in the Paediatric Palliative Care: An Operative Model

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**Background:** The psychological support is a crucial element in the paediatric palliative care (PPC). This support could be supplied in different settings. In this report we are focusing on home care. The aims of this operative model are:

1. Encourage expression of emotions.
2. Increase disease awareness.
3. Develop personal resources.
4. Improve interpersonal skills.
5. Create a care space where the suffering can be elaborated.

**Methods:** The model to construct this “home based psychological approach” was created by literature reviewing, health care professionals’ experiences, analysis of cases in charge of the PPC team, and, mainly, an accurate evaluation of the psychological needs of sick children.

**Results:** The model structure is developed through these 5 points:

1. Start point
   - When the PPC team discloses any child needing a psychological support, the psychologist of the team meets the child’s parents as to discuss the difficulties of the child, the need of a structured intervention and to share the goals and the best way to achieve them.

2. Structure
   - The psychologist of the PPC team meets the child at home every week, for 60 to 90 minutes. In addition, another psychologist would be involved to supervise the work in progress once a month.

3. Instruments
   - Drawing, play-therapy, selected children’s literature, observation, role-playing, individual clinical interview.

4. Assessment
   - Periodic evaluations with appropriate questionnaires (non-standardised) by the psychologist who conducts the meetings, by the psychologist supervisor and by the child and his family.

5. Conclusion
   - When all the objectives have been achieved, the weekly home meetings can finish.

**Conclusions:** The importance of the work is to propose a new model for psychological home support in PPC, which has not been previously described in literature. It is an ongoing study, so the results are not definitive.
P031
Medical Marijuana Use in Pediatric Oncology Patients: Single Institution Experience
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Background: The use of medical marijuana (MM) has become widespread in various fields of medicine, including oncology. Using MM in pediatric oncology has been limited, and research on this topic is scarce, often showing conflicting results.

Methods: We report our experience with MM treatment in 51 children, adolescents, and young adults (6.4% of all patients) with various types of cancer who received anticancer therapy between 2010 and 2017 in our hospital. The main indications for MM prescription were nausea and vomiting, decreased mood, disturbed sleep, and pain. MM was given as oil drops to 30 (58.4%) patients and smoking to 11 (21.3%) patients, while other patients received MM via vaporization, capsules, or in a combination of various routes.

Results: Positive effects were reported verbally by children and parents in 80% of cases. No significant side effects were noted. Short-term side effects occurred in a minority of patients and were observed predominantly in children who received MM by smoking.

Conclusion: We can conclude that MM is a safe and effective treatment in pediatric oncology populations. MM may serve as complementary therapy to conventional medical treatment of a child with cancer and should be considered as an integral part of supportive care directed at the improvement of the quality of life of children suffering from cancer at the end of life. Taking into account that we have a profound deficit of knowledge on possible unwanted consequences of the prolonged use of MM in pediatric populations, further research in this field is needed.
Improving Medication Safety in a Children's Hospice: A Quality Improvement Project

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Background: Medication errors are recognised as a common source of adverse healthcare incidents. Children with life-limiting conditions often have multiple medical co-morbidities each requiring medical intervention and can be on complex medication regimes which increase the risk of medication prescribing, reconciliation or administration errors. Following a number of low harm medication errors, an improvement in medication safety was identified as a key quality improvement priority in our hospice.

Methods: Assessment of the problem included measurement of all medication incidents or near-miss incidents between January and September 2017, total 109. An aim statement, driver diagram and on-going data collection were the first steps in the project. Process mapping of key steps was completed in conjunction with multidisciplinary staff members to help identify potential areas for improvement. A number of Plan, Do, Study Act (PDSA) cycles have been completed and will be described in detail.

Results: A number of PDSA cycles have been completed with good effect. The use of a “sterile cockpit” aimed at minimising interruptions during prescribing has been implemented and has contributed to a reduction in prescribing errors from 4 per month to 1 per month on average. Staff and service user education sessions have been implemented with a focus on the use of the “Red Apron” to reduce interruptions during medication administration, this has supported the reduction in medication administration errors. A medication awareness week and newsletter to all families highlighting the importance of medication safety and prescription requirements has improved medication reconciliation. Full data and charts will be available to present.

Conclusion: This quality improvement project has led to a significant reduction in drug related incidents in our hospice. Work in ongoing to embed the learning throughout the service and to ensure continuation of the project.
Caring for the Team, Caring for the Child: Developing a Culture of Staff Support in a Children's Hospice

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Background: It is well recognised that working in children's palliative care can be rewarding but challenging, staff can experience high levels of stress and burnout. Caring for children at end-of-life (EOL) can be associated with feelings of failure and grief. It is recommended that organisations provide regular, structured and dedicated support focusing on staff wellbeing.

Method: The need for staff support has been recognised in our hospice and a suite of both informal and formal staff supports have been developed. Internal processes to ensure a supportive culture during EOL will be described.

Results: A supportive workplace acknowledges that the care of a child at EOL can be especially challenging, in each case a multi-disciplinary staff “huddle” is held before the admission of the child and family followed by twice daily “huddles”. These provide a forum to discuss both the practical, emotional and ethical challenges of the case.

A recent increase in clinical nurse specialists (CNS) allows daily CNS presence on the unit, advising more junior staff on symptom management and assisting with complex communication.

Emotional and clinical debriefs are held both during the EOL phase and following the death, these provide a safe place for staff to consider the case and to think about learning points. The family support team including psychology, social work and chaplaincy provide emotional and spiritual support to the staff and family. Formal bereavement support begins on admission and care staff are encouraged to work with the bereavement team including home visits after death to continue holistic care to the family after the death of a child.

Conclusion: The need for staff support is well recognised, we have described our suite of support, which is constantly evolving to meet the needs of staff. We believe that the involvement of the MDT throughout provides multiple opportunities for emotional staff support and is a model which could be shared with others.
**P034**

**Half-hourly Buccal Medications for End of Life Symptom Management for Infants Too Small for Subcutaneous Infusion**

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**Background:** Continuous subcutaneous infusion provides consistent reliable delivery of medication for end of life symptom management but may be very difficult in small neonates.

**Case report and series:** We describe a 5 week old baby with CHARGE syndrome & complex congenital heart disease whose end of life distress was well managed with ½ hourly buccal medication, alternating Diamorphine & Midazolam.

Oral Morphine 25mcg/kg 4 hourly was started for distress at day 28 of age.

On day 30 he became very distressed. Rectal bleeding & increased gastric aspirates indicated poor absorption due to probable gut ischaemia. Subcutaneous infusion was contraindicated because of failure to thrive & inadequate subcutaneous tissue.

He commenced regular buccal Diamorphine but experienced persistent end of dose distress for 3 days in spite of rapid dose escalation of Diamorphine (90mcg/kg/day to 400mcg/kg/day), sub division of Diamorphine to give 2-hourly then hourly doses, addition of buccal Midazolam increasing from 300mcg/kg/day to 600mcg/kg day given as 2-hourly then hourly doses. Both drugs were initially given together.

On day 32 doses were not increased but administration was staggered to give alternating Diamorphine or Midazolam on each ½ hour. From this point, symptoms completely settled until death on day 36.

Over 2 years, 8 infants, 4 female, aged 7 days to 11 months, received buccal medication alone for end of life symptoms (pain, distress, agitation) 2 in hospice, 6 at home. Duration 6 hours to 7 days, frequency of dosing varied from 'prn' to ½-hourly as determined by symptom response

**Conclusions:** Frequent administration of buccal medication can be a useful substitute for continuous infusion in infants who are too small or have other contraindications. If symptoms occur with conventional 4 hourly dosing, the dose may be divided & given as more frequent smaller aliquots up to hourly. Alternating Diamorphine and Midazolam every ½ hour may control symptoms without further dose escalation.
Options for Management of Pontocerebellar Hypoplasia in Light of a Systematic Review and Patient Cohort Analysis

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Background: Pontocerebellar hypoplasia (PCH) is a rare neurodevelopmental disorder that comprises underdevelopment of cerebellar and pontine structures of the brain with an early onset. There have been scarce publications elaborating on the treatment options. The aim of this study is to describe the course of disease in PCH and to define (palliative) treatment options in the different phases of the disease.

Methods: A systematic review of literature was conducted in PubMed regarding symptoms and management and also a retrospective cohort analysis of 12 patients from 4 hospitals in The Netherlands with PCH, diagnosed between January 2010 and August 2017.

Results: The spectrum of PCH consists of 18 subtypes (PCH1A-D, PCH2A-F, PCH3-10). From the literature 46 articles regarding symptoms and 27 articles regarding interventions were included in the analysis. The retrospective cohort consisted of n=10 PCH-2A and n=2 PCH-6-like patients, with a mean survival of 23 months (0-69) (n=6/10) and 5 months (na) (n=2/2) respectively. Symptoms were present in the domains pain and comfort, movement, appearance, epilepsy, communication and development, gastro-intestinal tract, respiratory tract. Interventions were of symptomatic and partially of a preventive manner. Most symptoms proved hard to treat especially discomfort. The symptom management required increasing frequency and dosage of multiple medications or sometimes surgical interventions involving a multidisciplinary approach. Decisions on treatment restrictions were present in 8 patients. A diversity of potential therapeutic measures as described has been summarized in an overview.

Conclusion: PCH-subtypes comprise a considerable clinical variety. An overview of possible options in symptom management is made as important step forward in the care for children with PCH, to improve wellbeing and quality of life.
P036
Sustainable Innovations in CPC, Based on the Real Patient Story!
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Background: For 10 years now, The PAL Foundation is committed to improve Children's Palliative Care (CPC) in the Netherlands. However, families often feel that they have to rely on themselves, and that sufficient information, coordination and guidance are lacking. In order to improve CPC, we must understand the needs and wishes of families better.

Aims: Aims are to gain insight in best practices and bottlenecks in CPC from the perspective of parents, and to evaluate developments from their point of view. Moreover, we aim to translate their perspectives into new initiatives, and gain awareness amongst policymakers on the needs of families regarding CPC. Furthermore, by sharing stories from parents to parents, a form of peer support will be created.

Methods: A pilot study among 20 parents was conducted to test the tool's validity. We used the online, narrative collection tool SenseMaker®, in which experiences of parents caring for a child in need of CPC were captured. Respondents were asked what is significant about their story; by interpreting his or her narrative, the parent acts as expert. The output was qualitative information, indexed by the sources so that quantitative data emerged without any external interpretation.

Results: During a pilot phase of two months, 17 narratives were collected. The stories contained valuable information about both best practices and bottlenecks. Three main topics emerged: organisation of care, communication and emotional impact. These topics and the feedback from parents were incorporated in a final version. At the time of submission, the final tool is open for use. We expect to report results at this congress.

Conclusion: Based on the pilot results, we were able to design the final version of the tool. In order to be able to translate families' perspectives into policy and to involve them in evaluating current developments, the data from the main study is necessary.
Care Analysis at a Pediatric Palliative Care Unit
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Introduction: Patient records allow for monitoring of the quality of care and facilitate comparative analysis. In 2015 the Palliative Care Unit our hospital started to use the Electronic Registry System for Pediatric Palliative Care in Argentina (RECuPPeRA) in order to define patient population seen and the clinical practices used.

Aim: To analyze a year of work at the PCU using the RECuPPeRA tool.

Material and methods: A retrospective, cross-sectional, observational study was conducted considering different dichotomous variables and categories expressed in percentages and standard deviations. A period of one year between June 1, 2016 and May 31, 2017 was evaluated. All patients seen at the PCU within this period were included in the study.

Results: 486 patients in following, 69 deaths (14%). Pediatric clinicians, who are the base of the care system of our hospital, refer around 50% of the patients to us when the patients are admitted because of an event. On the other hand, patients' referral by specialists is poor. Days between first consultation and death < 15 days 24 (35%), 16-30 d 10 (15%), > 30 days 35 (50%). EoL practices: Palliative sedation 25 (36%), without MVA 60 (87%), without enteral nutrition or hydration 42 (61%)

Conclusions: A registry tool such as RECuPPeRA allows us to conduct an analysis of our current situation and to define goals for the future. Around 50% of the patients with a life-threatening disease who are referred to us die within 30 days after the first visit. This shows the difficulties for early intervention we encounter, an issue we share with PCUs worldwide. We consider this tool may be useful to evaluate the quality of our care using end-of-life practices as a parameter; Results in palliative sedation as well as the percentage of patients that dies while on mechanical ventilation and withdrawal of food are those found in other studies.
**P038**

**Perinatal Palliative Care: A Protocol Is Enough?**

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**Background:** In Italy, neonatal mortality represents 70% of infant deaths, mainly due to perinatal and congenital conditions (70% in the first month, 48% during the first week). 94% is due to perinatal conditions and/or congenital diseases. Perinatal palliative care (PNPC) offers a global care to this population.

**Methods:** At the Maternal-Infant Department of a University Hospital, we created a multidisciplinary working-group to define a shared care pathway for newborns eligible for PNPC. In 2016, during 12 meetings, the eligibility criteria, pre/post-natal management procedures, and best practices for PNPC were defined. The aim was to offer PNPC to all eligible fetuses/infants/families and ensure the quality of the care.

**Results:** At the end of 2017, prenatal consultations by neonatologists for extreme preterm neonates or newborns with life-limiting conditions had increased (8 vs 18/year). The number of newborns who died in the NICU (Neonatal Intensive Care Unit) was reduced by 30% (17 vs 24). On the contrary, the number of eligible newborns receiving PNPC has been still limited (5 newborns of 24 eligible in 2016, 1 newborn of 17 eligible in 2017). The prenatal consultation was not followed by PNPC for the eligibles. Despite a multidisciplinary care pathway, our protocol was only partially implemented.

