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Transforming children’s palliative care - from ideas to action

BOOK OF ABSTRACTS
February 2014
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A Welcome Message from the Scientific Chair of the Conference

WELCOME TO THE ICPCN CONFERENCE IN MUMBAI
“TRANSFORMING CHILDREN’S PALLIATIVE CARE – FROM IDEAS TO ACTION”

I would like to welcome you all to this 1st ICPCN International Conference on Children’s Palliative Care. The calibre of keynote and plenary speakers presenting at the conference as well as the exciting events we have lined up for this conference will make it one to remember. Over 140 abstracts were submitted to the conference, sent out for peer review, and have resulted in the wide and varied programme. Along with the eight plenary presentations there are 73 oral 43 poster presentations from 30 different countries. It will be a great opportunity to learn from each other and to meet old friends and make new friends. India has never before been host to this many 'greats' in the world of children's palliative care and it is hoped that many people will take the opportunity to attend the conference.

As we spend time together at the conference I urge you to step out of your comfort zone, to speak with people you have never met before, to attend sessions to learn about new things and new ideas, and to take this opportunity of networking with delegates from around the world.

I hope that you find the conference stimulating and that each of you finds something within the scientific programme that excites you, that fuels your passion for children’s palliative care, and that we will go from this meeting having seen how you can put ideas into action, such that we can continue to transform children’s palliative care around the world.

Prof Julia Downing
Chair of the ICPCN 2014 Conference Scientific Committee
ICPCN
**ABSTRACTS FOR ORAL SESSIONS**

**Day 1 – Breakout Sessions 14.15 - 15.30**

**Applied workshop on Advocacy**

**O1. Access to Palliative Care: The Right of Every Child – Nkosi B, Marston J. (South Africa)**

We speak of palliative care as a child’s right but is this an ethical or moral right, a right bound by Covenant or Convention, or a combination of both? This presentation will look at the meaning of a right and the Conventions, Covenants and Statements supporting this. The ethical issues around advocating for palliative care to be recognised as a children's right when so many other issues involving larger numbers of children globally are of importance, will be examined.

A submission to the UN Committee on the Rights of the Child submitted by the International Children’s Palliative Care Network and Human Rights Watch, includes the right of the child to be pain free, in light of the report from the UN Special Rapporteur on Torture, cruel and degrading for children as well as adults.

Examples from the findings of the survey carried out by Human Rights Watch in Kenya show the impact of a lack of palliative care for children.

The discussion will show the impact of such a report and examine the response in Kenya and the lessons that can be carried over to other countries and regions.

**O2. CPC Project in India – Gangolli L (India)**

Palliative care is in a very rudimentary stage in India, with only the State of Kerala having a Palliative Care Policy at present.

The Government of Maharashtra passed a resolution on 15 June 2013 announcing the decision to implement palliative care program in Maharashtra, which includes the guidelines, strategies and activities to be conducted to implement the program.

At the forefront of the advocacy campaign for this program is the ‘Children’s Palliative Care (CPC) Project’ of Indian Association of Palliative Care (IAPC), supported by International Children’s Palliative Care Network (ICPCN), Department for International Development (DFID) and Help the Hospices (HtH), and mentored by Tata Memorial Centre.

Providing palliative care to children with life limiting diseases in the State of Maharashtra, had a number of obstacles:

- lack of awareness amongst policy makers, the public and health care professionals of the concept and need for palliative care,
- lack of trained personnel and infrastructure
- laws impeding access to morphine for pain relief.

Over the 3 years that CPC had been started in Maharashtra, the project was able to:
- advocate for the introduction of Palliative Care in medical and nursing curricula,
- the introduction of post graduate course in Palliative Care,
- the amendment of relevant laws enabling access to painkillers and,
- the inclusion of children with life limiting disease in the State Integrated Child Protection Scheme.

