Pre-conference workshops – Wednesday 30th May 2018

Half day

**Room 1**
- 09.00-12.00 - CPC in Humanitarian situations – Joan Marston (South Africa) and Danai Papadatou (Greece)
- 13.00-16.00 - Reaching out to develop a CPC programme – Paul Quilliam (Australia) and Lynda Gould (China)

**Room 2**
- 09.00-12.00 - Perinatal PC – Chakrapani Vasudevan (UK) and Rut Kiman (Argentina)
- 13.00-16.00 - Ethics in CPC – Julia Ambler (South Africa), Delia Birtar (Romania) and Richard Hain (UK)

**Room 3**
- 09.00-12.00 – Research in Children’s Palliative Care – Julia Downing (ICPCN), Jan Aldridge (UK) and Marie Friedel (Belgium)
- 13.00-16.00 - Difficult conversations in CPC – Tracey Brand (South Africa), Marianne Phillips (Australia) and Hanneke Brits (South Africa)

Full day
- 09.00-16.00 - Managing pain in CPC from birth to young adulthood – Sat Jassal (UK), Regina Okhuysen-Cawley (Mexico), Michelle Meiring (South Africa), Catherine Habershy (USA) and Pat Carragher (UK)

Opening Ceremony - Wednesday 30 May 2018

| 17.30 – 19.00 | Opening Ceremony, with speeches by the Mayor of Durban, Prof Julia Downing and Sister Frances Dominica |

Day 1 – Thursday 31 May 2018

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<td>Pain &amp; Symptom Management <strong>Chairs:</strong> Richard Hain (UK) and Justin Baker (USA)</td>
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<td>Assessment of Pain in Children: Knowledge and Practice of Healthcare Providers at a Tertiary Centre, Southern Nigeria Gracie Eke (Nigeria)</td>
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<td>Standardization of Analgesia and Sedation Infusion Solutions in a Pediatric Palliative Care Unit Andres Morgenstern (Spain)</td>
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<td>11.45-12.00</td>
<td>Understanding Palliative Sedation as a Life-Affirming Intervention Regina Okhuysen-Cawley (Mexico/USA)</td>
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<td>Children with non-oncological life-limiting conditions deserve the same high-quality palliative care as children with incurable cancer Archana Soman (UK)</td>
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<td>Symptoms and concerns among children and young people with life-limiting and life-threatening conditions: A systematic review</td>
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<td><em>Julia Downing (ICPCN)</em></td>
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<td>14.45-15.00</td>
<td>How can we evaluate quality of life of children with life-limiting conditions? Pilot-test at one PPC centre in Belgium.</td>
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<td><em>Marie Friedel (Belgium)</em></td>
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<td>It’s Possible! To evaluate the emotional well-being of children and their parents attended in a pediatric palliative care unit</td>
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<td><em>Daniel Toro Perez (Spain)</em></td>
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<td>Transition from Childhood to Adulthood in Palliative Care: Exploring needs and developing provision Jan Aldridge (UK)</td>
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<td><em>Jan Aldridge (UK)</em></td>
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<td>Through the introduction of palliative care, quality of life has improved and the course of illness has been positively influenced thus leading to an increase in referrals</td>
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<td><em>Tracey Brand (South Africa)</em></td>
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| 08.00-08.50 | Meet the expert                                      | Managing Complex Symptoms  
Sat Jassal (UK), Hanneke Brits (South Africa) and Regina Okhuysen-Cawley (USA/Mexico)  
Therapeutic Touch: 5 simple strokes to use each day  
Marie Wrinn (USA)  
Advocacy in CPC  
Stephen Connor (USA), Busi Nkosi (ICPCN) and Kelly du Plessis (South Africa) |
| 09.00-10.30 | Plenary Session                                      | Chairs: Tracey Brand (South Africa) and Emmanuel Luyirika (Uganda)         |
| 09.00-09.10 | Inspiration – PATCH Youth Ambassador               | Huyaam Samuels (South Africa)                                              |
| 09.10-09.30 | Inspiration – the Parents Perspective               | Parents supported by Umduduzi, Hospice Care for Children (South Africa)    |
| 09.30-09.50 | Integration through developing and introducing policy on CPC in South Africa | Dr Michelle Meiring (South Africa)                                          |
| 09.50-10.10 | Inspiring others through the lessons learnt in developing CPC nationwide | Ana Lacerda (Portugal)                                                     |
| 10.10-10.30 | Inspiration – lessons learnt re the development of CPC from Latin America | Regina Okhuysen-Cawley (Mexico/USA)                                        |
| 10.30 | Close                                                |                                                                            |
| 10.30-11.00 | TEA                                                  |                                                                            |
| 11.00-12.30 | Children, Young People & Parents                    | Service Delivery  
Chairs: Zipporah Ali (Kenya) and Sat Jassal (UK)  
Workshop  
Chair: Sue Boucher (ICPCN) |
| 11.00-11.15 | Professional parents and personified doctors: an interview study on decision making in paediatric palliative care | Marije Brouwer (Netherlands)  
Use of different services in a complex Paediatric Palliative Care Unit  
Delia Birtar (Romania) |
| 11.15-11.30 | Young people as direct stakeholder advocates for palliative care | Huyaam Samuels (South Africa)  
A loving link between a children's hospice and inmates of two prisons  
Joan Marston (South Africa) |
| 11.30-11.45 | The Importance of Parents Being Heard and Acknowledged In Their Child's Healthcare Journey | Melissa Williams-Platt (South Africa)  
The paediatric palliative care emergency: understanding the interface between parents and ambulance services  
Christine Mott (Australia) |
<p>| 11.45-12.00 | Experiences of Care Givers of Children Receiving Palliative | From oncology to non-oncology palliative care                               |</p>
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<td>Eva Zsak (Hungary)</td>
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<td>Integrating Paediatric Palliative Care into a public health structure: What do we need in order to provide paediatric palliative care at an intermediate care facility?</td>
<td>Alex Daniels (South Africa)</td>
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<td>Innovative models of transitioning from Children’s to Adult PC services</td>
<td>Pat Carragher (UK)</td>
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<td>Chairs: Liz Gwyther (South Africa) and Marianne Phillips (Australia)</td>
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<td>A Mixed Method Systematic Review of the Experience of Communication in the Care of Children with Palliative Care Needs</td>
<td>Evolving children’s palliative care training online: reviewing the ICPCN e-learning platform</td>
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<td>Maha Atout (Jordan)</td>
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<td>Play of children with life-threatening/limiting conditions: a scoping review</td>
<td>Envisioning a sustained novel model for effective delivery of Pediatric Palliative Care in resources limited settings: case study of University Teaching Hospital of Kigali, Rwanda Prosper Karamane (Rwanda)</td>
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<td>Zainab Jasem (UK)</td>
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<td>Communication with Children using Stepping Stones with Children Approach</td>
<td>Integration of Paediatric Palliative Care Services at the M.P Shah Hospital: A Pilot Project</td>
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<td>Nelson Chziza (Tanzania)</td>
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<td>CHOC Psychosocial Services - Embracing Paediatric Palliative Care</td>
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<td>#CPC by WhatsApp?</td>
<td>Children’s Palliative Care: Pilot Project on a New Concept in Lesotho</td>
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<td>Julia Ambler (South Africa)</td>
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<td>Innovations in the pharmacological treatment of Pain Dr Sat Jossal (UK)</td>
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<td>Innovations in psychological care in CPC Danai Papadatou (Greece)</td>
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### Day 3 – Saturday 2 June 2018

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<td>08.00-08.50</td>
<td>Design in Children’s Palliative Care Edwina Fleming (South Africa) and Amruta Talawadekar (India)</td>
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<td>CPC in SADC Michelle Meiring (South Africa), Busi Nkosi (ICPCN) and Beverly Sebastian (Zimbabwe)</td>
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<td>09.00-09.15</td>
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<td>09.00-09.15</td>
<td>Remember the Spring Joan Marston (South Africa)</td>
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<td>ICPCN - Making a difference in a culturally diverse world Sue Boucher (ICPCN)</td>
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<td>09.30-09.45</td>
<td>Developing a European Children’s Palliative Care Taskforce through the EAPC Julia Downing (ICPCN)</td>
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<td>09.45-10.00</td>
<td>Advocating for Children’s Palliative Care in Africa Busi Nkosi (ICPCN)</td>
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<td>Strategies for introducing palliative care in schools Ruth Kemigisha (Uganda)</td>
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<td>09.15-10.00</td>
<td>Expanding Interdisciplinary Borders: Lecturing Perinatal Palliative Care within Midwifery Rut Kiman (Argentina)</td>
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<td>09.30-10.00</td>
<td>Experience from a home-based palliative care service in Malaysia Leelai Chong (Malaysia)</td>
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<td>Paediatric Palliative Care: Are we doing enough? A Retrospective Review of Paediatric Deaths over 5 years in an Academic Tertiary Hospital Mei Chan Grace Ng (Singapore)</td>
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**Day 3** – Saturday 2 June 2018

- **08.00-08.50** Meet the expert
  - Psychosocial issues in CPC
    - Danai Papadatou (Greece), Tracey Brand (South Africa) and Marli Robertson (Canada)
  - Design in Children’s Palliative Care
    - Edwina Fleming (South Africa) and Amruta Talawadekar (India)
  - CPC in SADC
    - Michelle Meiring (South Africa), Busi Nkosi (ICPCN) and Beverly Sebastian (Zimbabwe)

- **09.00-10.30** Concurrent Session
  - Networks and History
    - Chairs: Stephen Connor (USA) and Sabine Kraft (Germany)
  - Service Delivery
    - Chairs: Hanneke Brits (South Africa) and Zipporah Ali (Kenya)
  - Workshop
    - Chair: Lynda Gould (China)

- **09.00-09.15** Remember the Spring
  - Joan Marston (South Africa)

- **09.15-09.30** ICPCN - Making a difference in a culturally diverse world
  - Sue Boucher (ICPCN)

- **09.30-09.45** Developing a European Children’s Palliative Care Taskforce through the EAPC
  - Julia Downing (ICPCN)

- **09.45-10.00** Advocating for Children’s Palliative Care in Africa
  - Busi Nkosi (ICPCN)
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<td>Cara Noble (South Africa)</td>
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<td>Zimbabwe: Integration of Children’s Palliative Care for the world’s most needy.</td>
<td>Chenjari Bhodheni (Zimbabwe)</td>
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<td>Neil McKerrow (South Africa)</td>
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<td>Integration, Innovation and Inspiration – the role of education in CPC</td>
<td>Linda Ganca (South Africa)</td>
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<td>Sabine Kraft (Germany)</td>
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ABSTRACTS FOR ORAL PRESENTATIONS

DAY 1: THURSDAY 31 MAY
Concurrent Session 1: Pain & Symptom management

129. ASSESSMENT OF PAIN IN CHILDREN: KNOWLEDGE AND PRACTICE OF HEALTHCARE PROVIDERS AT A TERTIARY CENTRE, SOUTHERN NIGERIA
Gracia Eke, Uju Azubogu

Background: Pain is one of the major reasons why children present to healthcare facilities however, it is inadequately assessed and undertreated worldwide. Whenever feasible, optimal relief of pain in children should be attained. Whereas the principles of assessment of paediatric pain which include among others the use of pain rating scales, which are useful for establishing a baseline and for measuring response to treatment, good pain assessment remains the cornerstone for good pain management.

Objectives: To determine the knowledge and practice of healthcare providers towards assessment of pain in children at the University of Port Harcourt Teaching Hospital (UPTH).

Methods: A semi-structured and self-administered questionnaire, used as instrument for data collection, was distributed amongst a convenient sample of physicians and nurses attached to clinical departments/units where children are cared for, and those in educational units.

Results: One hundred and ninety-seven subjects participated in the study, 95(48.5%) physicians and 102(51.8%) nurses. Majority (33.5%) of them had 5-10 years’ work experience while 25% had more than 15 years. Commonest source of knowledge of management of pain in children was school for 30% of respondent (14.7% of doctors and 44.1% of nurses), in-service training (23.4%) and self-development (16.2%). More physicians (29.5%) did not know any pain assessment scale compared to nurses (17.6%), while 65.3% of doctors had never used any scale for assessing pain in children, as well as 44% of nurses. The most accurate judge of the intensity of the child/adolescent's pain was the child (41%), followed by the child's primary nurse (14.7%), the treating physician (11.7%) than the child's parent/caregiver (11.2%)

Conclusion: There are gaps in the knowledge of healthcare providers concerning assessment of pain in children. Capacity building interventions are required to enable application of standard practice and optimal pain relief in children.

79. DEVELOPMENT OF A DIGITAL APP: ICPCN PAIN ASSESSMENT TOOL FOR CHILDREN
Sue Boucher, Julia Downing

Aims: Development of a digital tool for the assessment and recording of a child's pain levels over time.

Design, methods and approach taken: Research indicates an under assessment of pain in children. ICPCN noted that those caring for children with chronic and complex illnesses may not always have easy access to pain scales and responses are not always recorded or easily accessible. The ICPCN Pain Assessment Tool for Children is a mobile app with the option of a faces, hand or numeric pain scale and records answers to questions related to the pain for use with children from between 3.5 years of age. The ICPCN Pain Assessment Tool for Children keeps an ongoing record of the child’s pain level scores and allows monitoring of the type and level of pain a child's pain.

Funding allowed ICPCN to approach a South African app designer to develop and host the app. After an extended process of design, testing, redesign and bug fixing, the app can be downloaded onto both Apple and Android devices.
Results: The app was introduced to a group of medical professionals at a workshop on pain and pain assessment held in Uganda in August 2017 who provided helpful feedback on improvements to functionality. At the time of submission, the app is being piloted by a selected group of medical professionals and families around the world. We hope to report the results and officially launch the app at this conference.

Conclusion/Lessons learned: App development is a complex process requiring careful planning and research. Our ultimate goal is the regular and accurate assessment and recording of a child’s pain levels, leading to consistent and effective pain control. Improvements and updates to the app will be ongoing.

58. STANDARDIZATION OF ANALGESIA AND SEDATION INFUSION SOLUTIONS IN A PEDIATRIC PALLIATIVE CARE UNIT
Beatriz Garcia Palop, Andres Morgenstern, Carla Cuso

Background: Parenteral medication administration by continuous infusion has become a common practice in end-of-life home care setting, because portable infusion pumps are well tolerated and maintain more nearly constant drug plasma levels. However, operator errors, physicochemical incompatibilities or bacterial contamination of infusion solutions are major concerns limiting effectiveness and safety of these treatments.

Aims: To ensure the effectiveness and safety of analgesia and sedation therapy in pediatric patients nearing end of life in the community setting, by establishing a standard operating procedure based on elaboration by dose banding.

Methods: First, most commonly used drugs reported within pediatric palliative care literature were identified. Secondly, patient weight ranges and fixed drug concentrations were established. Finally, a literature review was performed in order to assess compatibility and stability of drug solutions prepared under aseptic conditions in polyvinyl chloride medication cassette reservoirs and stored at 2 – 8ºC protected from light.

Results: Four different drug solutions (morphine, fentanyl, midazolam, morphine–haloperidol) and five weight ranges (< 6Kg, 6 - <11Kg, 11 - <20Kg, 20 - <30Kg, ≥ 30Kg) were established. Drug standardized concentrations according to respective weight ranges were defined as: morphine (alone or combined) 0.4, 0.8, 1.6, 2.4, 4.0 mg/ml and haloperidol 0.02, 0.04, 0.08, 0.12, 0.2 mg/ml. Fentanyl and midazolam cassettes were set to contain 0.02, 0.04, 0.05 mg/ml and 1, 2.5, 5 mg/ml for all weight ranges corresponding to < 6Kg, 6 – <11 Kg and ≥ 11Kg. According to compatibility and stability data, the shelf life of all reservoirs was defined to be 30 days except for morphine-haloperidol mixture (21 days).

Conclusions: Morphine, fentanyl, haloperidol and midazolam are frequently administered (alone or in combination) by continuous infusion in palliative home care setting. Standardization of drug solutions and long-term stability data permit the establishment of a rational program to ensure the effectiveness and safety of these treatments.

172. UNDERSTANDING PALLIATIVE SEDATION AS A LIFE-AFFIRMING INTERVENTION
Regina Okhuysen-Cawley

Aims: To review current concepts in palliative sedation for dying children.

Introduction: Although palliative sedation has been recognized as an important resource for symptom control in dying patients with truly refractory distress, the concept “Palliative Sedation” is fraught with confusion with the term “euthanasia”, in which there is an explicit, deliberate action to
end life. Misconceptions may delay implementation of appropriate symptom-control measures in dying patients, and as such, lead to unnecessary patient, family and clinician distress.

**Design/Methods:** Publications on this subject in the English medical literature were reviewed, using the PubMed search engine through November of 2017, utilizing the terms “palliative sedation” refractory pain in both the adult and paediatric context.

**Results:** Few publications specific to paediatric palliative sedation exist. Highlighted in the (primarily adult) literature are proportionality and precaution/intentionality as guiding principles to life-affirming symptom control, with use of holistic, non-pharmacologic and pharmacological interventions to address all physical and spiritual dimensions of distress, inclusive of the use of interventional procedures when available and appropriate. Emerging concepts also include consideration of the intermediate steps of respite (overnight to ensure adequate sleep) and intermittent (hours to days) sedation prior to the institution of traditional unidirectional continuous deep sedation until death. The use of titratable intravenous agents such as ketamine, Propofol, dexmedetomidine, benzodiazepines and barbiturates outside traditional intensive care and procedural environments merits investigation; non-intravenous titration methods suitable for a wide range of settings likewise should be studied to inform clinical practice and guideline creation.

**Conclusions:** Palliative sedation, appropriately applied, does not hasten nor does it delay natural death. Professional education to ensure optimal multimodal, multidimensional symptom control coupled with impeccable anticipatory guidance for patients and family members, emphasizing key concepts of proportionality and intention, may assuage concerns regarding implementation of this life-affirming resource for dying patients.

10. **CHILDREN WITH NON-ONCOLOGICAL LIFE-LIMITING CONDITIONS DESERVE THE SAME HIGH-QUALITY PALLIATIVE CARE AS CHILDREN WITH INCURABLE CANCER**

Archana Soman

**Introduction:** The need for pro-active planning and delivery of multidisciplinary (MDT) care to children with life-limiting conditions (LLC) is widely acknowledged, and ‘standards frameworks’ have been recommended by Together for Short Lives and others. However, the palliative care needs of children with non-oncological LLCs are commonly under-recognised.

**Methods:** We conducted a retrospective case-notes audit of 20 children (8 cancer and 12 non-cancer), aged 28 days to 16 years, who had died as a direct result of a LLC against seven pre-agreed standards.

**Results:**
1. A ‘breaking-bad-news’ meeting was documented in 95% (Oncology 100%, non-oncology 91.6%), but this focussed on the diagnosis, and discussion of prognoses was lacking in most.
2. A MDT meeting was documented in 85% (Oncology: 100%, non-oncology: 75%).
3. A key worker and a lead professional were both identified in 45% (Oncology: 87.5%, non-oncology: 16.7%; p = 0.01).
4. MDT assessment of palliative care needs was documented in 60% (Oncology: 100%, non-oncology: 33.3%; p = 0.015).
5. Symptom management plans were found in 65% (Oncology: 100%, non-oncology: 41.7%; p = 0.0225).
6. Family and psycho-social needs were documented in 75% (Oncology: 100%, non-oncology: 58.3%).
7. End-of-life care plans were documented in full in 40% (Oncology: 75%, non-oncology: 16.7%; p = 0.0325).
Discussion: Recognition of needs and planning for palliative care continues to be sub-optimal overall, especially so in children with non-cancer LLC. This audit has led to much introspection and acknowledgement of the need for hearts-and-minds change in clinicians’ approaches. A sub-regional working group’s finding mapping services to needs and identifying gaps has been submitted to commissioners. A comprehensive care pathway that will incorporate palliative and end-of-life care plans has been written, with input from parent groups. We hope to influence commissioners to develop a robust regional children’s palliative care service.

DAY 1: THURSDAY 31 MAY
Concurrent Session 1: Bereavement & Nurses’ Experience

146. LET’S TALK ABOUT IT: LEARNINGS FROM A SUPPORT GROUP FOR FRENCH BEREAVED CHILDREN AND ADOLESCENTS
Alexis Revet, Jean-Philippe Raynaud, Michel Vignes, Patricia Timsit, Eric Bui, Agnès Suc
Aims: French South West Regional Network for Pediatric Pain and Palliative Cares developed in 2006-2007, together with the Department of Child and Adolescent Psychiatry of Toulouse University Hospital, an accompanying protocol, named Let’s talk about it, for bereaved siblings. Since 2011, specific groups were also developed for children who have lost one of their parents. A ten-year analysis of practices was performed, highlighting the difficulties encountered in the development of this project, families’ feedback on the program since 2011, and future improvement of the protocol.
Approach taken: After a family interview realized by a pediatrician and a child and adolescent psychiatrist (CAP), children and adolescents started a support group of 4 to 8 participants, animated by two psychotherapists, at a pace of 4 sessions on a period of 4 months. Each session was divided in a mediated activity part (drawing, mandala, cutting/gluing and sculpting) and a speaking time. At the end of the 4 sessions, the family met again the pediatrician and the CAP to discuss of the future monitoring of the child.
Results: Since 2011, 198 children (143 families) have been supported by this care setting. 5 children withdrew from the protocol. Families’ levels of satisfaction and feedbacks are currently being assessed through the use of the Client Satisfaction Questionnaire.
Conclusions: Let’s talk about it represents an original support program for bereaved children and adolescents, which could serve as a model for the development of bereavement programs in the fields of pediatric palliative care. In the future, support groups for children and adolescents bereaved by a specific cause will also have to be experimented and studied.

114. BUILDING CAPACITY IN BEREAVEMENT: AN EMERGING MODEL OF TRANSITIONAL BEREAVEMENT CARE
Leigh Donovan, Claire Wakefield, Vera Russell, Wendy Lichtenthal, Richard Cohn
Aims: Following the diagnosis of childhood cancer and throughout the treatment regime parents’ often come to think of their child’s hospital as a ‘second home’. Parents describe a growing disconnect with their existing support networks, including friends in their local community, schools and colleagues. Distance between the treatment centre and home, the impact of a new life experience and associated personal adjustment, and the reality of those in the local community ‘getting on with life’ are all factors which contribute to this growing divide. A contemporary model of transitional bereavement care will be presented.
Methods: This model complements existing models of integrative palliative care honouring the symbiotic transition between curative and palliative care and acknowledging the continual cycle of
bereavement experienced by parents following the diagnosis of childhood cancer and other life-limiting conditions. The Dual Process Model of Grief further supports the gradual oscillation between formal hospital bereavement care and community support. Through the gradual reintegration into their community family members oscillate between hospital-based care (loss-oriented coping) and their community (restoration oriented coping). The public health model of bereavement care underpins this model of bereavement care acknowledging the variety of experiences and needs of family members in bereavement.

**Results:** This model recommends bereavement care take a community capacity building approach through anticipatory guidance and support for families and their community of supporters prior to the death of a child; facilitating connections with formal and informal support providers early in bereavement; and, rebuilding of relationships that may have broken down throughout a child’s health care trajectory between bereaved parents and their community.

**Conclusions:** This emerging model of transitional bereavement care offers a theoretical foundation that acknowledges the importance of building capacity in a family’s community throughout a child’s health care trajectory and following the death of a child from cancer and other life-limiting conditions.

103. DRAW ME A LADDER, SO I CAN CLIMB TO HEAVEN. YOUNG CHILDREN’S UNDERSTANDING OF THEIR OWN END OF LIFE; A QUALITATIVE STUDY IN THE NETHERLANDS

Marije Brouwer, Els Maeckelberghe, Agnes van der Heide, Irma Hein, Veerle van de Wetering, Eduard Verhagen

**Background:** So far, little is known on how young incurably ill children’s understanding of end-of-life, and on their capability to be involved in decisions concerning their palliative treatment. We investigated how incurably ill children understand and cope of with their disease and the end of life.

**Aims:** To get insight in the understanding and coping of young, incurably ill children with their disease and end of life, and what their role in decisions regarding the last phase of life is.

**Methods:** We performed a nationwide qualitative interview study, in which we included narratives about:
- Children aged 1-12 years who were receiving palliative care and
- Children who had died at the age of 1-12 after a medical trajectory.

We interviewed parents and physicians. The interviews were recorded, transcribed, and coded. Subsequently, the coded interviews were thematically analysed.

**Results:** In the preliminary results, parents and physicians described well-considered involvement of children themselves in decisions concerning their palliative treatment, and adequate understanding of their own end of life. Children as young as 3.5 years were seen making authentic valuations of their own end of life or palliative treatment. Several testimonials of parents and physicians illustrate the depth and maturity of the considerations of these children.

**Conclusion/Discussion:** Children were seen to make considerations in very mature ways. These findings could have an important impact on palliative care, where the end of life is often not discussed with children. Both parents and health care professionals should take children’s input seriously in decision-making regarding palliative care.

92. RELATIONSHIPS BETWEEN PARENTS AND HEALTHCARE PROVIDERS WHEN A CHILD DIES FROM CANCER AT THE HOSPITAL: ENCOUNTERS THAT SURVIVE THROUGH TIMES

Maiara Rodrigues Santos, Maira Deguer Misko, Regina Szylit
Background: The relationship between family and healthcare providers during the child’s end-of-life can affect parents’ long-term outcomes due to their perception of the care. Evidences need to emphasize how these relationships during the child’s last hospitalization influence familial adaptation after loss.

Aim: To interpret parents’ experience in their relationship with healthcare providers during the child’s end-of-life with cancer in the hospital.

Methods: Qualitative research, guided by Gadamer’s philosophical hermeneutics. Data collection was through field observations conducted in a pediatric oncology hospital with hospitalized families in end-of-life situation, interviews with bereaved parents at least 6 months after the child’s death and medical records’ analysis. For the data analysis, the process of transcription, reading and re-reading the data, reviewing field notes and reflection on the data helped understand the phenomenon to generate units of meaning and themes, which were submitted to an interpretation process.

Results: Parents-providers’ relationships during a child’s end-of-life process unveil key elements in encounters and interpersonal interactions during illness and loss trajectory. These relationships are established in a dynamic way with various bonding. There are evident components in a child’s end-of-life context, such as presence, silence, deterioration, tolerance, hierarchy, collaboration and trusting, as well as internal and external factors which influence these interactions. Through relationships, parents re-evaluate their own role and attribute meanings to the unexpected experience of losing a child.

Conclusion: Relationships serve as a basis for strengthening and supporting parents in guaranteeing excellence in the child’s care. The quality of each relationship is a remarkable memory of the child’s life during the bereavement process. The results of this study highlight components to improve the quality of these relationships, that need to be incorporate into end-of-life policies, as a starting point for a care focused on developing a safe base for parents’ bereavement process.

81. LEARNING ABOUT NURSES’ EXPERIENCES OF SUPPORTING PARENTS AND FAMILIES TO CARE FOR CHILDREN WHO ARE DYING, IN QATAR

Karen K. Gauthier, Kathryn Banks, Jessie Johnson, Arlene Masaba, Mihirani Chandraratne, Nicola D’Souza, Alka Cherian, Inca Kriel, Suzette Isaac, Maria Baluya

Background: Currently, there is no formal pediatric palliative care service in Qatar for the dying pediatric patient and their family. Educating nurses to work with families, needs to start in nursing schools. In this innovative project, we trained student nurses to do interviews with staff nurses who had cared for a child who had died. We collected data about the nurses’ experiences of supporting families who had a child die.

The aim of this study is to gain a deeper understanding of the meaning of the lived experiences of nurses in Qatar supporting parents and families to care for children who are dying.

Method: Interpretive Description helps us to understand the subjective human experience by asking about the experience in a systematic way. In this design, the researcher identifies characteristics, structures, and patterns of a phenomenon and uses these elements to build knowledge about the phenomenon for the study participants. A purposive sample of six to twelve nurses will be interviewed to talk about their experiences. During data analysis the researchers will identify commonalities and differences in the experiences of the nurses. This is an Undergraduate Research Experience Program (UREP) study; student researchers, paired with Faculty Mentors will conduct the interviews.

Results: A conceptual description of what we learned from the nurses about their experiences of supporting families who had a child die will be presented.
Discussion: A highlight of this presentation will be a contrast between what is known about palliative pediatric care and why it is important that we share these caring practices with students so that they can use this foundational knowledge to support family-centered care.

DAY 1: THURSDAY 31 MAY
Concurrent Session 1: Workshop

ADVANCING PAEDIATRIC MEDICATION ACCESS THROUGH POLICY MAKING—INTERLOCKING PIECES
Zodwa Sithole, Andrew Gray, Sindi Mthethwa, Michelle Meiring, Julia Ambler
This workshop will look at the steps/activities taken that has resulted in a Palliative Care policy for South Africa. It will look at the work undertaken to include palliative care medicines in the Essential Medicines List (EML) and at home based oxygen therapy. Participants will discuss their experiences regarding off-licence prescribing and EMLs.