**Conclusions:** The multidisciplinary approach must begin at the antenatal counseling, despite the prognostic inaccuracy and unpredicted. A consensus on an ethical framework for the decision-making process should be established. It’s essential to integrate palliative care into intensive care, to identify eligible newborns to teach NICU clinical teams to provide primary palliative care and to involve the pediatric palliative care team.
How EPEC-P Training Changes PPC Ukraine

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Background: The aim of Education in Palliative and End-of-Life Care programs for healthcare educate healthcare professionals in the essential clinical competencies of palliative care.

Aims: To review changes in Ukraine after educational training EPEC-P in 2017.

Methods: The presentation of highlight successful educational trainings providing quality PPC.

Results: In Ukraine there are no PPC regulations, guidelines, and education. No any palliative care specialists were listed in the catalog of medical professions. The challenge of EPEC-P is to have educators and professionals in developing countries supporting the development of policies and programs that can act as mentors for development. In 2017 two PPC leaders have trained in EPEC-P. After visit the educational programs were created with main principles of adult learning: interactive lectures, advantages of small group teaching, using cases, role play, and assessment of effectiveness, etc. There 86 medical specialists have been studied of main principles and philosophy of PPC during Nov 2017 - May 2018 in Western part of Ukraine (Rivne, Ternopil’) and Center (Kiev). The number of participants - 86, trainers - 4, topics - 16, films - 11, handouts - 29, cases - 15, etc. Additional didactic material - 28. Positive responses from participants as like “most valuable for me were;”... teamwork... the opportunity to ask questions... foreign experience... detailed analysis of the essence of PPC... I found like-minded people... therapy of pain syndrome... scales and specific schemes... analysis of clinical cases... legal aspects... information about EPEC-P and about leaders EPEC-P. The training plays role in lead-up staff in Eastern, Western and Central Ukraine for stakeholders who are creating regional programs of PPC development.

Conclusions: In spite of loss educational programs in PPC in high medical schools and postgraduate course in Ukraine, EPEC-P training made a step forward in understanding and education changes.
Development and Implementation of a Community-based Pediatric Palliative Care Network in the Presence of a Well Rooted Adult Network

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Background: Development of a community-based Pediatric Palliative Care (PPC) network in the presence of an adult network in a mountainous area with a population of 96,646 minors and the nearest pediatric hospice at more than 140 km. By a recent survey in this area, 88 children (0-16 years old) are likely to require PPC services.

Results: In 2014, following national legislation, local government has approved the creation of a PPC network in order to guarantee continuity and quality of patient- and family-centered care as close as possible to the place of life.

From 2015 to 2016 the network began to develop through an outpatient clinic and training in pediatric palliative care of the members involved. In 2017 network was implemented with the creation of a PPC team (second level of PPC) which coordinates general pediatrician and community providers of the adult network (first level of PPC).

Starting with an interdisciplinary meeting, the team defines an individualised care plan shared with the family, which includes regularly scheduled home visits, 24H/7 availability and psychosocial services. Currently 33 patients eligible for PPC with an average high level of intensity are in charge to the network. 13 children died during a 1-year span, 80 % in the place chosen by the family.

Conclusion: This model of PPC network needs an interdisciplinary approach. The second level supports the home-based, around-the-clock level of care provided by first level of PPC. Major difficulties consist in time and resource allocation, collaboration between inpatient and outpatient realms, creation of collaborative environment.

Future implementation of the network includes monitoring outcomes, continuing training of hospital and community staff, keeping PPC process separate from adult one. In order to enable more children with life-threatening conditions to receive high-quality PPC in their homes and communities throughout the illness trajectory and into the bereavement period.
An Assessment of the Learning Needs in Paediatric Palliative Care in Ireland

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Aim: To determine baseline learning needs of Paediatricians in Ireland when caring for children with palliative care needs.

Methods: A survey of Paediatricians working in Ireland was conducted. The Quality of Care Collaborative for Australia in Paediatric Palliative Care Project Research Study Group Learning Needs Assessment template was used with kind permission. Ethical approval was granted.

Results: One hundred and eleven people responded to the survey, 69.4% female. The majority were specialist registrars but almost half were consultant paediatricians (45.3%). Almost all worked in a tertiary (56.8%) or regional hospitals (36%). The median number of children cared for with a life limiting condition per year was 10 (mean 19, range 0-200), and with palliative care needs was 5 (mean 7, range 0-50). The median number requiring end of life care per year was 2 (mean 3, range 0-50), the estimated number of children who died was also 2 (mean 3, range 0-50), and those receiving specialist palliative care team input was 2 (mean 4, range 0-20).

Most had never had formal education in paediatric palliative care (56.8%), with some having completed a short course (8.4%). Areas of future training that were ranked as highly important (percentage of respondents) included: Preparing families for the death of their child 63.8%, Management of the dying child 63.8%, Pain management 57%, Advanced care planning 55%, Other symptom management 47.5%, Communication skills 47.5%, and Practical support 39.2%. Those surveyed were also asked to comment on the challenges of their most recent clinical interactions with children requiring palliative care support, a number of common themes emerged including communication, symptom management and difficulty in coordinating community support.

Conclusions: This survey highlights the learning needs of paediatricians and will inform the development of meaningful education sessions for doctors who are caring for children with palliative care needs.
Background: Most children in palliative care in the Netherlands die at home. In our multidisciplinary Pediatric Palliative Care team (PPCT) of a large university children's hospital in the Netherlands the specialized pediatric nurses coordinate care at home. In later course of disease they arrange prescriptions and equipment for intravenous or subcutaneous medication for symptom management. The aim of this study is to define indications for individual adaptation of the standard solutions for morphine or midazolam.

Methods: A retrospective study of prescriptions for parenteral application of morphine and/or midazolam at home for patients of the PPCT in 2016 & 2017.

Results: During 2016 and 2017 31 patients died, while in care of the PPCT, at home, mean age 9 years (0-19), 14 non-malignant disease, 17 with cancer). Treatment of pain, dyspnea and/or discomfort with parenteral administration of morphine was necessary in 24 (77%) and/or with midazolam in 20 (64%) of children.

Standard solutions in infusion cassettes were ≥ 500mg/100ml for morphine and 500mg/100ml for midazolam. Individual adaptations of the standard solutions were indicated for morphine in 58% and for midazolam in 35% of children. Indications for adapted concentrations were: very low weight, increasing doses, maximum fluid intake, minimal central venous flow and minimum speed of infusion.

Awareness of this individual adaptation is part of targeted advance care planning. Timely access to medication prevents unnecessary prolongation of pain, dyspnea and/or discomfort and provides comfort for child and parents. Involving the pharmacist in this strategy in time prevents delay in the delivery of the essential medication.

Conclusions: Adjustments of standard solutions for morphine and midazolam infusion cassettes are frequently required. Anticipation of individualized appropriate solutions for medication is necessary to provide timely relief of pain, dyspnea and discomfort.
Ensuring their Voice is Heard: Parental Recruitment Challenges in Children's Palliative Care Research

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This presentation emerges from an ongoing Doctoral study which aims to provide understanding about children’s palliative care (CPC) specifically in relation to understanding how parents choose a certain location of care for the terminal phase of their child’s illness. Using grounded theory methodology, the researcher wishes to understand the factors that impact on how parents decide the final location of care.

**Study population:** Recently bereaved parents who had lost a child in the previous 6 to 36 months were initially recruited. This ceiling was later raised to 5 years. It was anticipated that the sample would include parents of children who had a variety of life limiting conditions and who came from a range of geographical areas within southern Ireland.

**Study design:** This presentation focuses on the recruitment phase of this study. The literature recognises the challenges in obtaining a suitable cohort of bereaved parents for children’s palliative care research (Dyregov, 2004, and Crocker et al 2015). A key element of grounded theory methodology is theoretical sampling whereby participants are recruited and any further sampling is influenced by the dynamic emerging theory. This process necessitates careful initial selection processes, allowing the researcher to fill gaps, clarify uncertainties, test interpretations and build emerging theories. However, this presentation will outline some challenges around identifying and sourcing 'appropriate parents'.

**Results:** This presentation will outline some of the challenges experienced during the recruitment phase and describe the creative strategies utilised by the researcher to encourage an appropriate sample and facilitate the parent voice.

**Conclusions:** Following initial challenges during the recruitment phase of this study, 12 parents agreed to participate in interviews lasting 2 to 5 hours. The researcher will outline the creative strategies to ensure bereaved parents had the opportunity to participate in research.
Pediatric Palliative Care Service Markedly Reduce Hospital Resource Use: A Southeast Asian Experience

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Background and aims: Thailand is a country in Southeast Asia with 66 million population, including 15 million children. Thailand implemented universal health care since 2005. Pediatric palliative care service was implemented at a university hospital in central Bangkok for over 10 years, initially for children with cancer. The service has expanded to include non-oncology cases in the last 5 years. Due to limited resource, hospital utilization an important issue and a measure of efficiency.

Methods: Pediatric Palliative Care (PPC) team was consulted in children with a variety of life-limiting conditions. After consultation, a family meeting was arranged. Families who chose palliative care were prospectively followed at home by telephone, LINE® social media platform, and home visits. Family accessed medications at PPC clinic. Hospital utilization was recorded and compared before and after PPC consultation.

Results: Twenty-four non-cancer children were enrolled in PPC service during the 5 years period. The median (mean) age at consultation was 1.5 (1.9) years. Diagnoses were hydranencephaly (5), hypoxic-ischemic encephalopathy (4), multiple anomalies (3), mitochondrial disease, chronic renal failure, metabolic disorders, spinal muscular atrophy (2 each), and other diagnoses (4). The median (mean) survival time was 3.6 (68) months. The median (mean) hospital admission days before PPC consultation was 82 (153) days, while it was 5 (11) days after PPC. When taking into account people with limited survival after PPC has started, the comparable median (mean) pre-PPC hospital admission was 60 (66) days. The median home visits was two per patient. Eighteen children have died, 8 at home, 4 at local hospital, and 6 at the tertiary care center. Six children continued to survive, ranging from 10-76 months.

Conclusion: Pediatric palliative care service markedly reduce hospital resource usage.
Specialist Paediatric Palliative Care for Children and Young People with Cancer: A Mixed Methods Systematic Review

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Background: Specialist paediatric palliative care (SPPC) is an important component of children and young adult cancer services. However, there are uncertainties about how and when to involve SPPC, and the impact of doing so. This systematic review synthesises existing evidence on the impact of and factors affecting access to SPPC for children and young people with cancer (Prospero registration: CRD42017064874).

Methods: Database searches (2000-18) identified primary studies of any design exploring the impact of and/or factors affecting SPPC access in this population. Integrative narrative synthesis methods were used to integrate evidence from multiple study designs. Study quality was assessed using the Mixed Methods Appraisal Tool.

Results: 33 studies were included; 23 examined the impact of SPPC and 23 reported factors affecting access. The review found a growing evidence base of mainly low and moderate quality studies finding that SPPC is associated with less intensive care at the end of life, more advanced care planning, and fewer hospital deaths. There was also evidence of inequality in access, with fewer referrals of younger children, those with haematological malignancies and children receiving active treatment. Studies reporting provider (n=6) or family views (n=1) identified barriers to access, including uncertainties about what SPPC offers; concerns about involving a new team; what palliative care symbolises to clinicians or families; and indecision about the timing of SPPC involvement.

Conclusions: Existing, mainly North American studies offer consistent evidence that children and young people with cancer who receive SPPC are cared for differently. However, few studies include families’ views or take account of how inequalities in access may influence end of life care. Although different SPPC models were identified (e.g. hospice, integrated oncology model, hospital team), further research is needed to determine which are effective, feasible and acceptable.
P046
Development of Paediatric Goals of Patient Care Document
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Background and aims: International and national recommendations identify best care of paediatric palliative care patients requires exemplary communication within and across the medical and psychosocial multidisciplinary teams (MDTs) involved. Identification of patient and family goals of care ensures family centred care. Goals of Patient Care (GoPC) are complimentary but not synonymous with Advanced Health Care Directives and change as a child's disease status changes.

Methods: To identify and improve documentation and communication, audit of deceased paediatric and adolescent oncology patients between January 2012 and June 2017 at our institution was performed. Audit identified documentation of medical decision-making for the cohort including use of the national Death Review Form from 2016.

Results: 96 deceased patient notes were reviewed. Clear documentation of medical decision-making following discussions with parents/carers was found for 75 patients (78%). However, documentation was difficult to retrieve from multiple volume notes, documented and filed inconsistently. There was no documentation for 5 patients (5%). Full volumes for 16 patients could not be retrieved for a variety of reasons. Death review was performed in 19 of 21 patients from 2016. Gaps in documentation confirmed the need for development of a GoPC document to best ensure appropriate communication of complex decision-making for paediatric patients in our hospital. Development of an acceptable document proved challenging and implementation was delayed due to various identifiable obstacles. Draft versions of the form were used inconsistently in oncology patients prior to a hospital-wide release. Following production of the finalised document, an ongoing audit identifies use, acceptability, documentation and retrievability.

Conclusions: A hospital-wide GoPC form ensures best patient care and is encouraged to prompt and document medical decision-making discussions in all patients.
"I Didn't Knew a Newborn Could Die!" Evaluating the Impact of a New Course in Paediatric Palliative Care for Midwife Students in Belgium

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Context: Since 2016, a new course of 7 hours in paediatric palliative care was introduced for 1st year midwife students at a francophone Nurse Midwifery College in Brussels.

Objectives: To evaluate the impact of a new course in PPC offered to midwife students.

Methodology: Data collection: At the first lesson, 30 student midwives of 1st year were invited to write down the words they associated with PPC in order to explore their representations before starting the course. After the last lesson, the same students were invited to write down what they have learned about PPC. Data analysis: Words associated to PPC expressed by midwife students before starting the PPC course were classified into categories, whereas qualitative thematic analysis was conducted to identify emerging themes related to apprenticeships in PPC expressed by midwife students after PPC course ended.