The paper will describe the above process, including provisions from the Indian Constitution, and international covenants that India is signatory to, highlight need for locally and culturally relevant interventions for advocacy and offer recommendations for advocacy in similar situations where resource constraints, illiteracy and poverty are challenges for empowerment and change.

O3. Advocating for the integration of Palliative Care in the caring of patients with life threatening illness by Traditional Healers – Sithole Z (South Africa)

Background
One of the biggest challenges that palliative care in Africa faces is the projected increase in the number of cancer patients in the developing world by 2050, many of whom will need palliative care. In African countries, 80% of the population depends on traditional medicine for primary health care.

Methods
Formal meetings were held between Traditional Healers and Palliative Care practitioners where current clinical challenges, approaches to end-stage illness, priorities and possible solutions were discussed. It was decided that knowledge sharing and up-skilling in a bi-directional manner would benefit both sectors, and their patients.

Results and discussion
A Palliative Care Training Manual and Learner’s Manual for Traditional Healers has been developed and UNISA has agreed to assist in translating the manual into all the African languages at no cost to HPCA. The National Department of Traditional Medicine has supported this goal and the training has been rolled out to the following provinces:
- KZN:
- Limpopo:
- Gauteng

11 Traditional Healers have been trained to use this SMS system to communicate with hospices when they need information.

Issues
Traditional healers report difficulty in treating patients with end-stage disease. In an effort to increase access to care for patients with end-stage HIV/cancer, work is being done to
build partnerships between Palliative Care and Traditional Healers in order to up-skill both sectors.

**Description**
A pilot project of the Hospice Palliative Care Association, based in Durban, KwaZulu-Natal, was started in 2010. A task team consisting of representatives of both sectors was formed to develop the curricula. Phase 1, which focuses on training Traditional Healers primarily around essential concepts in palliative care, basic skill development, and methods for referral, was undertaken. A curriculum was developed, and training took place in the second half of 2012. Palliative care and includes. Phase 2 will focus on expanding Palliative Care practitioners’ understanding of Traditional Healing systems, and on exploring how this could enrich palliative care.

**Lessons learned**
Traditional Healers is a close community, which respects culture and leadership. They also want to be assured of what they are going to gain from the relationship with Palliative Care community.

**Recommendations**
Traditional Healers needs to be the part of the team who provides Palliative Care to the patients with life threatening illness. The majority of the communities trust the Traditional Healers more than the Health Professionals

**Clinical care**

**O4. Emerging Ethical Debates - Involving the Workforce – McNamara K, Carragher P, Hain R. (United Kingdom)**

**Issues**
A number of challenging ethical debates in the UK have more recently started to include considerations relating to the care of children and young people, leading to a need to promote sector-wide exploration the key issues relating to children

**Description**
During 2009 a proposed Bill for Assisted Dying Bill was debated by the Scottish Parliament, this has recently returned to the agenda for further debate. More recently a Government Committee considered the law governing abortion for fetal disability.

**Lessons learned**
Together for Short Lives the UK children’s palliative care organisation is supported by an expert advisory group to support the staff team in work relating to ethical issues.

The approach has included the development of an agreed interactive process with members to contribute to consultations and has enabled submissions and evidence have contributed to government committees and national debates and hosting a national conference focusing on ethical issues in children’s palliative care
This approach has helped the organisation to be able to inform and influence the national debates relating to the care of children with palliative care needs.

**Recommendations**
National organisations can usefully provide a forum to support those considering ethical issues within children’s palliative care and make recommendations on principles of ethical and children’s palliative care practice.

Assisted Dying is an issue being considered and the paediatric community can usefully discuss issues and contribute to the learning of the wider sector.
If we don’t talk about it someone else will

**O5. Multiple losses in children: Martha lost everything - even her mind! – Brits H (South Africa)**

Studies have shown that multiple losses may be traumatic for children and result in a need for intervention and support for issues of grief, loss and bereavement. If experiencing multiple losses in the absence of an adequate social support network, long term negative effects are likely to occur. Although very little is written about multiple losses in children a recent study in South Africa found that 69.4% of children had multiple losses as defined by the loss of three or more physical or emotional losses. The case of Martha is used to highlight the importance of palliative care in children with multiple losses.