DAY 1: THURSDAY 31 MAY
Concurrent Session 2: Outcomes & Transitions

173. SYMPTOMS AND CONCERNS AMONG CHILDREN AND YOUNG PEOPLE WITH LIFE-LIMITING AND LIFE-THREATENING CONDITIONS: A SYSTEMATIC REVIEW
Background: Lack of patient-level outcomes data hampers the development of paediatric care services. A recent review found no valid person-centred outcome measure for paediatric palliative care. Development should be informed by outcomes that mirror children and young people’s (CYP) and family priority symptoms and concerns.
Aim: To identify and appraise the evidence on symptoms and concerns that matter to CYP with life-limiting and life-threatening conditions and corresponding meaningful health outcomes.
Methods: Systematic review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The search strategy combined terms associated with symptoms and concerns with keywords for CYP; life-limiting and life-threatening conditions (LLC). Single case studies, studies on pharmacological interventions or family carers alone and mixed samples without disaggregated results for CYP were excluded. Included studies were assessed for quality and reporting rigour using the Hawker quality assessment checklist. Narrative and thematic approaches were used for data analysis. Themes on health outcomes were clustered using WHO definitions for health.
Data sources: MEDLINE, EMBASE, PsychInfo, CINAHL, Scopus, Web of Science and relevant grey literature.
Results: 13567 articles were identified, and 81 studies included. Types of respondents: CYP (n=29), parents (n=14), health workers (n=6), parents/CYP and siblings (n=21), CYP/parents/health workers (n=7), record reviews (n=4) Themes on priority concerns and symptoms are presented by domain and an example. 1) Physical: (n=62) e.g. physical symptoms, symptom distress, 2) psychological (n=65): e.g. emotional, cognitive function, 3) social (n=31): e.g. relationships, social function 4) spiritual/existential (n=37): e.g. worry about death, existential concerns, 5) other concerns (n=28): e.g. communication and information, decision making.
Conclusion: Data exist to inform face and content validity of a novel measure. Although half of CYP can self-report, methods of completion and proxy versions are needed. These priority outcomes should inform the outcome measurement in paediatric palliative care and stimulate outcomes-based service development and research.

74. HOW CAN WE EVALUATE QUALITY OF LIFE OF CHILDREN WITH LIFE-LIMITING CONDITIONS?
PILOT-TEST AT ONE PPC CENTRE IN BELGIUM
Marie Friedel, Bénédicte Brichard, Jean-Marie Degryse, Aujoulat

Background: Paediatric Palliative Care’s (PPC) major aim is to promote quality of life (QoL) for children with life-limiting conditions. Measuring QoL is challenging because of heterogeneity in age and disease, lack of consensus when PPC starts, legal and ethical requirements for involving children in research and the necessity to capture QoL in a family-centred, holistic approach. PPC is delivered in Belgium through 5 paediatric liaison teams (PLT).

Objectives: to analyse how QoL of children can be evaluated by PLT. Sub objectives include:

i) Exploring children’s individual QoL
ii) Evaluating parental QoL
iii) Documenting the degree of palliative care stage in relation to evolution of disease
iv) Analysing feasibility and acceptability of instruments by PLT

Methods: A collaborative, iterative approach is chosen throughout the study. Four instruments were selected, from which 2, not available in French, needed first a cross-cultural validation (forward/back translation, expert review panel). Semi-structured interviews based on the CPOS (Downing 2015) and SEIQoL (Hickey 1996) were conducted (n=6 children; 9 parents) and parents filled out the QOLLTI-F (Cohen 2006) (i and ii). For (iii), physicians in charge of the child completed the PaPas (Bergstraesser 2014). Finally, to attempt iv) several meetings and think aloud protocols among PLT were performed.

Preliminary Results: Even children with limited verbal capacity are able to express important dimensions affecting their QoL. Dimensions such as social interactions seem not be covered by the CPOS. Parental QoL scores revealed high distress. PaPas Scale might not be appropriate to document palliative stages for children with neurological diseases. Overall feasibility and acceptability of using CPOS, SEIQoL and QOLLTI-F was observed.

Perspectives: Further adaptations of instruments till saturation of data is achieved, are requested before extended field-testing.

47. IT'S POSSIBLE! TO EVALUATE THE EMOTIONAL WELL-BEING OF CHILDREN AND THEIR PARENTS ATTENDED IN A PEDIATRIC PALLIATIVE CARE UNIT
Daniel Toro, Lucia Navarro, Jose Antonio Porras, Marta Palomares, Ester Fernandez, Silvia Cipres, Cristina Gutierrez Veronica Velez, Miguel Flores, Balma Soraya Hernandez, Pau Miquel, Nuria Carsi, Sergi Navarro

Background: Little prospective research has been conducted to examine the longitudinal impact of the disease, treatment, and imminent or proximate death in the psychological and spiritual well-being of dying children and their families.

Aims: To know the emotional state of the children and their parents when the child is in an end of life situation.

Methods: Descriptive cross-sectional study carried out at the Pediatric Palliative Care Unit of the Hospital from May to December 2017.

Data collection
- Visual analogue scale about parents’ and children’s well-being for children, parents and professionals (0 to 10).
- Emotional thermometer for children (0 to 10).
- Emotional distress detection questionnaire (Detección Malestar Emocional- DME) for parents and professionals.

Preliminary results about 79 assessments of the emotional state of children and/or parents. The sample was composed of 16 families selected by non-probabilistic sampling and they participated voluntarily (children, parents and professionals).

Analysis: Multivariate analysis.

Results:
- Higher scores were obtained in the evaluation of the emotional state of children and parents when they were carried out by their parents (Mchildren:7.25, Mparents:7.07) than by children (Mchildren:6.85, Mparents:6.44) and professionals (Mchildren:6.59, Mparents:5.87).
- Children evaluate the presence of happiness in a superior way to the rest of the emotions (M=7.75).
- In 100% of the cases, children point out illness as a preoccupation.
- The most present external signs to assess the emotional state of children by parents are facial expression (87.50%) and decreased of interaction (62.50%). For the professionals, the main one is the alteration of behaviour of the child (90.48%).
- There are no significant differences in the evaluation of the emotional state made by the professionals according to the type of illness of the child, although there are in the presence of external signs of discomfort.

Conclusion:
- Children at the end of life present all the basic emotions, including happiness.
- Professionals are those who evaluate more negatively the emotional state of children and parents.
- There are differences between the external signs of well-being valued by parents and professionals.

170. TRANSITION FROM CHILDHOOD TO ADULTHOOD IN PALLIATIVE CARE: EXPLORING NEEDS AND DEVELOPING PROVISION
Jan Aldridge, Jo Taylor

Background: The limited research available on transition in palliative care has focused particularly on aspects of health and education and has rarely explored wider aspects, such as the impact on social inclusion and psychological well-being, or systematically sought the views of the young people themselves.

The current paper reports on focus group consultations with young people with life-limiting conditions and life-threatening illnesses and the subsequent development of a joint venture between a children and young people’s hospice (Martin House), an adult hospice (St Leonard’s) and a group of young people with palliative care needs in the region (Yorkshire, UK). Conceptually this new, integrated day service draws upon Together for Short Lives broad pentagon of support (housing, work, social care, healthcare and education), and upon social identity theory.

Methods: Qualitative thematic analysis of data collected from 14 young people (aged 12-18) with a life-limiting condition, who took part in focus groups or interviews.

Results: The findings of the focus groups that helped inform the development of a new service for young adults aged 18 to 30 years will be presented, including their reporting of a range of negative feelings related to having a serious health condition but nevertheless the importance to young
people of living well rather than the primary focus being on their deteriorating health and end of life. The subsequent development and piloting of a new collaborative service for young adults will be outlined.

**Discussion and Practice Implications:** The challenges of developing and delivering an innovative new model of care and development with the young people themselves and the adult services, the implications for training in the adult sector and the focus of the evaluation will be shared in the hope of being useful to others.

**127. THROUGH THE INTRODUCTION OF PALLIATIVE CARE, QUALITY OF LIFE HAS IMPROVED, AND THE COURSE OF ILLNESS HAS BEEN POSITIVELY INFLUENCED THUS LEADING TO AN INCREASE IN REFERRALS**

*Tracey Brand, Julia Ambler*

**Background:** Palliative care should be provided from the point of diagnosis and beyond death. However, within the South African context, palliative care is poorly understood. Many practitioners believe it to be synonymous with end of life care or ‘giving up’ and are thus reluctant to refer early to the team. Through our work we have come to realise that this misunderstanding is common and is not specific to any discipline. In addition to this, palliative care is not a recognised speciality in South Africa hence there are limited numbers of health professionals trained in palliative care. As they cannot specialise in the field, there are no government posts. Currently almost all palliative care services are offered by the not-for-profit / non-governmental sectors. (NPO/NGO)

The authors have compiled a retrospective case study analysis of their patient base. They have explored how presenting palliative care cases to health care professionals at academic meetings has led to increased referrals. Referrals are also being made earlier in the course of illness. Health care professionals, when they have seen the benefits of palliative care, are more inclined to recognise the need for a palliative care approach and refer earlier. Through their interactions with the palliative care team, health care professionals have been empowered and are more willing to provide palliative care themselves, accessing the team for telephonic support. Discussing and presenting such case studies with and to health care professionals improves referrals and thus improves access to palliative care.

**DAY1: THURSDAY 31 MAY**

*Concurrent Session 2: Perinatal Palliative Care*

**49. DELAYED PEDIATRIC PALLIATIVE CARE INVOLVEMENT IS PREDICTIVE OF PICU-RELATED DEATH IN A PEDIATRIC ONCOLOGY COHORT**

*Justin Baker, Eric Kaye*

**Background:** In the United States, more children die from cancer than from any other disease, and more than one-third die in the hospital setting. However, attributes predictive of location of death for pediatric palliative oncology (PPO) patients have not been investigated.

**Methods:** Demographic, disease, treatment, and end-of-life variables were collected using a standardized tool for 321 PPO patients treated at a large academic pediatric cancer center who died between 2011 and 2015.

**Results:** Race and enrolment on a phase I protocol were not significantly associated with location of death for PPO patients. Higher odds of dying in the PICU were found in patients with Hispanic ethnicity (OR: 4.02, p=0.002), hematologic malignancy (OR: 7.42, p<0.0001), history of hematopoietic stem cell transplant (OR: 4.52, p<0.0001), total number of PICU hospitalizations (OR:
1.98, p<0.0001), receipt of cancer-directed therapy during the last month of life (OR: 2.96, p=0.002), and palliative care involvement occurring less than 30 days before death (OR: 4.7, p<0.0001). Conversely, lower odds of dying in the intensive care unit were found in patients with hospice involvement (OR: 0.02, p<0.0001) and documentation of advance directives at the time of death (OR: 0.37, p=0.033).

Conclusions: In this unique patient population, delayed palliative care involvement was predictive of dying in the PICU, whereas hospice involvement was predictive of dying outside of the PICU. Pre-emptive identification of vulnerable subgroups may afford opportunities for development and investigation of targetable interventions to enhance delivery of goal-concordant care at the end of life for children with cancer.

11. COMPASSIONATE CLINICAL PRACTICE: SUPPORTING MEN FOLLOWING PERINATAL DEATH
Kerry Jones

Aim: The aim of this paper is to demonstrate through men’s accounts of loss, the importance of appropriate psychosocial support for men. While there is no doubt that compassionate, sensitive care is valuable for bereaved parents and families, practices vary as to what comprises best practice.

Methodology: This investigation into men’s accounts of loss forms part of a larger qualitative study in which 28 men and women participated in interviews and focus groups about their experiences of perinatal death. In drawing on parents’ experiences, a voice centred relational method was employed to analyse data. The method as framed by Brown and Gilligan at Harvard (1993) and later by Mauthner and Doucet (1998).

Results: Guidelines developed in the UK (SANDS, 2017; NICE 2016) recognise that basic care of the family after perinatal loss involves facilitating the grieving process. For men in this research this means listening to and encouraging parental expression of grief; facilitating memorialisation practices. Critically, men wanted their child personified as a human being and to have the enormity of their loss validated.

Discussion: Supporting parents in end-of-life care when a baby is dying, includes clear, compassionate communication, and emotional care and often reduces the potential for conflict (Koopmans et al, 2013). That means avoiding checklists of instructions from bereavement protocols and engaging in clinical practices for some men include the experience of parenting and the creation of memories, which is most valued in the creation of a bond.

63. FAMILY CONFERENCES IN PRENATAL PALLIATIVE CARE: A QUALITATIVE ANALYSIS
Lisandra Bernardes, Glaucia Benute, Fernanda Figueiredo, Nathalia Bertolassi, Tercilia Barbosa, Renata Bolibio, Ana Gomes, Roberta Jesus, Andresa Vilhegas, Luana Rocha, Gladys Rosa, Guta Gibelli, Rossana Francisco
GAI- Group of study in perinatal palliative care
Clinics hospital, University of São Paulo, São Paulo, Brazil

Background: Prenatal diagnosis of fetal malformation impact families and health professionals and follow up in a prenatal palliative care model allow preparation of care and planning of birth together with families. There is a paucity of descriptions of family conferences contents in this model.

Aims: To describe the main themes observed in the documentation of the family conferences in the GAI group follow up.
Methods: Women followed by the GAI group from May 2015 to September 2016 were studied retrospectively. The family conference documentation was evaluated using a qualitative content analysis with an inductive approach.

Results: Fifty patients were included in the study. The median number of conferences during gestation was three (minimum one conference, maximum seven) per pregnant woman. The qualitative content analysis of the family conference records revealed five main themes: Theme 1, Talking about the fetal disease; Theme 2, Understanding the context; Theme 3, Preparation of care; Theme 4, Delivery and the postpartum period; and Theme 5, Feedback about the GAI group and the importance of the family conferences. Main representations of each theme and categories are presented using concrete examples.

Conclusion/Discussion: There is a wide variety of feelings, suffering causes and values expressions reported in family conferences of prenatal palliative care follow up. This panorama may help health professionals to better investigate families in this setting. Based on our results, a model to guide health professionals in the prenatal field is proposed.

115. PERINATAL DEATH AFTER A LETHAL FETAL MALFORMATION DIAGNOSIS: HOW TO CARE FOR THE GRIEVING FAMILIES?
Roberta Jesus, Glauceia Benute, Maria Augusta, Gibelli Nathalia Nascimento, Tercilia Barbosa, Renata Bolibio, Ana Gomes, Fernanda Oliveira, Maria Silvia Setubal, Raquel Ferreira, Rossana Francisco, Lisandra Bernardes

Introduction: The diagnosis of a lethal fetal malformation that precedes perinatal death triggers an intense grieving process.

Objective: To review the literature on perinatal grieving processes and to describe a proposal for an intervention to help bereaved families.

Method: The literature review included searching MedLine, Scielo, American Psychiatry Association and Lilacs databases using the keywords grieve, lethal fetal malformation; neonatal death.

Results: The work with families that received a lethal fetal diagnostic followed by death and their uprising difficult to handle the loss provided the ground for reflecting upon the kind of care that should be offered by the health care team. The literature describes three interventions: support groups, support programs and psychotherapy, offered to all grieving people (primary intervention), to individuals at risk for developing problems (secondary intervention) and to those experiencing complicated grief (tertiary intervention). The terminology used to describe the perinatal grieving process varied from far from expected, far from normal to pathological, complicated and complex. Based on this literature review two strategies are being proposed: a) To create an open support group to allow the emotions and experiences related to the loss to be expressed facilitating grief resolution; and b) a closed group with 12 encounters, discussing specific topics, allowing the participants to reflect upon their individual experiences. Those diagnosed with persistent complex grieving would be offered treatment.

Conclusion: Given the specificity of perinatal loss, the discussion and planning of interventions to help bereaved families are important to prevent complications in the grieving process.

131. REACHING THE WORLD ABOUT PERINATAL PALLIATIVE CARE
Tammara (Tammy), Ruiz Ziegler, Amy Keubelbeck
In the US, half of all pediatric deaths occur in the first year of life, many of those deaths occurring in the first 28 days of life making Perinatal Palliative Care (PPC) an area of great need. The US
currently has two-thirds of the approximately 300 PPC programs in the world. Ziegler and Kuebelbeck come at the topic from different beginnings, Ms Kuebelbeck began as a PPC parent with the powerful life of her son Gabriel chronicled in her book Waiting with Gabriel. Her writing (A Gift of Time, Continuing Your Pregnancy When Your Baby's Life is Expected to be Brief), speaking and maintaining the widely known and used perinatalhospice.org website informs her breadth of knowledge she shares in the many presentations and media appearances she does each year. Ms Ziegler has the experience of being a Pediatric & Neonatal critical care nurse and founder of an early and successful PPC in her region. She has taught internationally on the topic and hosted site visits from Ireland and Japan. Her perinatal hospice video is available in 8 languages and is used all over the world. Her area of passion is the founding of PPC programs in community settings. Their outreach and use of media has allowed them to reach families, caregivers, learning institutions and those hoping to start PPC programs throughout the world.

DAY 1: THURSDAY 31 MAY

Concurrent Session 2: Workshop

36. ACCOMPANYING THE SUFFERING STRANGER. AN AWARE EXPLORATION OF THE EXISTING GENUINE TIE BETWEEN THE HEALTH WORKER AND THE PATIENT

Martín Ignacio Mindeguía

Aims:
- Explore the characteristics of the therapeutic bond (Health worker - Patient) during Palliative Care accompaniment, favoring awareness of those personal resources capable of giving room to an empathetic and supportive accompaniment towards the suffering stranger.
- Awareness of personal limitations or Blind Spots appearing during the accompaniment.
- Provide work tools for the accompaniment of patients in Palliative Care.

Materials: Resources for learning: oral presentation, power point with projected images, and music.

Workshop structure: Each participant carries out a personal and private work regarding the information displayed during the presentation and the associated repercussions. The workshop divides into two parts: an awareness exercise based on conscious breathing between them, and a final exercise of integration.

Here are the issues which will be addressed in each part of the workshop.


Awareness Exercise: Exploration of the following aspects: Emotional – Cognitive – Behavioral.

DAY 2: FRIDAY 1 JUNE
Meet the Expert Session

13. THERAPEUTIC TOUCH: 5 SIMPLE STROKES TO USE EVERYDAY
Marie Wrinn
Touch is an essential sense, often overlooked when a child is ill. A fear can exist that touch may harm the child, or the caregiver may not know how to effectively and appropriately provide soothing touch. We know that lack of touch can lead to poor emotional, physical and mental health. This workshop will provide 5 simple strokes that anyone can perform. Hands-on demonstration and practice will provide the attendees a basic introduction to touch therapy.

134. ADVOCATING FOR CHILDREN’S PALLIATIVE CARE IN AFRICA
Busi Nkosi, Julia Downing, Joan Marston, Sue Boucher, Fatia Kiyange
Goal: Advocating for the development and strengthening of Children’s Palliative Care (CPC) services in Africa.
Approach taken: Advocating for CPC in Africa is a complex and ongoing issue. A variety of approaches have been taken including: a) undertaking a survey of CPC services in Africa. b) creating a database of networks in African countries; c) establishing an advocacy group; d) holding regular meetings about CPC issues; e) developing the advocacy group into the African CPC Network (ACPCN); f) developing terms of reference for the steering committee; g) appointing members of the steering committee; h) drawing up and ongoing implementation of a roadmap.
Results: Key individuals involved in advocacy for CPC were identified in: Malawi; Rwanda; Swaziland; Zimbabwe; Nigeria; Botswana; Uganda; South Africa; Sudan; Mozambique; Kenya; and Tanzania. The needs for CPC have been identified in different countries and the ACPCN are in the process of developing evaluation tools to measure impact. The ACPCN is preparing for a strategic planning workshop and this group has made it easier to disseminate information from the global community to the African region.
Conclusion: There are very few palliative care services for children in Africa and the need is great. According to a study which was carried out by ICPCN in collaboration with UNICEF to determine the palliative care needs of children in three African countries in 2013 it was found that in South Africa, 801,155 children need PC yet provision covers >5% of these; In Kenya, 680,717 children need PC with provision covering <1%; and in Zimbabwe, 312,046 need PC with <5% receiving care. This situation is similar in other African countries especially within sub-Saharan Africa and so we need to continue to advocate for the development of CPC within the region.

DAY 2: FRIDAY 1 JUNE
Concurrent Session 1: Children, Young People & Parents

102. PROFESSIONAL PARENTS AND PERSONIFIED DOCTORS: AN INTERVIEW STUDY ON DECISION MAKING IN PAEDIATRIC PALLIATIVE CARE
Marije Brouwer, Els Maeckelberghe, Agnes van der Heide, Irma Hein, Veerle van de Wetering, Eduard Verhagen
Background: Palliative care for incurably ill children is often complex and may involve difficult medical decisions. We investigated the role of children, their parents and their attending doctors in making decisions about medical care at the end of life.
**Aims:** To gain insight in how and by whom decisions are made concerning palliative and end-of-life care for children aged 1-12 years in the Netherlands.

**Methods:** We performed a nationwide qualitative interview study, in which we included narratives about:
- Children aged 1-12 years who were receiving palliative care and
- Children who had died at the age of 1-12 after a medical trajectory.

We interviewed parents and physicians. The interviews were recorded, transcribed, and coded. Subsequently, the coded interviews were thematically analysed.

**Results:** In the preliminary results, we found that parents often become ‘parent-professionals’ in up-taking their role in palliative care and decision-making for their child. An unexpected outcome is that the role of physicians changes as well: there is a shift from medical-professional deliberations towards more personalized considerations. Physicians described using personal views and life-experiences when making decisions concerning the alleviation of suffering and the improvement of quality of life. This shift may be qualified as ‘personified professionalism’, where including personal experience seems to strengthen the physicians’ professionalism.

**Conclusion/Discussion:** Decisions in palliative care for incurably ill children are informed by personal concepts such as quality of life. This has implications for how parents and physicians position themselves towards each other: they are no longer laypersons versus professionals, but both obtain a unique allotment of knowledge concerning the child, its health status and care needs. There is a transition in their respective roles in the decision-making process: they become professional parents and personified physicians.

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155. YOUNG PEOPLE AS DIRECT STAKEHOLDER ADVOCATES FOR PALLIATIVE CARE

**Kate Jackson, Huyaam Samuels, Lucy Watts, Claire Morris**

**Amis:** To
- investigate barriers, opportunities and power dynamics in relation to people, including young people, affected by serious chronic and life-limiting illness as advocates;
- strengthen the voice of direct stakeholders and increase their impact as advocates to improve access to quality palliative care worldwide;
- improve the power balance and look at who is speaking on behalf of whom to develop a more impactful social justice movement on palliative care;
- share learning widely.

**Design, methods and approach taken:** Research was undertaken through a mixed method approach with data gathered through a rapid literature review, semi-structured interviews with key informants including affected people and professionals and an online survey targeted at palliative care organisations globally. The research was then utilised to co-produce a project and access funds to implement the recommendations.

**Results:** The survey generated 24 responses from 18 countries. 91% (n=29) of the respondents to the survey and the interviewees believed that people affected by life-limiting illnesses were critical to the development of palliative care globally. 100% (n=8) of those interviewed believed that people affected by life-limiting illness did not have an adequate voice in national and international policy making fora.

As a result of the research, funding was accessed to implement a co-produced project involving direct stakeholders and palliative care paid advocacy and communications staff.

**Conclusion:** People, including youth, affected by life-limiting conditions can have significant impact on palliative care development but they are not being fully enabled to participate in advocacy. The barriers to affected people’s participation are numerous and not universally understood but
individuals and organisations could enable greater involvement of people affected by life-limiting conditions. Advocacy projects can be co-designed with direct stakeholders and direct stakeholders want to and can be enabled to demand quality palliative care for all.

138. THE IMPORTANCE OF PARENTS BEING HEARD AND ACKNOWLEDGED IN THEIR CHILD’S HEALTHCARE JOURNEY

Melissa Williams-Platt

Aims and Goals: Acknowledging the parent and family voice in healthcare.

Developing a generation of healthcare practitioners that have a palliative mindset.

Design, methods and Approach

During my late son Samuel’s hospital journey, which in total was 15 1/2 months (his whole life), one thing that stands out emblazoned on my heart is the feeling that for the better part of his life we had no voice. Our opinions were seemingly unimportant, as parents we felt that we were seen and not heard. We were essentially powerless and despite education and resources were simply seen as the funders of our child. Any questions were interpreted as us not trusting the doctors instead of simply questions. How disempowered and desperate less fortunate families must feel when they have the added burden of cultural differences, language barriers, little to no education and are of poor social economic circumstances?

Results: In memory of Samuel, we have created a Trust, Footprints4Sam, to give that voice to parents and to ensure that they are an integral part of the healthcare team. A primary pillar is advocacy including advocacy for the parent, child and palliative care. Advocacy to give parents a say in their child’s care, to have access to palliative care and to be a considered and valued part of the professional healthcare team.

Collaborating with similar organisations e.g. Rare Diseases, PatchSA.

Conclusion: The values, hopes and dreams of the family and of the child need to be the driver behind every medical decision. All interventions need to translate the families wishes into a concrete care plan, for then both the child and family will feel heard and validated and the child’s care will be relevant, considered, inclusive and offer hope to both family and child.

The answer is Palliative Care.

189. EXPERIENCES OF CARE GIVERS OF CHILDREN RECEIVING PALLIATIVE CARE SERVICE AT MZUZU CENTRAL HOSPITAL IN MALAWI

Bertha Chaputula, Ellen Chirwa

Background: The number of children requiring palliative care service is increasing every year. In response to this growing number family involvement in care giving has expanded. Care givers play a major role in caring for children with life limiting /threatening conditions at home as well as in hospital. However, these caregivers have their own challenges in care giving and responses to patients’ diagnosis and prognosis

They may require support for them to maintain their well-being and their role as a care giver.

Despite what care givers go through in Malawi the researcher did not find any study conducted to explore the experiences of children with life limiting or life-threatening illnesses.

Design: A descriptive qualitative research method was used

Data collection method: Data was collected from 30 care givers using semi structured interview guide for in depth interviews and a tape recorder. Analysis was done using thematic content analysis.
Findings: Findings revealed that care givers play a major role in caring for their children receiving palliative care. Care givers of children receiving palliative care reported facing financial, physical, social, psychological and health service challenges
Conclusion: Proper assessment and availability of adequate support would positively influence the care givers' experiences and the child's quality of life, hence there is need to develop practical interventions that will lessen the care givers' challenges.

121. PROFESSIONAL AND PSYCHOLOGICAL CHALLENGES OF PERINATAL BEREAVEMENT IN HUNGARY
Eva Zsak
Introduction: Losing a child in the perinatal period is a highly demanding event for both families and health care providers as well. While in 2015 the statistical number of perinatal death is relatively low (0.65%), the total number of babies lost in perinatal mortality was 553, yet, the burden it conveys is all the bigger. At the moment no standardised perinatal bereavement care is provided on an organized level in Hungary, yet, there are attempts to implement it.
Objectives: (1) Present the current health care system with the services provided for the families facing child loss. (2) Highlight the main challenges of introducing perinatal bereavement care.
Methods: Study of the presently applied protocol and practices in neonatology departments (7 PICs at 4 university clinics, already visited 5 of them, interviewed 36 health care specialists (5 department heads, 12 doctors, 7 mid-wives, 10 nurses, 2 psychologists) concerning infant death and support for the bereaved families. Results: The comparison of the valid protocol and the actual practices and needs these events convey in the already visited 5 departments reveals the lack of proper knowledge of the protocol in 4 institutions and its scarce application in 1. The professional and personal requirements of bereavement care those working in neonatology may face shows that while there is a growing need for this care, and specific trainings are also necessary in the formation processes.
Conclusions: For proper perinatal bereavement care in Hungarian institutions a shift of attitude and skills development are needed in the competency fields of the clinicians as much as the established cooperation of a multidisciplinary group. It requires new protocols, competency trainings, supportive and psychological measures.

DAY 2: FRIDAY 1 JUNE
Concurrent Session 1: Service Delivery

175. USE OF DIFFERENT SERVICES IN A COMPLEX PAEDIATRIC PALLIATIVE CARE UNIT
Delia Birtar
Background: Our unit provides complex palliative care to children with malignant and non-malignant disease. Our services include home care, in-patient unit, day care, out-patient clinic and rehabilitation department.
Aims: To evaluate the use of different services for the last 3.5 years in order to further develop the services according to the needs.
Methods: Retrospective study, with data collection from our data-base and electronic files -January 2014 and June 2017. To analyse the data, we used descriptive statistics.
Results: In this period, we cared for 251 patients. From them 48 died, representing 19.16 %. 111 patients (44.22%) benefit admissions in the in-patient unit, summing 934 admissions. The main reason for admission was symptom control -47%, followed by respite care -41%.
The majority of children had 1-5 admissions (44%), followed by 23% who had 6-10 admissions, and 13% between 11-15 admissions.

According to diagnosis: 45% had cerebral palsy, 8% cancer, 8% spina bifida, 7% heart diseases, 5% SMA, 5% DMD, 4% Cystic Fibrosis, 18% other diseases.

The distribution according to age showed that majority of children (44%) had 5-14 years. 37% from our patients benefited from home visits for symptom control, education regarding the care, psycho-social support, assistance for obtaining the legal benefits and necessary supplies. 23% patients benefited the Day Centre to integrate in a peer group and develop their abilities through play, music, art therapy, occupational therapy, counselling. A new addition is the room of Virtual Reality.

The rehabilitation service which aims to prevent the complications of the diseases and to maintain the mobility of our patients was requested intensely and was used by 56.10% of our beneficiaries. Conclusion: All the services were intensely used, the main reason for admission being symptom control for neurological patients. The service which needs to develop is rehabilitation service.