Results: Before starting the course in PPC, most midwife students strongly associated PPC to death, suffering and negative feelings (sadness, fear, anxiety and distress). After PPC course ended, the same cohort expressed that i) they discovered the possibility a baby could die ii) they completely changed their perception on PPC, not anymore linked to death, fear or sadness but to quality of life, comfort, human presence iii) they realized that PPC was about providing care to a whole family iv) they felt less helpless to comfort parents and babies by having learned concrete ways of caring for them at end of life.

Conclusions: Even a short PPC course can change representations of midwife students and empower them to feel better equipped to care for a dying baby and to accompany their parents.
A Prospective Study of Preference in the Place of Death for Children with Life Limiting Conditions Cared for by a Tertiary Palliative Care Service

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Background-context-aims: A recent systematic review found a lack of compelling evidence for both the claim that home is the preferred place of death (PPOD) for children and young people (CYP) and that place of death is a measure of quality of care. One study suggested that a discussion about PPOD might be associated with better outcomes. Yet, despite these findings, elicitation of preference and achievement of preference are used in the evaluation of paediatric palliative care (PPC) services. This study explored factors which influenced initiation of discussions, preferences, achievement of preferences and their value as an outcome measure for a tertiary UK PPC service.

Methods: A prospective case series review was conducted from March 2015 to February 2017. Data included: 1) Routinely collected PPC PPOD data for CYP and their parents including the offer of a discussion, preferences expressed and if preference was achieved 2) Field notes taken at multidisciplinary team (MDT) meetings where preference was discussed after the death of the child 3) Documentation of advanced care planning and place of care data extracted from medical notes.

Results: Data was available for 256 CYP (117 female). 29% of CYP had a solid tumour malignancy, 10% had a haematological malignancy and 61% died of non-malignant disease. Parents of CYP with malignant disease were more likely to be offered discussion of PPOD (60/73 compared to 84/156 of those with non-malignant disease). Only 8 CYP were offered a discussion. Hospital was preferred by 38% of cases, home 28% and hospice 18% of cases. When hospital or hospice was preferred this was more likely to be achieved. Per clinician report preference was influenced by the patient condition, family and social factors and availability of services.

Conclusions: Influenced by a multitude of factors outside PPC control, achievement of PPOD is unsuitable as a measure of service performance.
Anticipating the Future in Pediatric Palliative Care by Parents and Health Care Professionals: A Qualitative Study

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Background and aims: Advance Care Planning (ACP) is a process of sharing preferences for future care and treatment in anticipation of illness progression. Growing evidence suggests that anticipating future care improves the quality of patient-clinician communication and increases concordance between preferred and received care in adults. ACP could also improve care of children. To elucidate how to implement ACP in daily practice, this study aimed to explore in which manner parents of children receiving Pediatric Palliative Care (PPC) and involved Health Care Professionals (HCPs) currently anticipate and future care.

Methods: A qualitative study, using thematic analysis. One-time and repeated, in-depth interviews were conducted with 42 parents (24 mothers and 18 fathers) of 24 children and 35 involved HCPs (pediatricians, nurses, case managers or family physicians). This resulted in 105 interviews, 47 with parents and 58 with HCPs.

Results: Both parents and HCPs anticipated future care, but thoughts were not shared to a large extent. Three approaches of anticipating future care were identified: 'ACP-conversations' to share thoughts about future care and treatment. Most conversations were the result of an intentionally and goal-directed initiative by either the parent or the HCP. HCPs initiated a conversation to prevent medically futile treatments, to ask consent for advance directives or to prepare parents for difficult decisions. Parents did so to ensure a good life for their child, to prevent suffering or to manage family life. The initiator often intentionally framed the content of the conversation to ensure that the other party could connect with his/her point of view. 'Anticipated Care' by preparations to organize care in advance as felt appropriate for anticipated future needs. Both parents and HCPs used 'Anticipated Care', mainly to safeguard the child's quality of life and/or death. HCPs often started with 'closed' anticipated care, mainly to prevent unnecessary burdening the parents or to harm the parents' coping. They struggled with the timing of disclosure. Parents also predominantly used closed Anticipated Care, unless they needed the HCP's support or felt invited to share thoughts. 'Guidance on the job' is a short-term anticipation and guidance on managing concrete problems or symptoms in the near future, mainly conducted by HCPs. It entailed guiding parents through situations they felt nog (yet) prepared for values, goals and preferences, discerned from ACP discussions, directed which Anticipate Care to organize. Guidance on the job could consecutively build on earlier ACP-conversations and organized Anticipated Care.

Conclusion: Parents and HCPs are aware of future care needs, but these thoughts are not shared to a large extent. Sharing these thoughts and anticipating treatment options often occurred intentionally by parents and HCPs using a goal-directed approach, which can sometimes be better characterized as care negotiation than as ACP. Combining ACP, Anticipated Care and Guidance on the Job can enable HCPs to provide high quality PPC. A more open approach could improve timely ACP.
P050
“Capturing the Voice of Families” A Service Review of an Irish Children’s Charity on its 20th Anniversary

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Children's palliative care is a unique area of healthcare which focuses on improving the quality of life of children who are living with a life-limiting condition. It focuses on enhancement of quality of life for the child and support for the family. The aim of this review was to evaluate the impact of the service provided on the holistic collaborative care of the children with a life-limiting or life-threatening illness. Qualitative and quantitative methods were employed to satisfy the aims. This included a survey tool, parent focus groups and table top discussions; these potentially offer richer and stronger evidence. The captured data collected from families was analysed using a modified framework adapted from Donabedian’s (1988) and Reeve et al (2015). This provided a platform for the review of the data set which led to the emergence of themes.

The emerging finding revealed that the central thread throughout the data was that of ‘child and family centred care’. Three major themes that emerged were Standards of Care, Transformation of Family Dynamics, and Equity and Empowerment.

The focus of this service evaluation was to capture the voice of the families and their perception and experiences with the service provider. Analysis of the data indicate that the service provider works to ensure the children are cared for at home, enabling the continuation of family life. The data shines a light on the challenges and barriers faced by parents but it doesn't fully demonstrate how many of the parents have become experts in their child’s care. It also provides a rich insight into the fragility of their world and experiences. From listening to the voice of the families, a clear message for the service provider is the need to continue to improve support for families and maintain services that are centred on the child and their family and not on processes and funding streams.
Paediatric teams often say that dealing with parents is one of the most difficult component of paediatric palliative care. But what happens when there are no parents involved, either in reality or symbolically? For Nils and Milo, born of an anonymous childbirth, labeled as dying from the beginning of their life? For Mia, whose parents drowned into anticipated grief right after they were told the seriousness of her HIE (Hypoxic-Ischemic Encephalopathy), and became unreachable to our calls? And for Zoé, with pathological parent figures, who relied during three years on the caring teams to provide much more than care?

Parents’ absence results in a deficit of triangulation in the relationship between child and paediatric teams. Subjectivation role, inscription of the child in a family history, and attachment figures remain vacant. Paediatric professionals commonly feel the urge to fulfill those needs at the risk of losing their ability to take proper medical decisions, either on therapeutics or temporality.

Furthermore, is it possible to come out unscathed when the child's need to get attached or get detached is so acute: in the early days of life or in adolescence?

Not surprisingly, those situations are the ones still vivid in paediatric teams. Both leaving concrete prints (like pictures or gifts), and more silent ones, like the reactualisation of the conflicts in place every time something echoes. Paediatric palliative care teams can therefore be used in order to think out of the box, introducing and maintaining a triangulation, taking a different look at the child's symptomatology, questioning the decisions, and pointing at the risks for professionals.

However, long-term care abrades the ability to keep a distance, and they are, in their turn, exposed. From those clinical cases, we would like to initiate a discussion with PPC teams who are more often confronted to those quite rare situations, in order to identify new care processes for those children and their paediatric care teams.
**P062**

**Osteosarcoma and Severe Treatment Refractory Cardiomyopathy: A Case Report**

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**Background:** The cardiotoxicity of some chemotherapy agents and the occurrence of heart failure during or after the treatment of cancer patients are well known. Nevertheless, the subsequent management and clinical support may be complex given the state of the patient and the prognosis of the underlying disease, the level of compromise of the heart and the response to treatments that are implemented.

**Case report:** A 12-year-old girl with osteosarcoma larger than 12 cm in the right femur. Treatment was started according to the GLATO 2006 protocol with 6 courses of cisplatin, doxorubicin, and methotrexate. The tumor was completely removed with tumor-free margins and less than 90% tumor necrosis, considering the patient to be a poor responder. When the patient completed the treatment, she was in remission. She presented with a severe alteration of the ejection fraction due to cardiotoxicity caused by anthracyclines with a progressive course and no significant response to medical treatment (carvedilol, levosimendan, milrinone).

An interdisciplinary meeting, with participation of the Ethics Committee, was held to evaluate the management of the patient, considering she was not a candidate for heart transplantation or implantation of a ventricular assistance device. In this context, the challenge of what type of care should be provided in the next period was proposed.

**Conclusion:** Establishment of a care plan and clinical support is a challenge for the medical team treating a patient with cancer in recent remission with the risk of relapse and severe treatment-refractory cardiac involvement.
The Ethical Challenge of Providing Palliative Care when a Parent Refuses Potentially Curative Treatment: A Case Study

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Background: Child protection in India focuses on children facing extreme abuse or deprivation but not safeguarding children in healthcare. Lack of policies and procedures to protect children from potential harm of treatment refusal poses unique ethical challenges.

Case: With family's consent, we describe the case of SW, a 9 year old girl with pre-B ALL diagnosed 8 months prior to referral to our palliative care center (PCC). SW received incomplete induction chemotherapy. Second line chemotherapy offered good prognosis. The multidisciplinary Palliative Care (PC) team facilitated multiple meetings with hematologists to emphasize need for treatment, good prognosis and offered financial support. Despite being a caring parent, SW's mother refused chemotherapy - based on possible treatment failure, dependence on extended family and being a single parent. Ethical issues: Was PC alternative instead of adjunct to chemotherapy and hence detrimental to SW's best interest? Was parental decision making absolute? What were the team's obligations to safeguard SW? Legal opinion showed no processes or agencies to ensure SW's safe custody and care, making it impossible to challenge parental decisions. SW's mother continued to care and followed the PPC management plan. SW had a good quality of life with 8 admissions (6 respite and 2 clinical) to the PCC. She spent memorable days with her family, enjoyed trips to the cinema, shopping and celebrations. As SW got sicker, she was aware and accepting of her impending death; she wrote a good-bye letter to her mother, gave away her pocket money and found comfort in prayer. During her last admission to PCC, SW had pain and irritability- well controlled with medications and comfort measures. She died peacefully in her mother's arms.

Conclusions: This case highlighted the ethical obligation to provide PC despite refusal of treatment. Continuing PPC ensured access to symptom management, psychological support and the opportunity to say goodbye.
P064
Benefits of the Use of Upper Limb Orthoses in Pediatric Palliative Patients with Brain Damage
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Introduction: One of the processes and changes suffered by children with high disability due to irreversible diseases in the palliative stage is the joint degeneration of the locomotor system. For this reason, we developed an implementation programme for the use of orthoses in upper limbs to increase the range of joint movement, stabilise unsuitable movements of the joint and help to prevent or correct deformities maintaining an adequate alignment in order to increase the well-being of each child. There is no previous literature about the studied subject.

Methods: The sample consists of four subjects with a primary diagnosis of congenital or acquired brain damage between 3 and 13 years who meet the selection criteria. An intra-subject design of repeated measures is developed. The assessment of flexo-extension and abduction movements is made by goniometry through a fortnightly record. Each individual splint is molded by hand with thermoplastic or orfit according to the characteristics and needs of each child. Jointly, a coadjuvant treatment of passive mobilizations performed three days a week, for 5 minutes, is performed in the joints that require it. The orthosis is used daily at the centre and tolerance and exposure time are controlled.

Results:
In subjects 1 and 2, a 10 degrees increase in metacarpophalangeal abduction is observed, starting at 0 degrees in both.
In subject 3, an increase in the extension of the proximal interphalangeal of the five fingers is observed, especially in the fifth finger.
In subject 4, a large fluctuation is observed.

Conclusions: Due to the numerical characteristics of the sample, we cannot objectify the benefits of using orthoses statistically. However, we emphasize that its use has a positive influence and an immediate effect on the increment of joint range of the joints to be treated and increases the ease of care of the healthcare team in activities such as dressing and undressing the subjects.
P065
Palliative care for children in Ukraine. Current state, problems and prospects of development

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Background-context-aims: In the framework of the reform of the healthcare system in Ukraine the medical service "Palliative Care" (PC) is included in a guaranteed package of medical services provided by the state. In 2017, a syrup form of morphine has been registered.

Goal: analysis of the current state of development of PC for children, identification of the main problems and prospects of development.

Methods: The research was conducted in Ukraine. An analysis of the legislative framework of Ukraine was conducted using the official website - Rada.gov.ua. To calculate the children’s need for PC, Ukrainian Center for Social Data research results and data from regional health departments were used.

Results: In Ukraine, there is no single system for calculating the need for PC for children and adults. According to the regional health departments, PC for children in 2016 was provided to 5% of the estimated need of the population (data UCSD).

- There are no standards for providing PC. However, it is expected to develop standards for the provision of medical care, including PC.
- Low level of practical knowledge about PC among medical staff.
- Lack of cooperation between the medical and social sectors and the family support system with children who require PC at home.