Martha (10) and her brother Richard (8) stayed with their grandmother (72) in Lesotho after their mother died three years ago of HIV. Both were happy and attended school. Martha was ill for a while and one day when she arrived from school she found her grandmother dead in their hut. Her father’s family came to fetch them and took them away.

Three weeks after the funeral the children were brought to hospital as they were severely malnourished, short of breath and dehydrated. Richard passed away an hour later. Martha was diagnosed with pulmonary tuberculosis, chronic diarrhoea and stage-III HIV disease and treatment started. The next morning she became acutely psychotic, with auditory and visual hallucinations.

**Discussion:** Previously she lost her mother, her home and her school. Then she lost her grandmother, her friends, her country and then her brother, her health and her mind.

Her psychosis resolved and her medical condition improved on HAART and TB treatment. She was referred to the paediatric hospice. She was reunited with her father’s family and passed her Grade VI exams as the top student in her class in 2009. Different members of the multidisciplinary team played an important role in her recovery.
O6. Maintaining hope along with palliative care: a case study of an adolescent in a Buddhist-based alternative medicine practice medicine – Nuchprayoon I (Thailand)

An 11-year old boy with a second relapse of acute lymphoblastic leukaemia refused the third round of chemotherapy. His family chose to participate in a loco-regional Buddhist-based alternative therapy program consisting of daily detoxification with herb enema, adjusting thermal balance with herb-based application onto the body, restricted regimen of bland natural diet, drinking a homeopathic solution of diluted urine, manipulation of skeletal structure, application of ‘Kuasa’ wooden tool on wax onto body parts that is diseased, prescribed by a practitioner known in Thai society as Mor Kheaw, provided through regional week-long workshop or at a community in Mukdaharn province, 642 km Northeast of Bangkok, where daily Buddhist sermon is preached in plain language.

While receiving this life-style modification practice in hope for cure, he continued to seek our palliative care service for monthly evaluation of his leukaemia status. His complete blood count was normal for 4 months from the start of workshop followed by home treatment. In the third month into therapy, he developed several neurological symptoms and deficit including esotropia from bilateral 6th cranial nerve palsy, clinically assessed to be meningeal leukaemia. Parents refused radiation and intrathecal chemotherapy but elected to intensify the alternative therapy in the community in Mukdaharn, where some 60 cancer patients are receiving treatment with daily lecture on Buddhist philosophy, under strict diet provision, in natural setting with minimal technology. In his 5th month visit, esotropia had completely resolved, although new neurological symptoms waxed and wanes and leukemic cells appeared in blood smear.

A Thai adolescent who grew up with cosmopolitan life-style has gradually transformed his way of thinking. After living in the community of advanced cancer patients, many of whom eventually died peacefully among fellow patients, his mother did not lose faith in the treatment but has become comfortable with the impending loss of her son. On the last visit at 6 months, leukaemia progressed but symptoms were minimal. He was interested in the practice himself. Upon return to the community, he developed an abscess, cared for by traditional medicine, and expired peacefully among family and supportive cancer community.

In summary, we have observed a functional hospice, where people initially engaged in hope for cure, live with limited quality by worldly standard, but acquired a new perspective in life and spiritually prepared for death.