162. A LOVING LINK: BETWEEN A CHILDREN’S HOSPICE AND INMATES OF TWO PRISONS

Joan Marston, TsegoFatoso Taunyane

Aims and Goals of the work: A children’s hospice in South Africa and inmates of both a men’s maximum-security prison there and a women’s prison in Columbus, Ohio may seem to have nothing in common. Sunflower Children’s Hospice (SCH) has shown that vulnerable populations can link effectively and in different ways. Training community caregivers as part of the rehabilitation of long-term offenders in a maximum-security prison in South Africa; and enjoying a wonderful musical link via skype with the women in a drug and alcohol rehabilitation programme in Ohio (The Tapestry Project) benefits the children and the inmates.

Design, Methods and Approach: SCH developed a community caregiver training course, trained a nurse tutor who then trained over 1000 inmates, supported by staff of SCH. Some now work as caregivers and one opened his own organization. The Tapestry Project at Ohio Reformatory for Women (ORW) includes a weekly choir practice. As their community outreach the women sing via skype for the children. The women knit and crochet gifts for the children and have a sunflower wall in the Tapestry room. The project has strong support from the prison authorities.

Results: The inmates of the men’s prison now have personal and marketable skills on release. For some it is their first ever qualification. The women of ORW often relate to the children as they are separated from their own. They enjoy making items for their SCH children. Children are kept warm by the garments made with love by the women. For the children it is a time of enjoyment and interaction.

Conclusion: Members of vulnerable populations may be open to connections that would otherwise not be considered. Both groups benefit.

53. THE PAEDIATRIC PALLIATIVE CARE EMERGENCY: UNDERSTANDING THE INTERFACE BETWEEN PARENTS AND AMBULANCE SERVICES

Dr Christine Mott, Dr Anthony Herbert, Karel Malcolm, Prof Meera Agar

Background: Paediatric palliative care services (PPCS) care for many patients based in the community who are medically unstable and rapidly changing, and at risk of requiring ambulance services.
Aims: To explore the interface between PPCS patients and ambulance officers from the ambulance officers’ perspective, with a goal of developing strategies to support and educate ambulance officers managing these children.

Methods: The 50 most recent PPCS referrals were identified. In collaboration with the Queensland Ambulance Service (QAS), officers involved in their care were identified and sent an online survey exploring their experiences and opinions.

Results: 22 responses were received. Although the proportion of ambulance officers with exposure to PPCS patients was low (1.3%), the percentage of PPCS patients exposed to ambulance officers was high (68%). QAS attendance was indicated for management of escalation of previous symptoms most frequently (50%). Fifty-five percent of participants felt these cases were challenging enough to require debriefing supports, although only one recalled being offered it. In many cases a Paediatric Acute Resuscitation Plan was not identified, and the majority of these did not set limitations on resuscitative measures. QAS officers were most likely (55%) to use paperwork provided by the family from their usual team as a guide for resuscitation decisions. There was a divided opinion on whether all PPCS patients should have a not for resuscitation order. Respondents selected ways in which they felt they could feel more supported, the most popular options were increased documentation and promotion of existing supports, as 95% of respondents were not aware of the state-wide 24-hour paediatric palliative care contact numbers.

Conclusion: These findings suggest practical and achievable ways in which PPCS can better support ambulance officers in managing patients linked to a paediatric palliative care service. Examples of such support could include improved documentation, clinical guidelines and education.

136. FROM ONCOLOGY TO NON-ONCOLOGY PALLIATIVE CARE SERVICE IN HONG KONG CHILDREN
Chi-kong Li, Wing-Chee Shirley WAI, Chi-hang Assunta HO, Suk-wai Cheung, Kwok-yin Molin LIN

Background: Paediatric Palliative Care (PPC) service to oncology (ONC) children was started in Hong Kong since 1999, and PPC service was extended to non-oncology children (N-O) from 2011 under the same care team.

Aim: To compare the patients’ characteristics and service pattern of N-O and ONC patients receiving PPC in a tertiary hospital.

Methods: From 2011, N-O and ONC patients received PPC service were compared. Patient characteristics and service utilisation were collected: age, sex, diagnosis, ICU care, duration of PPC care and death.

Results: From 2011 to 2017, 159 children were served by PPC team, 34 N-O patients (21.4%) and 125 ONC patients (78.6%), male to female was 95 to 64. The underlying conditions were (1) leukaemia (n=47, 29.6%), (2) brain tumour (n=30, 18.9%), (3) solid tumours (n=48, 30.2%), (4) Inborn error of metabolism (IEM) (n=9, 5.7%), (5) neurological and muscular diseases (n=17, 10.7%), (6) organ failure (n=5, 3.1%), (7) other conditions (n=3, 1.9%). Mean age at time of referral to PPC was 10.5+6.9 years and 6.6+6.0 years for ONC and N-O patients respectively (p=0.004). Two ONC (1.6%) and 14 N-O patients (41%) were referred by ICU team. Follow-up duration was 257 days, significantly longer in N-O patients, 455D versus 203D (p<0.001). 101 patients died and more happened in ONC patients (69.6% vs 41.2%, p=0.004), time from referral to death tended to be longer in ONC (286D vs 120D, p=0.08). There was no difference in the mortality whether the patients were referred by ICU team.

Discussion and conclusion: ONC constituted majority of patients under care of PPC team. Low referral rate from paediatricians and lower acceptance towards PPC by parents of N-O patients are the main hurdles. Education to health workers and public on PPC should be enhanced, hoping that more N-O patients can receive PPC service.
181. INTEGRATING PAEDIATRIC PALLIATIVE CARE INTO A PUBLIC HEALTH STRUCTURE: WHAT DO WE NEED IN ORDER TO PROVIDE PAEDIATRIC PALLIATIVE CARE AT AN INTERMEDIATE CARE FACILITY?

Alex Daniels

Background: Children living with long term health conditions and their families need care and support to get them through challenging times when the burden of care may increase eg: managing distressing symptoms or during the terminal phase. The integration of a new children’s palliative care approach at Sarah Fox Convalescent Children’s Hospital in Cape Town created an opportunity for families to access appropriate 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 palliative care needs.

Methodology: A mixed method longitudinal prospective study was conducted over a six month period. Data was retrieved from case report forms, questionnaires and focus groups discussions.

Results: Of the 25 patients reviewed toddlers n=9 were the largest group, followed by infants and pre-schoolers both (n=5). HIV was the most prevalent diagnosis (n=9) followed by Cerebral Palsy (n=7). Most prevalent symptoms managed were pain (n=11), secretions (n=9) and seizures (n=7). In terms of caregiver experience; 23 were very worried about their child and 24 received meaning from the experience of caring for their child. Health care professionals valued access to information, training, supervision, mentoring, debriefing and working together in a strong team.

Discussion: Whilst health policy may set the tone for integrating a service of this nature, effective care and support for children and families with long term health conditions at intermediate care level is multidimensional and can only succeed if supported by a committed trained team, adequate resources and buy in from management and health authorities.

DAY 2: FRIDAY 1 JUNE
Concurrent Session 2: Communication

40. A MIXED METHOD SYSTEMATIC REVIEW OF THE EXPERIENCE OF COMMUNICATION IN THE CARE OF CHILDREN WITH PALLIATIVE CARE NEEDS

Maha Atout, Jane Seymour, Pippa Hemingway

Background: A mixed method systematic review was undertaken in order to explore issues related to the experiences of health care providers and parents in the care of children with palliative care needs. Aim: The aims of this systematic review were to identify existing evidence about the experiences of communication in the care of children with palliative care needs.

Method: A mixed method systematic review of research on the experience of communication in the care of children with palliative care needs, conducted with parents and health professionals was undertaken. The electronic databases of CINAHL, Cochrane, PubMed, OVID, Social Care Online, Web of Science, Scopus, and ProQuest were searched for the period of 2000-2016. Inclusion was limited to studies of communication experience in the care of children with palliative care needs. Result: Thirty-eight studies were found. The studies were conducted in a variety of countries: Uganda, Jordan, USA, UK, Taiwan, Turkey, Ireland, Poland, Brazil, Australia, Switzerland, Sweden, Netherland, Lebanon, Spain, Greece, and China. The current review shows that parents tend to protect their children when they are discussing their illnesses with them, particularly where they
have a life-threatening or life-limiting condition. The approach of parents towards the discussion of sensitive issues concerning death with their children is significantly affected by the cultural background of the families. Conservative cultures encourage collusion behaviours which tend to keep children unaware of the incurable nature of the disease. The major communication challenges reported by health professionals are facing difficulties in judging how much information should be given to parents, responding to difficult questions, conflicts with families and inadequate skills to support grieving families.

Conclusion: Continuous education for professionals, which provides staff with specialised communication skills and emotional support for children and parents, is crucial. Further studies are required to investigate the experience of communication of parents of children with non-malignant life-threatening and life-limiting illnesses.

9. PLAY OF CHILDREN WITH LIFE-THREATENING/LIMITING CONDITIONS: A SCOPING REVIEW
Zainab Jasem, Jani Grisbrooke, Anne-Sophie Darlington, Danielle Lambrick, Duncan Randall.

Background: Play is essential to children and provides opportunities to promote their health and wellbeing. Children living with life-threatening/limiting conditions experience disruption/deprivation in their play, which can result in negative consequences on health. Regardless of the child’s condition, it is their right to live and act as children. As prognosis is uncertain, some of the children will need the (pre)learning skills developed by play in childhood to provide a basis for their adulthood skills.

Aim: A scoping review of the factors influencing children with life-threatening/limiting conditions participation in play as part of their everyday life.

Method: A search of literature published between 1990–2017 was conducted in relation to the play of children with life-threatening/limiting conditions and the factors influencing their play. Relevant health, social care and built environment electronic data bases were searched (e.g. EMBASE, CINAHL, Medline, PsycINFO) using defined criteria, in addition a manual search of relevant journals and the end list of selected papers. Aveyard (2014) guidance was followed in reviewing the literature and CASP tool was used to review the quality of the papers. The analysis was reviewed by the research team and another external reviewer.

Results: Thirteen papers which met the inclusion criteria were reviewed. Findings demonstrate that children’s play is influenced by the health condition itself as well as by the play opportunities, including the limited available appropriate play equipment and the need for more play spaces that are easily accessible allowing play and social interaction.

Conclusion: There is a need to maximise the available appropriate play opportunities by considering the environmental enablers and barriers for children living with life-threatening/limiting conditions.

22. COMMUNICATION WITH CHILDREN USING STEPPING STONES WITH CHILDREN APPROACH
Nelson Chiziza, Martha Kamuhabwa, Dorothy Mandwa.

Introduction: Available evidence shows that there is poor communication between children aged 5-14 years living with HIV, their parents and caregivers. In order to identify communication barriers and mitigation measures, PASADA and Salamander Trust UK developed and tested the Stepping Stones with Children manual in Tanzania to children affected by HIV and their caregivers. The aim was to create a transformative process to convey information, enable participants to explore norms, discover their abilities and create stronger ways of coping with the disease.
**Method:** Training of children and caregivers was conducted at PASADA in year 2016 using combination of methods such as lectures, drama, role play group discussion and presentations. A checklist of leading questions was prepared and used to explore the holistic needs of these children. Children were asked leading questions and requested to answer in the form of drawing, writing, storytelling and drama. After training follow-ups were made to clinics to identify progress for children attendance and adherence to medication.

**Results:** During discussion children expressed their inner feelings and opinions freely to their care givers and facilitators, this created easy disclosure process between children and their care givers. During follow-up it was observed that clinic attendance, adherence to treatment and school performance had improved. Available data at the clinics showed suppression of Viral Load among trained children. Overall this training created strong support between parents, caregivers, children and peers.

**Conclusion:** The result of this training shows the possibility to effectively communicate with children as young as 5 years of age who are living with HIV and AIDS using the Stepping Stones with Children Approach. This approach improved attendance to clinics, adherence to medication as well as performance in schools.

68. THE USE OF CYBERSPACE BY ADOLESCENTS IN PALLIATIVE CARE- AN ETHNOGRAPHIC APPROACH

*Camila Amaral Borghi, Regina Szylit*

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

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

**Methods:** This is a qualitative study that used the combination of two ethnography's methods in two different environments – the virtual and the real one. In a period of six months, ten adolescents in palliative care were observed and interviewed in an outpatient clinic. In the virtual environment, their social network profiles were observed since the begging of use. We have collected 8861 posts. All the posts with the ten interviews were decoded for the Symbolic Interactionism analysis.

**Results:** It was possible to identify that adolescents in Palliative care use the cyberspace in their routine and we found three themes that explain this study: Being an important space for me; Using the cyberspace for being a normal adolescent and My disease in the cyberspace.

**Conclusion:** The social networks are an important tool to promote care for adolescents with life limiting disease, because the social network encourages them to communicate with their friends and family, besides being a space where the adolescents can share their experiences and learn with others. The health care professionals need to work with adolescents and families who are in Palliative Care using those tools to interact with them and promote more care and support.
140. #CPC BY WHATSAPP?
Julia Ambler, Tracey Brand (South Africa)
Working in a small team to provide paediatric palliative care services across enormous geographical areas is logistically very difficult. The advent of a free internet service such as WhatsApp has revolutionised the way in which we connect and communicate with our patients. However, there are inherent problems which need to be considered.

**Approach Taken:** The authors conducted a retrospective analysis of patient/parent communications evaluating the use of WhatsApp as a communication tool.

**Conclusion/Lessons learned:**
1) Parents are very willing and eager to use WhatsApp to communicate with the palliative care team for non-emergency situations
2) The tool provides a permanent record of all conversations
3) It is not appropriate for emergencies
4) Communication is interrupted when parents do not have airtime or signal
5) There are medicolegal implications to storing patient details on a hand-held device

DAY 2: FRIDAY 1 JUNE
Concurrent Session 2: **Workshop**

COMMUNICATION FOR MAXIMUM IMPACT AROUND CHILDREN’S PALLIATIVE CARE
Sue Hill (Australia), Sue Boucher (ICPCN), Lorna Sithole (ICPCN)

**Workshop objectives:**
a) The use of available communication tools to advocate for children’s palliative care to health professionals, the general public and parents of children with palliative care needs.
b) The use of available communication tools to deliver a message that will translate into funds for an organisation.

**Workshop content:** Workshop participants will be given insights into the latest innovations and ‘tricks of the trade’ to increase their online and public visibility and to enhance their visibility using a variety of social media platforms. Sue Hill, film producer from Moonshine Agency, will compare different film formats and ways of presentation of the same, looking at the advantages and possible drawbacks of each and an overview will be provided of the effective use of different print and online media communications. Using a case study, participants will brainstorm the best way to achieve the above stated objectives using tools of communication available to them and will leave the workshop with 3 clear key messages around creating the greatest impact possible through the use of accessible resources.

DAY 2: FRIDAY 1 JUNE
Concurrent Session 2: **Service Delivery**

187. EVOLVING CHILDREN’S PALLIATIVE CARE TRAINING ONLINE: REVIEWING THE ICPCN E-LEARNING PLATFORM
Alex Daniels, Julia Downing (ICPCN)

**Background:** Education is integral to the development of children’s palliative care (CPC) globally. Following a needs assessment, ICPCN developed an e-learning programme to ensure education was available, affordable and appropriate for the setting. A successful pilot programme ran from
October 2011 – March 2012. Currently there are seven courses available and they are available in English, Portuguese, French, Spanish, Mandarin, Russian, Serbian, Czech and Dutch.

**Aim:** To demonstrate the range and global reach of CPC courses available through the ICPCN elearning platform.

**Method:** The review utilised 3 data sources: 1) Data from the virtual learning environment (VLE), including 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:** Analysis is ongoing. Over 2,000 participants have accessed the elearning from 100+ countries. The highest proportion coming from sub-Saharan Africa and Europe. Around 75% of participants access the courses but do not undertake the assignments, but work through much of the information provided. 82% of survey respondents said the courses were clear and understandable and rated them highly, 80% found them useful. 75% reported improved knowledge, skills and change in attitude, whilst 61% reported change in clinical practice.

**Discussion:** The ICPCN E-learning platform is an innovative way of improving knowledge and understanding of CPC, increasing accessibility and availability to information on CPC. Whilst not all participants undertake the assessments, they are accessing the course information thus meeting ICPCN’s aim of making information accessible and available. The review will help ICPCN know how to improve courses, access and experience for participants. Understanding of the challenges will help clarify how these can be overcome. Updates on new course material as well as additional languages are planned and new courses are being identified and developed.

**169. ENVISIONING A SUSTAINED NOVEL MODEL FOR EFFECTIVE DELIVERY OF PEDIATRIC PALLIATIVE CARE IN RESOURCES LIMITED SETTINGS: CASE STUDY OF UNIVERSITY TEACHING HOSPITAL OF KIGALI, RWANDA**

*Prosper Karame, Diane Mukasahaha, Clarisse Musanabaganwa, Aimable Kanyamuhanga*

**Background:** Medical advances have enabled access to quality services for patients with Non-Communicable Diseases (NCDs) and palliative care needs, largely influencing the improvement of health outcomes for palliative cases especially children with life-threatening illness. However, palliative care services are often disconnected from other treatments while their integration into the broader healthcare ecosystem could provide quality and comprehensive care [1]. Rwanda, like some other African countries has adopted care models through which non-physician health workers provide pain relief services to patients nearing the end of life [2,3]. In this context, the Home-Based Care Practitioners Program (HBCP) in Rwanda has been adopted, emphasizing on redistributing palliative care services, follow-up services for stable patients with NCDs, facilitating linkages to higher levels of care if patients experience worsening symptoms, community-based NCDs educational activities and performance of verbal autopsies. Despite this promising undertaking, it is particularly disturbing however that planning for children’s palliative care remains a worldwide critically under-researched aspect mainly with regard to children and parents’ engagement in palliative care resources planning, choosing and deciding care preferences and corresponding delivery modality [4].

**Aims:** Develop a Rwanda tailored Home (family) Based Pediatric Palliative Care Model (HBPPC)

**Methods:** This study builds from the HBCP’s lessons learnt and appraises potential barriers of and facilitators to successful implementation of community-based palliative care to generate evidence-based recommendations building the HBPPC model.
Results: Insights into developing a Rwandan model to delivery palliative care and home-health programs into a single package of services within the Maternal, Child and Community Health approach and sharing the lessons learnt.

Conclusion/lessons learnt: Delivering evidence-based information on mitigating challenges of caring for children with palliative care in the community who may require different resources and entail different challenges, thus enabling delivery of pediatric disease-directed treatment or life-extending treatments until the very latest phases of life.

44. INTEGRATION OF PAEDIATRIC PALLIATIVE CARE SERVICES AT THE M.P SHAH HOSPITAL; A PILOT PROJECT
Dr. Esther Nafula, Dr. Shamsa Ahmed (Kenya)

Background: Access to comprehensive palliative services is limited in Kenya, with only a single center offering dedicated Paediatric palliative care. An assessment at the M.P Shah Hospital (Private referral facility) in Nairobi revealed an average of 4 children monthly admitted with diagnoses of life limiting illnesses requiring dedicated services that are currently unavailable.

Objective: To integrate Paediatric palliative care services at the M.P Shah Hospital.

Methodology: The project has started off with a cross sectional descriptive study over a two-week period to assess the knowledge of healthcare professionals in the Paediatric department. After getting ethical approval from the hospital committee, all permanent staff were invited to participate. Data was collected using a validated tool; the Palliative Care Quiz for Nurses. Good knowledge was defined as >75% score. Part two of the project is training health care providers on paediatric palliative care and the final phase is offering the services which will include formal clinic days and ward reviews with a proper referral system.

Results: Out of 50 staff, 30 met the inclusion criteria; 4 declined consent and 5 did not return completed questionnaires thus 21 anonymously self-administered questionnaires were analyzed. 71.5%(15) of the participants were nurses; 19.04%(4) were consultant pediatricians and 9.5%(2) senior registrars. 52.3%(11) had postgraduate qualification in either paediatrics or critical care. 85.71%(18) had no previous experience with hospice or palliative care and 90.47%(19) had no previous training in palliative care.

All of the participants had poor knowledge on palliative care scoring <75%. 16.9%(14) Scored >50% while 33.3%(7) <50%. Respondents scored higher on questions related to pain and symptom management.

Conclusion: There was overall poor knowledge in palliative care attributed to lack of formal training, which is to be addressed in the next phase of our project through targeted short course trainings.

CHOC PSYCHOLOGICAL SERVICES – EMBRACING PAEDIATRIC PALLIATIVE CARE
Alta Bence (South Africa)

Background: CHOC Childhood Cancer Foundation S A (CHOC) was established in 1979 by a group of parents with the aim of supporting children diagnosed with cancer or life-threatening blood disorders and their families. Through public-private partnership relationships, CHOC currently has a psychosocial team of seven social workers/counsellors and two social auxiliary workers serving nine paediatric oncology units throughout the country.

Aim: The diagnosis of a life-threatening illness in a child is devastating with far-reaching psychosocial and emotional implications not just for the child, but also for the family system as a whole. The aim of the CHOC Psychosocial Programme is to provide holistic psychosocial services to
these children and their families while undergoing treatment in Paediatric Oncology Units (POU’s) in South Africa. The social worker/counsellor’s role encompasses paediatric palliative care in the context of alleviating pain and suffering from the time of diagnosis and supporting the child and family through the arduous journey until the end of treatment or preparing them for, and supporting them through, the death of their child and providing bereavement support thereafter.

**Method:** The child and family’s psychosocial palliative care needs are addressed through the following key aspects of the social worker/counsellor’s role: Counselling at the time that the bad news of the diagnosis is broken; breaking down medical jargon and explaining the diagnosis and procedures in the family’s own language; psychosocial assessments through which a bigger picture of the family’s functioning is gained and identifying possible problems further down the line. The patient and family is also prepared for medical treatment procedures and this alleviates the fear and anxiety and impacts positively on compliance and cooperation with the treatment process. In the cases where no more curative treatment can be offered, the focus of palliative care moves to end-of-life care and support to ensure quality of life, dignity in the dying process and bereavement support thereafter. This aspect of the social worker/counsellor’s role builds on the foundations set by Lynda Schutte, long term serving volunteer of CHOC.

**Results:** The path the CHOC psychosocial team walks with the family enables and empowers them to access internal and external resources with which to come to terms with, take ownership of, and walk their journey with courage and resilience.

**Conclusion:** While significant work has been done to make paediatric palliative care more accessible for all children in South Africa, there is still a long road to go to integrate it into the South African health system. This however does not detract from the work the NPO sector, including CHOC is doing to render paediatric palliative care services.

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**64. CHILDREN’S PALLIATIVE CARE: PILOT PROJECT ON A NEW CONCEPT IN LESOTHO**

*Mabatho Thatho, Phaaroe Sejojo, Dr Letsie Mosilinyane et.al*

**Aims**

1. To raise awareness of the need for palliative care in Lesotho
2. To build capacity through education and training for provision of children’s palliative care (CPC)
3. To monitor and evaluate the children’s palliative care programme in Lesotho

**Method:** The Ministry of Health in partnership with the International Children’s Palliative Care Network engaged in CPC pilot project from November 2016. A cross sectional design with focus on building CPC capacity of service providers at the regional levels of health care delivery system used. Three CPC awareness campaigns held at each of the three regions. Each region tasked to nominate 10 participants for the CPC training at the end of each campaign. 30 participants formed the first team of participants trained on CPC. Planned number of activities to address the three stated objectives were successfully implemented from November 2016 to October 2017.

**Results:**

- Awareness campaigns held
- Training of multidisciplinary team members conducted
- Development of IEC material done
- Participants send for clinical attachment in Bloemfontein
- Training of CPC trainers conducted
- CPC guidelines and curriculum developed
- Developed CPC scale up plan
- Developed CPC training plan for staff working in paediatric settings
• Follow up meeting of participants at the regional level by facilitators
• Launched CPC pilot project
• Data clerks and supervisors training

Conclusions:
• Nominations for CPC training must be guided by a standardised criterion for selection
• CPC clinical placement is an essential phase for acquisition of clinical CPC skills.
• CPC clinical placement sets a platform for the recipient to make decisions and choose appropriate CPC model for Lesotho
• Open communication with 2-way feedback mechanism is vital for achievement of set objectives

DAY 3: SATURDAY 2 JUNE
Meet the Expert Session: Building design in children’s palliative care

192. ARCHITECTURAL INNOVATION FOR PAEDIATRIC HEALTH DESIGN IN RESOURCE CONSTRAINED COUNTRIES
Edwina Fleming
Aims of the work: The importance of the building envelope and interiors within are so often ignored when considering health service provision. The aim therefore is to illustrate the importance of the built environment as part of a comprehensive health service package, especially when treating or caring for children and that, even in resource constrained countries, this factor remains important requiring innovative solutions to be effective.

Design, methods and approach taken: In the course of my work as an architect specializing in health planning and design, I am often forced to find innovative ways of making an existing building conform to provide the best health service possible within the constraints of poor available space provision and low budget allocation. This is particularly true of the public hospitals where resources are very low, skilled staff underprovided and facilities are in a bad condition. To begin any project of this nature, it is important to apply principles of good design which are informed by both experience in the field and research inclusive of lean design and salutogenic design principles. The approach therefore will be to illustrate these simple, yet crucial, steps that should be followed and implemented in any design, in this case, relative to designing spaces for the health care of children. The challenge is to respond, incorporating these principles, innovatively making the best of what is available.

Results: The result should be a facility that responds to the healthcare needs of the child in a built environment that is conducive to healing - body and soul.

Conclusion: An innovative response, applying clear principles of good health design and planning of the built environment, can only benefit the process of caring for the health of a child.

93. ROLE OF ARCHITECTURAL DESIGN IN IMPROVING QUALITY OF LIFE OF CHILDREN
Amruta Talawadekar
Aim: To design a hospice where fusion between place, physical surroundings, and users’ needs are created in an integrated design solution. An architecture ensuring the user’s well-being and contributing to the relieving process with the aim to increase the patients’ quality of life and make them able to enjoy the terminal stage of life. A hospice and palliative care centre is needed which architecturally improves the quality of life of patients who are ill.

Approach taken:
• To analyse the factors that affect human and human health and their influences which improve the quality of life.
• To establish the need for an architectural design in healthcare environment with emphasis on terminal stage of the disease.
• To study the model centres (case studies).
• To plan and design a centre where holistic care is given to children and their care giver.

Result: Need based design of the hospice and palliative care will help in improvement of quality of life of patients and caregivers. Needs of patients varies according to the diseases. Planning and designing a centre keeping in mind the age segregation and disease symptoms will create a useful and effective place for patients.

Conclusion: An architecture with the intervention of providing a ray of hope and emotional distress is required to improve the quality of life of children. The environment needs to be therapeutic and needs to promote wellbeing of patients and staff. Gardens, raised flower beds, a water body, importance of natural light, needs to be emphasised. Innovative architectural design of a Hospice and Palliative Care centre will be able to motivate the government bodies and the stakeholders to provide funding and other aid to construct many more such centres, which is the need of the society

DAY 3: SATURDAY 2 JUNE
Concurrent Session 1: Networks and History

150. REMEMBER THE SPRING
Joan Marston, Julia Downing

Aim: Children's Palliative care has a very recent history and most of the early pioneers are still alive and willing to share their personal journeys. This part of a larger history project aims to identify the early pioneers; discover their motivations for developing their particular model of children's palliative care (CPC), look at their impact on development, identify social events that stimulated the development of the field and others whose work influenced the pioneers and led to the present development of palliative care for children globally.

Designs, Methods and Approaches: Identifying the Pioneers was done through semi-structured interviews with present CPC leaders both globally and in the UK, Europe and the US, and an extensive literature review. A questionnaire was distributed to present identified leaders that included the question, “Who do you consider to be the pioneers?” Pioneers were interviewed either personally or via Skype sing a semi-structured interview format. Interviews were recorded with permission, transcribed and confirmed by the pioneers. They were asked to identify other pioneers who, if alive, were also interviewed. For those who have died, interviews were carried out with those who knew them well and/or family members. From the interviews, important influencers who did not work in CPC but affected the field, e.g. Elisabeth Kubler-Ross, were identified. The study also looked at their work. An international advisory group was set up to review the history.

Results: A fascinating picture developed of the early history of CPC and the great visionary women and men whose ideas affect our work today. Their work deserves to be recognised. Common themes and influencers were identified. A website, and texts are to be developed by May 2018 to share this history.
Conclusion: We build on the work of others and our work inspires others. The history of CPC should be better understood. The influence of the early pioneers and those who influenced them can help us to understand and grow CPC.

2. ICPCN - MAKING A DIFFERENCE IN A CULTURALLY DIVERSE WORLD
Sue Boucher, Julia Downing, Busi Nkosi, Alex Daniels, Lorna Sithole, Barbara Steel
While a child is a child, wherever they are in the world, every country and every culture will identify a different hierarchy of needs when it comes to providing palliative care for its children. The International Children’s Palliative Care Network (ICPCN) began in 2005 with a mission to achieve the best quality of life and care for children and young people with life-limiting conditions, their families and carers worldwide, by raising awareness of children’s palliative care, lobbying for the global development of children’s palliative care services, and sharing expertise, skills and knowledge. And a vision to live in a world where children’s palliative care is acknowledged and respected as a unique service, and every child and young person with life-limiting or life-threatening conditions and their families can receive the best quality of life and care regardless of which country they live in. This presentation will look at the impact ICPCN has had on children’s palliative care globally and how far the network has come in realising our vision and mission. It will highlight successes and projects from the past 12 years as well as future plans for the network. Topics covered will include information on plans for a global mapping of children’s palliative care, successes of our regional and international advocacy work, the depth and extent of our education and training programmes, the value of membership and a call for support for our 3rd International Conference to take place in May of 2018.