Conclusions: We consider the primary tasks for the state and the professional community to be the following:
2. Implementation of a quality control system for the provision of PC for children
3. Creation of an extensive system of mobile PC services for children.
4. Creation of multidisciplinary teams to provide PC.
5. Implementation of educational programs for health workers at all levels of educational process.
6. Extending access to adequate pain management through the pharmacy network.
P066
Fastening the Integration of Palliative Care Services, into the Cameroon National Health System through Trained Community Volunteers (Adaptable Model of Hospice Africa Uganda)

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CHIMISSIONS as the main IP(initiator program) in Cameroon uses TCV (trained community volunteers), health professional ,clergyment, family heads. Who together does routine home visits to the needy palliative care patients in faith based communities (Mosques, churches) and local communities. Ensuring clinical monitoring and Organized planned Mobile outreaches programs, for proper identification and referral of the patients in need of palliative care to CHIMISSIONS.

CHIMISSIONS work in partnership with the Cameroon ministry public health in the field of HIV/AIDS for the past 10 years(Prevention, Care and Support Presently over 1500 HIV patients are benefiting from the community ARV dispensation in our various offices and the fight against stigma). Practically, CHIMISSIONS in partnership with the ministry of public health has been working for the integration of palliative care services through trained community volunteers; our targets are especially children (Under 15). Most of them suffering from diseases such as Cancer due to HIV/AIDS, Sickle Cell, epilepsy, Kidney Failure , Hepatitis, that depend on their parents, family relative , care givers to make adequate decision on where and when to seek medical or therapeutic alternatives.

CHIMISSIONS together with a team of trained community volunteers work with 02 Health district in Cameroon (1in urban Yaoundé and 1in rural areas in Baffia) Which together made of up 3518 health centers In reference to this, CHIMISSIONS based interest in the Rural health district were a team of health professional and well TCV 184 capable to speaking and writing in English/French working together with 730 natively based well trained community volunteer precisely working in Baffia health district successfully identified and referred hypertension (171), HIV/AIDS(56), Cancer(21) Epilepsy(47).

Conclusively using TCV is an effective, reliable approach to integrate and support of palliative care services in the Cameroon health system.
A New Period: A Mutual Help Group for Parents that Lost a Child

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Background: The loss of a child generates anger, disbelief, despair, guilt; when it happens, for parents nothing really makes sense and everything ends. This pilot study presents the activities of Pediatric Palliative Care Unit (of Pordenone), which in recent years has shown the need to accompany parents through the process of child's bereavement. The scientific literature supports the efficacy, as well as individual psychotherapy, also of treatments in homogeneous groups.

Aims: One purpose is to offer a psychological support to the parents, giving them a different mean (the group), in order to promote the dialogue between persons that have lived the same experience, to elaborate the pain for their child's loss, in order to dream a new future. Moreover, this project has the aim of analyze the parents' needs, for understand which type of conduction (structured or not, with predefined times and themes) is more useful.

Methods: The group will be guide by psychologists and it will start in September 2018. There will be 11 meetings (one every two weeks), which will touch specific areas: the knowledge of themselves and others, sons, relationships, time, future planning. We will use techniques and specific readings for each topic in order to motivate the dialogue. Conduction's method has been subject of discussion and study by the team. Is more helpful an unstructured group (with undefined number of meetings and free themes) that offers more spontaneity, or a structured group (with defined meetings and themes) that gives more safeness?

Results: Since it is a pilot study, now there aren't certain results. Desirable results concern the understanding which group's conduction is more helpful.

Conclusions: Starting in September, after a few months we could analyze first parents' needs, and we could understand which methodology is more helpful for a group of parents that lost a child.
Barriers in Providing Pediatric Palliative Care in University Hospital in Prague: Our First Experience

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Approximately 8,000 children with life-limiting or life-threatening disease are taken care of in our hospital every year. These patients may benefit from pediatric palliative care. Multidisciplinary team was established in September 2017 to offer pediatric palliative care and to provide support for the families in our hospital.

Our multidisciplinary team has been offering palliative care to children across the whole hospital for the past 9 months. All pediatricians were informed about the existence of the new team via email and via several seminars. We set up a contact person (usually nurse) on each department with the aim to identify and recruit patients for palliative care.

Only 18 children with life-threatening and life-limiting disease were referred to our multidisciplinary team from September 2017 to May 2018 by the treating physicians despite the fact that children for palliative care were frequently identified by our contact persons during the 9 month period. In total, 46 consults were led with families of these children. Patients presented a heterogeneous group of diagnoses: 11 diagnoses of cancer, 4 neuromuscular disease, 2 cardiovascular disease and 1 congenital disorder. The main barriers in recruiting patients for palliative care were identified in physicians (lack of knowledge about principles of palliative care, insufficient evaluation of patients’ needs, false judgment of parental perspectives, prejudice). Only 6 (33%) children recruited to our care died.

Despite the high number of patients with life-limiting and life-threatening disease who shall benefit from pediatric palliative care only few children are referred to palliative care every month. Several barriers in providing palliative care were identified in treating physicians. Further advocacy and promotion of palliative care is needed to ensure that children in need of palliative care are recommended by their physicians.
Current Bereavement Services within Paediatric Palliative Care Services in Ireland: A Review of the Literature

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With an estimated 4000 children living with life limiting conditions in Ireland, 350 of whom die each year, the importance of effective and timely bereavement care for those effected by this loss is more crucial than ever as this population grows with the advancement of medical capabilities. The Irish Hospice Foundation define bereavement care and paediatric palliative care (PPC) as interlinked elements of care. In Ireland, PPC services are still developing but with further awareness in this area, some progress in the provision of bereavement care has occurred. The development of various strategies, policies and subsequent services including the Palliative Care Needs Assessment for Children and the National Policy for children for Children with Life Limiting Conditions have significantly contributed to the development of palliative and bereavement services for children and their families. Over recent years, the evidence revealed that general theories on bereavement have expanded from Freud's task based theory in 1957 and Bowlby's stages of grief in 1961 to the more contemporary theory of Continuing Bonds as explored by Klass in 1996. This theory of 'Continuing Bond's has developed overtime with the emergence and challenges of online grieving and other web based support groups for families with children with life limiting conditions. Research evidence supports the instigation of creative interventions, supports and bereavement models to facilitate greater positive outcomes for families who will have long lives to live after the death of their child. The literature suggests that by understanding and embracing the theories of grief, the experiences of families and the evolution of bereavement over time, HCPs working in PPC can better support families. The death of a child on the family unit is complex and closer systematic examination of research enables professionals to truly respond to the unique needs of families through this pivotal point in their lives.
The Seeds-of-Silent Words in Prenatal Palliative Care - Prof. Luisella Magnani in Memory of Giampaolo Magnani Born on 5th March 2009 Died on 17th October 2010

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Background - context - aims: If Paediatric Palliative Care is a Celebration of Life (Ehospice, 19th October 2017), even if that Celebration lasts few years, few days or even few hours, it´s universally urgent that the Baby in the womb to whom a delicate condition has been diagnosed ´takes extra care to respect his right to life and dignity (Peter Limbrick et al. - International Guide - Are you worried about your child? - 2018 Team Around the Child, TAC). As Babies in the womb are ´conscious, sentient Beings´ (Sandra Bardsley, 2016), they deserve all the best approaches in order to create Always a special communication with them above all when they have special needs, above all when a Syndrome is diagnosed. And, when I ask their mother ´How did your Baby live the nine months in your womb, how did you live with your Baby in your womb? How were you supported in the communication with your Baby? How were you supported in your intimate relation with your Baby? How were you taught to create the interconnectedness with your Baby? Were you taught that the contact is vital?´ Mother´s words are Always these ones in their different measures and rhythms: ´I felt a great fearness, loneliness, darkness. Nobody never spoke to me in such a way. My Baby grew up inside me, in my same fearness, loneliness and darkness.´


Results: It´s nurturing all the possible potential of the Baby whatever is his delicate diagnosis, it´s not letting the Baby feel alone in the womb, because he needs to be and feel considered, cradled, treasured, waited for, cared and Loved.

Conclusions: Interrelation with the Baby in the womb is an answer to his continuous seeking communication, even if his communication is silent and motionless, but it´s living and loving in his There-Being.
Fetal Echocardiography: What Every Paediatric Palliative Care Provider Should Know

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Aims and background: Congenital heart disease (CHD) found on routine obstetric ultrasonographic survey is a common indication for referral to maternal-fetal specialty services and to perinatal palliative care providers, when available. We sought to summarize the literature to assist practitioners caring for these families.

Methods: A medical literature review was performed in English using the PubMed search engine through May of 2018.

Results: Pediatric cardiologists with expertise in fetal echocardiography can provide important interdisciplinary antenatal guidance. Many lesions such as isolated ventricular septal defects or Tetralogy of Fallot with mild-to-moderate pulmonary stenosis can be safely managed expectantly after birth. Critical CHD, such as transposition of the great arteries, ductal-dependent pulmonary or aortic stenosis and aortic arch anomalies require tertiary referral for neonatal medical management and surgical intervention, as well as close coordination of care to minimize maternal and perinatal morbidity and mortality.

Critical CHD associated with high risk of fetal and neonatal mortality - even in high-resource settings - includes hypoplastic left heart syndrome with a restrictive atrial septum, other single-ventricle anomalies, and obstructed, anomalously draining pulmonary veins. Fetal heart block associated with complex CHD, the presence of hydrops fetalis, and findings of other major anatomic malformations, including neurologic, aerodigestive or urinary tract defects, as seen with trisomies 13, 18 and other genetic syndromes are associated with significant risk and, as such, benefit from timely ante-natal palliative care referral.

Conclusions: Dedicated and targeted fetal imaging and genetic evaluation are important when counseling families of fetuses with complex CHD. Close collaboration with obstetric and perinatal palliative care services may facilitate seamless, comprehensive delivery plans.
Meaningful Outcomes in Pediatric Palliative Care
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Background: Measuring outcome in Pediatric Palliative Care (PPC) is a challenge for several reasons. First, the majority of patients suffer severe psychomotor impairments, rendering verbal communication impossible. Therefore, carers need to provide information on outcome by proxy. Second, a comprehensive outcome measure needs to cover all relevant biological, psychological, social and spiritual dimensions concerning the patient and his/her family or carers. So far, research on relevant outcome dimensions is scarce. Hence, the aim of the current study is to identify outcome dimensions that are relevant to the patient and his/her family or carers and are applicable for a variety of medical conditions and developmental ages.

Method: A mixed methods approach will be utilized in the study. First, guided interviews with the patient's family and PPC professionals were conducted to determine outcome dimensions of PPC. In a second step, the identified dimensions will then be quantitatively rated by the patient's family and PPC professionals according to their relevance. Thereby, the truly relevant outcome domains will be singled out.

Results: The interviews to date yielded 7 main outcome dimensions, namely the quality of life of the patient and his/her family, the satisfaction with the quality of care, empowerment of the patient's family/carers, relief of the strain, acceptance of and coping with the disease, normalcy and security. Data on the relevance of outcome dimensions are yet to be collected and will also be presented.

Conclusion: The identified outcomes represent different dimensions of PPC that are potentially relevant to the patient and his/her family. The following quantitative relevance assessment of these identified outcomes will reveal which domains are truly regarded as being relevant.

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P073
'Cold Bedrooms and Cooling Blankets' Provided by Children's Hospices: Mapping Practice and Exploring Bereaved Parents' Experiences

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Background: The ways parents are supported at the end of their child's life and after death can profoundly affect the grieving process. Within children's hospices cold bedrooms/cooling blankets are provided to enable families to be close and have unrestricted access to their child after death. Such facilities are thought to support parents in the initial stages of grief. However there is wide variation in practice and almost no evidence to inform parents' decision-making during advance care planning. We aim to map current practice and explore parents' experiences of using cold bedrooms/blankets - either in the hospice or at home - and the perceived impact of this on immediate and long term bereavement.

Methods: This study comprises two stages. First, a cross-sectional survey to gather data on previous and current practice, and reasons for inclusion of these facilities within the portfolio of care and support, collected via structured telephone interviews with heads of care in all UK children's hospices (n=52). Second, qualitative interviews with parents (n=30) exploring stories of the early days of bereavement and the support received from the hospice, their needs and desires in those early days, and the perceived role of cold bedroom/cooling blankets on early and subsequent experiences of bereavement. Survey data will be analysed using descriptive statistics and content analysis. Interviews will be analysed using narrative and thematic approaches.

Results: We will not have data to report but hope presenting this work will alert others to this research and generate connections and meaningful conversations with others with an interest in this area. The research has significant ethical implications. One of our outputs will be a reflection on learning with particular focus on researcher well-being.

Conclusions: Findings will have implications for practice within children's hospices and also for statutory services who are beginning to offer this provision.
The View from Adolescents Cancer Survivors about Family Management
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Background: Adolescents are the best source of information about what occurs with themselves, through them we can understand the dimension that the disease takes in their lives. Nursing has been moving toward the practice of giving voice to the patient, respecting their desires and opinions. Comprehending the variability of the experience of the adolescent cancer survivor and her family allows an opportunity to widen the aid and resources for those that have a cancer history. This study has as objective to know the Family management of a cancer survivor teenager and her family.

Methods: This is a qualitative research that used the Family Management Style Framework as theoretical outline and thematic analysis as a methodological framework. Four Cancer survivors teenagers and her family were the participants of this study. They followed in a specialty outpatient clinic in the city of Sao Paulo, Brazil. This study was submitted to the Ethics Committee of the University of São Paulo.

Results: Despite this continuous accompaniment towards the health, this adolescent considers her life within the normality. Although, she believes that there is an overprotection from her family. This adolescent defines that as much as with the family, she is also adapted to her survival situation, even though the family management’s behaviors are shaped according to unpredictabilities and the fear of a relapse, the expectations of this teenager are optimistic towards the her future and the future of her Family.