O7. Addressing professional quality of life among pediatric palliative care clinicians – Harris M, Kohlman S. (USA)

Pediatric palliative care refers to an approach that “… improves the quality of life of [children and families] … 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” (Wolfe, Hinds, &Sourkes, 2011,p.3). Coupled with this conceptualization is a” relationship- centred approach” to care, which emphasizes reciprocal
The responsibility of clinicians caring for patients, as well as caring for themselves. Nevertheless, the role of self-care among clinicians may be under-emphasized, as they prioritize child- or family-centred care in their clinical practice (Liben & Papadatou, 2011). One important consideration within the context of pediatric palliative care service provision is professional quality of life, an aspect of self-care (Sanchez-Reilly et al., 2013). Specifically, assessment and treatment of clinicians’ experiences of compassion fatigue, burnout, and/or vicarious traumatic stress is essential for effective implementation of a relationship-centered palliative care approach.

The current presentation will review findings from clinicians engaged in pediatric palliative care service provision. The study’s correlational design will explore the relationship between clinician demographics, including clinical practice, and components of professional quality of life (i.e., compassion satisfaction, burnout, secondary traumatic stress). Further, the study will explore, through use of a regression model, the most salient contributing factors to professional quality of life among clinicians. Research findings will illuminate (a) the consequences of providing pediatric palliative care services; (b) clinicians’ self-reported aspects of professional quality of life; and (c) opportunities to provide education and support to clinicians engaged in pediatric palliative care.

Taken together, in order to appropriately identify and assess children’s and families’ palliative care needs, clinicians must also recognize the critical role of self-care. Such recognition will likely enhance and facilitate a truly relationship-centered approach to pediatric palliative care.

Programme Development

O8. Different models of short breaks in urban and rural areas in Belarus (Supported by UNICEF) – Garchakova A. (Belarus)

Caring for a disabled child can be extremely stressful for parents, reducing effective care services and deteriorating or disrupting family relations. Parental stress impacts on quality of life of a child and his siblings. There are at least 3000 (78%) children in Belarus living with non-cancer diseases that require short term breaks. In Belarus this service was introduced in 1996 but from the very beginning it wasn’t in great demand. Parents were unwilling to acknowledge their need for short term breaks and felt guilty at leaving their child with others. With the support of UNICEF Law on Social Services was adopted in 2012 which encompasses information on short breaks as a parents’ right to have a break. Currently short breaks are rendered by the Belarusian Children’s Hospice as well as state organizations: a Boarding School and Baby Home. Short breaks enable families to have a break from caregiving and to spend more time carrying out daily tasks.


Background
Butterfly Children’s Hospices (BCH) set out to pioneer paediatric palliative care in China, a country with a tragically high number of abandoned sick and dying children. At present, the
concept of palliative care is poorly understood, and families have little or no access to help for a dying child.

**Methods**
With no pre-existing framework, BCH is developing a model specifically applicable in this culture. In order to achieve sustainability, gain credibility and garner support, cooperation with the government is crucial. Many NGOs work without this cooperation as it is less challenging. However this means that their valuable work ceases when the organization leaves the area. Challenges have included encouraging foreign professionals to provide support and teaching, obtaining and administering appropriate medications, and living as an expat in a developing city.

**Results**
To date 74 children have been cared for in a Butterfly Home age from 1 day to 10 years. Currently 21 children are receiving care, 38 have died, 7 have been adopted and 6 more waiting for adoption. 10 families have received help.
Within three years of opening the first home, BCH is opening a second in another city. 61% of income is from within the country (plus donated goods). BCH has been invited to work with Chinese doctors delivering cancer care for children in Shanghai to provide a palliative care service. BCH is also exploring a partnership with a children’s cancer foundation in Hong Kong, to provide palliative care initially in the community, and eventually the first children’s hospice in Hong Kong.

**Discussion**
Although an extremely challenging project, BCH has worked with the government to successfully develop a sustainable and expanding service in a country in which there is very limited access to, or knowledge of, palliative care.

**O10. Advances in Paediatric Palliative Care in Kenya – Ali Z. (Kenya)**

**Issues**
Until recently, Paediatric Palliative Care in Kenya was ignored, with less than 5% of patients seen in hospices being paediatric patients. Kenya Hospices and Palliative Care Association (KEHPCA) is strongly advocating for Paediatric Palliative Care (PPC) at the national level.