124. DEVELOPING A EUROPEAN CHILDREN’S PALLIATIVE CARE TASKFORCE THROUGH THE EAPC
Julie Ling, Julia Downing, Finella Craig, Lizzie Chambers
The European Association for Palliative Care (EAPC) is a European membership organisation with 55-member associations from 34 European countries and individual members from 52 countries globally.
A group of professionals working in Children’s palliative care established a taskforce with the following aims & objectives:
1. To bring together the wide range of professionals working to develop children’s palliative care in European countries and provide opportunities for sharing of information, research, education and advocacy.
2. To support the development and dissemination of the evidence base in children’s palliative care through identification of specific work streams leading to published guidelines and standards.
3. To provide educational opportunities for those working in children’s palliative care through the development of paediatric sessions at EAPC events.
4. To support the development of palliative care for children and young people across Europe, through advocacy and awareness-raising, signposting organisations to the support offered by the International Children’s Palliative Care Network, the guidelines and standards developed by the Paediatric Taskforce and other useful resources.
This presentation will focus on the work of the taskforce and the progress that has been made over the last two years.
182. A MULTI-ORGANIZATIONAL APPROACH TO PAEDIATRIC ONCOLOGY CHILDREN AND FAMILIES THROUGH THE CHILDHOOD CANCER NETWORK IN KZN

Cara Noble, Julia Ambler, Tracey Brand

Aims or goals of the work:

• To assist cancer patients and their families more holistically
• To ensure that organizations work in their focus areas and minimize the duplication of services
• To create an active and healthy referral system where more than one organization is servicing a child and family
• To create open lines of communication and working on cases jointly to ensure the best outcome for the child
• New thinking around sharing cases and becoming open-minded to working with other organizations, instead of working against them
• To encourage mutual respect towards the skills and knowledge of other’s and benefitting the greater team by sharing information and skills transfer through training and meetings

Design, methods and approach taken:

• A committee was born and represented by 8 local organizations
• Numerous meetings were had to decide on the purpose of the committee
• An info session was held for all organizations to learn more about one another and their role and mandate in the community
• A summary was made of the services provided by all and the channels that need to be followed to access the support

Results:

• Communication lines opened, and the referrals and mutual support started
• Patients started receiving a well-rounded and better service that was not possible by only working with one organization
• Relationships between organization’s improved and strengthened
• Donations received were passed on to other organization’s that needed them, and a sense of community was born

Conclusion/Lessons learned: South Africa does not have the luxury of multi-disciplinary teams available to cancer patients and their families at organizational level or easily available or in working order in the public sector. In order to offer a holistic service, we can no longer work in silo’s and in order to meet the growing needs that add to a cancer diagnosis such as poverty, unemployed parents, transport challenges etc. local organizations need to work together and create a multi-organizational approach so that everyone can stay within their mandate and refer when necessary to ensure the best outcome for patients and their families

DAY 3: SATURDAY 2 JUNE

Concurrent Session 1: Service Delivery

7. STRATEGIES FOR INTRODUCING PALLIATIVE CARE IN SCHOOL

Ruth Mary Kemigisha, Saudah Namuli

Aims:

• To educate and empower teachers enhance continuity of management for children with palliative care needs
• Increase awareness of pediatric palliative care in schools.
• To enable children take medicines with support of teaching staff.
• To encourage schools draft and adopt a policy for children with palliative care needs

**Introduction:** Concern that HIV positive school going children have high viral loads was sighted among which has been attributed to school structure. This included the inability to identify, assess and refer or manage a sick child with psycho-social problems that may affect adherence and cause child regression in several aspects. In light to this evidence there is inadequate holistic care for these children therefore strategies to successfully introduce palliative care to teachers who are supposed to be caretakers of these children while at school have not been well described. We sought to understand how to introduce palliative care in schools for children having chronic illnesses.

**Method:** A qualitative interview study was conducted at schools in Makindye Division in Kampala with children receiving care from Alive Medical Services. Teacher’s numbers were availed for a phone to prepare for interviews and focused group discussion focusing on attitudes, experiences and practices relating to availing palliative care services to their children who have chronic illness. A multi-disciplinary team analyzed the interviews, transcribed using constant comparative methods and refining a code framework. The analysis focused on practices for introducing palliative care.

**Results:** The number of teacher participants were 40, 28 female and 12 males. The transcribers described 3 main strategies for introducing palliative care in schools.
1. Training school staff on identification, assessment and management children with palliative care needs including referrals.
2. Use a strong physical children relationship and patient trust to increase acceptance of disclosure.
3. Restructuring the school structure to include palliative care needs

**Conclusion:** The research identified the need to introduce palliative care services in schools to enhance effective management of chronic conditions holistically. This will normalize children’s development and life quality since school is a routine process for them.

**177. EXPANDING INTERDISCIPLINARY BORDERS: LECTURING PERINATAL PALLIATIVE CARE WITHIN MIDWIVES**

*Rut Kiman, Lara Doumic, Fernando Tello, Felipe Acosta*

**Introduction:** The dissemination of Palliative Care in the perinatal area of our institution, engendered a request from midwife residents to the Palliative care team for educational training in order to improve their skills in situations of stillbirth or life-threatening events for a fetus or baby.

**Objective:** Describe an educational training in the area of perinatal palliative care with midwives.

**Material and Methods:** Educational Meetings were designed with the aim of introducing a palliative care approach within the perinatal area. The Pediatric Palliative care team asked midwives residents to write anonymously questions which came from distressing situations generated in practice. From this, 5 face-to-face meetings with different topics were designed. At the end, they presented care processes in three dilemmatic situations incorporating palliative care issues.

**Results:** Prior to the design of 5 face to face meetings, 18 questions were received from 10 participants, classified into the following categories: breaking bad news; conflict- resolution; grieving; team- work and burn-out. Weekly face to face meetings of two and a half hours were designed consisting first on a lecture and then class discussion. Topics developed consisted on: Perinatal Palliative Care definitions, Communication, Coping strategies and grief.

Every time we stimulate, once they have reflected on their own performance, share their reflections with the rest of the class: aspects that they found challenging about the experience and how they think they could improve as a group next time. During the last meeting they presented
three models of care incorporating a palliative care approach. In this last encounter, statements like these examples emerged: “As midwives we work with everything that is happy, joyful … bringing a child to the world and we don’t know what to do when something doesn’t go well. We don’t know what to say”. “I haven’t any training before. As I don’t know what to do, I close the door and leave the mother alone” or “It is a change of language, of attitudes … a way of making visible what is happening. It’s not a dead fetus, it’s a dead baby.”

**Conclusions:** Educational meetings alone or combined with other interventions with midwives, can improve professional practice and healthcare outcomes for perinatal palliative care.

**148. EXPERIENCE FROM A HOME-BASED PALLIATIVE CARE SERVICE IN MALAYSIA**

*Yi Leng Yong, Lee Ai Chong*

**Background:** Awareness of children requiring palliative care in Malaysia is growing with in-patient services developing more rapidly than in the community. Home-based palliative care services in Malaysia started in the 1990s mainly for adult patients.

**Aims:** We aim to describe the experience of a home-based palliative care service which sees all children with a life-limiting condition.

**Methods:** This retrospective cohort study of children 18 years and below referred from 1st January 2014 to 31st October 2017 was carried out.

**Results:** There were 184 patients (55.4% males) with a median age of 84 months (3 days-216 months) referred. Malignancy was the most common diagnosis (51.6%) with an increasing annual trend in non-cancer referrals. About a third of were hospital in-patients at referral. Most (78.3%) referred had home visits and death was the most common reason for not receiving any home visits. Majority (80.3%) of patients had at least 1 symptom when first seen; two most common symptoms were pain (37.7%) and constipation (16.0%). Many patients (53.5%) had medical devices at referral, 46.5% of them had feeding tubes; and 44.4% required loan of equipment (oxygen concentrators were the most common). Out-of-hours call service and home visits occurred in 55(38.2%) and 39(27.1%) patients respectively. More than half (59.7%) had advanced care discussions. During the study period 94(64.3%) patients died and 13.9% were discharged clinically stable. Location of death were home (56.4%), hospital (35.1%) or in transit (7.4%). Median interval from referral to death were 65.5 days (2-1315 days). Majority (91.5%) had bereavement follow-up.

**Conclusion:** Children with non-cancer are being referred more frequently for palliative care. Palliative care for children at home requires adequate training to meet the holistic needs of patients and their families.

**21. PAEDIATRIC PALLIATIVE CARE: ARE WE DOING ENOUGH? A RETROSPECTIVE REVIEW OF PAEDIATRIC DEATHS OVER 5 YEARS IN AN ACADEMIC TERTIARY HOSPITAL**

*Mei Chan Grace Ng, Pei Lin Koh*

**Background & Objectives:** The death of a child is probably the most traumatic experience that any parent will encounter. However paediatric palliative care is a relatively new subspecialty in Singapore. We aim to study the epidemiology of paediatric deaths in our institution over the past 5 years. With this information, we hope to better understand the dying experience of these patients, identify any service gaps and improve on palliative care for our patients with life-limiting illnesses.

**Methods:** The medical records of all patients who died in the paediatric wards and the intensive care unit, from 2012 to 2016, were reviewed. Information including demographic data, past medical history, cause of death, referral to palliative care and use of life-sustaining therapies were recorded.
Results: A total of 98 patients died in the 5 years and the average mortality rate was 0.34%. Most deaths occurred in children aged 11 to 18 years old (31%), with a median age of 17. 86 (88%) patients had pre-existing life-limiting medical conditions, such as cancer and neurological disease. Of the 98 patients, 9 (9%) were known to palliative care services prior to admission and 10 (10%) were referred to palliative care during the admission. Of the 9 patients known to palliative care, 5 had advanced care plans. Out of the 93 patients in whom death was expected, all had documented discussions with family regarding goals of care during the course of illness. In terms of life-sustaining measures, 67 (68%) had invasive ventilation, 20 (20%) had cardiopulmonary resuscitation, 11 (11%) were on extracorporeal membrane oxygenation and 63 (64%) required inotropic support. In those whom death was expected, 69 (74%) patients received analgesia during the last 24 hours before death. 78 (80%) patients died after withdrawal or withholding of life-sustaining measures, 17 (17%) died after unsuccessful CPR, while 3 (3%) were certified as brain dead.

Conclusion: Although majority of paediatric patients who died had pre-existing life-limiting conditions, very few were referred to palliative care. More can be done to improve the care of paediatric patients with life-limiting conditions, such as early referral to palliative care and establishment of advanced care plans. In addition, more efforts should be made to improve end-of-life care such as providing adequate analgesia.

30. ZIMBABWE: INTEGRATION OF CHILDREN’S PALLIATIVE CARE FOR THE WORLD’S MOST NEEDY
Monalisa Nhengu-Matonda, Val Maasdorp

Aim: To Integrate Children’s Palliative Care into the National Health System of Zimbabwe.

Design, methods and approach taken: Zimbabwe’s staggering need for Children’s Palliative Care (CPC), estimated to be the highest in the world at 120 per 10,000, is daunting in a country with limited resources in terms of health services provision. Island Hospice & Healthcare (Island) has made progress in providing CPC in the pediatric oncology ward in the country’s largest Ministry of Health referral hospital. Partnering with Parirenyatwa Hospital, Island adopted an approach aimed at improving the holistic quality of care, in which palliative care practitioners (Doctor, nurse and social worker) join the hospital team of consultants, oncology doctors and nurses for hospital ward rounds. This model of care started 2 years ago initially on a fortnightly basis was recently increased to weekly. Follow up service is provided after the patient has been discharged. This includes bereavement should the child die. These steps towards integration are in combination with ongoing training of post basic nurses, medical students and the attachment of oncology nursing students to Island.

Anecdotal Results: The holistic service providing pain management and counseling of patients and family has improved the quality of life of patients and family.

Most of the nurses in this ward are now trained in palliative care and have completed placements at Island.

Partnering, collaboration and sharing of skills and resources has been a strong relationship and network builder to the benefit of the patient, family and health professionals involved.

Conclusion/Lessons learnt: Being a country with limited resources, this kind of approach has yielded promising initial results. Linkages have been created with other organizations that support children.

Some patients might be unable to access the service due to financial constraints to travel to the capital. Training of more health professionals in palliative care and decentralizing this service to other hospitals would help reach more children in need.
ABSTRACTS FOR POSTER PRESENTATIONS

POSTER PRESENTATIONS
DAY 1: THURSDAY 31 MAY

5. EXPLORING PALLIATIVE CARE NEEDS OF CHILDREN WITH CEREBRAL PALSY AND THEIR FAMILIES, AT UMODZI CHILDREN’S PALLIATIVE CARE UNIT, QUEEN ELIZABETH CENTRAL HOSPITAL-MALAWI

Medson Boti, Julia Downing, Jane Bates

Cerebral palsy (CP) is the leading cause of childhood disability affecting function and development. The incidence of the condition has not changed in more than four decades, despite significant advances in medical care. CP is not a single diagnosis but an umbrella term describing non-progressive brain lesions involving motor or postural abnormalities that are noted during early development. There may be problems with sensation, vision, and hearing, swallowing and speaking. It is a common cause of physical disability in children worldwide, but little is reported on this condition in the African context including Malawi where this research took place.

In Malawi, while there has been much attention on Palliative care for children, less attention has been given to children with CP for a variety of different reasons such lack of skills in assessment and management of these conditions. The aim of this study was to explore the palliative care needs of children with cerebral palsy and their families. A qualitative research design was used to answer the question using semi-structured interviews. One-to-one interviews were conducted with nine (9) mothers with children with CP children. A convenience sampling technique was used in selection of participants. Thematic analysis was undertaken utilizing the four phases of: organisation; familiarization; reduction and analysis. The following themes were identified: The understanding of CP by the children and their guardians; the palliative care needs of the children; and the palliative care needs of the family. CP brings negative impacts on children and their families: physically, psychologically, socially, and spiritually. The neurological deficits can bring about issues of poor feeding, spasticity and weakness, educational challenges, difficulties in identifying pain and other symptoms and how to come up with the best management. The findings should be disseminated at UCPCU staff during team meetings, Palliative Care Support Trust management meeting and Paediatric departmental meeting and National or international conferences so that Children with Cerebral palsy and their families are managed properly.

An exploration of the palliative care needs of children with Cerebral palsy and their families at Umodzi children’s palliative care, QECH-Malawi was the topic of this study. CP and palliative care is an area that needs more studies/researches.

6. INTEGRATIVE THERAPIES IN PEDIATRIC PALLIATIVE CARE

Marie Wrinn

The access to effective measures in treating distressing symptoms in pediatric palliative care is often limited. In many countries, the availability of medications is scarce. The shortage of trained and qualified caregivers in traditional medical and nursing practices further narrows the pathway to symptom management.

Caring for the very sick and dying children involves some of the most difficult and most important work we provide for families. We often put aside our own needs and families to take care of those less fortunate than ourselves. We give with our hearts, souls, and knowledge to make the journey for a sick child a little bit gentler.
The integration of complementary therapies using music, art, writing, massage, and aromas is an important part of pediatric palliative care. When science fails, we can turn to additional measures in support of the comfort of children, their families, and their caregivers. Though ancient in use, we have forgotten the basic principles of touch, sight, scent, hearing, and taste as tools to use in the effort to alleviate pain and anxiety, lift depression, and improve bodily functions. This presentation will utilize some of the five senses to demonstrate the benefits of alternative modalities in simple, easy-to-deliver techniques. The audience will participate in massage, music, and aromatherapy as part of the session. The experience can translate into direct patient care, and for self-care.

8. ART AS SELF-CARE: CREATING YOUR OWN ZENTANGLE

*Marie Wrinn*

First 5-10 minutes to present the idea of art as a therapeutic intervention. The participant will practice creating a Zentangle art piece through step-by-step instructions. This can take 10-15 minutes to get started. Creating a Zentangle is a calming and focusing technique. A Zentangle is a simple art form using pencil, pen and paper. The participants will leave with a piece of art they create. The technique is easily shared with others in their organizations and with their patients.

12. COMMUNICATION IN CPC BEYOND GENERATION, CULTURAL AND LANGUAGE BARRIERS: A CASE SERIES OF DRAWINGS

*Hanneke Brits*

**Background:** Do we really know what our children know, think or want? Due to generation, culture and language barriers it’s easier to assume than to find out. In a children’s palliative care (CPC) programme it’s even more difficult to communicate with the children due to the added illness, underlying emotional state and low self-esteem.

**Aim:** The aim of this study was to investigate if drawings could be used to encourage communication and better understanding of the issues that children in a CPC programme battle with, but not necessarily express.

**Design:** This was a sub-study of a bigger study which investigated the role of drawings to assess emotional well-being in children in a CPC programme. A qualitative study design was used. Primary school children were assessed while they were busy to draw pictures. Picture drawing is part of their daily activities. Only the results of the first encounter with each child was included in this study. Privacy was ensured, and the same researcher assessed all the children. The same opening statement was used in all the children: Would you like to tell me about your drawing?

**Results:** All 10 children that were approached were included in the study. The children expressed opinions regarding their disease, feelings, caregivers and faith. These opinions were grouped in themes that included the individual (body, mind and spirit), the caregivers and the community.

**Discussion:** All the children were comfortable to discuss their drawings and feelings. The more they talked the more detail they added to the pictures. Without encouragement most of the children expressed opinions regarding total care. None of the children experienced distress during the assessment. A better understanding was gained regarding the issues that children in a CPC programme battle with. What stood out was their desire to be included in decisions.

24. INTUITION IN THE INNOVATION PROCESS OF PAEDIATRIC PALLIATIVE CARE – IN MEMORY OF GIAMPAOLO MAGNANI BORN ON 5TH MARCH 2009 – DIED ON 17TH OCTOBER 2010

*Professor Luisella Magnani*
Innovation and research in Childrens' Palliative Care is firstly focusing on a new mode of caring, on a new style of care which belongs to the intuitiveful Person who totally cares, absorbed in her Scientific dimension. Secondly, considering Palliative Care for Children a Celebration of Life (Ehospice, 19th October 2017), even if that Celebration lasts few years, few day, or even few hours. A Celebration of Life where feelings, perceptions, emotions, intuitions help in the concertation and orchestration of Care.

**Design, Methods and approach taken:** Fully and deeply understand the Infant's external and internal susceptibility along with his parents'. Observe carefully and intuitively the Infant, the Baby, the Child. Listen carefully and intuitively to his parents in their ongoing special interests and particular needs. Create a dialogue among thoughts, feelings, perceptions and intuitions. The value of voice is, millisecondly, the articulation of Your presence at the Child's bedside and towards his Parents. Babies' and mother’s intuition must be valued, estimated, considered, treasured. Compassionaly, look at the Baby in the womb, or the Baby who is born, with a life-limiting or life-shortening condition and create for him the uniqueness of the approach as if he were the only Baby you must care.

**Results:** Intuition is gaining acceptance as a legitimate form of knowledge in clinical nursing (Anne Lise Holm et al., 2016). Intuition helps Action. Caregivers are much more sensitive to Children's needs and wishes. Millisecondly. It guides decision about Child's Care. As an emotional awareness, intuition helps the Caregiver to Be-in-his-Actions wholly and constantly.

**Conclusion:** This approach is taught and practised at the Paediatric Hospital of Varese (Italy). It is based on B.A. Carper's four fundamental patterns of knowing: Empirical knowledge, Personal knowledge, Ethical knowledge and Aesthetic knowledge (1978).

25. **DOING PALLIATIVE CARE WITH CHILDREN IN LESOTHO: AN INTERCULTURAL APPROACH**

*Lekholokoe Leshota*

**Background:** Palliative care as an approach that seeks to improve the quality of life of patients, who in their familial contexts face problems related to life-threatening illness, has been around for some time now. With the rise in the number and complexity of illnesses, palliative care has not only become urgent, it has also become an indispensable part of what it means to be human in the life and death continuum. Patients who are faced with life-threatening illnesses and end-of-life challenges, do so as individuals who are immersed in a contextual trilogy.

**Objective:** This article seeks to identify and interrogate challenges and opportunities associated with the application of an intercultural approach in offering palliative care to children in Lesotho.

**Approach:** This desk-top research employs an Intercultural approach to tease out the dynamics of caring for patients with life-threatening illnesses who, in the first place, share the characteristics that makes them all human (Like all others); who, in the second place, are patterned by the values, beliefs and basic life assumptions that are tied to their culture; and lastly, each one of them has a distinct genetic pattern and unique life story (Like no other).

**Results:** It emerges that children are human too. In their attempt to make sense of what is happening around them, they resort to patterns that are proffered to them by the universal, cultural and unique dimensions of their live. As we go about relieving the pain and offering care to children within the context of palliative care, we should do so mindful of the fact that they live in the intersection of the human, cultural and unique spheres.

**Conclusion:** Balancing these three spheres not only offer us an opportunity for a holistic care but it also presents us with the challenge of holding them (trilogy) in creative tension every time we care for children with life-threatening illness and end-of-life challenges.
31. DEVELOPMENT OF A MULTIDISCIPLINARY PEDIATRIC PALLIATIVE CARE PROGRAM IN MBeya TANZANIA

Liane Campbell, Beatrice Malingoti, Nazarena Myenzi, Asulwisye Kapesa, Jason Bacha

Aims: A multi-disciplinary palliative care program was established in March 2014 at an outpatient pediatric HIV clinic in Mbeya, Tanzania to support children and adolescents with life-limiting illnesses.

Method: Retrospective chart review was conducted to describe characteristics and outcomes of patients enrolled in the palliative care program between 1 March 2014 and 31 Dec 2016. Palliative services included evidence based medical care, pain and symptom management, nutrition interventions, psychosocial support, multidisciplinary home visits, and memory and wish making activities.

Results: 99 patients were enrolled with a median age of 13 years (Range: 6 months-20 years). 69% were adolescents (ages 10-19 years). 84% were HIV positive with median CD4 of 92 cells/mm3 (range: 0-1360). Common conditions in HIV positive patients included Kaposi sarcoma (35%), end organ dysfunction (10%), chronic lung disease (5%), stroke (5%), and extrapulmonary TB (5%) and other (40%). Common conditions in HIV negative patients included cerebral palsy (38%), acute myeloid leukemia (13%), Kaposi sarcoma (13%), extrapulmonary TB (13%) and other (23%). 69% of all patients had severe acute malnutrition.

Of all patients, 29% died, 7% were lost to follow up, 5% transferred care and 58% survived despite their life-threatening conditions. Of those who died (n=29), 83% were adolescents. 24% of patients reported pain and received effective analgesia. 56% completed memory making activities.

Conclusion: Despite resource limitations, a multidisciplinary approach to palliative care can be successfully implemented for HIV positive and negative children and adolescents in an outpatient pediatric HIV clinic. Despite the increasing availability of antiretroviral therapy, patients with HIV still present with advanced disease and need palliative care. In this cohort, the majority of patients were adolescents, highlighting the vulnerability of this population.

32. THERAPEUTIC CONTRAST ENEMA FOR RESOLUTION OF REFRACTORY OPIOID-ASSOCIATED CONSTIPATION IN A TODDLER

Regina Okhuyzen-Cawley, Kimberly Lehecka, Jared Rubenstein, Tammy Kang

Background: Constipation is a common distressing symptom in patients requiring opioids, and usually responds to appropriate oral laxative bowel program.

Aims: Describe the use of the commonly available contrast agent iothalamate meglumine (Cysto-Conray®) for resolution of refractory opioid-associated constipation.

Case report: A 10 kilogram 14-month-old boy with intractable leukemia and presumed bone pain requiring intravenous morphine developed severe constipation (1 week) unresponsive to diet, oral lactulose, milk of magnesia, senna, docusate and polyethylene glycol 3350; glycerine suppositories, phosphate and soapsuds enemas were attempted without success; subcutaneous methylnaltrexone was attempted as well, without effect. Progressive abdominal pain and distention prompted a trial of iothalamate meglumine 1:1 water given as a 500 ml contrast enema by the radiologist, under fluoroscopic guidance with visualization of the cecum. 350 g of stool were passed a few hours later; a second iothalamate meglumine: water enema (250 ml) given by the nurse on the ward resulted in passage initially of 250g then an unquantifiable, very large stool, with resolution of the abdominal distention and improvement in overall appearance, appetite and level of activity. There were no apparent side effects. The child’s urea and creatinine remained at baseline, despite having had acute kidney injury 2 weeks prior to the enema. He was placed back on
an oral laxative regimen given persistent need for opioids given rapidly escalating blast count and suspicion of bony pain.

**Lessons learned:** Iothalamate meglumine is an iodinated contrast agent similar but possessing a lower osmolality (~ 1000 mOsm/kg) than the diatrizoate meglumine (Gastrografin® ~ 1415 mOsm/kg) traditionally used for meconium ileus. These agents are capable of penetrating and progressively softening the fecal mass, likely due to their high osmolality relative to colonic mucosa. Therapeutic contrast enema, with its inherent risks, may be reasonable in patients with truly refractory constipation.

### 34. DEVELOPING A PROTOCOL FOR PEDIATRIC PALLIATIVE TRANSPORT: PROCEDURES, POSSIBILITIES AND PROVOCATIONS

*Leander Timothy, Lezlie Andersen, Megan Thorvilson, Christopher Collura*

**Aims:** The majority of pediatric deaths occur in the hospital, predominantly in the intensive care unit. We aim to describe pediatric palliative transport (PPT) as an innovative program and underutilized resource in the United States. PPT focuses on end-of-life goals to empower the family-centered experience at end-of-life and address disparities in cultural, religious, and value-driven preferences not possible in the hospital. We will describe our pediatric palliative care program’s ad hoc experiences in partnering with neonatal and pediatric critical transport teams via air and ground ambulance to create opportunities for death at home.

**Method:** We reviewed the current literature on location of pediatric deaths and compared that to parental preferences. Our literature review demonstrated that though the majority of children die in a hospital setting, there has been a slight uptrend in home deaths over the last 20 years. We identified obstacles to achieving a safe home death for children currently hospitalized, including increasing use of medical technology, gaps in hospice availability and expertise in pediatric end-of-life care, provider distress, resource utilization, and cost.

**Results:** The data identified areas to best target in building safe palliative transport practices. Through this review, providers from the critical care units and pediatric palliative care team collaborated to develop a palliative transport protocol to ensure quality and meaning for all involved, particularly for the family.

**Conclusion:** A home death is preferred by most families for their terminally-ill child, yet most patients die in the hospital. To address this disparity, palliative care providers have the opportunity to help families plan for location of death and facilitate palliative transport when that aligns with the family’s goals. A palliative transport protocol can serve as a tool to deliver quality care.

### 35. TEAM MEMBERS ARE FAMILY: EXAMINATION OF THE RELATIONSHIPS BETWEEN ONCOLOGY STAFF AND BEREAVED PARENTS AND THE IMPACT ON PARENTAL GRIEF

*Justin Baker, Carlos Torres Jennifer Snaman, Belinda Mandrell, Amanda Linz*

**Background:** Following the death of a child, many parents cope with their grief via making meaning. Meaning making is a social construct, occurring within relationships. Given the prolonged nature of pediatric cancer treatment and the difficult decisions it entails, relationships between parents and care team members are fostered over time and through extensive collaboration. These relationships have the potential to be sources of support for parents during the child's treatment and conduits for making meaning of the child's life and treatment journey after their death. However, the extent to which relationships with care team members influence parents’ ability to make sense of and successfully cope with their loss has not been examined.

**Objectives:** The purpose of this study was to examine how interactions with their deceased child’s pediatric oncology care team impact parents’ grief.
**Design/Method:** This study employed a convergent parallel mixed methods design. Data was collected from 30 bereaved parents whose children died from progressive cancer or cancer-directed treatment 1–3 years prior to participation. The quantitative component included standardized depression and grief-related symptom questionnaires and a meaning making questionnaire. The qualitative component included a semi-structured interview protocol. Spearman’s correlation was utilized to measure the associations between questionnaire scores and parent and child treatment demographics.

**Results:** Statistically significant correlations were found among depression, grief, and meaning making, with higher levels of depression correlated with higher levels of grief, and both grief and depression correlated with lower levels of meaning making. The duration of treatment, amount of time passed since the child’s death, whether the parent had any other children, and all other demographic variables did not correlate significantly with parents’ level of depression or grief. A thematic analysis of the interviews identified the following overarching themes: parents’ necessity to assimilate throughout and beyond the cancer journey; the importance of functioning as a good parent during treatment and after the child dies; parents’ viewing the care team like family during treatment; and the care team’s ability to aid parents’ sense making, benefit finding, and identity reconstruction after the child dies. Parents endorsing severe depressive and grief symptoms did not describe forming close relationships with any particular care team members. However, those parents who did describe forming close relationships with team members endorsed high meaning making levels.

**Conclusion:** Results from this study may form a foundation from which to further assess the care team’s impact on parental bereavement as well as future considerations for clinical intervention.

**38. SHARING THE VOLUNTEER EXPERIENCE IN PAEDIATRIC PALLIATIVE CARE**

*Martha Mherekumombe, Sarah Potter, Elizabeth Shepherd*

**Background:** The Family Support Volunteer Program has provided invaluable emotional and practical support for families cared for by the Palliative Care Service at the Children’s Hospital at Westmead (CHW) since 2009. There are limited opportunities available to share the wonderful work these volunteers do with families. We created a short video for the dual purposes of education (health professionals and for training new volunteers) and promotion of the program. This resource was developed to target volunteer recruitment in specific high need areas of Western/South Western Sydney which have a high population of culturally and linguistically diverse people some of whom are isolated and are from a lower socioeconomic group. The video demonstrates the difference that volunteers can make in the lives of families and children with a life limiting illness and they describe the personal gains and satisfaction this special role provides for volunteers.