Conclusion: The adolescent cancer survivor will have to adapt herself to a condition of chronicity. The continuity in the attention to the health of those teenagers is necessary even after the end of the treatment. Adolescent survivors' parents live surrounded by the fear that his child come to get sick again. With the comprehension of the family management, proposing interventions that allows the strengthening and a better family management to this condition becomes possible.
Motivation of Voluntary Works in Pediatric Oncology

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**Background:** Voluntary workers in pediatric oncology play an extremely important role because children are often subjected to long and invasive treatments, making them debilitated. It is known that the technological structures in hospitals make it difficult for health professionals and patients to get involved, and it is often the responsibility of the voluntary workers to exercise a kind of emotional care for children and their families.

**Aims:** Know the motivation of voluntary workers in pediatric oncology, as well as to describe the activities carried out in the volunteer work in pediatric oncology; To know the resources used by the voluntary workers and to understand the perception of the feelings of the children before and after the activities.

**Methods:** This is a qualitative study guided by a semi-structured interviews for data collection. The snow ball sampling was used to approach 18 people who works as a volunteers in a pediatric oncology hospitals in Sao Paulo, Brazil. This study was submitted to the Ethics Committee of the Paulista University.

**Results:** Through the thematic analysis of the data it was possible to find five central themes: Feeling the need to help others; Experiencing cancer in the personal life; Using strategies for volunteering; Developing activities with children with cancer; Perception of feelings before and after activities.

**Conclusion:** The role of voluntary works in pediatric oncology is motivated by helping others, or by experiencing cancer in their personal lives. Since the nursing team often does not have time to play with the children, the voluntary workers fill this gap and perform a work of humanization and interaction with the children, thus making them more collaborative and consequently facilitating the work of nursing.
P076
Assessment of the Needs for Pediatric Palliative Care in our Province

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Aim: Assessment of the needs for pediatric palliative care (PPC) in terms of volume of activity, virtually necessary for the population of our Province; strategies of answer.

Methods: first phase: request to family-pediatricians and children specialized Departments to indicate children potentially eligible for palliative care suffering from an incurable pathology; second phase: assessment of the level of care intensity using ACCA-PED.

Results: Among 166 children reported potentially eligible for palliative care, 78 only don’t need complex clinical assistance. 81 ACCA-PED were administrated with the result of 33 children with low intensity care, 15 with medium intensity care and 33 with high intensity care; 7 children with oncological incurable disease were considered medium-high intensity care.

Discussion: In the structuring phase of the activity of the different levels of the network, the most expendable data is the number of 55 children who need at least a second level of care. The identification of the needs of the children eligible for palliative care will allow us to assume the best assistance. The limit of the present survey is the involvement only of the pediatric population in the 0-16 age range because the family-pediatrician takes care child up to 16 years old.

Conclusions: This survey allowed to identify children with specialized pediatric palliative care needs and, at the same time, it allowed us speaking about PPC with family-pediatricians and increase their sensibility on this subject. It also helped us to define the needs for organizing different and integrated paths between territorial and hospital reality, with the involvement of Domiciliary Palliative Care Service for the adults and the second level team for pediatric palliative care, which is now recognized at an institutional level.
**P077**

**Telephone Consultation to Improve Pediatric Palliative Care Across Regions**


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**Background:** The corner stones of Pediatric Palliative Care (PPC) in the Netherlands are the Pediatric Palliative Care teams (PPCT) in 7 regions around the academic centers. These teams support care at home and in the hospital. Parents and professionals can ask these them for advice on PPC issues. The PPCT of our hospital covers 4 regions, because some of the other teams are not yet operational. The aim of this study is to analyze the content and frequency of questions and to examine the effects of the advices.

**Methods:** After announcement by the Dutch expertise center for PPC we started a prospective study of telephone and email consultations between January 15th 2018 and June 11th 2018. Consultations were followed by a written questionnaire on perceived quality and effectiveness.

**Results:** Until now 11 consultations (10 primary, 1 follow up), 10 from health care professionals (doctors, nurses and pedagogical employer) and 1 parent. One consultation concerned organizing pedagogical care within a newly formed PPCT, the other 10 patient cases.

Patients were 0-14 years (median 4), 8 with non-malignant and 2 with cancer. The majority of the consultations concerned the Individual Advance Care Plan and Dutch guideline for Pediatric palliative care, symptoms and its treatment, organization of care and psycho-social aspects.

Evaluations in 5 out of 11 consultations assessed expertise, accessibility, care improvement and overall evaluation at a ten-point scale with a median of 10 (6-10). The parent did not return the questionnaire despite dissatisfaction.

A comparison between the regions did not reveal significant differences in patient characteristics, duration and topics of the consults.

**Conclusions:** The PPCT can provide meaningful support, not only in our own region but also for other regions and patients that are not familiar to the team. The feedback reflects improvement in PPC by these consultations.
P078
Rapid Access Service for Children with Palliative Care Needs facilitated by Clinical Nurse Coordinator for Children with Life Limiting Conditions at a Regional Paediatric Centre
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Background: In Ireland the Clinical Nurse Coordinator for Children with Life Limiting Conditions (CNC-LLC) role is involved with children aged 0-18 years, often from diagnosis, through periods of clinical instability as well as at or nearing end of life. We describe the Rapid Access Service that has evolved to meet the needs of the children with life limiting conditions attending a Regional Paediatric Centre.

Method: The Rapid Access Service co-ordinated by the CNC-LLC in 2017 was reviewed. This service is provided at the Paediatric Day Ward at a Regional Paediatric Centre. It is a multidisciplinary involving the CNC-LLC, Consultant Paediatrician, Neurologist, Nurse, Phlebotomist, Dietician, Play Specialist, Physiotherapist, Adult Specialist Palliative Care and Community Nursing. Data was collected by reviewing the CNC-LLC diary and hospital Patient Administration System. Numbers of children, time to assessment from identified need for service, and outcome of assessment were recorded.

Results: 38 Rapid Access Service assessments were scheduled in 2017 for 11 children with deteriorating symptoms. The clinical symptoms assessed were respiratory deterioration, secretion management, pain, seizures, weight loss and the need for equipment review. The range of time for assessments was 4-72 hours. None of the children were admitted at the time of or within a month of the assessment and continued to receive care at home. 3 represented to the Emergency Department within 2 weeks with unrelated symptoms. 1 child died expectedly at home.

Conclusion: The Rapid Access Service provides prompt assessment of children with life limiting conditions that could not wait for their scheduled review. By providing a timely responsive service to assess and manage the children's changing symptoms, the CNC-LLC role resulted in reduced presentations to the Emergency Department and admission. Continuing prospective studies are required to validate this.
P079
The Importance of a Family Foundation in the Global Development of Children's Palliative Care

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Background: The importance of a family foundation in the early development of children's palliative care (CPC) was identified as part of a larger study on the early pioneers of CPC which identified those individuals and organizations that influenced global development.

Method: Information was gained through a literature review; interviews with key individuals; and the completion of a history questionnaire by others involved with the early programmes. Documents developed by the Foundation were reviewed. Key individuals working in CPC were interviewed and identified the Foundation as providing pioneering programmes.

Results: The Foundation has played a major role in:
- Collaboration with the Church from early establishment as a Vatican Foundation;
- One of the earliest CPC home care programmes from Bambino Gesu Hospital;
- Development of widely-used materials: CPC Standards; a Children's Rights Charter; CPC the Facts; Charter Religions Together for CPC;
- Influencing a regional palliative care association by supporting a children's task force;
- Successful advocacy leading to a national policy in Italy;
- Collaboration in global advocacy at the World Health Assembly;
- Education through global conferences, a Lyceum and education of health professionals;
- National network for CPC within Italy;
- Successful promotion of CPC.

Conclusions: Through strategic development and goals; and through collaboration with government, other palliative care organisations and the Church; a family foundation has had a positive impact on the development of children's palliative care globally.
P080
Survey of Primary Care Nurses on Pediatric Palliative Care
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Introduction and Objectives: Pediatric Palliative Care (PPC) is an approach aimed at improving the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention, identification and treatment of physical, psychological and spiritual problems. Effective PPC should embrace several disciplines and use every resource available in the community. It should be provided from the Primary Care (PC) level but also continuously in children's homes. Therefore, it is important that PC nurses have the capacity to perform this task. The objective of this survey is to assess Primary Care nurses' knowledge of and involvement in PPC in a province.

Methods: Descriptive and cross-sectional analysis using an anonymous self-completed survey which was sent via e-mail to PC nurses in the province between November 2017 and February 2018.

Results: 114 surveys were answered. The average length of service was 14 years. 98% made home visits to their patients, while 51% had made visits to patients under the age of 14. 26% had taken care of at least one pediatric patient suitable for PPC. 24% identified a death due to a foreseeable cause among the pediatric patients in their area. 45% identified a pediatric patient suitable for receiving PPC, and 92% believed that children should die at home. 86% of the respondents were open to assisting patients at the end of their lives if they were managed by a centralized PPC unit. 92% thought that PC nurses should offer PPC, although only 15% had received training in PPC and 94% asked for training.

Conclusions: Due to their deep knowledge of children and their families, Primary Care nurses are the ideal candidates to assist children at home when managed by a centralized PPC unit. This results show that most nurses are willing to perform this task. Therefore, it is essential that public health authorities develop an improved training program which is aimed at these Primary Care professionals.
Poor Support to Siblings of Children with Cancer: a Swedish and Finnish Parental Follow-up

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Background: Siblings of children with cancer have expressed a need for own support throughout the cancer experience. Poor support to siblings have been found to increase the risk for long-term psychological distress. Support for siblings is organized differently across countries. In Sweden, sibling-supporters, was introduced 2012 on all pediatric oncology centers.

Aim: To examine the proportion of siblings in Sweden and Finland who received support from the health care, and the association between family-related factors and received support.

Method: This survey is based on 255 parents of 145 children who have undergone treatment for acute lymphoblastic leukemia according to ‘NOPHO treatment protocol ALL 2008’ during 2008-2017 in Sweden and Finland (response-rate/family=32%). The data were analysed with descriptive statistics and univariate logistic regressions. Family-factors examined in relation to received support to siblings were: siblings’ age, number of siblings in the family, the parents’ civil status, the parents’ educational level, the parents' income, and in which country the family lived.

Preliminary results: 71% of the parents reported poor support to siblings, aged 4-19 yrs, while 26% reported that the siblings had received support to some or to a large extent (3% reported not applicable or don't know). There was no significant difference in received support in Sweden since the introduction of sibling-supporters 2012. However, the descriptive numbers show that more parents, that have a child that started treatment 2012 or later, reported that the siblings received support to some or to a large extent than before (35% vs 20%). None of the family-related factors examined did have an impact on received support, not even siblings' age.

Conclusion: Support to siblings was received to a little extent in Sweden and Finland. Despite organized sibling-support in Sweden, resources might still not be sufficient.
P082
Perception of Palliative Care Organizations in Republic of Korea toward Providing Pediatric Palliative Care

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Background: Despite the social and institutional progress of palliative care in Korea, there is no systematic methods for the provision of palliative care for children. We need to examine the current status and awareness of the pediatric palliative care, which currently provides palliative care organizations, and consider ways to expand palliative care for children.

Methods: We executed the questionnaire of experts working in the hospice palliative care facilities from September, 2017 to October, 2017, and carried out a descriptive research study.

Results: Of the total 61 institutions, 17 organizations are currently providing pediatric palliative care for cancer patients. Pediatric palliative care providers are distributed only in Seoul, Gyeonggi, Incheon, and Gyeongsang provinces regardless of the type of provision. We confirmed that the insufficient number of trained specialists were the main obstacles in providing pediatric palliative care. The burden of caring for the patient is known to be the lack of professional manpower to treat pediatric adolescents in the palliative care agency. The biggest obstacles in providing pediatric palliative care are ´concern about the lack of knowledge and experience of children´. It is necessary that we develop an education program for professional workers which supplement the lack of knowledge of practitioners and team experts and that we train, and educate them. 73.9% of respondents said they need to establish a separate pediatric palliative care system from the existing adult palliative care agency. The reason for this can be categorized depending on the characteristics of adults and other children and adolescents, the lack of specialists, and the lack of institutions’.

Conclusions: We introduced the perception of palliative care organizations in Korea toward providing pediatric palliative care. The results of this survey will present the future form and strategy for providing pediatric palliative care in Korea.
Mortality in a Pediatric Palliative Care Unit: Who, How, Where and Why?

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Introduction and objectives: The death of a child is usually difficult for the family and those close to them to understand and accept. In Spain, pediatric palliative care units (PPCU) are becoming facilities that are increasingly specialized in meeting all the needs of the child and their family. The objective of this study is to characterize the patients who died in a PPCU and analyze the underlying diseases, the causes and the environment in which the deaths occur.

Methods: Retrospective descriptive study of patients who died in a PPCU between 2012 and 2017.

Results: 55 deaths, 62% boys. Main underlying diseases: oncological 25 (45%) (13 CNS tumors), neurological 16 (29%), metabolic 5 (9%), and polymalformative syndromes 3 (5%). Place of death: 29 patients (53%) in a hospital ward, 19(35%) at home and 7(12%) in ICU. Median monitoring time: 4 months (IQR 1-9 months), with a longer period of monitoring associated with death at home (p< 0.01). 51 patients (93%) were monitored exclusively by the PPCU. Causes of death: 33 patients (60%) due to progression of the underlying disease, 19(34%) due to diseases related to the underlying disease and 3(5%) due to an unexpected cause. We found a significant link with the underlying disease; cancer patients died from progression of the underlying disease (p< 0.01) and neurological patients from comorbidity (p< 0.01). 25 patients required terminal sedation (45%), and all the families were monitored during the bereavement process.

Conclusion: As found in the literature, patients who die while under the care of a PPCU mostly belong to two main groups of patients, namely cancer and neurological patients. We made two key findings: the majority of patients were not monitored by other specialists, and the longer a patient was monitored by the PPCU the more likely they were to die at home; these facts reveal the families' trust in the PPCU. It is important to promote the creation of PPCUs to care for these patients and their families.
Introduction: In Spain, pediatric palliative care units (PPCU) are becoming facilities that are increasingly specialized in meeting all the needs of the child and their family, with the aim of improving the child's quality of life and supporting the family. However, they are not always available and Emergency Departments (ED) becomes very important in the attention of these patients. The objective of this study is to characterize the patients in PPC and their visits to ED.