**Description**
KEHPCA has been working closely with International Children’s Palliative Care Network (ICPCN) to train health care professionals in Kenya. Two major trainings have been conducted since 2011, with over 80 health care professionals being trained, 21 of these being paediatricians. KEHPCA has conducted symposiums at various paediatric conferences in the country. KEHPCA has included one day training on paediatric palliative care in the 5 day introduction to palliative care training.

**Lessons learned**
These activities have resulted in awareness on the palliative care needs of children. As a result, there are now 4 government hospitals which have started paediatric palliative care
services within their respectful institutions, while all government hospitals that have integrated palliative care have been encouraged to include children in their services.

Recommendations
There are still many challenges which need to be addressed. These include integration of PPC in the pre and post graduates curricula for health care professionals; policies for paediatric palliative care; setting up specific services for children; creating awareness on the need for PPC and de mystifying the common myths about children’s palliative care. This paper will share the Kenyan journey.

O11. Development of a specialist paediatric palliative care team at a tertiary hospital in Japan –Tatara R. (Japan)

Background
In Japan, while for adult patients comprehensive palliative care is considerably established all over the country, paediatric palliative care services are still rare. On the basis of the fact, National Cancer Plan 2nd edition published by Ministry of Health, Labour and Welfare in 2012 demanded that all Paediatric Oncology Principle Treatment Centres (POPTCs) should provide comprehensive palliative care for children.

Methods
Osaka City General Hospital, which is a 1060-bed (including 200 beds for paediatric patients) tertiary centre in Osaka area and is one of the 15 POPTCs in Japan, has developed the first hospital-based consultant-led specialist paediatric palliative care team in the country since 2011. Team services, available from the time of diagnosis, are provided by a multidisciplinary health care professionals composed of a consultant in paediatric palliative medicine, a certified nurse in palliative care, a paediatric psychiatrist, psychologists, social workers and a hospital play specialist.

Results
Of 132 children seen in 2012, almost one fourth was referred before age of one year and another fourth were aged one to five years at the time of referral. The three most common diagnoses included cancer (43%), heart diseases (14%) and neurodegenerative disorders (9%). The team identifies children with current palliative care needs and collaborates with primary teams to address these needs. Daily rounds address pain and other distressing symptoms, psychosocial problems and end-of-life issues. In addition, education and training opportunities for health care professionals with special interest in paediatric palliative care are widely provided.

Discussion:
Specialist paediatric palliative care services are successfully launched in our hospital. As next steps of development, it is being planned to structure outreach home care service, and moreover, to extend services into patients from local hospitals and other tertiary centers.
Applied Workshop on Leadership (1)


Evidence has shown that health care teams function best when leaders are strong and there is alignment between leaders and their colleagues. These issues are emphasized in pediatric palliative care where multidisciplinary teams are the norm and interactions with colleagues vary according to the patient and circumstances. As such it is easy for pediatric palliative care professionals to be distracted and not devote the resources to leadership development.

In this exciting workshop will focus on self-assessment and skill development in two areas: communication and generating alignment. Communication learning will focus on the importance of communication, understanding the ways in which colleagues communicate, and strategies to improve individual and team communication. Generating alignment will focus on creating a clear and concise message, sharing this message with colleagues, and capitalizing on opportunities to share that message with stakeholders. Participants will enjoy an interactive workshop with activities and games. Learning will be a combination of oral presentation and hands on activities.

Workshop

O13. The Impact of Arts Based Therapies on children in palliative care – Shah M, Sanadhya B, Tatiya A. (India)

Music is a universal language! It helps in evoking emotions in a healthy way; creates a light and soothing atmosphere, gives pleasure, enriches senses and brings joy. Music is healing.