**41. HOW FAR CAN THE HEALTHCARE PROFESSIONAL ACT IN THE BEST INTEREST OF THE CHILD IF THE PARENT OR GUARDIAN HAS DIFFERING VIEWPOINTS?**

*Chenjerai Bhodheni*

**Aims:** Improving care and support for children with life threatening illnesses Understanding issues of decision making in life threatening illnesses and their impact on the child’s quality of care and quality of life.

**Methods:** A single case study of a patient was used with field notes used to capture the data. Each subsequent visit was documented with a process of coding and theme development.

**Results:** Integration of services and collaboration by various stakeholders is important in achieving improved quality of care. Discussion and understanding the goals of care with the parent/guardian
as well as the sick child proved quality care can be achieved despite the child’s advanced stage of illness. When working with families, it is important to be patient with parents faced with their child’s incurable condition as they gradually deal with accepting the prognosis.

**Conclusion:** Integration of palliative care with other healthcare services creates a good environment for improved care for children as there is little or no need to make referrals outside care providing systems for palliative care. In instances where a child is diagnosed with a life-threatening illness, the child has little or no ability to make decisions regarding the impact on their quality of care as adults do. A multi-sectorial, multidisciplinary approach to caring for challenging child illnesses improves the quality of the child’s care while ensuring available resources are effectively used for the child’s benefit.

43. GRIEF IN SIBLINGS: OVERVIEW AND INTERVENTIONS

*Patricia Shearer, Lanise Shortell, Khaliah Johnson*

**Aims:**
1. Identify age-specific understanding of death among children and adolescents
2. Describe common grief reactions among children of various ages
3. Provide resources for support of children and adolescents who are grieving

**Approach:** The authors focused on a case involving the sister of a boy with an inoperable brain tumor to highlight the features of grief in siblings and its impact on families.

**Background:** Life-limiting illness in children affects the global environment of the child. Siblings may feel invisible and exhibit signs of grief that begin at diagnosis. These are developmentally specific, culturally similar, and may be anticipated in order to sharpen awareness and promote healing.

**Results:** The patient is a 6 year-old boy with diffuse intrinsic pontine glioma diagnosed in March 2016. He received radiation (XRT) and chemotherapy (CT) followed by a second regimen of CT when the tumor progressed. He was enrolled in hospice 4 months after progression. Following two experimental therapies and palliative XRT, he remains at home with support of the hospice interdisciplinary team (IDT).

The patient’s 4-year-old sister has developed anxiety, hyper-vigilance, loss of boundaries (getting into things that are not hers), and mimicking existential ideations expressed by her brother while creating religious objects resembling his. She is now increasingly bonding with a family friend and two cats as her mother’s attachment to the dying child intensifies. Books dealing with loss of a sibling have been provided, as well as ongoing input from the nurse, chaplain, and social worker on the IDT to assist the child and her family with anticipatory bereavement.

**Conclusion:** Expression of grief in siblings is age-specific and may be non-verbally expressed, affecting the dynamics of the family. Early recognition and interventions for grief in siblings may improve adaptation to loss.

48. INTENSITY OF INTERVENTIONS OF A PEDIATRIC PALLIATIVE ONCOLOGY COHORT

*Justin Baker, Erica Kaye*

**Background:** The field of pediatric palliative oncology is newly emerging. Little is known about the characteristics and illness experiences of children with cancer who receive palliative care.

**Methods:** A retrospective cohort study of 321 pediatric oncology patients enrolled in palliative care who died between 2011 and 2015 was conducted at a large academic pediatric cancer center using a comprehensive standardized data extraction tool.

**Results:** The majority of pediatric palliative oncology patients received experimental therapy (79.4%), with 40.5% enrolled on a phase I trial. Approximately one-third received cancer-directed...
therapy during the last month of life (35.5%). More than half had at least one intensive care unit hospitalization (51.4%), with this subset demonstrating considerable exposure to mechanical ventilation (44.8%), invasive procedures (20%), and cardiopulmonary resuscitation (12.1%). Of the 122 patients who died in the hospital, 44.3% died in the intensive care unit. Patients with late palliative care involvement occurring less than 30 days before death had higher odds of dying in the intensive care unit over the home/hospice setting compared to those with earlier palliative care involvement (OR: 4.7, 95% CI: 2.47-8.97, P<0.0001).

**Conclusions:** Children with cancer who receive palliative care experience a high burden of intensive treatments and often die in inpatient intensive care settings. Delayed palliative care involvement is associated with increased odds of dying in the intensive care unit. Prospective investigation of early palliative care involvement in children with high-risk cancer is needed to better understand potential impacts on cost-effectiveness, quality of life, and delivery of goal concordant care.

**50. PALLIATIVE CARE INVOLVEMENT IS ASSOCIATED WITH LESS INTENSIVE END OF LIFE CARE CHARACTERISTICS IN ADOLESCENT AND YOUNG ADULT ONCOLOGY PATIENTS**

*Justin Baker*

**Background and Objective:** Adolescent and young adult oncology (AYAO) patients often receive intensive care and experience significant symptoms at the end of life (EOL). Integration of palliative care into the care of AYAO patients may help alleviate suffering. This study aimed to describe the characteristics of AYAO patients who died in the hospital and compare the experiences of those patients who did and did not receive palliative care.

**Study Identification:** Retrospective, chart-review study of 69 AYAO patients aged 15 to 25 years who died hospitalized from 2008 to 2014.

**Data Extraction and Synthesis:** An investigator-created, standardized data extraction tool was used to collect information about demographics, treatment, EOL characteristics, and symptoms during the last month of life (LMOL) for AYAO patients.

**Results:** AYAO patients who died in the hospital were more likely to have a hematologic malignancy, required considerable medical and psychosocial care and experienced numerous symptoms during the LMOL. When compared to those patients who received no palliative care involvement, patients followed by the palliative care team were less likely to die in the intensive care unit (38% vs. 68%, P = 0.024) and less likely to have been on a ventilator (34% vs. 63%, P = 0.028). They also received fewer invasive medical procedures during the LMOL (median, 1 v. 3 procedures, P = 0.009) and had a do-not-resuscitate order in place for a longer time before death (median, 6 vs. 2 days, P = 0.008).

**Conclusion and Implications for Practice, Policy and Research:** AYAO patients who died as inpatients received intensive therapies, had numerous symptoms, and required significant support from the medical and psychosocial teams. Involvement of the palliative care team was associated with the receipt of less intensive treatments and fewer deaths in the intensive care unit. Early integration of palliative care into the routine care of AYAO patients is recommended and should be prospectively studied.

**51. PALLIATION BEYOND DEATH: FACE-TO-FACE INTERDISCIPLINARY POST-MORTEM REVIEW AS A TOOL TO MITIGATE COMPLICATED BEREAVEMENT AND PROMOTE LEGACY-BUILDING**

*Justin Baker*

**Background:** Palliative care does not end with death. Many palliative care programs offer bereavement support to families; however, few programs have formal infrastructure in place to offer all bereaved families face-to-face follow-up with an interdisciplinary clinical team for
posthumous review of medical information, including autopsy results. Although the majority of bereaved families report a desire to meet with the clinicians who cared for their loved one, unfortunately only a minority of families are provided an opportunity to participate in formal follow-up meetings. Bereaved families report that receiving post-mortem information, such as autopsy results, aids in coping with grief, assuaging feelings of guilt, finding closure, and promoting legacy-building. Particularly for those bereaved families who choose autopsy, the importance of coordinating a follow-up meeting to review post-mortem medical information cannot be overstated.

In this session, we will review the literature in support of post-mortem conferences as an integral component of the provision of optimal bereavement support. Attendees will gain familiarity with the preferences of families and clinician regarding timing, location, and other components of post-mortem follow-up meetings. We will review the topics that families and clinicians identify as most valuable to include in these follow-up sessions, including the benefits of reviewing autopsy results with bereaved families. We will discuss the requisite infrastructure to design, implement, and sustain a bereavement program that offers post-mortem interdisciplinary follow-up sessions to all bereaved families with integrated sibling support. Attendees will gain understanding of the barriers to coordination of this type of program, including lack of infrastructure to facilitate initiation and planning, shortage of available staff, limited time, and inadequate reimbursement, with subsequent identification of strategies to overcome these barriers. Finally, we will review cases from our institutional experience to provide examples of how post-mortem meetings can mitigate complicated bereavement, heal fractured family dynamics, and promote legacy-building.

**Objective #1:** Lead a discussion integrating evidence from the literature in support of face-to-face post-mortem follow-up meetings with clinicians and bereaved families.

We will review data from the literature that includes perspectives of both bereaved families and clinicians describing the importance of providing post-mortem medical information to bereaved families. Specifically, we will focus on the benefits of providing face-to-face discussion of autopsy results, as reported by families and clinicians. We will examine data-driven family and clinician preferences regarding logistical aspects of post-mortem meeting coordination, including timing, location, invited attendees, and available on-site ancillary staff and resources. Finally, we will describe the topics that families and clinicians identify as most valuable to include in these post-mortem follow-up meetings, thereby offering a framework for developing flexible guidelines for facilitating successful discussions.

This objective will be achieved by introducing a compelling case presentation to establish the importance of this topic, with subsequent expansion of the discussion through use of a didactic power-point presentation that concisely summarizes the background literature upon which the optimal design of a post-mortem interdisciplinary program is predicated.

**Objective #2:** Identify the components required to create, implement, and sustain a post-mortem interdisciplinary program, as well as the barriers to successful programmatic execution and strategies for overcoming these barriers.

The medical director of an interdisciplinary pediatric palliative care program and director of a hospice and palliative medicine fellowship program will share her expertise in designing, realizing, and maintaining a bereavement program that includes offering post-mortem interdisciplinary meetings to all interested bereaved families. Specifically, she will review the administrative and logistical components intrinsic to creating and sustaining the requisite infrastructure, as well as the mechanisms by which interdisciplinary providers (including pathologists, subspecialty consultants, and psychosocial providers) are integrated into the program. A palliative care program coordinator and certified child life specialist will share her expertise in providing sibling bereavement support in
synergy with post-mortem follow-up meetings. Finally, we will identify common institutional barriers to programmatic success, including lack of infrastructure to facilitate initiation and planning, shortage of available staff, limited time, and inadequate reimbursement, and subsequently offer strategies to overcome these barriers.

This objective will be achieved through a case-based didactic power-point presentation to highlight and disseminate the lessons learned by a palliative care program as it progressed through the nascent stages of designing, instituting, and maintaining a successful post-mortem interdisciplinary follow-up program.

Objective #3: Describe the ways in which post-mortem interdisciplinary medical follow-up serves as an integral component of psychosocial bereavement support.

We will highlight several difficult cases from our institutional experience that offer specific and compelling examples of the benefits of reviewing autopsy results and providing other post-mortem medical information to bereaved families in an interdisciplinary forum. Specifically, we will present cases in which post-mortem medical discussions enabled bereaved families to better cope with grief, find closure, repair fractured family dynamics, provide anticipatory guidance, and promote healing and legacy-building. During this section, we will encourage attendee participation to reflect on these cases and share other patient stories from their respective institutions.

This objective will be achieved through a case-based didactic power-point presentation to highlight the potential psychosocial benefits of reviewing post-mortem medical information and autopsy results with bereaved families, augmented by audience participation with the goal of collaborative learning through discussion of other institutional experiences.

52. INCORPORATING BEREAVED PARENTS AS FACULTY FACILITATORS AND EDUCATORS IN TEACHING PRINCIPLES OF PALLIATIVE AND END-OF-LIFE CARE

Justin Baker

Background: High quality medical education for interdisciplinary providers requires training in principles of palliative and end-of-life care. The experiences of bereaved parents can inform and enhance palliative care educational curricula in uniquely powerful and valuable ways.

Objective: To present an innovative palliative care educational program facilitated by trained bereaved parents who serve as volunteer educators in local and national palliative care educational forums; to describe how incorporation of bereaved parents in these educational forums affects participant comfort with communication and management of children at the end of life.

Design: Survey tools were adapted to determine how bereaved parent educators affected participant experiences in 3 different educational forums: institutional seminars on pediatric palliative and end-of-life care, role-play-based communication training sessions, and an international symposium on pediatric palliative oncology.

Setting/Subjects: Participants at palliative care educational forums at a pediatric oncology institution were included in this study.

Measurements: Pre- and post-session surveys with incorporation of retrospective pre-program assessment item were used in the evaluation of institutional seminars and communication training sessions. Results from feedback surveys sent to all attendees were used to appraise the participants experience in the international oncology symposium.

Results: Involvement of trained parent educators across diverse, interdisciplinary educational forums has been lauded by attendees. Importantly, parent educators also derive benefit from educational with interdisciplinary clinicians.

Conclusions: Integration of bereaved parents into palliative and end-of-life care education is an innovative and effective model that benefits both interdisciplinary clinicians and bereaved parents.
54. A YEAR IN THE LIFE OF A NEW AUSTRALIAN CHILDREN’S HOSPICE: HUMMINGBIRD HOUSE
Christine Mott, Kelly Oldham

**Background:** Hummingbird House Hospice opened in Brisbane in July 2016 to service the children of Queensland and Northern New South Wales with life-limiting illnesses.

**Aims:** To understand the population accessing the service, and the ways in which the hospice was utilised to improve quality of life.

**Methods:** Guest and admission characteristics were reviewed from facility data over a 12-month period from 1st October 2016 to 30th September 2017.

**Results:** The service received 77 referrals of which 88% were accepted. The average age of accepted referrals was 7 years. The majority had a primary neurological diagnosis (38%), followed by metabolic diagnoses (30%), oncology (10%) and congenital (10%). Over the 12 months there were 221 admissions, the vast majority of which were for planned respite (87%). Only 5% of admissions were for end of life care or after death care, although 23 children known to the service died over the 12-month period. Of the 23, 9 (39%) died at the hospice. The majority of admissions were short, with 67% being one to three-day length, and only 3% of admissions were more than seven days. Complex high-level care in the hospice included extubations, ventilatory support and collection of donated tissue after death. In addition to admissions Hummingbird House has offered community in-home support, allied health interventions and a range of unique and positive experiences for children with life limiting illnesses and their families. A case study of a 14-year-old with refractory T Cell Acute Lymphoblastic Leukaemia who required non-invasive ventilation but did not wish to stay in a hospital environment, is presented. Close connections with the hospital-based paediatric palliative care services have facilitated continuity and integration of care.

**Conclusion:** Care for paediatric palliative care patients is complex, and there is an important role for hospice alongside hospital and home-based care options.

55. NATIONWIDE STRUCTURE FOR INTEGRATED CHILDREN’S PALLIATIVE CARE
Stephanie Vallianatos, Carolien Huizinga, Meggi Schuiling-Otten, Eduard Verhagen

**Aims:** Expertise in care for children with a life-limiting or life-threatening disease in the Netherlands is still fragmented and not easy available and accessible for parents. Professionals have difficulties to timely recognize care needs and often lack skills to provide the required care. Also, coordination and guidance is lacking, due to a multiplicity of disciplines involved. Families often feel they have to rely on themselves while already being in a stressful, insecure and vulnerable situation.

Aim is to create a nationwide structure for integrated children’s palliative care (CPC) with substantive quality, coordination, and continuity.

**Design/methods/approach taken:** Since 2012, children-hospitals in the Netherlands have been developing CPC-teams. Professionals in 1st/2nd/3rd-line care have been developing regional networks of integrated CPC for coordination and continuity of care, and increasing expertise, to organize care close to home.

**Results:** An integrated and high-quality nationwide structure has been created, revealing a shared ambition. CPC is now recognized as a specialized field of care by the government. CPC-teams and -networks coordinate the care in close collaboration with parents. One central point is accessible for parents. A Centre of expertise is in creation and will provide a basis to preserve the CPC-structure with expertise, information, training and development.

Established values since this structure of CPC-teams and -networks:
1. A comprehensive and timely approach of the palliative process from hospital to home with a focus not only on the medical aspects but also psycho-social, pedagogical, spiritual aspects.
2. Not merely focusing on the ill child, but also on parents and siblings.
3. Focus on health instead of illness, awareness that a child can still be a child.

**Conclusion/Lessons learned:** A process is activated that CPC is so much more than terminal care. The difficult dialogue about ethical dilemmas is still challenging, but open. Five years ago, this was inconceivable.

### 57. A JOURNEY TO ÍTACA: IMPLANTATION OF A PEDIATRIC PALLIATIVE CARE UNIT IN A TERTIARY PUBLIC HOSPITAL IN SPAIN

**Carla Cuso Cuquerella, Andres Morgenstern, Beatriz Garcia Palop, Maria Morillo Soriano**

**Background:** During our training we were told that being a doctor, or a nurse, means dedicating oneself to one of the most beautiful and difficult professions that exist. But they forgot to tell us that palliative care does not mean to talk about failure. To speak of palliative care is to speak of accompanying suffering, dignity, total pain relief. Is to speak of humanism, shared decisions, knowing how to listen and when to remain silent. It means putting the child and his family at the centre of all care.

**Aim:** To present the process of implantation of a new Pediatric Palliative Care Unit (PPCU) in a Spanish tertiary public hospital and to evaluate the impact from the beginning of its activity

**Material and methods:** Descriptive study of the implementation process of the Vall Hebron University Hospital PPCU from April to October 2017 by reviewing the activity record.

**Results:** Over a 7-month period, a total of 26 patients were referred to the PPCU. A total of 7 deaths have been accompanied. There was a total of 206 hospital visits, 60 home visits and a total of 3000 kilometres travelled. Implementation of the unit required 23 informative sessions, elaboration of the referral algorithm, structuring of the computer program for recording the activity in the public health system and creation of a patient database.

**Conclusions:** Implementing a pediatric palliative care unit in a tertiary hospital is a step-by-step process based on multi-professional work and care coordination. It involves the challenge of guiding health professionals in a new approach and of responding to the physical, social, psychological and spiritual needs of the child and their family.

### 60. THE IMPORTANCE OF A PEDIATRIC PALLIATIVE CARE DIFFUSION CAMPAIGN BEFORE THE IMPLANTATION OF A NEW PEDIATRIC PALLIATIVE CARE UNIT IN A SPANISH TERTIARY PUBLIC HOSPITAL

**Andres Morgenstern**

**Background:** In a hospital where previously there has not been a specific pediatric palliative care unit, one of the first steps to start a new project should be a diffusion campaign to all those professionals who may be involved with patients with palliative needs.

**Aim:** To implement a diffusion campaign about pediatric palliative care for pediatricians and nurses of a tertiary public Spanish hospital before implanting a new pediatric palliative care unit (PPCU)

**Approach taken:** During the first month since the beginning of the project (April 2017) an informative session was held in each of the hospital pediatric services. In these sessions, basic concepts about pediatric palliative care were explained (definition, patients who should receive palliative care, inflection point, care levels). The expected short-term chronology of the implementation process and a long-term plan to offer an integral attention to the pediatric chronic
complex patient were exposed. It was registered the degree of interest, barriers, expectations and proposals after the sessions for pediatricians.

**Results:** Informative sessions for pediatricians in 11 different pediatric services and 15 sessions for nurses of the different hospital pediatric units were made, reaching more than 100 health workers. 9 of the 11 pediatric services showed high level of interest. Most of the barriers detected were related to an erroneous understanding of palliative care. The expectations and proposals were related to domiciliary care, multidisciplinary and comprehensive care and advance care planning.

**Conclusions:** After the informative campaign was completed there was an improved sensitivity in the detection of palliative needs and PPCU evaluation requests increased. A dissemination campaign should play a major role during the implementation of a new PPCU to improve visibility and promote referral of patients who require it. The need to extend the diffusion campaign to pediatric surgical specialties and pediatric anesthesiology was detected.

61. OPPORTUNITIES FOR CHILDREN’S PALLIATIVE CARE AND E-HEALTH PLATFORMS ENHANCING QUALITY PATIENT-CENTERED CARE IN LESOTHO

*Sejojo Phaaroe, Mabatho Thatho, Mosilinyane Letsie*

**Background:** Children palliative care in Lesotho is at its infancy, more has to be done by Policy makers, community leaders, stakeholders, and health professionals on advocacy and policy, mainstreaming and integration. Services delivery currently faces many challenges including unnecessary pain from insufficiently personalized treatment, doctor-patient communication breakdowns, and a paucity of usable patient-centric information. Advances in informatics for consumer health through eHealth initiatives have the potential to bridge known communication gaps, but overall these technologies remain under-utilized in practice.

**Aims:** This paper seeks to identify effective uses of ehealth and mhealth to improve children palliative communications and care within the clinical setting, home based and community settings.

**Methods:** A needs analysis was conducted by surveying three regional hospitals staff. Needs were mapped onto an existing inventory of emerging eHealth systems to assess what existing informatics solutions could effectively bridge these gaps.

**Result:** Through the caregiver interviews, a number of communication challenges and needs in children palliative care were identified from the interconnected group perspective surrounding each patient. These gaps mapped well, in most cases, to needs for cyberinfrastructure use. Adoption and adaptation of appropriate technologies could improve, including for patient-provider communication, behavioural support, pain assessment, and education, all through integration within existing work flows and regulation.

**Conclusions:** This paper provides an advocacy blueprint for more optimal use of innovative eHealth and mhealth effectively to improve communication, knowledge society and policy issues. This paper aims to further stimulate the development and adoption of user-friendly eHealth platform and context-sensitive information to substantially improve the quality of care patients receive within children palliative care clinics and other settings.

65. BIRTH PLANNING IN PERINATAL PALLIATIVE CARE

*Lisandra Bernardes, Maria Gibelli, Fernanda Figueiredo, Nathalia Bertolassi, Tercilia Barbosa, Renata Bolibio, Ana Gomes, Roberta Jesus, Andresa Vilhegas, Luana Rocha, Gladys Rosa, Glaucia Benute*

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**Background:** Prenatal palliative care after prenatal diagnosis of a life-limiting malformation is a recent field. There are few authors that published models of follow up, and only one of them described the implementation process. No study, studied the development of conjoint birth plan with families followed in this setting.

**Aims:** 1) To describe the implementation process of a group, with challenges inherent to the insertion of a new model in a tertiary centre that emphasizes treatment. 2) To describe the practical model of follow-up. 3) To study factors related to the possibility of the construction of birth plan in this model

**Methods:** Women followed by the GAI group from May 2015 August 2016 were studied retrospectively. Quantitative and qualitative analysis were performed. A logistic regression model was used to verify which variable(s) were related to birth plan development.

**Results:** The implementation process and model of follow up is described. Fifty patients were included and 36 (72%) of them developed a conjoint birth plan with the health team. The final logistic regression model demonstrated that the only variable associated with the development of a birth plan was the number of prenatal conferences (beta 1,750,147 (IC: 0.730, 2.771), p = 0.001).

**Conclusion/Discussion:** Implementing perinatal palliative care after diagnosis of fetal malformation is possible in tertiary centers. The factor related to the likelihood of developing a conjoint birth plan in the proposed model was the number of prenatal conferences attended by the family.

66. **BREAKING BAD NEWS: A STUDY ON FORMAL TRAINING IN A HIGH-RISK OBSTETRICS SETTING**

Fernanda Figueiredo, Glaucia Benute, Maria Gibelli, Nathalia Bertolassi, Tercília Barbosa, Renata Bolibi, Ana Gomes, Roberta Jesus, Maria Silvia Setubal, Rossana Francisco, Lisandra Bernardes

GAI- Group of study in perinatal palliative care

Clinics Hospital, University of São Paulo, São Paulo, Brazil

**Background:** Breaking bad news in a high-risk obstetrics clinic is frequent. Few studies had examined the role of medical training in improving such difficult task.

**Aims:** To evaluate the influence of a training program in the participants’ perception on bad news communication at a high-risk tertiary obstetrics center.

**Methods:** Obstetrics and Fetal Medicine physicians from the Hospital das Clínicas at the University of São Paulo, answered a questionnaire based on the SPIKES protocol for communicating bad news before and after a formal training in braking bad news. Training consisted of theoretical lectures and small groups practices using role play techniques based on SPIKES strategies adapted to Obstetrics. Answers were compared using non-parametrical tests to evaluate the differences in the physicians’ perceptions in the two moments. Physicians’ evaluation of the training program included quantitative and qualitative analysis.

**Results:** All the 89 physicians who answered the pre-training questionnaire received training. Forty of them answered the post-training. Baseline parameters were similar in both groups. After training, there was a significant improvement in preparing the environment before delivering bad news (p, 010), in feeling prepared and able to transmit the news (p, 000), in feeling able to discuss prognosis (p, 026), in feeling capable to discuss ending the pregnancy/ initiation of palliative care (p, 003), and end-of-life issues (p, 007), as well as feeling secure to answer difficult questions (p, 004).

**Conclusion/Discussion:** Training seems to enhance physician’s ability to communicate bad news bringing institutional awareness to the theme.

69. **UNDERSTANDING THE RELATIONSHIP BETWEEN ADOLESCENTS, IN PALLIATIVE CARE, AND THE CYBERSPACE: AN ETHNOGRAPHIC MODEL**
**Camila Amaral Borghi, Regina Zyli**

**Background:** To take care of adolescents with some life limiting and/or long threatening disease, we must take some importance into the fact that in this period the adolescent will pass through two transitions - the infant stage to adulthood and the pediatric treatment for to adult. All these changes in a life of a adolescent in palliative care can affect the social and psychological development. Cyberspace has become an alternative social space, causing a great technological, social and cultural change in society, especially for adolescents, becoming a very important tool in their lives.

**Aim:** To know the relationship between adolescents in palliative care and the cyberspace and to propose an explanatory model for this relation.

**Methods:** This is a qualitative research supported in two ethnographic methods (usual and the netnography). Ten adolescents were submitted for a double data collection, where they were interviewed and their social network has been observed. In total we have three hours of interviews and 8861 posts from each adolescent on Facebook profile.

**Results:** The adolescent in palliative care use the cyberspace in their routine looking for support, distraction, communication and for managing their pain. When the cyberspace is used, the adolescent in palliative care can assumed two personas, one’s who are inside the internet an adolescent who doesn’t have any problem, have a lot of friends, receive a lot of likes and comments. In another hand, when they assume who they are in real life, they post about their disease, treatment and feelings, but always looking for something, like emotional support in a sad moment or for self-promotion.

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

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**70. THE NEED FOR SUSTAINING HOPE DURING COMMUNICATION OF UNFAVOURABLE NEWS IN THE CARE OF CHILDREN WITH PALLIATIVE CARE NEEDS: THE EXPERIENCE OF MOTHERS AND HEALTH PROFESSIONALS IN JORDAN**

*Maha Atout, Pippa Hemingway, Jane Seymour*  

**Background:** A preliminary systematic review shows that health professionals experience a tension when communicating with the parents and family members of children with life-threatening and life-limiting conditions. On the one hand, they want to promote open and honest communication, while on the other, they are apprehensive about fostering an unrealistic sense of hope. Defining the boundaries between information that might offer reasonable hope versus that which results in false reassurance is challenging. Some healthcare providers worry that instilling a false sense of hope could motivate parents to seek continued aggressive treatment for their child, which in turn might cause the patient further unnecessary suffering. To date, there has been a lack of research in the Middle East regarding how healthcare providers do or should communicate bad news; in particular, the issue of hope in the field of paediatric palliative care has not been researched thoroughly.

**Aim:** This study aims to explore, from the perspective of patients’ mothers, physicians, and nurses, the experience of communicating and receiving bad news in the care of children with palliative care needs. Methods: Data were collected using a collective qualitative case study approach across three paediatric units in a Jordanian hospital. Two data collection methods were employed: participant observation and semi-structured interviews. Findings: The overall number of cases was
15, with a total of 56 interviews with mothers (n=24), physicians (n=12), and nurses (n=20) completed, as well as 197 observational hours logged. The findings demonstrate that mothers wanted their doctors to provide them with hopeful information about the future progression of their child’s illness. Although some mothers asked their doctors to provide them with honest information regarding the condition of their child, they still considered a sense of hope to be essential for coping with caring for their child. According to mothers, hope was critical to treatment as it helped them to stay committed to the treatment and protected them to some extent from the extreme emotional suffering that would occur if they lost hope. The health professionals agreed with the mothers on the importance of hope, so long as it was congruent with the stage and severity of each patient’s disease.

**Conclusion:** The findings of this study conclude that while parents typically insist on knowing all relevant information when their child is diagnosed with a severe illness, they considered hope to be an essential part of life, and they found it very difficult to handle suffering without any glimmer of it. This study finds that using negative terms has extremely adverse effects on the parents’ emotions. Hence, although the mothers asked the doctors to be as honest as they could, they still wanted the physicians to provide them with a positive message by communicating this information in a sensitive manner including hope.

### 75. DO WE EVALUATE THE OUTCOMES OF OUR INTERVENTIONS IN PAEDIATRIC PALLIATIVE CARE?
**A SYSTEMATIC REVIEW**

*Marie Friedel, Jean-Marie Degryse, Anne-Catherine Dubois, Isabelle Aujoulat*

**Background:** Paediatric palliative care (PPC) mainly intends to promote children’s quality of life in a family-centred approach, but measurement of this multidimensional and highly subjective outcome remains challenging. However, patient-reported (self-reported) outcome measures remains difficult in a paediatric context.

**Objectives:** This systematic review had 2 objectives:
- (i) to identify PPC interventions/programs, related to specific defined outcomes, which were evaluated.
- (ii) to document the psychometric properties of the instruments used to measure those outcomes.