Methods: Retrospective descriptive study of patients followed up by a PPCU that come to the ED between January 2015 and December 2016.

Results: 31 visited the ED. Base disease was neurologic (11 patients), oncologic (8), polymalformative syndrome (8), metabolic diseases (2), severe gastrointestinal diseases (2). The median time of follow-up by the PPCU was 10 months. The median number of visits to the ED was 2, placing under the median oncologic patients (p 0.008) and above the median patients with neurologic disease (p 0.03) and polymalformative syndrome (p 0.01). Support they needed: enteral nutrition (77%), oxygen therapy (55%), mechanical ventilation (26%), tracheostomy (6%). Those with non-invasive mechanical ventilation (NIMV) and enteral nutrition had a higher number of emergency visits (p 0.05). Reasons for consultation were appearance of new symptoms (49%), technical support (30%), exacerbation of existing symptom (21%). The most frequent type of symptomatology were respiratory (36%) 23% of episodes needed admission to the hospital. 65% of episodes took place out of activity schedule of PPCU.

Conclusion: Patients suffering from neurological disease, polymalformative syndrome and those with NIMV went to the ED more often. The predominant symptom that generated more income was respiratory. Most visits to the ED were found outside the PPCU period. It is important to promote and extend the hours of their availability and to know the characteristics of this patients for their management in ED.
Tracheostomy Care at Home: Yes We Can. Caregivers' Perceptions and Concerns

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Background-context-aims: Tracheostomy increases complexity in home care of children with severe disability, and in caregivers' concern about their knowledge. Complication rate of tracheostomy and mechanical ventilation is high, leading to repeated hospitalization. The role of a multidisciplinary team in the care of these patients could influence safety and quality of care, and improve support for their families.

Methods: A team for tracheostomy care was created within Bologna Paediatric Palliative Care Team, trying to improve management of children with severe disability at home, reducing hospital accesses, training caregivers to face emergencies, evaluating efficacy and compliance to mechanical ventilation. We administered a 45 item survey (derived from Canadian Kidsvent Checklist) to investigate caregivers' (laic or healthcare professionals) perceptions of their knowledge (totally confident (TC), partially confident (PC), needing training/retraining (NT)) about tracheostomy care, mechanical ventilation and emergency situations.

Results: A total of 11 surveys were analyzed: the TC answers rate was 38,9%, the PC rate was 22,2% and the NT rate was 38,9%. Community paediatricians never answered TC for any item. The highest TC answers rate was observed about the identification of respiratory distress and infection symptoms, and for secretions management. The highest NT answers rate was observed about humidification and emergency manual ventilation.

A cardiopulmonary resuscitation (CPR) training was attended by the 27% of caregivers.

Conclusions: Tracheostomy home care in children with severe disability represents a source of concern and complexity perception among laic and healthcare professionals caregivers, particularly among community paediatricians. CPR training should be offered to all caregivers, with particular attention to manual ventilation techniques and devices. Periodic monitoring of caregivers perceptions and concerns should be performed.
P086
Thinking Out of the Box: Non Opioid Rotation Method for Management of Opioid Induced Neurotoxicity OIN in Pediatric Cancer Patient Case Report
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**Background:** Opioid-induced neurotoxicity (OIN) is a term used to describe symptoms of cognitive impairment, severe sedation, hallucination, myoclonus, seizures and hyperalgesia. It is usually treated with opioid rotation. It is an uncommon adverse effect of Oxycodone and it is often missed and misdiagnosed.

**Objective:** We report a case of a 16 year old girl with metastatic osteosarcoma, progressed on disease-modifying treatment, who was admitted to hospital complaining of uncontrolled leg pain. Patient developed OIN during upward titration of intravenous Oxycodone and treated successfully by switching temporarily to epidural Bupivacaine.

**Method:** Epidural catheter with continuous infusion of Bupivacaine was subcutaneously implanted for one week, with small rescue doses of oral Oxycodone to avoid withdrawal symptoms.

**Results:** Pain was dramatically improved after epidural insertion and neurological symptoms like delirium, hallucination and tremors were rapidly subsided. We managed to remove the epidural catheter after one week and patient was put on small dose of long acting Oxycodone which satisfactorily controlled her pain.

**Conclusion:** OIN should be considered in pediatric patients when rapidly escalating opioid doses with poor or paradoxical response and CNS dysfunction occurs. This case report gives alternative non-classical method for treatment of OIN by using epidural local anesthetic for short duration until pain subsided and CNS symptoms disappear. This method may enable physicians to control pain later with small oral doses of opioids.
The Experience of Losing a Sibling in Childhood or Adolescence

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Background and aims: The experience of losing a sibling in childhood or adolescence has repercussions in the sibling's lives and may have consequences throughout their lives. This experience, once it breaks a significant emotional attachment, appears as a phenomenon essentially based in the bonds established and in the repercussions that the death brought to these people. This work arises from the development of a PHD Nursing Study, which purpose is to describe the experience of losing a sibling in childhood or adolescence, its meaning in adult life and to identify the impact on healthcare provision.

Methods: A phenomenological and interpretative study was made, having as a starting question: Which is the meaning of health to people who lost a sibling during their childhood or adolescence? Twenty one adults, who had lost a sibling during childhood or adolescence, were interviewed. The information related to feelings, experiences and behaviours of each participant was analysed and discussed in order to obtain an answer to the research question and to describe the consequences of the experience of sibling bereavement process until adolescence.

Results: The meaning of health to people who have suffered the death of a brother during childhood or adolescence, was exposed through five themes common to all the participants in this research, one of them “Echoes of the experience of sibling bereavement”. Four variations were disclosed through the data analysis: “Consequences in life”; “An inspiration for life”; “Life limitations of the one who stays” and “A trace for life”.

Conclusions: The loss of a sibling during childhood or adolescence has unquestionably echoes in the life of the siblings and may continue to reflect itself throughout their lives. The perception, the knowledge and the comprehension of the bereavement sibling experience, contributes to a view of the real meaning of health at present time (adulthood) and of what is indeed important to appreciate
**P088**

**PPC Programmes and Approaches in the Biggest Regions in Ukraine - Questions or Barriers?**

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**Background:** Ukraine, a country with a population of 45 million, does not have a national PPC policy. The biggest regions in Ukraine Kiev (4 million) and Kharkiv (3 million) start to develop PPC in 2017-2018.

**Aims:**
(1) To review Ukrainian programs of PPC.
(2) To analyze initial experiences of a mobile palliative care team in Kiev in 2017.

**Methods:**
(1) Review of existing practice.
(2) A retrospective site audit. (3)

**Results:**
**In Kiev.** The Kiev's Working Group was established in 2017 with the aim to set up standards of palliative care for children. However, no valid data regarding the need of palliative and end-of-life care in children in our country are available. The first step of model PPC was to create mobile palliative care team. All 47 children have had 319 visits. Among them: congenital respiratory tract defect - 3%, central nervous system pathology - 85%, orphan diseases - 4.2%, mental disorders - 3%, oncology - 6%, congenital malformation - 29%, cerebral palsy 35.4%, genetic disorders 12.9%. The age distribution is following: 1-3 yrs - 9, 3-5 yrs - 6, 5-7 yrs - 10, more than 7 yrs - 22. Our 319 setting-up has 26 psycho - and 73 social support, others one - medical.

**In Kharkiv.** The Working Group started working in March 2018 and created plan for 2018-2028 yrs PPC development. The model of PPC differed from Kiev. The PPC service started by tertiary hospital based palliative care teams and perinatal center palliative care team plus home model by primary physicians in rural area. Both models are appropriate recommendation of WHO 2016. But there are many legal barriers: lack of education, EoL in hospitals, lack of social support and integrating social and medical care, fear of opioids applying, etc.

**Conclusions:** In spite of lack national policy in PPC, and no access needs for Ukrainian population, and legal barriers, and integrating social services, some sites start develop infrastructure and service in condition of low income and resources of the country.
Children with Extreme Complexity: Developing and Maintaining Nursing Competency in a Children’s Hospice

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Background: As the prevalence of children with life-limiting conditions (LLC) increases and medical and technological advances allow for intervention in previously fatal conditions, the range of life-sustaining supports provided to children with complex medical needs continues to expand. The relatively infrequent use of these interventions in children with LLC presents a challenge to nursing staff in a children’s hospice, without effective training programmes there is a risk that children will be unable to access short breaks.

Method: Recent novel medical treatments which have required upskilling in our hospice include insulin pump and peritoneal dialysis. A comprehensive training and education programme has been developed for each treatment and these will be described providing examples of projects to support safe standardised care.

Results: Initial steps involved liaison with clinical nurse specialists (CNS) (renal and diabetes) and the children’s parents to obtain support to develop appropriate training programmes. Training of all relevant staff nurses was provided by external experts with the support of hospice CNS with further ongoing training as required.

An all-inclusive toolkit has been developed for each process which provides full details of all procedures and checklists in an easily accessible format. A hospice CNS with extra training has taken a lead in each case and provided additional support to staff during the initial short breaks.

All staff involved in the child’s care and the family have reviewed the process after each stay to ensure competence and to review processes. This supports a cycle of continuous operational and clinical pathway improvements and ensures ongoing service development.

Conclusion: The use of new therapies presents a challenge in ensuring nursing competency in a children’s hospice. We have described a comprehensive process to assist in the development and maintenance of competency which supports staff training.
A Path to Specialized Pediatric Palliative Care. Screening Tools for Attending Pediatricians and Members of Palliative Care Teams

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Background: Timely identification of children with life limiting diseases profiting from specialized pediatric palliative care (SPPC) challenges people working with this patient group. The aim of this multicenter-study was to facilitate shared decision making for attending pediatricians and members of palliative care teams (PCT). For this purpose, the Screening for Indication of specialized Pediatric Palliative care (SIPP) and the Semi-structured Interview for Allocation of specialized Pediatric Palliative care (SIAPP) were developed and evaluated.

SIPP (methods + results): The first step on the path to SPPC is the attending physician considering the inclusion of a PCT. The SIPP, containing the physician's assessment of
a) the patient's current situation and
b) the patient's and family's preference concerning future therapies,
was developed by a group of palliative care experts. 50 pediatricians with different medical subspecializations from five different university hospitals in Baden-Württemberg, Germany evaluated 50 case vignettes. The screening has an overall sensitivity of .79 and a specificity of .81.

SIAPP (methods + results): When SPPC is requested for a patient, the PCT needs to decide whether it is the appropriate healthcare provider. The SIAPP, containing the topics
a) introduction,
b) disease (trajectory, worries/wishes),
c) need of assistance (medicine/nursing, psychosocial/spiritual, legal support/coordination),
d) preference concerning future therapies (maximum therapy or limitation of therapy),
e) services provided by SPPC,
aims to structure the shared decision making process. The SIAPP comprises an abbreviated version with prompts, a version with advised phrasing and a table for documenting the results of the interview.

Conclusions: SIPP and SIAPP are efficient and transparent tools for determining the indication of SPPC and shared decision-making.

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Predictors of Place of Death among Terminally Ill Children: A Systematic Review with Meta-analyses

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Background: Despite common acknowledgment of home being the preferred place to die, several studies have documented that most terminally ill children die in hospitals. Hence, knowledge of facilitators of home death is needed.

We aimed to determine predictors of place of death among terminally ill children.

Method: A systematic review was conducted in accordance with the PRISMA statement. We searched databases (Pubmed, Scopus, Cinahl and Embase) for studies published in 2007-2018 on original quantitative data regarding place of death among children. Newcastle-Ottawa Scale (NOS; 0-9 points) was used to assess the quality of studies. Meta-analyses were conducted using generic inverse variance method with random effects on exposures considered in three or more studies. Adjusted odds ratios were used when accessible.

Results: In total, 11 retrospective cohort studies met inclusion criteria comprising data on 105,173 decedents. The quality of studies ranged from 4 to 7 points on the NOS (mean 5.9) and proportions of home death varied from 7 to 45%.

Lower age was associated with 1.4- to 5.8-fold increased odds of hospital death in seven studies (meta-analysis was not possible due to dissimilar categorizations). Female gender was associated with reduced odds of home death in three studies. This association was small in the meta-analysis (OR 1.0; 95% CI: 0.9-1.0). Compared to cancer patients, children with non-cancer diagnoses were less likely to die at home (OR: 0.5; 95 % CI: 0.5-0.5). Parental socio-economics were related to place of death, as children in deprived families less frequently died at home (OR 0.8; 95% CI: 0.7-0.9).

Conclusion: In all included studies, the majority died in hospitals or other care facilities. Important predictors of home death were older age of the child, cancer diagnosis and higher parental socioeconomic position. Knowledge of these predictors may facilitate a targeted effort to enable children to spend their last time at home whenever possible.
Polypharmacy in Children with Life-limiting Conditions

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Background: Children receiving paediatric hospice care commonly have multiple medical comorbidities each of which may require medication use. Polypharmacy is most commonly defined as greater than five medications per day. It is widely described in geriatrics and is a recognised risk factor for adverse drug reactions and medication errors. There has been a paucity of paediatric research in this area.

This audit aimed to explore the rate of polypharmacy in children with life-limiting conditions attending a children’s hospice. This has been completed as part of a broader medication safety project.

Method: Prescription sheets of all children attending for short breaks were reviewed and data recorded on Excel. Data collected included number and frequency of routine and PRN medications. Number of anti-epileptic drugs, opiates and adjuvant analgesics was also collected.