This was observed very closely as a part of ‘Sing a Smile (SAS),’ a volunteer oriented group that believes in ‘triggering happiness through the medium of music’ Since October 2011, SAS has organized 50 events with various age groups in Mumbai, 40% have been with children. They received a 100% positive response with children. The organization heads have reported a difference in the energy levels of the children. The events are conducted at various institutes/organizations, viz, hospitals, orphanages, children’s home, communities. These events are music centric; the song list is customized. When it comes to children, the list comprises of peppy songs, happy songs, jingles, and rhymes. In the events that SAS has conducted so far, they have observed that children are more receptive to music than adults; they have seen children shed their inhibitions and enjoy music.

SAS organized over 6 events with an organization that provides shelter to children fighting cancer. They have seen children forget about their pain; laugh out loud, dance and play. Caregivers take a much needed breather when they see their children happy. Music creates a mood of gaiety and lightheartedness. Children follow the volunteers from this group till the gate with loud chatter and claps, they keep asking them to revisit and they keep humming songs hours after the event comes to an end. Music evokes responses like joy, retrospection, introspection, depending on the kind of music and the mood of the listener.
Based on the experience from SAS, Happy Feet Home is going to conduct a study on how music helps children in palliation. The results will be ready by the conference.

Day 1 – Breakout Sessions 16.00-17.15

Presentations

O14. Care Journeys and Pathway Approaches – McNamara K (United Kingdom)

Issues
There are over 300 conditions which fall into the life-threatening or life-limiting category. The Core Care Pathway is relevant to each and every child in these circumstances, no matter what their age or condition or the setting of their care.

Description
In 2013 a new edition of the Core Care Pathway for Children with Life-limiting and Life-threatening Conditions, the world’s first care pathway for children with palliative care needs was published. This edition of the Pathway aims to integrate the many developments in children’s palliative care and the advances in our knowledge, as well as recognizing the many changes within the health and social care structures. There is a focus on making the most of the time that the family has together and ensuring robust risk assessment and parallel planning.

Lessons learned
Our research with families has shown that care co-ordination can be one of the most daunting and often unsuccessful elements of a family’s palliative care experience. Families told us that they have to deal with up to 35 professionals during their care journey, the pathway aims to ensure the provision of ‘joined-up’ care, meaning families can focus on spending time together instead of navigating a way through the maze of services and coordinating the input of the many professionals involved in their care.

Recommendations
Using the Core Care Pathway approach enables the delivery of individualized, need-focused and locally-adaptable care, for the entire palliative care journey – from diagnosis to end of life care and bereavement, keeping the child and their family at the centre of care decisions throughout. Good communication between professionals across all care settings is fundamental to high quality care, using a pathway approach helps the coordination of services to enable professionals to deliver holistic care to children and families.

O15. Supporting primary care teams in delivering end of life care at home – Neefjes V (United Kingdom)

Background
Many families prefer their children to die at home. In remote and rural areas, the end of life care is then devolved to primary care teams with little experience. To support the primary
care teams, a palliative care bundle consisting of a symptom control manual and 'just in case' boxes with end of life guidance were developed and made available via the internet. Additionally, for children planned to die at home, an individual end of life care plan was written and discussed in a face-to-face meeting between hospital staff and primary care team. To evaluate whether the palliative care bundle was helpful to the primary care teams a survey was conducted before and after implementation.

**Method**
Before implementation of the bundle thirty primary care teams, randomly chosen were asked to complete a questionnaire and post implementation ten primary care teams that had used the palliative care bundle. For each practice a GP, practice nurse, health visitor and practice manager were asked to answer the questionnaire. For both groups, the questionnaires included items on demographics, proposed (or actual) end of life care, local organization of care and support for staff.

**Results**
For both groups, the response rate was around 40%. The pre-implementation group's main concerns were symptom control, lack of training/experience, lack of continuity of care especially out of hours and concerns regarding their ability to meet the needs of the family. The post implementation group reported the individualized end of life care plan and improved support from hospital staff were most helpful. The child was reported to be comfortable and the needs of the family met.