**Methods:** We performed a systematic literature review, according to the PRISMA guidelines (Moher et Liberati et al. 2009). Five databases (Embase, Scopus, Cochrane Library, Psychinfo, Medline) were searched from 1 January 2006 to 1 February 2016. Keywords following PICO included: child/children/adolescent/p*p*d*iatr* + palliative/supportive/respite/bereavement care+ impact/ evaluation/outcome/ assessment. From 2150 articles, after removal of duplicates, 302 papers were included based of the title and abstract. A total of 54 papers were cross-matched by 3 researchers for full-text assessment. Finally, 23 studies met the eligibility criteria, which were a) definition of PPC and b) documented PPC intervention and c) description of outcomes and d) description of instruments used. Data extraction and coding was performed by 2 independent researchers and discrepancy was discussed with 2 other researchers. Quality assessment of studies was done using the checklist standard quality assessment criteria for evaluating primary research papers from a variety of fields. HTA initiative, 2004.

**Results:** Outcomes in PPC are not systematically measured yet, data collection and/or data analysis are not always reported following standardized criteria. Instruments used to measure outcomes demonstrate scarce psychometric properties. However, research in measuring outcomes in children receiving PPC should be reinforced because outcomes measures in PPC improves legitimacy, funding and integration of PPC in sustainable health systems.
76. A BIG Dream?
Lynda Gould
Goals
• introduce and spread the concept of paediatric palliative care (PPC) in China
• create culturally appropriate replicable models
• show what palliative care looks like within limited resources
• ensure sustainability
• reduce the need for abandonment

Background: Butterfly Children’s Hospices (BCH) set out to pioneer ppc in a country with a tragically high number of abandoned sick and dying children. At the time of starting the concept of ppc was poorly understood, and families had no access to help for a dying child.

Methods: With no pre-existing framework, BCH developed a model applicable to the culture. To achieve sustainability, gain credibility and support, they worked within the government system.

Results: To date 197 children have been cared for in a Butterfly Home, 22 children are receiving care, 112 have died, 27 have been adopted and 8 more waiting. 10 families have received help. Two years after opening the first home and using that model, BCH opened a second in another city, now running independently. 60% of income is from within China.

BCH has
• organised and hosted 3 national conferences in China, one attended by HRH Princess Anne.
• Translated education and training materials into Chinese
• Funded and produced the first educational video in Chinese
• Delivered training for healthcare professionals in two major hospitals, assisting them to develop services for families
• Advised on healthcare policy

The Founder/CEO was elected an honorary member of the board of the national China Care for Life Association. She was awarded the MBE by the British Queen.

Discussion: Although extremely challenging, BCH successfully influenced a sustainable and expanding service in a country with limited access to, or knowledge of, palliative care.

Learning: Government involvement is more difficult but provides sustainability and spread. Passion, resilience and perseverance are crucial.

77. NEEDS OF ADOLESCENT CHILDREN AND THEIR CAREGIVERS: TO IMPROVE THEIR QUALITY OF LIFE
Dr Pradnya Talawadekar, Dr Maryann Muckaden

Background: The life limiting conditions bring with them pain, discomfort, hospitalizations and emotional, psychological and social challenges for children and also for their families as they cope with taking care of the sick child and coming to terms with their own feelings like sadness, helplessness and anxiety. Children in adolescent age group have various issues. Assessment of these issues helps in providing ‘Quality Care’ to these children and their caregivers.

Aim: To evaluate the needs and concerns of Adolescent Children and caregivers to provide quality care.

Methods: The Focus Group Discussions and interviews are held with the caregivers and children with different life limiting conditions to evaluate their concerns and needs. The voices of the participants are documented and a plan of ‘Quality Care’ is decided in collaboration with a Multidisciplinary team to provide need-based services.
Results: The focus group discussions with the children and their caregivers have been helpful in building rapport and that has helped to assess the behaviour, needs and concerns of adolescent children.

Conclusions:
- Adolescent children have varied needs ranging from information about the disease to sexuality.
- The needs differ as per the disease trajectory.
- Need assessment help the team to plan the ‘Quality Care’.
- Different models of care may be necessary for different needs.

78. FOCUSED ULTRASOUND AT PARENTAL REQUEST TO FACILITATE SHARED DECISION-MAKING AT END-OF-LIFE IN TWO NEONATES
Regina Okhuysen-Cawley, Jonathan Davies, Amy Mehollin-Ray, Sahar Siddiqui, Kimberly Lehecka, Tammy Kang, Samara Potter, Barbara Levy

Aims: Describe the use of an additional ultrasound testing at parental request to facilitate decision-making at end-of-life.

Methods: Medical record review (exempt per our institution’s investigational guidelines).

Baby A, 2.4-kilogram girl, had renal dysgenesis and cloacal agenesis diagnosed in utero, with renal failure when spontaneously delivered at 32 weeks gestation. The infant was feisty and able to feed by mouth despite these problems and could excrete liquid and fecal waste via an ectopic uterus on her back. She was not deemed to be a candidate for dialysis due to anatomic constraints, including anal atresia and absent bladder. Her father, an immigrant construction worker disconcerted by the baby’s vigor, asked for one more ultrasound to confirm the diagnosis.

Baby B, a 3.2-kilogram boy, had presented with fetal distress and massive abdominal tumor at 36 weeks requiring urgent caesarean delivery, ultimately confirmed to be neuroblastoma with diffuse metastatic infiltration of the liver. He had renal failure and hemodynamic instability due to vascular compression. His father, a paramedic, requested one more ultrasound, hoping vascular flow could be quantified in the various positions to inform proposed management options, including possible bridging extracorporeal support while awaiting tumor response to chemotherapy.

Approach Taken: Repeat ultrasounds were performed as requested.

Results: The baby girl’s exam was unchanged; her parents elected to take her home with hospice support. Although some enhanced position-dependent vascular flow was documented on the Doppler ultrasound in the boy with neuroblastoma, it was not enough to support any other intervention, and the parents elected to redirect care by stopping vasoactive infusions. Both sets of parents expressed their gratitude at this one last imaging, which afforded them a sense of closure.

Lessons learned: Additional non-invasive imaging, if context-appropriate, may promote trust and facilitate shared decision-making.

83. SUSTAINABLE INNOVATIONS IN CPC, BASED ON THE REAL PATIENT STORY!
Carolien Huizinga, Friso Gosliga, Bianca den Outer, Judith Aris, Meggi Schuiling-Otten

Background: For 10 years now, The PAL Foundation (PALliative care for children) is committed to improve Children’s Palliative Care (CPC) in the Netherlands. However, families often feel that they have to rely on themselves, and sufficient information, coordination and guidance are lacking. In order to improve CPC, we must understand the needs and wishes of these families better. Also, we must involve parents in a structured way in evaluating current developments.
Aims: The aim is to gain insight in best practices, problems and bottlenecks in CPC from the perspective of the families and evaluate current 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, this study will support other families with a child with a life threatening or life limiting condition. By sharing stories from parents to parents, a form of peer support will be added.

Methods: By using the narrative collection tool, SenseMaker®, experiences and stories of parents caring for a seriously ill child are captured. The respondent is then asked what is significant about their story; the parent acts as expert by interpreting his or her narrative. The output is qualitative information, indexed by the sources so that quantitative data emerges, without any external interpretation. The narratives will be collected on a continuous basis, at least during one year. Thereafter it will be repeated cyclically. Parents are invited to participate via our own network, patient associations and social media. They can share their story online at any time they wish.

Results & Conclusion: Data collection is ongoing and will be analysed for trends and patterns in the first quarter of 2018. Pilot result look promising. We will be able to present the results at the conference.

84. A CASE-BASED CASE FOR AN ADOLESCENT MULTIDISCIPLINARY TEAM IN AN ADULT ONCOLOGY UNIT
Louise Walker

Introduction: Adolescent and young adult oncology (AYAO) patients have been described as inhabiting a no-man’s land between paediatric and adult services. The developmental stage, disease profiles, social demands and treatment protocols fit neither the predominant models of children’s nor adult clinics. The South African Department of Health designates paediatric services as under age 12. This mandates that adolescent patients be treated in adult oncology clinics – regardless of maturity or cancer type - compounding challenges to holistic care.

Aims: Through two case studies, to reflect on the importance of integrating the multidisciplinary team (MDT) into holistic oncology care.
To review the supportive literature for routinely incorporating an MDT into care.
To propose a locally-appropriate AYAO care and referral checklist.

Design & approach: Within a constructivist, pragmatic context, two case studies highlighting critical aspects of the AYAO MDT experience in a single centre will be critiqued. A literature review will be undertaken to generate a practical, evidence-based argument for an integrated MDT and a tool designed to streamline this integration proposed.

Results: The first case focused on the pivotal nature of communication and information needs - both for MDT members and for patient and carer. In contrast, the second case was characterized by minimal contact opportunities and thus highlighted the need for efficient teamwork. In both cases, multidisciplinary support was central to optimal care. The role of the MDT to foster an environment of experiential learning and reflective practice was evident. The complex needs of AYAO patients are well documented and MDT integration may offer solutions.

Conclusions: The MDT has a globally recognized role in providing palliative care for adolescents with cancer. It behoves units to streamline use of existing resources and a fully integrated and well-organized MDT contributes to this.

85. CARE 24 MAKING CHOICE A REALITY: DEVELOPING A SERVICE TO SUPPORT END OF LIFE CARE AT HOME FOR CHILDREN AND YOUNG PEOPLE IN NHS LOTHIAN, SCOTLAND
Katrina Marshall, Rachel McAndrew, Julie McGill, Christine Thompson
**Introduction:** All children and young people (CYP) who are recognised as entering the end of life phase of their illness, deserve high quality, child and family centred end of life care, delivered in the place of their choice. In 2013, NHS Lothian recognised a significant inconsistency and inequality in end of life care support available to CYP under the age of 16 years. These CYP did not have access to 24/7 specialist nursing advice and support during end of life.

**Aim:** To support and facilitate choice in preferred place of care by providing a nurse led service that offers access to 24/7 nursing advice and support for those CYP who chose to remain at home for end of life care.

**Method:** Through collaborative working between NHS Lothian and the Children’s Hospice Across Scotland (CHAS), a framework for the delivery of end of life care at home was developed. Production of the framework required many meetings over several months from all invested services. Approval was sought from clinical management teams. This framework details how NHS Lothian Services and CHAS will work together to deliver this service. This joint service is known as CARE 24.

**Results:** Since the implementation of CARE 24 in December 2014, there has been an increase in the number of deaths and more CYP and their families identifying ‘home’ as their preferred place for end of life care through advanced care planning discussions. Informal verbal feedback from families has been very positive.

**Conclusion:** Practical aspects of the service were continually reviewed, and improvements made to implementation following lessons learned through each case. Since implementation of service we have seen increase in the number of deaths at home affirming that NHS Lothian is now able to support real choices in preferred place of care.

**91. AN APPROXIMATION TO THE SPIRITUALITY OF THE CHILDREN WITH SERIOUS NEUROLOGICAL ILLNESS**

*Jose Antonio Porras Cantarero, Martinez Rodriguez, Miquel Diego, Lucia Navarro Marchena, Marta Palomares Delgado, Cristina Gutierrez Rada, Ester Fernandez Morell, Veronica Velez Delgado, Josep Anton, Balma Soraya Hernandez Moscoso*

**Background:** The child with neurological illness is unique and unrepeatable, as a human, and he has an intrinsic dignity. The aim of palliative care is the good care and to promote the quality of life until the death in the physical part and in the others dimension of the person: emotional, relational, social, moral and spiritual.

This job wants to be an approximation to the spirituality of the children with serious neurological illness across a qualitative study from the Symbolic Interaction (Blumer, 1969).

**The goals of this work** are to think about my medic daily practice and the relationship with children with serious neurological diseases, to describe which elements are important in the spiritual dimension of this children and understand how the answer to spiritual needs are managed.

The collection of data is made through a narrative of the professional, with a later analysis with two investigators and categorization in ten groups.

**Conclusion:** The conclusion is the difficult to reach the spiritual dimension of this kind of children and we need more studies to delve into this issue.

**94. PARENTS’ MEANINGS FOR THE RELATIONSHIPS WITH HEALTHCARE PROVIDERS DURING THEIR CHILD’S END-OF-LIFE CARE**

*Maiara Rodrigues dos Santos, Maira Deguer Misko, Patricia Stella Silva Sampaio, Camila Amaral Borghi, Thaisa Carolina Silva Mesquita, Regina Szylit*
**Background:** Losing a child is a traumatic event for parents and a real life-changing experience. Revisiting loss may arise positive or negative feelings associated with the caring experience. Evidences in health field have the challenge to align a more concrete caring practice to benefit parental adaptation after their child's loss. Aim: For this reason, the purpose of this study was to identify the meanings parents attribute to the relationships established with healthcare providers during their grieving process for the death of their child.

**Method:** This was a secondary analysis of data derived from a qualitative interpretative study, grounded in Gadamer’s hermeneutics. Data were derived from field observations in an oncology ward and pediatric intensive care unit and by in depth interviews with bereaved parents at least 6 months after the child’s death from cancer in the hospital. Interview data were analysed using thematic analysis. Results: Parents’ narratives revealed meanings about the care given by healthcare providers during illness trajectory with emphasis in dying process. Meanings assigned by bereaved parents involved the cognitive (re)construction of their experience represented by the central theme: keeping the child’s legacy or leaving my legacy for the child, comprising negative and positive feelings involved in the parents’ attempt to make sense of their loss. Conclusions: In identifying meanings linked with positive feelings related to the experience of the care provided, during parents’ bereavement process, this study can enhance pediatric palliative care policies since the evidences point out to a long-term effective end-of-life care for children’s families. Parents showed the importance of strategies to promote closer relationships with healthcare providers during the illness trajectory aiming to establish a secure bond in child’s end-of-life. Hence, these relationships can enhance excellence in the care provided and help to prevent parents' complicated grief.

**95. COMPREHENSIVE CARE PLAN IN PEDIATRIC PALLIATIVE CARE**

*Jose Antonio Porras Cantarero, Cristina Gutierrez Rada, Sergi Navarro Villarubi, Marta Palomares Delgado, Lucia Navarro Marchena, Ester Fernandez Morell, Daniel Toro Perez, Balma Soraya Hernandez Moscoco, Pau Miquel Lopez, Veronica Velez Delgado*

**Background:** Pediatric palliative patients should be managed by multidisciplinary team. This team should be integrated by hospital and primary care specialists, members from the patient’s school and the palliative care team. The members of the palliative care team should coordinate all patient’s care by meetings with all the members implicated in focused on an individualized comprehensive care plan. This approach may improve patients’ quality of life and their prognosis.

**Aims:** To introduce the team working and implementation of individualized comprehensive care plans method in a Pediatric Palliative Care Unit (PPCU).

**Methods:** Retrospective evaluation of all patients from January to October of 2017 treated in our PPCU implementing multidisciplinary meeting and comprehensive care plan (CCP).

**Results:** We recruited 116 patients, 63 were females (54,3%) and with a median age of 7,6 years old. In terms of pathology: 62 (53,4%) with neurological diseases and 54 (46,6%) oncologic patients. We only conducted interdisciplinary meetings for neurological patients and achieved CCP in 34 of them (54,8%). In 85% of cases we could contact their primary care team. In 30 of the 37 patients who are enrolled in school we were able to work together with their school caregivers.

**Conclusion:** Interdisciplinary and integral management of paediatric palliative care patients should be the standard of care because this approach could have a vital impact in their quality of life and their families and could reduce complications rate. This approach entails big efforts from all the specialists implicated.

CCP are useful tools coordinating the integral care in these patients.
96. KNOWLEDGE, ATTITUDES AND PRACTICES OF COMMUNITY PHARMACISTS WORKING IN THE ETHEKWINI METRO OF KWAZULU-NATAL TO PALLIATIVE CARE; A CROSS-SECTIONAL, DESCRIPTIVE STUDY

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Background: The World Health Organization (WHO) defines palliative care as ‘an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’. Following the WHA resolution 67.19, there is a need for pharmacists to play a role in palliative care. A study was therefore undertaken to determine pharmacist’s knowledge, attitudes and practice to palliative care.

Method: Cross sectional, descriptive study was conducted amongst community pharmacists working in the eThekwini Metro of KwaZulu-Natal. One hundred community pharmacists were randomly selected and administered an anonymous questionnaire after obtaining their consent. The questionnaires were thereafter collected, the data captured and analyzed using SPSS version 22.

Results: Response rate of 91% was obtained. Even though 97.5% of participants were aware of what palliative care (PC) was, only 2.5% indicated they had “very good” knowledge with 52.5% having an “average” knowledge. Of the 89% that encountered PC, 11% stated they had “little to none” knowledge on PC. 55% of them indicated that there is more than one barrier to managing PC patients. Reasons cited were inadequate training and lack of financial incentive with 83.1% stating that their undergraduate degree did not include sufficient knowledge on palliative care. Over 80% of the participants indicated that palliative care ‘should apply to other conditions and not only cancer.

Conclusion: Even though pharmacist’s knowledge on palliative care is not optimal, their attitudes towards palliative care are positive. Majority of pharmacists do manage palliative care patients and have cited many barriers to the management of palliative care patients such as inadequate training.

99. THE MORAL DISTRESS’ DUALITY IN STRENGTHENING OR WEAKENING NURSES TO CARE OF PATIENTS WITH ADVANCED CANCER AND THEIR FAMILIES

Maiara Rodrigues dos Santos, Michelle Freire Baliza, Regina Szylit, Ana Lúcia Siqueira, Costa Calache

Background and aim: Considering the continuing exposure of nursing professionals to the poorly adaptive psychological responses related with care of children and adults in palliative care, associated with gaps in the literature of moral distress in the context of oncology, this study was proposed aiming to understand the occurrence of moral distress in nurses' professionals and their experience regarding the process of moral distress in an oncology hospital. Method: This study used the explanatory sequential model of the mixed methods approach, which is composed of two phases in sequence: first a quantitative prospective observational study was held, followed by a qualitative study guided by Grounded Theory. The Moral Distress Scale was used to collected data, followed by focus groups and semi-structured interviews conducted with nurses of two hospitals, who had cared of an adult or child with advanced cancer. Results: Moral distress was significantly associated with severe burnout and stress symptoms, evidencing consequences for the health of nursing professionals in the context of oncology. Qualitative analysis allowed to identify three categories linked to the moral distress process: Practicing moral agency; living moral distress related to palliative care and experiencing moral resilience. The synthesis of these categories
formed the central category: Moral Distress’ duality in strengthening or weakening nurses to care of patients with advanced cancer and their families.

**Conclusions:** The quantitative and qualitative findings allowed a broader comprehension of the phenomenon of moral distress in oncology nurses. Implications and recommendations include moral distress evidences to enhance palliative care policies by opening spaces in clinical setting as a mechanism to strengthen nurses to care of patients with advanced cancer and their families and to prevent psychological distress as consequence of therapeutic obstinacy and the provision of futile care.

100. INTEGRATING PALLIATIVE CARE INTO A PAEDIATRIC POSTGRADUATE TRAINING PROGRAM
Farah Khalid, Lee Ai Chong

**Background:** Integrating quality palliative care into national health care service requires effective education to all providers. Currently there is no structured palliative care education for paediatricians in Malaysia.

**Aims:** We aim to describe a pilot palliative care teaching programme for paediatric trainees.

**Methods:** This programme runs from March 2017 to February 2018. Trainees from a paediatric programme at a local university were recruited. These trainees were selected based on their training rotations to maximize attendance. Each session had 8-14 trainees. Each training session consists of 8-10 teaching modules over three months. Teaching materials and references were placed on an online platform. Feedback mid- and post-sessions were collected. There was also a 23-question test aimed at assessing knowledge.

**Results:** There are 4 training sessions in the 1-year period. As the project is on-going, the results are preliminary. There are 29 trainees so far; 12 are in their final year of training. The mean test score was 60.8% (34.8% - 82.6%). Three trainees scored 75% or more while 4 scored less than 50%. In one group of trainees the test was given before and after completing all modules. There was only a slight improvement in the mean pre- and post-test scores; 60.9% (34.8%-69.6) to 65.2% (47.9%-87.0%) respectively. Attendance was irregular. Only 4 trainees were able to attend all the modules. Nevertheless, the feedback was favourable; majority thought their knowledge of the specific modules they attended had improved and were confident in managing children with specific palliative care needs.

**Conclusion:** A common reason for not being able to attend the sessions was the need to perform clinical duties. To ensure clinical services are not disrupted, institutional support is required for concurrent education programs for trainees.

**POSTER PRESENTATIONS**
**DAY 2: FRIDAY 1 JUNE**

101. PARENTS` DECISION MAKING PROCESS OF CHILDREN IN PALLIATIVE CARE
Maira Deguer Misko, Regina Szylit, Maiara Rodrigues dos Santos

**Background:** Changes related to the parents’ decision-making process of children in palliative care have been reported in the literature, emphasizing the active role of parents and professionals in sharing information. Considering that professionals are unprepared to deal with the dying process and that parental involvement in decisions is important for the care and future of the family, this study aimed to understand the experience of parents of children in palliative care about the decision-making process in the hospital.
Method: This is a qualitative study using Symbolic Interactionism and Grounded Theory as theoretical and methodological framework. Data collection was performed in a pediatric hospital in Sao Paulo, through active observation, hospital records and semi-structured interviews with 12 parents who had their children hospitalized during the data collection period with a life-threatening condition. The interviews were recorded and transcribed. Data was analysed following the procedures of the Grounded Theory.

Results: After the theoretical saturation has been reached, it was possible to propose a theoretical model to explain the decision-making process of parents by the core category: Being good for my son is being good to me, and the following categories: being scary, recognizing that everything is being done for the child, needing information, deciding about the participation in decision-making, having faith and hope, valuing a relationship of trust with health providers.

Conclusions/implications: The results indicate that parents’ experience in decision-making is related to individual preferences and the relationship with the health care team, which allow them to trust some decisions to physicians and to play an active role as child’s advocates. Ensuring family care, from what parents consider good for their child, allows nurses to guarantee the active role of parents in the decision-making process.

110. Resiliency and Triumph in Texas: Project Joy and Hope
Regina Okhuysen-Cawley, Jan Wheeler, Joy Hesselgrave, Melody Hellsten
Aims: To describe the evolution of Project Joy and Hope (PJH) in Pasadena, Texas, USA, a holistic, replicable source of practical support for families facing life-limiting conditions, and as a platform for caregiver and professional education.

Description: PJH began with the loss of a remarkable 15-year-old young lady, Valerie Grace to cancer, in 1999. The experience revealed tremendous unmet palliative care needs for families and caregivers alike. Dr Jan Wheeler’s grief at the loss of her daughter gave way to a vision: Project Joy and Hope founded a year later, in 2000. Beginning in 2001, PJH began securing housing for families at high risk of homelessness due to life-limiting conditions. The Texas Pediatric Palliative Care Consortium (TPPCC) was launched in 2007 as an educational collaborative, partnering with bereaved families and academic, hospital and hospice institutions throughout Texas. Board Members are providers in these venues and refer families in need, interfacing with other organizations to facilitate policy change at community, state and national levels.

Results: In addition to practical and as-needed in-person emotional support for families and an online chat forum, PJH has awarded bereaved high school seniors over $600,000 USD in academic scholarships. Biannual professional meetings attract international participants. The Tulip Project (2013) includes six duplex handicapped-accessible homes for transitional residential needs of families with medically fragile children, with outdoor areas arranged to encourage multi-family interactions. Additional land was acquired for future expansion in 2014, and a Capital Campaign began in 2016 to expand the number of homes and build the first comprehensive pediatric palliative care center in Texas. In 2017, Hurricane Harvey devastated PJH’s office headquarters; thankfully sparing The Tulip Project, which is undergoing expansion.

Lessons learned: Grief can be a powerful catalyst for strategic partnerships and change, as evidenced by the success and resiliency of this program.

113. PICTURES AS MEMENTOS AFTER PERINATAL DEATH: A CASE STUDY
Roberta Jesus, Glauçia Benute, Maria Augusta Gibelli, Nathalia Nascimento, Tercilia Barbosa, Renata Bolibio, Ana Gomes, Fernanda Oliveira, Maria Silva Setubal, Raquel Ferreir, Rossana Francisco, Lisandra Bernardes
**Introduction:** The grieving process following perinatal loss caused by lethal fetal malformation present some particularities associated with the culture and the symbolic relationship with the deceased.

**Objective:** To reflect about the symbolic meaning attributed to mementos– particularly pictures taken immediately after birth

**Method:** Case study. Discourses of three women assisted by GAI who received a diagnosis of lethal fetal malformation and whose death occurred immediately after birth.

**Results:** All three patients had contact with their newborns while they were still alive. Deaths occurred in the Labor and Delivery room. One of the women chose not to take a picture and opted to take home the hood with her son’s name - a regular procedure to every birth at this center. Later she questioned her decision and related it to wishing the experience would had never happened. The two other women took pictures and still look at them affectionally. One of the women keeps the picture of her child in a shrine at home attributing a religious_symbolical meaning (child sanctification) to the whole experience alleviating her pain. Something good came out of that painful reality. Pictures represented the memory keeping element. They seem to make motherhood real. Pictures materialized special moments in live: pregnancy, labor and birth. Women attributed symbolic meanings to those pictures, identifying elements that could complicate or aid the grieving process.

**Conclusion:** The symbolical meaning attributed to pictures of the deceased can help processing grief. In Brazil there are few studies about the theme.

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116. **RISK AND PROTECTIVE FACTORS FOR PARENTS BEREAVED FROM CHILDHOOD CANCER**

*Leigh Donovan, Claire Wakefield, Vera Russell, Joanna Fardell, Richard Cohn*

**Background:** Parents bereaved from childhood cancer suffer a concertina of losses prior to and following their child’s death. Understanding the risk and protective factors for parents throughout this trajectory may help target interventions and resources to at risk parents throughout a child’s cancer care trajectory and through their transition into bereavement.

**Aims:** The purpose of this study was twofold: 1) to explore demographic and medical factors that may provide additional evidence to inform targeted interventions for parents throughout a child’s cancer care trajectory and continuing into bereavement, and 2) to allow parents to describe the factors they believe contributed to their grief and growth.

**Methods:** This study adopted a convergent parallel mixed method design. Participants were recruited through four paediatric oncology sites in Queensland and New South Wales, Australia (>6mths and <10years bereaved; n=119). Data was collected on participants’ demographic characteristics and on their grief outcomes using the Hogan Grief Reaction Checklist (HGRC) and via a semi-structured interview.

**Results:** The final multivariate model indicated six predictors of grief: parent employment status (Despair: β=4.748, p=0.038; Disorganistion (β=5.361, p=0.002; β=5.384, p=.008), child’s location of death (Despair: Hospital β=7.249, p=0.050; Hospice β=2.596, p=0.272); parent relationship status (Blame/Anger: β =7.926, p=.001); religious affiliation (Blame/Anger: β=6.932, p=.048); radiation treatment (Blame/Anger: β=4.942, p=0.045); referral to palliative care (Blame/Angerβ=11.815, p=.001). Mothers had significantly higher scores on the growth scale than fathers (β=6.155, p=0.010). Illustrative quotes extracted from the parent interviews provide qualitative support for the multivariate analysis.

**Conclusion:** This study further enhances our understanding of which parent and child characteristics should be acknowledged and attended to from the point of diagnosis throughout
the child’s treatment and end of life to support a preventative and targeted approach to bereavement care.

117. INTEGRATED BEREAVEMENT CARE IN PAEDIATRIC HEALTH: FINDINGS FROM A CHURCHILL FELLOWSHIP INTERNATIONAL STUDY TOUR

Leigh Donovan

Aims: Most tertiary children’s hospitals in Australia where children are treated for life-limiting or acute medical conditions do not offer coordinated care for all bereaved families (the exception is paediatric palliative care services in some states). Hospital bereavement care does not attract activity based funding in Australia as the ‘client’ is deceased and the family is not a patient of the service. This international study tour and Churchill Fellowship seeks to identify international best practice paediatric hospital bereavement services that can inform guidelines, and support advocacy for, the delivery of integrated bereavement services at each tertiary children’s hospital in Australia.

Methods: This study tour involves visiting bereavement programs in paediatric hospitals, hospices and community-based organisations in the United States, Canada, United Kingdom, Ireland, Sweden and South Africa.

Results: This paper will present preliminary findings and recommendations arising from the international study tour.

Conclusion: Integrating best practice transitional bereavement care programs at each tertiary children’s hospital in Australia will enhance social, psychological, mental health, marital and parenting outcomes for bereaved parents and surviving children and reduce costs to the health system. This project may further inform international guidelines for bereavement care for families following the death of a child.

118. EDWARDS AND PATAU’S SYNDROME: DOES PERINATAL PALLIATIVE CARE IMPACT THE OUTCOME?

Raquel Ferreira, Maria Augusta Gibelli, Nathalia Bertolassi, Glauzia Benute, Tercilia Barbosa, Renata Bolibio, Ana Gomes, Fernanda Figueiredo, Roberta Jesus, Rossana Francisco, Lisandra Bernardes

GAI- Group of study in perinatal palliative care
Clinics Hospital, University of São Paulo, Brazil (HC-USP)

Aims: To describe perinatal outcome of fetuses diagnosed prenatally with trissomies 18 and 13 and to compare the decision making in two groups (followed in perinatal palliative care and those having routine follow up), such as neonatal resuscitation, artificial life support, surgical procedure, vasoactive drug use, in addition to parents contact with the child, hospitalization time and survival rate.

Methods: Retrospective review of databases of children followed in a single center (HC-USP) in the last 5 years.