Results: The prescription sheets of all (total 106) children currently attending for short breaks were reviewed. The average number of prescribed regular medication was 8.2 (median 7, range 0-24). 89/106 (84%) were prescribed greater than 5 medications per day. Medications were administered on average 5.3 times per day (range 0-13). The average number of PRN medications prescribed was 8.3 (median 8, range 2-17). 78/106 (74%) of children were prescribed anti-epileptic medications (AEDs), mean number 2.5 (range 1-6) 17/78 (22%) were prescribed 4 or more AEDs. 36/106 (34%) were prescribed at least 1 adjuvant medication, most commonly gabapentin (24.5%). 28/106 (26.4%) were prescribed an opiate, 14/28 both regular and as needed and 14 as needed only.

Conclusion: This study confirms high rates of polypharmacy in children with life-limiting conditions. Complex medication routines are also highlighted which potentially increase the risk of medication administration errors. This area warrants further study with particular focus on potential drug interactions.
**P094**

Initiating Discussions with Advanced Care Planning in Children with Severe Neurological Impairment; Retrospective Review to Support Quality Improvement

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**Background:** Children with Severe neurological impairment (SNI) have both significant disability and complex medical needs resulting in limited-life expectancy. It is recognised that advance care planning (ACP) discussions with families months or years in advance of death supports the development of trusting relationships and an ethos of shared decision making. This allows agreement of realistic treatment goals with an emphasis on quality of life.

**Aim:** To review the timing of discussion of ACP with families of children with SNI with a view to service improvement.

**Methods:** Retrospective chart review of children with SNI who have died in the last ten years attending a neurodisability service. Diagnoses, age at death timing of ACP discussions and, place of death were collected.

**Results:** Over 10 years, 8 children with SNI attending the hospital have died. Full data was available on 7/8 children. 50% (4/8) had a diagnosis of Cerebral Palsy, 1 child had Batten's disease, 1 a genetic abnormality, 1 early onset epileptic encephalopathy, 1 a cerebral malformation. All children had epilepsy.

The age of death ranged from 2 years 5 months to 15 years 8 months. The number of hospital admissions prior to death ranged from 2-6. One child had a previous ICU admission. Timing of ACP discussion varied from few days to 10 months before death. 57% were held in the month before death. 62.5% (5/8) children died at home. Support from palliative care was provided to all.

Current practice shows improvement, 20% (10/51) children attending the neurodisability team with SNI have ACP plans in place. All discussions have occurred in an outpatient setting, not at a time of acute deterioration. ACP hard copy is readily available in the hospital notes and shared with relevant teams.

**Conclusion:** ACP discussions should be considered for all children with SNI. This retrospective review has prompted service evaluation and further quality improvement in this regard is planned.
Models of Pediatric Palliative Oncology Outpatient Care - Benefits, Challenges and Opportunities

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Background: The bulk of current pediatric palliative care (PPC) services in the United States are concentrated in inpatient settings, and do not reach patients and families in the outpatient and home settings, where a vast majority of clinical care, symptom assessment and management, decision-making, and advanced care planning occur. Outpatient PPC often fills a gap that exists when patients have high symptom burden, and significant supportive care needs, but are not yet enrolled in hospice.

Methods: As integrated PPC/pediatric oncology becomes the standard of care, novel pediatric palliative oncology (PPO) outpatient models are emerging. The optimal PPO model is unknown and likely varies based on institutional culture, resources, space, and personnel. We convened a group of experts to offer pragmatic guidance regarding PPO clinic development, implementation, and resource allocation. Additionally, we present five institutions' unique outpatient PPO clinical models with their respective benefits and challenges.

Results: Recommendations on clinic development including issues of staffing, coverage, space, operations, information technology, finances, referrals, communication, and marketing are presented. The five outpatient PPO models featured include a floating clinic model, embedded PPC experts within oncology clinics, consultative or trigger-based supportive care clinics, and telehealth clinics. These models vary in their institutional support, personnel, resources, and patient populations.

Conclusions: In the absence of a one-size-fits-all model, pediatric oncology and PPC groups with a spectrum of available personnel and resources can select, tailor, and implement the model that best suits their respective needs and capacities. Emerging PPO clinics must balance the benefits and burdens unique to their organization, and focus on achieving high quality PC for children with cancer and their families across all care settings.
Behind the Scenes: Care Coordination and Non-billable Time Associated with Outpatient Pediatric Palliative Oncology

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Background: Integrated pediatric palliative oncology (PPO) outpatient models are emerging to assist oncologists and patients with longitudinal support, symptom management, advanced care planning, and care coordination. Significant time is devoted to care coordination, but the scope, time per patient, and ratio of non-billable to billable (NB:B) minutes is unknown. This information is crucial to designing new PPO outpatient clinics in order to understand and advocate for appropriate personnel, physician time, and resources.

Methods: A single-institution 1-day per week PPO clinic started July 2017, and all encounters were tracked from June 2017 to April 2018. Administrative minutes and PPO inpatient time were excluded. Billable and non-billable (e.g. care coordination) minutes were recorded. SAS was used to conduct descriptive statistics. The overall ratio of NB:B minutes and ratios by diagnosis type and vital status were calculated. One-way ANOVA and chi-square tests were used to assess differences in the NB:B ratios.

Results: Out of 98 patients, PPO had billable visits on 54 (55%) and assisted without billing in the care of 44 (45%). Twenty-four (25%) patients are deceased; vital status did not differ by diagnosis type (p=0.29). Patients had solid tumors (ST; 42, 43%), brain tumors (BT; 33, 34%), leukemia/lymphoma (L/L; 21, 21%), and other diagnoses (2, 2%). Overall NB:B ratio was 1.03. NB:B ratios differed among diagnoses (p< 0.0001), with L/L the highest at 2.5 compared to ST (0.9), BT (0.8) and other (0.5). Compared to alive patients, deceased patients had a higher ratio of NB:B minutes (p< 0.0001; 1.9 vs 0.8).

Conclusions: Care coordination in a PPO clinic is time intensive and grows with clinic volume. For patients with L/L and those who were deceased, non-billable minutes outpaced billable clinical minutes. When devising a PPO outpatient program, this NB:B ratio should be accounted for in physician time, and personnel devoted to patient and family assistance.
On the Road of Pediatric Palliative Care...Integrated Care Pathways (ICP) for Children with Complex Chronic Condition (CCC). AUSL Bologna Experience

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Background: Children with Chronic Complex Conditions (CCC) usually need a high complexity care, due to the specificity of pediatric age and of the pathology, that often requires a high level of specialty and integration among the team. It becomes a priority for the Health Authority to designate an Integrated Care Pathway (ICP) centered on the child with CCC and his family, starting from their needs.

Methods: Patients eligible for ICP are patients under 18 years of age, living in the territory of AUSL Bologna and present a CCC (prevalence 2016: 6 / 10,000).

The pathway is divided into 5 phases: management of protected discharge, home management of the patient, hospital exacerbations, follow-up and the terminal patient.

Results: At the end of 2017, 79 children were in charge. One of the monitored aspects is the Individual Assistance Plan (PAI), whose drafting and review implies a continuous discussion and sharing between local and hospital professionals of the patient. Three years after application, 82% of the PAIs have been drafted. From 2016 to 2017 there was a substantial stability of accesses in the pediatric emergency room (from 1.14 to 1.2 average), a reduction in admissions due to exacerbations (from 1.03 to 0.65 on average) and an increase in children with a school project (from 47% to 68.3%) and in charge to social services (from 55% to 82%).

Conclusions: The construction of a patient driven ICP, other than a pathology driven one, allows the rationalization and integration of resources through the prevention of inefficient and unappropriate health interventions and the reallocation of resources towards essential services through an adequate coordination of the assistance.
Ethical Issues between Life Choice and Palliative Care: The Experience of a SMA1 Family

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Spinal Muscular Atrophy (SMA) is a rare, chronic, neuromuscular disease resulting in progressive muscular atrophy and weakness. SMA1 (Werdnig-Hoffman) is the most severe form which has short life-expectancy and needs ventilatory support. Since 2016, with the introduction in Italy of SMA new drug tested and approved by NHCS, we have seen clinically valid efficacy about motorial skills, but ventilatory support and emergency management are still needed. Difference in evolution was seen in cases treated before 7 months of age: we will try to point out ethical issues related to a single case description.

A. is an Italian male child, born prematurely (32ga), with severe hypotonia and GNT: SMA1 is diagnosed at 6 months. At 7 months parents take part of Program for Early Parental Empowerment (PEPE) in our service. They learn how to manage the ordinary and extraordinary practice of the SMA child’s daily life. At 10 months he has a first breathing failure and starts NIV, parents don’t want TV and are against aggressive treatment. New drug is now available and at 12 months he receives first drug infusion. The good results are evident: reappeared movements and words lost, feeding by mouth, nocturnal NIV 10h/day. For another year, during he receives 6 more infusions, he keep improving. At 25 months has an aspiration pneumonia and increase NIV (>16h/day). PEG is proposed. After 15 days new respiratory crisis at home (O2< 20, CF< 40): AMBU, cough machine, aspiration, NIV in emergency. A. is terrified: he feels the fear of dying. Then he is hospitalized: the SMA1 getting worse. TV is proposed again. The drug was able to give A. a quality of life certainly better but could not “cure” SMA1. The look of terror in his eyes was decisive in parent’s choice. With great pain but with the serenity of those who understood and accepted the disease, parents chose palliative care. In a few hours A. died, sleeping with a serene expression, without pain, without fear. Love also means letting go.
Teaching Pediatricians the Skill of Shared Decision Making: A Blinded, Randomized, Controlled Pilot Study Utilizing a Novel Online Curriculum

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Background: Competence in shared decision making for all pediatricians is becoming more and more important as children's hospitals are caring for more chronically critically ill children. Pediatric Palliative Care teams are often stretched thin, requiring primary providers to play an active role in helping families make hard medical decisions. However, the medical team is often unable to ascertain families' goals of care during rounds or bedside discussions, often due to lack of communication training and experience. We sought to create and test an open, easily accessible online module to teach the skill of shared decision making to pediatric providers.

Methods: 17 Pediatric subspecialty fellows were video-recorded in a simulated patient encounter with parents facing a decision to either go forward with a life-extending procedure or transition to a course of care aimed at comfort. An intervention group then participated in a brief online curriculum to teach the skill of shared decision making. Participants from both control and intervention groups then repeated the same simulated scenario and were reassessed. Members of the control group then became a delayed-intervention group and also underwent the curriculum. Recordings were randomized and evaluated by blinded reviewers with a validated scoring tool to assess the degree of shared decision making present in each conversation.

Results: Our study demonstrated the likelihood of improved shared decision making behaviors increased 40-fold with completion of our online intervention. Those who had lower baseline scores showed greater improvement than those whose baseline scores were already high.

Conclusions: As pediatricians and children's hospitals are increasingly caring for more chronically critically ill children, our study indicates that shared decision making skills can be improved through the usage of online, interactive curricula like the one designed by our group.
P100
Parental Experiences and Perspectives of End-of-Life Decision-making in Allogeneic Paediatric Stem Cell Transplant, a Retrospective, Multi-centre, Grounded Theory Approach
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For children with haematological, immunologic and metabolic diseases, a stem cell transplant (SCT) offers an opportunity for cure, but not all children survive. Bereaved parents of children who died after SCT are at risk of decreased psychological well-being. To improve parental support during SCT and to improve aftercare, this study aimed to gain insight in the parents' experiences and perspectives concerning End-Of-Life (EOL) decision-making in allogeneic paediatric SCT.

A qualitative study. In-depth interviews were conducted with 14 bereaved parents of eight children, who died within a year after allogeneic SCT.

Two main themes reflected the parents' position in EOL decision-making. Firstly, *Decision-making throughout the illness process*, which can be described as following the by Health-Care Professionals (HCP) advised treatments in order to create maximum chance of survival for their child. Four principles supported parents to make the most of opportunities: trusting in and hoping for victory, having a critical attitude, developing a frame of reference, feeling retrospective doubts, experiencing feelings of loss. Secondly, in order to fulfil their task of *Being a good parent*, parental decisions followed their child's wishes; focussed on keeping the child, the family and themselves going; prevented the possibility of decisional regret in the event of child death.

Parental (EOL) decision-making is not characterized by deciding themselves, but rather by following treatment opportunities and HCP's guidance, being driven by hope for cure. HCP's can guide parents throughout the illness course not only by discussing carefully all treatment decisions but also in helping them to be a good parent. It remains a challenge to achieve shared decision-making incorporating the parents' wishes, needs and anxieties and possible future scenarios of the complex SCT situation. Future research should focus on developing advance care planning for intense treatments, like SCT.
P101
Palliative Care for Newborns with Inoperable Cardiac Disease - The Development of a Hospice Care Pathway

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Background and aims: We aimed to develop a care pathway for newborns with inoperable duct-dependent cardiac lesions to optimise the quality of life for the baby and their families in the short period when their duct is still open and they are asymptomatic, and to provide end of life care and support.

Methods: The joint cardiology and palliative care pathway includes:

- Training for hospice staff on managing prostaglandin infusions;
- Counselling parents on their options for care after the birth of their baby, appropriate investigations, agreement on how long to continue iv prostaglandin and appropriate supportive care;
- Transfer to the hospice and end of life care;
- Bereavement care and follow up.

Results: In the first 10 months, three families chose to use the hospice.