Results: Twelve patients were included; 8 were followed by the GAI group and 4 didn’t. We compared the disclosure and the interventions of both groups. There was a predominance of vaginal delivery in patients in followed by perinatal palliative care (62.5% x 50%), greater skin-to-skin contact with the mother (62.5% x 0%). A longer average survival time was observed in patients with GAI follow-up (average 124 x 66 days), but with a shorter hospital stay compared to patients without this follow-up (51 x 66 days).

Conclusion/Discussion: The follow-up with the perinatal palliative care group has the objective of helping the formation of a stronger early bond between mother and newborn, with fewer
interventions in the delivery room and longer skin-to-skin contact. This follow-up also allowed for the elaboration of a plan of care with the objective of early de-hospitalization when possible.

128. KNOWLEDGE, PRACTICES, ATTITUDES AND OPINIONS ON END OF LIFE CARE, OF PEDIATRIC HEALTHCARE PROVIDERS, AT A GENERAL HOSPITAL IN COLOMBIA

Maria Cordoba-Nuñez, Paula Guzmán, Ana Catherine, Arevalo O’Byrne, Yudy Andrea Corredor Becerra, Isabel Cristina Eraso Paz

Introduction: Every day healthcare providers working at high complexity hospital face decision making involving children with life-threatening diseases and major impacts on quality of life. Concepts like disthanasia, euthanasia and limitation of therapeutic effort (LTE) arise as important concepts for attention models in pediatrics.

Objectives: Identify the knowledge, practice, attitudes and opinions of healthcare providers and faculty members on LTE on pediatric patients at a pediatrics department of a general teaching hospital in Bogotá, Colombia.

Methods: Cross sectional study. In 2006, an structured survey was applied to the healthcare providers and faculty members at a general teaching hospital in Colombia. Data was analyzed using R software raw percentages were calculated.

Results: 121 people answered the questionnaire (80% of the population). 96% of the people who answered are knew the term LTE and although 91.5% has been involved at least in one case LTE, only 25% considered received capacitation on the topic during their training. The 86% of cases deriving on LTE the decision was taken through a multidisciplinary meeting or with the family.

Conclusion: After a sensibilization process at the pediatrics department of Hospital Universitario San Ignacio (HUSI) at Bogotá, Colombia, most of the end-of-life decisions and LTE were taken through multidisciplinary meetings. Although the healthcare providers working in this department are aware of the existence of the LTE term, yet only a minority received training on the subject during medical/nursing school. We consider educational tools and support are needed for the healthcare staff regarding pediatric palliative care.

130. MANAGEMENT OF PAEDIATRIC PAIN: HOW KNOWLEDGEABLE ARE HEALTHCARE PROVIDERS AT A TERTIARY CENTRE, SOUTHERN NIGERIA?

Gracia Eke, Datonye Briggs

Background: Many disease processes and most interventional procedures in paediatrics are associated with pain, an unpleasant sensory and emotional experience associated with actual or potential tissue damage. In spite of its frequency, it is inadequately assessed and undertreated globally, exposing children to the risks of long-term physical and psychological sequelae, including among others, anticipatory anxiety during future procedures, a lowering of the pain threshold and sensitization to future pain.

Objectives: To ascertain the knowledge, perception and practice of healthcare providers towards management of paediatric pain at the University of Port Harcourt Teaching Hospital (UPTH).

Methods: A semi-structured and self-administered questionnaire, used as instrument for data collection, was distributed amongst a convenient sample of physicians and nurses attached to clinical departments/units where children are cared for, and those in educational units.

Results: One hundred and ninety-seven subjects participated in the study, 95(48.5%) physicians and 102(51.8%) nurses. One third of participants (30.4%) could name up to 3 non-pharmacological methods of pain management, of which the commonest were cold compress (24.4% with nurses>physicians), followed by hot compress (19%) and diversion (12%). Whereas non-pharmacological interventions of pain management were usually used for venepuncture (17%),
insertion of venous catheter (6%) and lumbar puncture (1.5%), pharmacological ones were used for venepuncture (5.6%), dressing changes (4%), lumbar puncture (8%). Half of respondents (52%) had never prescribed/administered morphine to children. Few of them (23% with nurses>physicians) knew that the most suitable dose of morphine for a patient in pain is a dose that best controls the symptoms; and that common side effects of morphine include constipation (10.7%), itching (2%), nausea (5.6%) and respiratory depression (20.%).

**Conclusion:** Healthcare providers had poor knowledge of paediatric pain management. There is an urgent need to build their capacity to enable optimal relief of pain among paediatric patients.

### 132. THE USE OF EDUCATION AND TRAINING AS AN ADVOCACY TOOL - THE ICPCN EXPERIENCE

*Busi Nkosi, Julia Downing, Sue Boucher, Alex Daniels*

**Goal:** Integration of Children’s Palliative Care (CPC) into countries’ health care systems in order to improve the quality of life of children with PC needs.

**Approach taken:** A variety of approaches have been taken including: a) collating data on the state of CPC in a particular country; b) liaising with the individual responsible for PC in-country e.g. the MoH or national palliative care association; c) ensure governments are involved and supportive of CPC development; d) source funds for education and training; e) Conduct meetings with key stakeholders to create CPC awareness; f) provision of education and training on CPC including clinical practice; g) developing strategy for implementation of CPC and the ongoing scaling-up of education and CPC provision.

**Results:** ICPCN has been working in a number of countries globally to provide appropriate CPC education. This has resulted in: CPC knowledgeable and skilled health care workers; National CPC trainers; National CPC guidelines; National CPC curriculum; Tools for M&E; the Integration of CPC into the country’s national health system. However, many challenges exist, both in terms of education and also the implementation of CPC.

**Lessons learned:** These include: Education is an important tool in advocacy because it removes the myths previously held by individuals and creates an interest in the subject matter; Government involvement is essential as the custodian of the country’s health care; To increase the number of CPC practitioners in the country it is important to develop a strategy for ongoing sustainable training. This will counter the effects of attrition and maintain quality in the provision of CPC; In many cases countries are not aware of the scale of CPC need in their countries. The development of M&E tools helps them to determine this need and plan appropriately for future CPC provision.

### 133. THE ATTITUDES OF CLINICIANS TOWARDS PALLIATIVE CARE BEFORE AND AFTER RECEIVING TRAINING IN PALLIATIVE CARE

*Busi Nkosi*

**Background:** One of the challenges to the integration of Children’s Palliative Care (CPC) is lack of understanding about CPC thus impacting clinicians’ attitudes to palliative care (PC). Thus, part of a project to develop CPC training in Lesotho was training for clinicians.

**Aim:** To determine a change of attitudes in clinicians after undergoing training in children’s palliative care (CPC).

**Method:** A questionnaire containing 11 questions was administered to 12 clinicians before and after undergoing basic training in CPC. The clinicians consisted of three medical officers, two pharmacists and seven nurses. The questionnaire was adapted from the City of Hope Pain/Palliative Care Resource Centre and had been utilised in previous training programmes conducted by ICPCN.

**Results:** Findings demonstrated a change of attitude after training. The most significant changes included: 75% said they were now able to talk about death to dying patients (Increased from 41%);
80% were comfortable to refer patients to a PC service (Increased from 42%); 100% agreed that a hospital is not a great place to die (an increase from 25%); 80% felt comfortable in caring for a dying patient (Increased from 67%); 91% were aware of the right of a patient to decline treatment (Increased from 58%). However, feeding at the end of life remained a controversial issue with only 33% comfortable to stop feeding and the perception by clinicians of seeing death as a failure remained a challenge (50% increased from 33%). 92% agreed that working with seriously ill patients made them aware of their own feelings regarding death.

**Conclusion:** Training in CPC can result in change of attitudes in clinicians and along with more exposure to children with life threatening illnesses, such as through clinical placements and continuous education a radical shift may occur. However, change in attitudes takes time, and requires an ongoing strategy.

**137. WHAT WORRIES PEDIATRIC PALLIATIVE CARE PROVIDERS IN LATIN AMERICA?**

*Regina Okhuysen-Cawley, Natalie Rodriguez, Yuriko Nakashima, Rut Kiman, Edgardo González, Marisol Bustamante, Silvia Rivas*

**Aims:** To describe dominant themes emerging from discussion of challenging pediatric cases submitted for a themed workshop during the biennial Asociación Latinoamericana de Cuidados Paliativos (Latin American Society for Palliative Care) in Medellin, Colombia, in 2014

**Design / Methods:** Blinded cases solicited in advance of the conference were distributed to random groups of 6 – 8 multi-professional, multinational attendees, for focused discussion regarding medical decision making, sharing bad news, and symptom management. Findings were presented by a group spokesperson. Monitors from the workshop leadership summarized the themes that emerged during the general discussion that ensued.

**Results:** Most patients had required admission to intensive care units. One adolescent with static encephalopathy was experiencing physiologic decline; another adolescent suffered from severe recurrent epistaxis, physical and existential pain due halitosis and progressive inability to speak as his nasopharyngeal tumor advanced. One girl with metastatic hepatoblastoma yearned to get home, far away from medical resources. The parents of an infant with a genetic syndrome demanded prolonged life-sustaining medical interventions expecting cure in another country. The parents of a hydranencephalic child were distressed by conflicting surgical recommendations regarding shunt placement.

Dominant themes included communication challenges within families and with their medical team, in all cases. All families feared inadequate symptom control at end of life, and the potential impact of death at home. Many described ‘dissonance’ in medical recommendations as a significant source of suffering, and an important contributor to breakdowns in communication. Workshop participants shared these concerns, and worried about basic resource availability and the consequences of medically inappropriate application of emerging technology, particularly prolonged suffering.

**Conclusions:** Use of strategies designed to improve symptom control, anticipatory guidance, education and communication within families, their teams, and at the interdisciplinary and multidisciplinary professional levels must be prioritized in all institutions caring for seriously ill children.

**139. WORDS, TERMS AND HOW YOU USE THEM - THE KEY TO ACCEPTANCE OF PAEDIATRIC PALLIATIVE CARE (PPC) BY PARENTS AND CHILD**

*Melissa Williams-Platt*
Aims and Goals: Acknowledging that the words and terms we use in PPC can be scary and misunderstood and are not commonly used by the public. Developing public awareness around PPC and debunking the myth that PPC is only end of life care.

Design, Methods and Approach: Motivated by our personal experience of 15.5 months in hospital with our late son, Samuel, my subsequent studies in PPC, our advocacy work in healthcare and in supporting families with children with chronic illness, I have become fundamentally aware of how PPC acronyms and terms such as ‘quality of life’, ‘a good death’, ‘life-limiting’ and ‘life-threatening’ are bandied about and often simply serve to confuse and terrify both parents and child. As healthcare professionals steeped in these daily terms we forget that this language may as well be Martian for the average person. Couple this with cultural differences, language barriers, poor education and communication becomes even more fragmented and frightening.

Results: In memory of Samuel, we have created a Trust, Footprints4Sam to help bridge this miscommunication gap, fragmentation of care and overall fear of PPC. A primary pillar of the Trust is advocacy to encourage healthcare professionals to choose their words wisely and to encourage empathy and compassion in their approach to care. Building the Samuel Generation of healthcare - A generation of professionals with a palliative mindset i.e. driven by the values and principles of PPC and child/family-centred care. Collaborating with organisations e.g. Rare Diseases, PatchSA, Kids Kicking Cancer.

Conclusion: Key to the acceptance of PPC is to mind our language and choice of words. As families, thoughtless words and terms used by healthcare professionals are often seared on our hearts, therefore words and terms used need to be thoughtful, considered and should meet parents and child at their individual level of knowledge and understanding.

143. PalNet - A HOLISTIC NETWORK PROVIDING PALLIATIVE CARE SUPPORT TO CHILDREN AND ADULTS IN KWAZULU – NATAL

Samantha Govender

Palliative care is a necessary discipline in Kwa-Zulu Natal. Through the author’s work it has been discovered that many patients do not have access to palliative care both in the public and private sector which is a grave injustice. Patients are being deprived of palliative care professionals who can help them achieve good quality of life after their diagnosis. Unfortunately, Healthcare professionals are not fully aware of palliative care services and the role that it can play, thus preventing us from considering what is in the best interests of the patient and their family and thus robs them from the opportunity to be a part of their health care decisions. We need to create awareness to achieve good quality of care, which encompasses the sensitive delivery of news, compassion, empathy and allowing for individualised holistic care plans. In South Africa palliative care is a growing speciality where further understanding, advocacy and networking are needed.

To bridge the gap of palliative care services, the author has been given the opportunity to contribute in the development of a network organisation named PalNet. PalNet is a group of dedicated professionals from varied specialities both within the private and public sectors as well as NGOs who see the need for palliative care in all sectors for both adults and children. PalNet aims to create opportunities for advocacy, networking, collaboration and training in order to achieve optimum goals of care. PalNet’s vision is to create an organisation to ensure that palliative care is available to all patients at the time of diagnosis and to assist them through the journey of life as peaceful and painless as possible. This is a ground-breaking initiative within KZN and the author would welcome the opportunity to discuss the formation of this group and the manner in which it functions.
147. THE EVOLUTION OF PALLIATIVE CARE COVERING 20 YEARS IN RURAL SOUTH AFRICA

Silvia Paz

This is my personal review of: My professional growth as a Cuban trained Doctor working in South Africa for 20 years and managing the adversities of the HIV epidemic and other life-limiting conditions affecting children; The challenges inherent in treatment when resources are limited; The contrast between the life-saving role of a Paediatrician versus the role of being a compassionate health-care provider for the dying; Experiencing professional burn-out and the reality of starting over again in a different role; and The motivation to practice Palliative Care along with the integration of holistic care for children and their families.

After a long journey in my role as ‘hero’ - saving lives and curing patients – I discovered that there were no means in place to assist and prepare children or their parents for the end of life. Paediatric Palliative Care training has brought to life a new side of me which embraces a profession that strives to prevent and fight illnesses. That training has moulded me into a doctor who cares for the life of her patients and their families. And a doctor who accepts death as a normal event of life’s end which can be assisted with the provision of continuous compassionate care.

153. SAFELY NAVIGATING THE PICU/NICU – A PARENTS’ SURVIVAL GUIDE – INSPIRED BY OUR BRAVE SON SAMUEL JOHN FREDERICK PLATT AND HIS INCREDIBLE JOURNEY

Melissa Williams-Platt

Aims and Goals: To provide parents with a useful and practical guide to help them safely navigate the quagmire and unknown world of NICU/PICU.

To immediately empower parents with key knowledge on arrival in the NICU/PICU.

To supply parents with a network of support during this difficult ICU journey with family-centred support organisations such as Footprints4Sam, Rare Diseases South Africa, Jenna Lowe Trust, PatchSA etc.

Design, Methods and Approach: Motivated by our personal experience of 15.5 months in hospital with our late son, Samuel, and the many times we felt alone, ill-informed and afraid as parents, I was inspired to gather all the information we learnt and to compile it into one helpful booklet that would be available to parents in the hospital NICU/PICU wards on their arrival. In this way parents would not have to face this difficult journey alone.

While compiling the Parents’ Guide I also checked in with other ICU parents and healthcare professionals to hear their views and suggestions on what I had compiled.

Results: The Parents’ Survival Guide is now finalised and will be printed by companies and NGO’s in the healthcare industry. For every ten brochures, a company prints, an additional one brochure will also be printed for distribution to NGO’s and government hospitals, thus ensuring a broad base of distribution and sustainability for this initiative.

Conclusion: Having a reference tool that is written by a parent who understands the ICU journey from the time of your child’s admission (or even before in the case of a suspected preemie birth) will help empower parents as they face this difficult, uncertain and scary journey.

Being informed and supported will provide parents with an essential foundation for paving the way towards getting themselves and their child safely home, while hopefully helping to soothe the many worries and uncertainty that they encounter along the way.

154. CHANGING LANDSCAPES - PAEDIATRIC PALLIATIVE CARE ACROSS WESTERN AUSTRALIA

Marianne Phillips, Burr C., Momber S.

Background: The provision of equitable culturally appropriate holistic palliative care for children with complex, rare life-limiting conditions to distinct populations living in diverse metropolitan,
rural and remote environments across the vast geographical region of Western Australia presents significant challenges.

The national Quality of Care Collaborative Australia (QuoCCA) project, co-ordinated through Queensland Health, aims to improve the quality of palliative care provided to children in close proximity to their home through various initiatives. The project ensures the provision of funding to facilitate programmes of education and awareness nationally, including across Western Australia (WA), with seminars, symposia, structured teaching, and primary health team support in didactic, one-on-one, videoconferencing and timely individualised pop-up models. QuoCCA funded staff ensure the delivery of case specific and directed, targeted paediatric palliative care education to improve the quality of care provided to children with life limiting illnesses, and to those at end-of-life, through initiatives to build the capacity of health professionals, and others, involved in the care and consequently provide high quality palliative care for children and families regardless of location.

**Method:** A variety of methodologies and techniques have been adopted in WA to meet the challenge of providing the same standard of care for all children and their families across the state, with peoples from vastly differing cultural understandings of medicine, palliative care, dying, ideas of family and the value of children. Evaluation of the sessions considered prior knowledge, confidence and efficacy and were performed pre- and post-delivery.

**Results:** The project commenced in WA in October 2015. Evaluation identifies over 25 scheduled educational sessions, 18 pop-up visits and 30 incidental educational opportunities to have been provided. Effective education was provided to multiple professional disciplines with nurses representing the largest group of attendees. From surveys there has been an improvement in the knowledge and confidence of participants across all domains evaluated.

**Conclusions:** All project KPIs have been surpassed with ongoing evaluation of the project identifying its significant value in facilitating improved patient and family outcomes through the provision of holistic paediatric palliative care to metropolitan, regional and remote areas of WA.

156. ESTABLISHMENT OF AN EDUCATION AND STIMULATION CENTRE FOR CHILDREN WITH DRUG RESISTANT TUBERCULOSIS: ADDING LIFE INTO THE DAY OF A CHILD WITH DRUG RESISTANT TUBERCULOSIS AND NOT JUST A DAY INTO THEIR LIFE

Nirupa Misra, Nalini Singh, Mari Van der Merwe, Kantharuben Naidu, Thiloshini Govender, Innocentia Khombisile Zungu, Babu Sunkari, Gloria Mtamzeli, Shamin Maharaj

Access to palliative services over the course of an illness to alleviate unnecessary pain and suffering is a basic human right. Section 28 of the Constitution provides that all children have the right to basic health care services, but children are unique but in addition to this being in an environment that appeals to a child, stimulates them and allows them to play is critical to their holistic wellbeing and early childhood development.

In KwaZulu Natal, South Africa, children affected with drug resistant tuberculosis are admitted to a central hospital for treatment which includes a daily injection for a minimum of 6 months. Exposed to a clinical environment without familiar faces and the trauma of the illness and treatment regimen, children found it difficult to cope and maintaining good quality of life, dignity and comfort was a challenge.

Palliative care, defined as holistic, interdisciplinary care of patients affected by life limiting or life-threatening illness is applicable from the time of diagnosis was identified as a key intervention that could improve the life of a child with DR TB. In an attempt to move children from a life-less environment that found them just lying in bed or walking around, partnerships were built with
artists from the Nelson Mandela Youth foundation, Umduduzi Hospice Care for Children, community support groups and partners to transform the environment at the hospital into an education and stimulation centre.

**Aim of the Initiative:** The aim of the initiative was to create an enabling environment that appealed to the child, stimulated them and at the same time provided education on the treatment journey.

**Method and Results:** Collaboration with partners resulted in the concept of an education and stimulation centre. Colourful wall murals, cartoons, toys, educational equipment and an educator transformed the environment into a children’s paradise that added life into their days. In addition to providing basic life skills, friendships are built, and children are not isolated.

**Lessons Learnt:** Collaboration with different sectors of society has been successful in establishing a child friendly environment that allows children to play, laugh and learn whilst dealing with a life-limiting illness.

### 159. MULTIDISCIPLINARY APPROACH AND TREATMENT OF THE CEREBRAL PALSY BY A PEDIATRIC PALLIATIVE CARE

*Jose Antonio Porras Cantarero, Jose Antonio Porras Cantarero, Marta Palomares Delgado, Cristina Gutierrez Rada, Lucia Navarro Marchena, Veronica Delgado Velez, Ester Fernandez Morell, Balma Soraya Hernandez Moscoso, Daniel Toro Lopez, Pau Miquel Diego, Sergi Navarro Vilarrubi*

**Background:** Cerebral Palsy (CP) is one of the Golden standard illnesses in pediatric palliative care which causes a group of permanent movement disorders that appear in early childhood. The children who are affected by CP require a multidisciplinary approach and treatment.

**Aims:** To give information about the CP treatments by a Pediatric Palliative Care (PPC) unit in the last four years (2014-October 2017).

**Material and Methods:** Retrospective, descriptive and observational description of patients affected by CP in the PPC.

**Results:** 384 patients were treated. 25 of those patients were with CP, 9 of them were females (36%) with an average age of 7.6 years old. The 81.25% of them were quadriplegic CP’s and all of them (100 %) were belonged to the 5th group of the GMFCS. The main complications that we reported were: neumological complications (chest infection and aspiration syndrome), digestion complications (Feeding difficulties and gastroesophageal reflux) and orthopedic complications (scoliosis and hip luxation). 72% of the patients had moderate or severe pain and they needed opioids. The emotional and social teams were working together to treat 87.5% of those patients. The 68.75% of the patients died and their 54% of them were dying at home. In one of the cases, we had to withdrawal the treatment. We achieved 940 phone calls, 162 visits in the hospital and 143 visits at home and 7 visits after their death. We worked together with the primary care specialists for the 68 % of cases. 6% of the parents were in the duel program.

**Conclusion:** CP is a complex illness with palliatives needs. The quadriplegic form is the most common in pediatric palliative care. The main problems are chest infection, feeding problems and pain. Interdisciplinary and integral management of pediatric palliative care patients should be the standard of treatment and care.

### 161. SERENDIPITY IN DEVELOPING A MODEL PROGRAMME FOR CPC IN A LOW-RESOURCED AREA

*Joan Marston, Olga Molahloe*

**Goals:** Identifying how Sunflower Children’s Hospice (SCH), as a non-governmental organisation (NGO) was developed as an effective and integrated model of children’s palliative care (CPC) through a combination of the external health environment, collaborative planning, and serendipity.
Design, methods and approach taken: Believing that only a collaborative approach could manage the growing HIV/AIDS epidemic, in 1998 SCH approached the provincial Department of Health (DoH) for premises to care for children dying mostly of AIDS. Positioning the SCH premises in the grounds of a district hospital led to the unexpected growth of a strong collaboration with the public health services that has led to a sustainable and cost-effective model of CPC for 20 years. A number of core free services are provided through the governmental health services and SCH benefits from the inter-hospital referral system. These are then linked to the extensive community home-care programme of SCH.

Time spent building relationships with the community, businesses, schools and churches has meant ongoing and increasing community support.

Education is given to health care professionals (including from other countries), community workers and recently to primary caregivers of sick children at home so that children continue to receive CPC wherever they are.

Results: An effective, integrated and cost-efficient CPC model of a continuum of care from the child’s home, through community organisations, into the formal health and social care system using state and NGO resources.

Conclusion: SCH developed an integrated and collaborate service, not through planning but through adapting to changing circumstances, good communication, and taking opportunities as they appeared. Programmes should be open to effective collaboration with public and private resources.

164. TALL FLOWERS FOR SHORT LIVES
Joan Marston, Gareth Evans, Ruth Smith (South Africa/United Kingdom)

Aims: The aim of the project was to raise awareness of Sunflower Children’s Hospice, children it cares for and the fact of their short lives, through planting sunflower seeds and competing to identify the tallest sunflower.

Designs, Methods and Approaches: Obtaining a large load of sunflower seeds from a very successful home-garden sunflower grower in the United Kingdom, these were sent to individuals across the UK, Channel Islands, Dubai and Ireland, to compete for a trophy for the largest, tallest sunflower grown. The theme of the activity was Tall Flowers for Short Lives. Those growing were asked to take photographs that went up on a lively Facebook page and active Twitter account. The prize-winning sunflower was almost three metres tall, required scaffolding to remain upright, and was grown in Jersey, Channel Islands.

The seeds from these sunflowers have been collected to distribute for Tall Flowers for Short Lives 2018.

While this was an entertaining and enjoyable marketing project, that reached many who did not know of Sunflower Children’s hospice it had a serious underlying message that hospice children do not live long lives, and like sunflowers they turn their heads to the sun for a short while, and then weaken and die. However, the Seeds of their lives are the memories left behind and the lessons learned from them that help other children.

Results: Increased awareness of both Sunflower Children’s Hospice and the children hospices care for; Funds raised for the children’s hospice; Involvement of many people not usually involved in hospice support; Beginnings of an annual project.

Conclusion: Marketing of children’s hospices involves activities that stimulate involvement and messages that may be subtle but effectively explain the purpose of the project.
165. PROVIDING SPIRITUAL CARE FOR CHILDREN WITH LIFE-LIMITING CONDITIONS AND SEVERE DISABILITIES THE SUNFLOWER WAY
Joan Marston, Melinda Muller

Aims and Goals: Children, like adults, are spiritual beings, yet spiritual care for children in palliative care is seen as difficult and seldom done well. To provide a holistic service, Sunflower Children’s Hospice (SCH) believes children must receive spiritual care in ways they can understand.

Designs, Methods and Approaches: The Consensus Definition of Spirituality in Health Care is a globally recognized definition. Using the concepts included in this definition – Meaning and Purpose in life, Connectedness to self, others, nature, the significant or sacred, SCH uses a simple plan for even the most severely disabled children. Through observation and questions (with older children) children can identify what is important to them. Touch, massage, singing, play and mirrors are used to help the child identify with self; interactions with others through play and other forms of communication are encouraged and observed; children are taken to enjoy different aspects of nature regularly; simple rituals and religious services include all the children. The stars and the wind may be used to show them the sacred.

Chaplaincy is an essential part of holistic care and spiritual songs are included when they sing. Spiritual well-being is assessed through observation in young and disabled children, and with discussion and observation in older children.

Results: Through using a very user-friendly definition and linking activities to the different elements of the definition, children are provided with simple but effective spiritual care.

Conclusion: While spiritual care does involve the mysterious and mystical, the practical aspects can be applied using a recognized and accepted global definition of spirituality.

Joan Marston (South Africa)

Aims: Elisabeth Kübler-Ross (EKR) was one of the most influential researchers and writers in the field of death and dying. Yet her influence on the development of children’s palliative care is not well-understood nor documented. Through interviews with her family, children’s hospice palliative care pioneers and leaders, and literature the effect of her work on this field will be discussed.

Methods: Through interviews and questionnaires completed by children’s hospice and palliative care (CPC) pioneers and leaders as part of information-gathering for a history of CPC, the influence of EKR on many of these became clear.

EKR is not usually identified with the history or development of CPC. Yet she not only influenced many, as her work still does today, EKR was also a mentor and friend to a number of CPC practitioners and visionary pioneers. Through interviews with her son and daughter, the president of the EKR Foundation and pioneers who were her friends, her influence is identified and recognized as an important part of CPC history and development.

Results: The influence of EKR on the development of the vision of certain pioneers, and her impact on their achievements; as well as her generous mentorship and meaningful friendship has been identified.

Conclusion: CPC history and development should be grateful to and recognize the impact of EKR and her pioneering work, which helped develop the field as we experience it today.
178. A TWO OR THREE-RUNG LADDER? RECENT TRENDS IN THE USE OF OPIOIDS IN A PEDIATRIC PALLIATIVE CARE UNIT IN ARGENTINA
Mariana González, Samanta Piccone, Nallar Martin, Florencia Blanco, Eulalia Lascar

**Background:** According to WHO (2012), moderate-to-severe pain in children is best treated with a biphasic strategy: paracetamol or ibuprofen for mild pain, and morphine or another powerful opioid for moderate-to-severe pain, thus altering the "three-rung analgesic ladder for the relief of cancer pain", since codeine for the second rung posed safety and efficacy problems and data for tramadol is insufficient. Morphine is the opioid of choice to treat moderate-to-severe persistent pain in children. Ideally, alternative opioids should be available.

**Aim:** To assess opioids use in a palliative care unit of a high complexity pediatric hospital between 2014 and 2016.

**Methods:** Medical histories and statistics were reviewed retrospectively. All patients as from first and subsequent visits were followed up; treatment with opioids according to age and diagnosis of oncological or non-oncological disease were analyzed.

**Results:** of the total of 559 pts. 69% received opioids. In non-cancer patients the most commonly used were morphine (38%), tramadol (37%), codeine (12%), and methadone (11%). Of the cancer patients, 60% received morphine, 32% tramadol, and 6% methadone. The use of morphine and tramadol remained stable, but an increase in methadone and decrease in codeine were observed. Although tramadol is mostly used in children > 10 y, we have gained experience in its use in younger ones. Of the 160 patients with chronic encephalopathy –the most prevalent non-oncological pathology– 57% received opioids: morphine (47%), codeine (31%), methadone (11%), and tramadol (9%).

**Conclusions:** The two-phase strategy is challenging when choosing an opioid for moderate pain. We confirm the need to use weak opioids, transitioning from codeine to tramadol, especially in children > 10. Long-term codeine-treated patients with chronic encephalopathy continue with the same treatment.

179. HOW TO IMPROVE NUMBER OF CHILDREN ACCESSING PALLIATIVE CARE THROUGH EXISTING PUBLIC HEALTH STRUCTURES - LESSONS FROM MALAWI
Fred Chiputula, Lajabu Ida, Thambo Lameck, Glenda Winga (Malawi)

**Aim:** To support Government public district hospitals to improve access for quality, affordable and sustainable palliative care services especially for children.

**Problem statement and gap addressed by the project:** Not many children are reported to have accessed palliative care services at district level as compare to regional hospital level in Malawi. Majority of children with life threatening illnesses that require palliative care are often referred to a central or regional hospital for investigations in order to confirm diagnosis and specialist care. When the diagnosis is made the child is started on treatment for pain and symptom control. To continue with care and support the patient is discharged back to the referral authority which is the district hospital unfortunately these cases are often missed by the district hospital. There are challenges faced by public health services managers to implement palliative care (Lack of knowledge, poor coordination and limited resources).

Adult patients are able to push their way back to the health facility hence there is increased number of adult palliative care patients than children who are dependent and vulnerable.

Palliative Care Association of Malawi through STEP-UP Project and the True Colours Trust is working on a project which is aimed at improving access for quality palliative care for both adults and children.

**Methods:** Used a specially designed scale up project that is ongoing from the southern region to central and northern regions of Malawi. A top down and a bottom up approach - targeting leaders and key decision makers for funding and strategy and training frontline staff. Palliative Care Association of Malawi (PACAM) with funding from True Colours Trust conduct continuous situation
analysis to monitor changes in service delivery specifically on number of patients (Both adults and Children) accessing palliative care through public health delivery system.

Results:
1. Increased number of palliative care clinics in the districts.
2. Increased access and availability for pain medication.
3. Increased number of children accessing palliative care and pain control medication such as morphine.
4. Increased number of trained palliative care providers.

Conclusions
1. It is possible to increase number of children accessing palliative care through the existing adult programs.
2. It is important to take a bottom up approach and a top down - targeting leaders and key decision makers for funding and strategy and training frontline staff.

Lessons learned: We need to focus on changing hearts and minds. It is not just about providing training, coming in with completely new projects or focusing on facts and figures, it is about supporting a change in mindset.

Recommendations for research: Find out where are the children in all the service delivery points dominated by adult beneficiaries.

Recommendations for practice: Take all patients as index patients to reach out to other patients behind them because behind all adult patients there are children who are vulnerable. It is important to take a top down and a bottom up approach - targeting leaders and key decision makers for funding and strategy and training frontline staff.

180. PLACE BONDING IN CHILDREN’S HOSPICE CARE
Helena Dunbar (United Kingdom)

Background: Relative to the numbers of children with LLI the overall numbers accessing hospices are low.
Aim: The study's aim was to explore parents’ perspectives of hospices in one region in England and identify characteristics of services that parents wanted

Methods: A two phase qualitative study underpinned by a constructivist grounded theory methodology was employed. Phase 1 - focus groups were run with 24 parents of children accessing the hospice. Phase 2 semi-structured interviews were conducted with 7 parents who did not have any experience of a hospice and a further 7 parents who had some awareness.

Results: Three main themes were identified. Coming Home depicts the desire and searching that parents had in seeking out a place, other than their actual home, where their child could be cared for. Coming to terms with this was a struggle and certain characteristics needed to be in place before parents would accept respite. This is living Now depicts the overall sense that parents with a child with a LLI are living life as it is now not as they had planned it. Life is described as a fight, dictated by routines, loss of identity, friendships, potential. Moving forward portrays the idea that there is however a clear sense of direction of travel into a future where the journey is much longer than anticipated, anxieties about the future and transition exist.

Discussion - A model of place bonding was developed which offers new insights into the journey that parents take when deciding whether or not to accept help. Five dimensions - familiarity, belongingness, identity, association and rootedness are described which culminate in a sense of rootedness and attachment to the hospice and when present led parents to a sense that they had found in the hospice a place where they felt at 'home'.
185. HAPPY FEET HOME
Mansi Shah, Joan Marston (India/South Africa)

Background: Happy Feet Home was established in Mumbai 3 years ago in the belief that every child, should have the opportunity to celebrate life, live life to the fullest and work to the betterment of every moment. 300 children receive palliative day care.

Aims: The aim of Happy Feet Home (HFH) is to provide palliative day care to help children with HIV, Thalassemia Major and other life-limiting illnesses to lead empowered lives and live as well as possible with hope for the future. Working collaboratively with Sion Hospital for medical care, ensures holistic palliative care and the best possible quality of life.

Methods: Palliative care is provided through Day care and outreach care, with the aim of enhancing the child’s whole life. Health is enhanced, through good nutrition, medical care, support for treatment adherence and motivation. A variety of activities are provided daily to 15-30 children in two shifts to help children grow and discover themselves. Children are supported academically and are helped to plan for the future. Some are enrolled in special courses. All children are helped to develop basic language and mathematical skills. Support is also provided at the end of life. Other services include counselling, art-based therapy, and psycho-social support. HFH holds a special Hospice Week with different activities to be a holiday week for children who cannot afford holidays. Celebrations are held for important days.

Results: Children’s physical and emotional health improves. Children gain weight and grow taller. Mental health improves, academic performance improves, and children gain confidence. They have hope for the future due to developmental activities, vocational training and education. Children enjoy time at HFH with staff, volunteers and other children.

Conclusion/Discussion: Day care is a cost-efficient way of providing effective palliative care and helping life-limited children develop optimally.

186. USE OF AROMATHERAPY AS A COMPLEMENTARY HEALING MODALITY IN CHILDREN’S PALLIATIVE CARE
Fiona McLennan (South Africa)

Aromatherapy has been used for many years now in hospitals and hospices. The authors have been working as Therapeutic Aromatherapists in a children’s hospital, and in a paediatric palliative setting, and find that the role of aromatherapy massage is wider than simply the massage itself, as it also gives the child a sense of control of their environment, a personal ‘healing space’ filled with attractive fragrances, and of course the benefits of the essential oils themselves on the child’s mood, emotions, skin and body. The power of compassionate touch also plays a role in the healing.

188. DESIGNING A MORPHINE MONITORING SYSTEM FOR PALLIATIVE CARE – FIT FOR PURPOSE FOR CHILDREN?
Andrew L Gray,1 and Candy Day,2 on behalf of the Drug Availability Task Team, Steering Committee on Palliative Care (South Africa)

1 Division of Pharmacology, Disciple of Pharmaceutical Sciences, University of KwaZulu-Natal
2 Health Systems Trust, Durban

Aims or goals of the work: South Africa’s National Policy Framework and Strategy on Palliative Care 2017 – 2022 calls for the development of a national morphine monitoring system. This commentary aims to describe the process of devising the proposed system and to examine the challenges of monitoring access to effective pain relief for children in particular.

Design, methods and approach taken: The design of the proposed national morphine monitoring system was based on examination of data obtained from the KwaZulu-Natal Provincial Medicines Procurement Unit (PMPU), combined with denominator data obtained from the District Health
Information System (DHIS). The proposed national indicator is defined as follows: numerator: total number of mg of morphine issued per quarter, combining all oral solid dosage forms, pack sizes and strengths and oral morphine powder, per district; denominator: combined Primary Health Care and out-patient department head count per quarter, per district (multiplied by 100). These data can also be presented in an annualised form.

**Results:** The KZN public sector data for 2016 showed that combined oral morphine issues varied from 2.8mg per 100 ambulatory care presenters per year (Umzinyathi) to 156.2 (uMgungundlovu). However, disaggregating those data for children only poses significant challenges. Oral liquid morphine is used in both adults and children. Headcount data is only disaggregated into those under 5 years of age and those 5 years and older. Estimates of public sector dependent population per district are available but not by finely differentiated age bands.

**Conclusion/Lessons learned:** Although the proposed national morphine monitoring system is an important start, greater accuracy in tracking children’s access to pain relief, let alone comprehensive palliative care, will require new data sources, and in particular electronic health records.

**Ethical approval:** Approval was obtained from the UKZN Biomedical Research Ethics Committee (BE276/17)

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**189. STRENGTHENING ACTIVE SERVICE DELIVERY FOR CHILDRENS’ PALLIATIVE CARE AT MZUZU CENTRAL HOSPITAL IN MALAWI**

*Beatrice Mang’anda (Malawi)*

**Background:** Mzuzu Central Hospital is the largest in the northern part of Malawi in Southern Africa. It is comprised of several departments including rainbow Anti-retroviral clinic and Palliative care unit. Five districts refer patients with complicated chronic conditions. At palliative care unit sickle cell disease is described as the highest common condition among children aged 3 – 18 years and mortality rate is also high. The extent of palliative care service delivery to such children is not much recognised.

**Aim:** To integrate active palliative care service delivery for children into the existing health system

**Method:** Data on all children registered between June 2016 and June 2017 at Mzuzu Central Hospital Palliative Care unit were extracted and analysed. Thematic analysis was used for qualitative data.

**Results:** One thousand two hundred and fifty (1250) children with sickle cell disease aged between 3- 18 years of different sex. Six hundred and fifty (650) with cardiac conditions and one hundred (100) with cancer conditions while one hundred and fifty (150) with different chronic conditions

**Conclusion/Discussion:** Sickle cell is highest and quality of care in terms of holistic assessment is almost not done as such most children suffer from uncontrolled pain in paediatric ward as well as at out- patient. With above results the hospital requires integration of active palliative care service for children

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**191. HOMEOPATHIC INTERVENTIONS IN PALLIATIVE CARE**

*Piyush Gupta, Neha Tripathi (India)*

Since ages; social evolution across the globe invariably lead to the development of different medical systems and beliefs, so as to keep the folk hale and hearty. Rise of scientific medicine changed the scenario by unfurling the mysteries involved, however development of drug resistant superbug bacteria due to misuse of antibiotics, side effects of the long term use of certain medicines and similar challenges suggest exploration and use of other medical systems side by side. India has no dearth of medical treasures used successfully for ages which are now integrated under Ministry of Ayush (Ayurveda, Yoga, Unani, Siddha & Homeopathy).
NTPC Sponsored a free Homeopathic Dispensary for Palliative Care in 2015 enabling us to establish the efficacy of Homeopathic Medicines by focusing on Pain and Symptom Management of the Acute as well as Chronic Patients coming in the OPD as well as Camps.

**Results:** In sharp contrast to the prevalent beliefs that homeopathy is placebo, slow acting etc. it was found that even patients of chronic pain got 50% relief within one week and patients of pain due to renal stone, tooth ache, migraine and other acute symptoms like vomiting, loose motion, cough, fever got response within a few hours.

**Conclusions:** We need replication and scaling of such efforts as it may bring down the costs of Palliative Care and improve the quality of life of not only the Terminally ill patients but humanity as a whole and specially children as they are free from side effects.

194. DEVELOPMENTALLY APPROPRIATE COMMUNICATION STRATEGIES TO EMPOWER CHILDREN AND THEIR FAMILIES TO BECOME ACTIVE MEMBERS OF THE PALLIATIVE CARE TEAM

*Karen van Zijl, Isabella Schimper (South Africa)*

**Background:** Palliative care is defined by the WHO as targeting improved quality of life for patient and families by confronting problems associated with life threatening illnesses (European Association for palliative care, 2010 & WHO, 1990). Palliative care is grounded in the social rather than the traditional medical model of services delivery. Palliative care focuses on and supports children and families for meeting their goals for participation in daily activities, decision making and promotion of quality of life as described by the ICF-CY (Pollens, 2012). By means of effective communication the child and family are supported to understand the disease and treatment as well as the implications of treatment. Furthermore, the acquisition of adaptive coping skills is facilitated. Effective communication also creates the opportunity for the child and family to express their feelings and fears while learning to integrate the implications of the illness into their daily routines and relationships thereby maintaining relationships and participation (Thompson, 2009).

**Aim:** The aim of this presentation is to supply individuals providing children and their families with palliative care with helpful information, practical suggestions, developmentally appropriate play-based activities and interventions that will promote effective communication and participation.

**During this presentation attention will be given to the following:**

- Play as a developmental appropriate strategy for the facilitation of communication and participation in: decision making, maintaining social closeness, fulfilment of psychosocial needs and end of life goals, identification and addressing misconceptions, dysphagia management and positive meal time interactions.
- The utilisation of techniques and tools such as: augmentative and alternative communication, art-based activities, medical play, guided imagery and alternate focus in order to facilitate communication and connection.

195. THE ROLE OF COMMUNITY OWNED RESOURCE PERSON IN PALLIATIVE CARE SERVICE DELIVERY TO HIV/AIDS AND CANCER PATIENTS AND THEIR FAMILIES AT KAWEMPE HOME CARE, UGANDA

*Maureen Asiimwe Buhiire*

**Purpose:** The study sought to identify the role of Community Owned Resource Persons (CORPs) in palliative care services for cancer and HIV/AIDS patients and their families in Uganda, with Kawempe Home Care (KHC) as a case study.

**Design/methodology/approach:** A cross-sectional study using quantitative methods was carried out using structured and self-administered questionnaires to a sample of 230 respondents composed of Cancer and HIV/AIDS patients, Caregivers, Palliative Care Specialists (Medical team
and Counsellors) and CORPs, selected out of a population of 500 patients using the Krejcie and Morgan’s (1970) formula of sample size determination in KHC.

Findings/results: The study found out that there was a significant positive relationship between CORPs characteristics of experience, training, satisfaction and their role in palliative care service delivery to the community (pearsons coefficient r = 0.867 and p value less than 0.01). CORPs of KHC were providing medical, psychosocial and spiritual support to palliative care patients. The medical support offered helped to improve quality of life for both the patient and the family through drugs administration and referrals, pain and symptom management and physiotherapy.

Conclusion/interpretation - The CORPs were considered to be of good quality in terms of competency and commitment although more was needed in identifying and managing patients’ illnesses, specifically to frequently screen palliative care patients for opportunistic infections and advise families of the patients to plan for the future given that the patients receiving palliative care are terminally ill.

196. QUALITY OF LIFE FOR PEDIATRIC CANCER PATIENTS AT NEW HOPE CHILDREN’S HOSTEL, KAWEMPE HOME CARE
Maureen Asiimwe Buhiire

Aim: The study aimed at determining the effect of the hostel model of palliative care on the quality of life and treatment outcomes of children with cancer who are receiving specialised care.

Methods: A longitudinal study design using quantitative methods was carried out among 30 respondents (patients and care givers) to enable us to assess the changes in quality of life over at least four times with in a period of 2 months and determined the final treatment outcomes of the patients after discharge from the hostel.

Results: Out of 30 respondents (8 were female 28%, 7 were male 23% children) with youngest being one and a half years and the oldest 18 years. Care givers (female 14 and 1 male). The commonest cancers for children admitted are Leukaemia 15, Burkitt’s lymphoma13, Wilms tumour 13, Nephroblastoma 11 and Rhabdomyosarcoma 10. The study found out that there was a significant impact of 30% in psychosocial interventions thus quality of life.

Conclusion: Hostels as a model of providing palliative care and psychosocial support for patients with cancer and their families is one way in which quality of life can be improved in care. Cancer being a chronic, long-term illness, change of environment is another crucial need for the patients. Care givers described the diagnosis and treatment of a child with cancer as one of the most stressful times in their lives. However, there is need to control and manage pain in the hostel and further research.

199. PATIENT HOSTELS – FUTURE PALLIATIVE CARE CENTRES FOR CHILDREN WITH CANCER.
Claire Namulwa, Maureen Asiimwe Buhiire and Dr. Samuel Guma

Background: Kawempe Home Care (KHC) is a private not for profit organisation, that started in 2007, aims at improving the quality of life for people living with HIV/AIDS, TB and Cancer through the creation of a sustainable community based model of holistic care that comprises of treatment, prevention and support. In September 2016, KHC opened the New Hope Children’s Hostel that provides palliative care services for children with cancer who are receiving treatment at the Uganda Cancer Institute (UCI). The hostel also provides free accommodation, food and daily transport to the UCI.
Methods: The package of palliative care includes; monitoring and supporting the children to adhere to pain and symptom controlling medicines prescribed by the paediatric oncologists. Emergency treatment is also given for new symptoms that arise while in the hostel and the child is referred for further management at UCI. The psychosocial issues that the children may have are handled using cognitive behavioural therapy, counselling, play therapy and music therapy. The children’s spirituality is achieved through daily prayers. The APCA children’s POS is used to measure the quality of life of the children every two weeks.

Results: A quantitative research method was carried out among 30 respondents to enable us to assess the changes in quality of life over at least four times within a period of 2 months. The study found out that there was a significant impact of 30% in psychosocial interventions thus quality of life has improved.

Conclusion/recommendation: The new hope hostel has helped to improve the quality of life of children with cancer through the provision holistic care and support. We recommend that all children’s hostels provide palliative care services to their guests.

200. USING PSYCHOTHERAPY TO MANAGE PSYCHOLOGICAL DISTRESS
Mary Prossy Nafuna, Palmer Aloyo, Samuel Guma, Shadad Muhumuza, Maureen Buhiire

Background: Kawempe Home Care (KHC) is a community-based organisation providing holistic care to people living with HIV/AIDS, and cancer within Kawempe and Wakiso district. The New Hope hostel a project under KHC has provided holistic care, psychotherapy support and music therapy to children with cancer. The children at KHC face a number of psychological stressors for example;

• Negative cognitive biases in terms of self-esteem for example self-blame, guilt and poor self-image that then manifests into anxiety i.e. fear of death and an external locus of control thus leading to depression
• External behavioural limitations like withdrawal, aggression and non-compliance.
• Depression and feeling over whelmed therefore triggering an external locus of control
• Fear for the future and abrupt death caused by misconceptions about cancer.
• No hope for the future therefore refusing to go to school.

Aims
• To show the effectiveness of psychotherapy in managing psychological distress in children with cancer
• To focus on how psychotherapy is used to reduce distress among children with cancer
• To help inspire others about children’s palliative care

Methodology
• Using group therapy, a collection of the children with the same cancer experience to openly deal with and discuss their negative feelings
• Using play therapy, symbolic nonverbal play with toys each game serves a different purpose for example, teaches anger management, self-control and problem solving hence lessens internalizing and externalizing symptoms after the therapy session practice of health coping skills.

Results
• Children managed to work through and deal with their internal conflicts.
• Negative cognitive biases were being reframed.

Conclusion
• Psychotherapy is much needed to help the children deal with the psychological distress that arises with chemotherapy specifically symbolic play in play therapy.
• Much more advocacy for availability of child psychotherapists, psychologists in creation of more intervention in child palliative care

201. NUTRITION SUPPORT; A PALLIATIVE CARE NEED FOR POOR CHILDREN WITH CANCER
Phionah Nagasha, Sarah Komugisha, Samuel Guma

Introduction: Kawempe Home Care (KHC) is a not for profit community based organization that provides comprehensive holistic care to people with HIV/AIDS, Tuberculosis and Cancer in Kampala and Wakiso districts in Uganda. According to WHO 2015, nutrition is the intake of food, considered in relation to body’s dietary needs. Good nutrition is an adequate, well balanced diet combined with regular physical activity. Poor nutrition can lead to reduced immunity, increased susceptibility to disease, impaired physical and mental development and reduced productivity.

Methods: Nutritional assessment is an integral part of optimal pediatric care. Using the clinical anthropometric parameters, the severe acute malnutrition and moderate acute malnutrition were identified thus putting them on special diet frequently than the nourished ones. The diet contains all the food values that help in improving their immune system and growth.

Results: Between September 2016 and March 2018, two hundred and forty children were enrolled in the hostel and their baseline weight and mid upper arm circumference was taken, with follow-ups. At enrolment thirty-one had severe acute malnutrition while forty had moderate acute malnutrition. Nutrition support contributed to an improvement in prognosis of cancer, a marked improved quality of life (happier and smiley faces) and also an increase in weight and mid upper arm circumference was observed in a period of two months.

Conclusion: Nutritional assessment and support should be highly prioritized by all palliative care centers because poor children with cancer are more likely to be malnourished than others and good nutritional status facilitates tolerance for treatment.

204. PAEDSPAL CAPE TOWN: INSPIRATION, INNOVATION AND INTEGRATION
Michelle Meiring, Tracey Nupen, Jodi Wiles, Alastair McAlpine, Teresa Jennings, Noncedo Nakani, Diane Burger, Fiona McLennan, Angela Rackstraw, Philna Badenhorst, Nompiyakhe Mfanta, Adelah Ederies, Manda Kanka

Aim: The main aim of this poster is to inspire others in resource constrained settings to start Paediatric Palliative Care (PPC) programmes that are inspiring, innovative and integrated.

Design, Methods and Approach: Paedspal Cape Town arose from the ashes of the Cape Town branch of a National NGO called “Bigshoes” that was forced to close at the end of 2012 after operating in 3 Provinces for 10 years. The NGO’s reputation was badly damaged after a newly appointed CEO committed fraud. This is not an uncommon challenge in Africa and learning to recover from corruption and continue the good work is key to success. This is a retrospective reflection on the setting up of Paedspal, Cape Town. This reconstructive process is examined by reviewing old document’s, data-bases, patient’s files and staff interviews.

Results:
Inspiration: An NGO’s true sustainability...lies in its most valuable asset, it’s staff. Passionate and committed team members who are able to keep the bigger picture in mind, are what really counts. The inspiration to keep on going lies in the patient’s and their families…and the realisation that we can learn as much from their struggles and capacity for resilience as they can learn from us.
Innovation: Innovative ideas are key to success. Living in resource constrained settings, calls for resourcefulness. The Paedspal model presented in this poster shows how careful planning and adaptation was needed.
Integration: We need to find ways of integrating PPC in to public health care services in a way that does not leave primary teams disempowered on the one hand, but also ensures that patients receive the highest possible quality of care on the other.

Conclusion: “The greatest glory in living lies not in never falling but rising every time we fall”.

Nelson Mandela.

205. "FINDING STRENGTH DESPITE THE PAIN": EXPERIENCE OF PARENTS WITH CHILDREN AT THE END OF LIFE
Maira Deguer Misko, Maiara Rodrigues dos Santos, Michelle Freire Baliza, Regina Szylit

Background and purpose: One of the most painful processes that a family can face is the death of a child. The impact of the dying process of a child on the family and the difficulties faced by parents with regard to care at this time are little explored due to the challenge of carrying out research in this area. This study aimed to understand the experience of the parents of the seriously ill child with regard to the care given in the end-of-life situation.

Method: This is a qualitative study. The Symbolic Interactionism and Grounded Theory were used as theoretical and methodological framework. Data collection was performed in a pediatric hospital, through active observation, hospital records and semi-structured interviews. Fifteen parents who experienced the hospitalization of a seriously ill child in end-of-life care attended in the study. The interviews were recorded and transcribed. Data was analysed following the procedures of the Grounded Theory.

Results: Through the data analyses was possible to propose a theoretical model to explain the experience of the parents of the seriously ill child with regard to the care given in the end-of-life situation by the core category: “Finding strength despite the pain”, and the following categories: “seeking quality of life for my child”, “recognizing that everything is being done for my child”, “needing the health team support”, “attending in decision-making”.

Conclusion: The prevention of mental and physical consequence that the complication of grief can lead for family is required and can be worked also in relationships between professional and family during the dying process. Understanding how these relationships can influence the meaning attributed to the death of the child in the grieving process, it is useful for the improvement of care and direct interventions for the care of these families and their children.

206. SUPPORT NETWORK FOR CHILDREN AND YOUNG PEOPLE WITH LIFE-LIMITING AND CHRONIC COMPLEX CONDITIONS IN CATALONIA
Andres Morgenstern Isaak, Teresa Gili, Lucia Navarro, José Vicente Serna, Sergi Navarro, Nuria Pardo

Background: In Catalonia, between 1500 and 1800 children and young people have a life-limiting illness, 50% of whom would need specialized palliative care (PC). Annually, around 400 children under 20 die, 63% as a consequence of predictable diseases.

Currently, thanks to the encouragement and financing of the third sector, it has been possible to design a care network for the specialized care of children and young people in a complex chronic condition and/or end of life situation, with the aim of improving the quality of life of the patients and their families. In this network, 4 Catalan hospitals and few private foundations with professionals from health, psychosocial and volunteer areas participated.

Aims: Communicate the data obtained by the Catalan healthcare network during the first year of assistance implementation.

Method: Retrospective descriptive study of the care given, and characteristics of the patients included in the program from January 2017 to December 2017.
Results: In the study period, 338 patients with limiting and/or life-threatening diseases were treated, representing approximately 37% of the patients who would require specialized care (22.8% oncological patients, 77.2% non-cancer patients). 63 patients died with the support of specialized PC teams (28 at home, 35 at the hospital), 25% of the estimated deaths <20 in Catalonia.

Conclusions: Although still insufficient, it has been possible to improve the care coverage of complex patients with palliative needs in Catalonia thanks to the design of a specialized network of professionals. Many families included in the program reported an improvement in the patients’ quality of life. The final goal of the network continues to achieve a coordinated response to all patients living in the territory.

207. FAMILY EXPERIENCES AND VIEWPOINTS OF PALLIATIVE AND SUPPORTIVE CARE FOR CHILDREN WITH CANCER: CAN WE DO BETTER?
Jan du Plessis, DK Stones, M Meiring
Paediatrics and Child Health, UFS; Palliative Care, UCT

Background: Palliative and supportive care needs of children with cancer and their families are unique and require special attention. Development of appropriate services sensitive to the needs of families and based on observed evidence has become more and more recognized. As an introduction to develop and improve supportive and palliative care services for children with cancer, families were questioned regarding their experiences and suggestions for improvements.

Methods: Sixteen family members, of children with cancer and treated at Universitas Academic Hospital were questioned regarding their children’s standard oncology and supportive/palliative care. Their responses were studied and repeating themes were identified.

Results: A number of areas of need were identified: erratic psychosocial support, minimal financial support, poor parental access to basic needs and food provision, preventable errors in procedures and lack of sibling support. Staff were also not always sufficiently equipped to attend to palliative care patients.

Conclusions: Supportive and palliative care for children with cancer need to be improved. Family members are a valuable resource and the interviews identified a number of themes, valuable to consider in the expansion of a supportive/palliative service. The intention of the study were to create the awareness that by making small and affordable changes the quality of care the children and families receive can be improved.

210. ALONE WE CAN DO SO LITTLE, TOGETHER WE CAN DO SO MUCH
Bronwen Simmons

Background: Bear Cottage is one of only three children’s hospices in Australia with a population of 23 million people. Many Australians are unaware of the need and importance of the services children’s hospices provide. At Bear Cottage one of our goals is to inspire others about the benefits of Children’s Palliative Care and for them to join with us as advocates for those children whose voices are not heard.

Aims: Bear Cottage’s annual fundraising event Superhero Week was designed to engage the community to not only fundraise for Bear Cottage but to also educate, raise awareness about the need for paediatric palliative care in Australia. This event has become a successful fundraiser, but more importantly, many of our participants (most without a personal connection to Bear Cottage) have gone on to become passionate advocates raising awareness about the importance of children’s palliative care. What is it about Superhero Week that inspires so many to get involved year after year.
Results: Over the last six years we have had hundreds of children, workplaces, community groups and dedicated individuals taking part in Superhero Week all across Australia. For most, this has been their first exposure to a children’s hospice and the service it provides. For many though, it has become more than just a fundraiser and these supporters have become long-term, committed advocates who then go on to inspire others to follow their lead.

Long-time supporter Reuben Rose illustrates this through his inspiring work each year and his encouragement to his work colleagues to support him: “So, friends, this year, I would like to issue the challenge to you - Superhero Week commences today. Share it, donate, or run an event at your workplace. Give small. Give big. But, my friends, if there is a noble thought amongst you which yearns to see heroism once again rise, not just on the silver screen but instead in our everyday lives, this is the time to see it unleashed. I can tell you, from personal experience that the reward of an incredible memory in the midst of unfathomable sadness is worth more than all the gold in all the world, and it is something that tragedy itself cannot steal. You can make that happen. We can make that happen. And I’d love for you to join me!”

Conclusion/discussion: Superhero Week inspires people year after year to get involved and provide support for our most vulnerable children and we in turn are inspired by the commitment, energy, enthusiasm and love shown to our Bear Cottage kids and families.

211. LIFE REVIEW IN NEONATAL INTENSIVE UNIT
Kai-Ling Chang

Aims or goals of the work: Approaches to and success of pediatric palliative care including bereavement care. How to provide bereavement in Neonatal intensive unit at the time of death? We usually used holding, bathing, dressing, baptizing, picture taking, and collecting locks of hair provides for parents. This study explores what life review in NICU to enhance bereavement care.

Design, methods and approach taken:
Case study. A framework for understanding the life review “what,” “why,” and “how,” of life review bereavement care phenomena and seeks to understand and interpret integrating comfort and meaning into parent’s spiritual care.

Results: We provided a 11 days old sick girl, diagnosis hypovolemic shock with severe anemia s/p cardiopulmonary-cerebral resuscitation and suspected non-immune hydrops or congenital infection with intracerebral hemorrhage and multi-organ failure ventilator withdrawal. When the loved baby dies, her mother’s emotion is very low. We promoted her mother introduced her family to this die baby, the finding shows that: (1) connection with baby and family; (2) the baby soul belonging the family; (3) mark the ending to say good-bye; (4) transition and launching a new beginning.

Conclusion/Lessons learned: What is holistic nursing care in pediatric nursing? What is NICU palliative and hospice care? Each parent’s need to experience mourning in their own personal way. We found lead parent life review to the sick(die)baby, are more sensitive to cultural and social variations bereavement care. Life review connect family and dying baby past-now-future, considers the baby and family as a unique entity. May be a possible way to empowerment parents.