<table>
<thead>
<tr>
<th></th>
<th>Baby H</th>
<th>Baby S</th>
<th>Baby J</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesions</td>
<td>Multiple cardiac lesions</td>
<td>Complicated hypoplastic</td>
<td>Complicated hypoplastic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>left heart syndrome</td>
<td>left heart syndrome</td>
</tr>
<tr>
<td>Age on transfer to hospice</td>
<td>Day 6</td>
<td>Day 5</td>
<td>Day 8</td>
</tr>
<tr>
<td>Duration of prostaglandin infusion</td>
<td>9 days</td>
<td>12 days</td>
<td>10 days</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Breathlessness, agitation</td>
<td>Breathing, agitation</td>
<td>Breathing, agitation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Peripheral oedema</td>
<td></td>
</tr>
<tr>
<td>Day of onset</td>
<td>Day 10</td>
<td>Day 13</td>
<td>Day 9</td>
</tr>
<tr>
<td>Management</td>
<td>Oral Morphine Buccal Midazolam</td>
<td>Oral Morphine Buccal Midazolam</td>
<td>Oral Morphine Infusion of Morphine &amp; Midazolam</td>
</tr>
<tr>
<td>Age at death</td>
<td>Day 11</td>
<td>Day 14</td>
<td>Day 13</td>
</tr>
</tbody>
</table>

[Summary of patients with incurable heart disease on a palliative care pathway]

All three families continue to engage in bereavement support at the hospice.

Conclusions: This is an effective strategy to prolong these babies’ stability for as long as possible in a non-hospital setting. This gives the families time together to bond and make memories in a supportive environment with medical, nursing and emotional care.
P102
Knowing the Children´s Literature on Death and Grief: The Possibility of Interventions with Families
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Although witnessing death is a part of life encountering, in general, the subject "death and mourning" tends to be denied. And for children it's not different: talking about death to the minors represents a great difficulty for adults. Revealing itself as an important tool, children´s literature has been identified as an effective method to help younger children deal with traumatic events, such as the death of a loved one or his own death.

Objective: Know the juvenile literature available in public collection that addresses the theme of death and mourning, analyzing and classifying the corresponding children´s literature in order to discuss the possibilities of using this literature in the communication between adults and children.

Methodology: The qualitative, descriptive-exploratory study, carried out a literary search based on the special public collection of the Biblioteca Infantojuvenil Monteiro Lobato - SP, Brazil. For the analysis and interpretation of the selected material is being used the technique of categorical content analysis by thematic.

Results: 16 books were selected in which the majority approach to the death of parents was verified using symbols, metaphors and illustrations for an indirect representation of death and mourning.

Discussion: Although indirectly approached in children´s books, death is mostly put as a natural event, surrounded by feelings of sadness and longing, but which is part of the cycle of life.

Conclusion: Playing a key role on patient and respective family caring, the nursing team can use the reading as a resource in establishing a clearer and more effective communication about death and its questions, allowing a better assistance in death process for those children, their families, and also to family members who need to tell their children about a close relative death.
P103
Training in Children's Palliative Care Provided to Postgraduates Specializing in Pediatric Medicine in Italy - The Evaluation of Training Programs and Achieved Levels of Competency
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The complex healthcare needs of children with life-threatening (LTI) illness and their families has led to the development of children's palliative care (CPC) and pain management (PM) practices. In Italy, the services provision is hindered by many issues and above all by the lack of specialized training programs for healthcare staff.

To examine the availability of training programs in PM and end of life (EOL) care for Italian postgraduates specializing in Pediatric Medicine and how the knowledge and skills training offered to them is structured.

An online questionnaire was sent to the Directors of Italian postgraduate pediatric medicine programs to gauge the specific training provided. Another online survey was sent to all the postgraduate students in pediatric medicine at the University Hospitals of Padua and Udine.

16 of 37 Directors responded to the interview. 80% of the pediatric medical schools offer PM and CPC training programs (90 and 50 minutes/year respectively). Training in CPC-PM was compulsory in 2 cases; in 3 institutes it was possible to devote the final year of specialization to PM and CPC. Of the 127 postgraduates contacted, 91% completed the questionnaire. It was revealed that a total of 40 minutes of EOL care training is provided each academic year. 16% of the interviewees declared to have received less than 6 hours CPC training during the postgraduate course. Whilst between 66% and 100% of the questions designed to test knowledge on CPC and EOL care were answered correctly, 76% of the postgrads interviewed considered their skills in these disciplines 'weak' or 'very weak'. A majority (68%) did not feel ready to care for children with LTI and an even greater majority (73%) not ready to deliver EOL care. Half of the postgraduates in their final year had no experience managing such a challenging clinical situation. Improved strategies for enhanced PPC knowledge and skills training are key to the development and accessibility of these fundamental healthcare services.
Inhabiting the Present: Exploring the Spirituality of Children

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Background: Palliative care for children is defined as ‘the active total care of the child’s body, mind and spirit.’ However, childhood spirituality is elusive and rarely explored in practice. This paper aims to clarify our understanding of it, drawing on both the literature and examples from practice. It challenges us to think in new ways about the spirituality of children, and makes suggestions for hearing the voice of the child in the midst of the needs of parents and professionals.

Methods: Case studies and observations of the manifestations of children’s spirituality in a children’s hospice were collected, together with themes from the wider, relevant literature on the spirituality of children.

Result: The force and freshness of children’s experiences, often seeking wholeness in the absence of cure, challenge us to think in new ways about their spirituality and how it might be meaningfully addressed. Examples are drawn from the literature and from practice.

Conclusions: Three important characteristics of childhood spirituality emerged, namely children’s capacity for relationship and connectedness, their openness, and their intuitive way of knowing and being. The authors reflect on how children’s energy for living in the present is at odds with the tendency of adults to strive to control in relation to both the body and the future. Children were open to not knowing, paradox and living with mystery, whereas many adults do not appear to be at ease with these, and instead seek control and predictability. The paper questions the reductionism of a materialist society, which devalues what it cannot measure or prove. In the words of Jung, ‘Our intellect has achieved tremendous things, but in the meantime our spiritual dwelling has fallen into disrepair.’ The implications for practice are explored.
A Case Series Exploring Expected Infant Death - Who, Where and When?

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Aims: All local Child Death Overview Panels (CDOP) in England have a statutory responsibility to review all child deaths (< 18 years). This study aims to evaluate expected deaths in infants (< 1 year), specifically in relation to chromosomal/genetic/congenital anomalies and perinatal/neonatal events [CDOP categories 7 and 8 respectively] for an ethnically diverse UK local authority population. The aim is to inform for whom and where to focus development and delivery of local palliative care services by developing a greater understanding of the population, including care setting at time of death and demographic factors such as ethnicity.

Methods: A retrospective case series assessing and describing demographics, age and CDOP category in expected deaths of infants recorded by CDOP between April 2013 and March 2016. Ethical approval was not required as data is anonymous, with no patient risk. Generic spreadsheet software was used for initial statistical analysis.

Results: There were 107 expected deaths in this time period, of which 49.5% were male and 50.5% female. 51.4% were category 7 (male 21.5%, female 29.9%) and 48.6% were category 8 (male 28.0%, female 20.6%). 84.1% were children under 3 months of age. Only 3.7% of deaths had identified modifiable factors. 71.0% of children born to consanguineous parents were category 7. 64% of total deaths and 100% of deaths in consanguineous families were of South Asian origin. 91.6% died in hospital (46.7% Neonatal Unit, 27.1% labour ward, 17.8% elsewhere), 2.8% at home and 5.6% in hospice.

Conclusion: The data suggests the majority of expected deaths in infants within this locality occur in hospital, particularly on the neonatal unit and in children less than 3 months of age. Greater than half of all deaths were in South Asian families, where consanguinity was highest. The local palliative care services should be reviewed to assess compatibility with population need.
The Relationship between Adolescents, in Palliative Care, and the Cyberspace: An Interaction Model

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Background: Professionals who work in paediatric palliative care must be attentive to the different stages of development of the child and adolescent, taking into account the characteristics of each stage. The adolescence is a transition phase from the childhood until the adulthood, it is when the adolescent deal with the development challenges.

Aim: The purpose of this study were to understand the relationship of adolescents, in palliative care, with the cyberspace; explore the online practices and cyberspace meanings for adolescents in palliative care.

Methods: This is a qualitative research, approved by an ethics committee, which used an ethnographic approach and the Symbolic Interactionism as references. This study was made in two environments, in the off line’s we used a paediatric palliative care outpatient clinic, and in the on line’s we used social networks. 10 adolescents in palliative care, aged 13 until 19 years old, were interviewed and their social networks profiles were observed.

Results: We identified two categories “The cyberspace is” and "My online life". The first one means the cyberspace for the adolescents, in palliative care, the cyberspace it's a place where they can be entertained and their pain are relief; it’s a place for interaction, for make some researches and a place for get some support. The second category bright the practices from the adolescents in Palliative Care on cyberspace. On it they could post everything they want, they are recognized, they can share information with their friends, they can think about their future and they could suffer the death from their equals.

Conclusion: The relationship created between adolescents in palliative care and the cyberspace is represented by the adolescent's interactions with other people, with the environments - online and offline - and with themselves. This relationship promotes a sense of autonomy, recognition and empowerment in adolescents in palliative care.
P107
Signs and Symptoms Experienced by Children in the Last 7 Days of Life
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Background: Identifying signs and symptoms that indicate a child could be imminently dying is a key research priority within paediatric palliative care. Some studies of dying children suggest a high symptom burden at end of life (EOL). Commonly reported symptoms include pain, dyspnoea, poor appetite and fatigue. Many of these studies retrospectively collected data from bereaved parents.

Aims: The primary aim was to investigate symptom prevalence in children under the age of 18 years in the last 7 days of life. Secondary aims looked at the interventions (pharmacological and non-pharmacological) used to manage these symptoms.

Method: A retrospective case note review of all children who died while under the care of a specialist palliative care team in the UK between Jan 2012 and Mar 2017. Data on symptoms experienced and their management were analysed using descriptive statistics.

Results: 187 children were included: mean age of 8.4 years at death. The most common diagnosis was malignancy (80.7%). Patients died at home (47%), hospice (25.7%) or hospital (27.3%). The mean number of symptoms per child was 8.4 (range 1-23), with changes in respiratory rate (68.4%), agitation (65.2%) and pain (51.4%) commonly reported. Comparatively, fatigue (35.3%) and appetite loss (11.2%) were less frequently reported. The mean number of interventions was 8.7 (range 1-24). The most common pharmacological interventions were opioids (84%) and benzodiazepines (57.8%). Non-pharmacological approaches included repositioning (18.7%) and suctioning (14.4%).

Conclusion: Although fatigue and loss of appetite are reported symptoms at EOL, pain and dyspnoea are much more prevalent. Symptom burden as a whole is high, with interventions reflecting the most commonly reported symptoms. The results of this study may aid the development of anticipatory EOL prescribing guidance. Furthermore, it is important to inform parents of expected symptoms and interventions that can support their child at EOL.
P108
Consistently Seeing the Same GP is Associated with Less Emergency Care for Children and Young People with Life Limiting Conditions

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Background-context-aims: Children and young people with life limiting conditions (LLC) have complex healthcare needs, visit A&E departments and have emergency inpatient admissions. There is some evidence that they go straight to hospital, bypassing GP care - improving GP care may reduce this. This study aimed to determine whether there is an association between consistently seeing the same GP and reduced levels of A&E visits and emergency admissions for this population.

Methods: An extract of GP consultations from the Clinical Practice Research Datalink with linked Hospital Episode Statistics was requested for 0-25 year olds who had ever had a diagnosis matching either an ICD-10 or READ code framework for LLC. Each year, the proportion GP consultations per person that were with the most commonly seen GP was calculated. Also each year, numbers of A&E visits and emergency admissions per person were counted. Separate models were developed for A&E visits and emergency admissions as the dependent variables; consistency of GP seen was the independent variable of interest. Age, ethnic group, main diagnostic group, deprivation category, year and number of GP consultations were also included. Multilevel negative binomial regressions were used as the outcomes were count data clustered by individuals.

Results: Greater consistency was associated with a lower rate of A&E visits and emergency admissions: those with 90% or more of visits with the same GP had 10% (95%CI 6-13%) fewer A&E visits and 9% (95%CI 6-13%) fewer emergency admissions than those with < 40% of consultations with the same GP. Age group, diagnostic group, deprivation category and year were also predictive of numbers of A&E visits and emergency admissions.

Conclusions: Ensuring that young people with life limiting conditions have consultations with the same GP as often as possible may have the potential to reduce their use of emergency care services.

Funding: Martin House Research Centre and the Health e-Research Centre.
P110
How Effective is the Paediatric Palliative Screening Scale (PaPas Scale) in Identifying Children with Cancer who May Benefit from Palliative Care Input?

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Background: Children and young people (CYP) suffer distress due to the effects of cancer. Palliative Care (PC) is effective in delivering integrated health care, however not all CYP require PC, and few data are available to differentiate these groups.

Aim: To identify if the PaPas Scale, a validated tool for identifying need for PC, could be applied to CYP with cancer.

Methods: CYP (0-19) on treatment were identified through hospital records from March-August 17. PaPaS Scale consists of 11 questions with the cumulative score aiming to identify level of PC involvement required.

Results: 64 CYP were included; 52 had stable disease with ongoing curative treatment and mild controllable symptoms. 9 CYP were enrolled in phase I/II trials. Symptom intensity was a predictor for a higher score, however there were 7 children not recommended for active PC with moderate/severe symptom profiles. 11 CYP identified as requiring active PC involvement, 6 of whom died during the study period. Only 2 CYP with relapsed disease and 1 child with metastatic disease were identified as requiring active PC, this was compared to total numbers of CYP relapsed (7) and metastatic disease (4). All 11 CYP were still receiving chemotherapy. Treatment was defined as being a high burden in 9 cases. Symptoms were difficult to control in 9 of these children with the remaining 2 having moderate symptoms. The 'surprise question' was the most sensitive indicator for the need for active PC.

Conclusions: The PaPaS scale effectively identified those who were most vulnerable in terms of stage of disease trajectory, treatment intensity, symptom burden and psychological distress. A high score on the PaPas scale was a positive predictor for challenging symptoms and death. However, a number of CYP with lower scores were found to have high-symptom intensity, potentially highlighting the role of PC in offering supportive care.
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