**Discussion**
Primary care teams can be supported in their delivery of end of life care by relatively simple methods.

**O16. Review of physiotherapy needs of paediatric palliative children in Kuwait – Balraj V. (Kuwait)**

**Background**
The study was carried out in BACCH (Bayt Abdullah children's care hospice) which is the first hospice in Middle East that provides paediatric palliative care (PPC). BACCH offers full time pt services to terminally ill children to improve their qol (quality of life).

**Aim**
To assess the improvement of qol of palliative children.

**Methods**
Children with end stage cancer were referred from the pediatric cancer hospital. Data were collected for 10 consecutive patients aged between 2-to18 year old. Physiotherapy provided using individualized case based approach performed with specific goal setting for each child. Measurement tools of assessment were (1) lansky score, ecog performance scale. (2) peds qol pre and post 8 -10 sessions, filled by the parent/care-taker.

Demographics: total =10 , male=4 , female=6 age: 2-18years
Pt technique used (3): number of patients:
1. exercise therapy 10
2. chest physiotherapy 9
3. electro therapy 5

Results:
The pediatrics QOL scores improved post 10 sessions, which sustained until the next disease progression occurred.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Pre pt QOL score:</th>
<th>Post pt QOL score:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combined immune deficiency</td>
<td>80/128</td>
<td>48/128</td>
</tr>
<tr>
<td>All</td>
<td>90/128</td>
<td>64/128</td>
</tr>
<tr>
<td>Congenital myopathy, respiratory Failure</td>
<td>76/128</td>
<td>40/128</td>
</tr>
<tr>
<td>Rare congenital myopathy Ebstien’s anomaly.</td>
<td>90/128</td>
<td>56/128</td>
</tr>
<tr>
<td>Aplastic ependymoma</td>
<td>74/128</td>
<td>44/128</td>
</tr>
<tr>
<td>Anaplastic ependymoma</td>
<td>80/128</td>
<td>40/128</td>
</tr>
<tr>
<td>All, spastic quadriplegia</td>
<td>90/128</td>
<td>64/128</td>
</tr>
<tr>
<td>Glioblastoma multiform</td>
<td>76/129</td>
<td>40/128</td>
</tr>
<tr>
<td>Progressive spinal atrophy</td>
<td>82/120</td>
<td>40/128</td>
</tr>
<tr>
<td>AML</td>
<td>72/128</td>
<td>50/128</td>
</tr>
</tbody>
</table>

Discussion
Early experience at BACCH indicates that children with advanced cancers and life-limiting conditions had improvement in the QOL following physiotherapy. Further research is needed to confirm these findings.

Limitations
The study group was small; no generalized evidence can be compiled for definitive results.

O17. Pediatric Palliative Care in Bangladesh - an overview – Jameela Z, Md Z, Kabir S. (Bangladesh)

Introduction
Childhood cancer is a small fraction of the global cancer burden. But it is deeply distressing for the children and their families. In developing countries childhood cancer is diagnosed too late for appropriate protocol based therapy, cannot afford treatment even though early cancer detection and fail to respond to curative treatment and come to hospital at terminal stage. Ultimately all of the above mentioned patients experienced their last days with severe pain and multiple symptoms related with disease, eventually without hope. But unfortunately palliative care is not identified as a basic need. While palliative care for adults has established towards recognition and improvement, pediatric palliative care has been still in the backseat. In our country there is only one palliative set up especially for children cancer patients.
Objective
To inform about present status of ASHIC Palliative Care Unit as well as Bangladesh and assess clinical profile and treatment modalities needed for symptom management in pediatric palliative patients.

Method
It is a retrospective, observational study among 540 patients. Place of the study is ASHIC palliative care unit, Dhaka, Bangladesh. Study group is less than 18 years of both sexes and children with cancer of palliative stage. Data collected from patients register book and bed head tickets. Frequency of distribution express in percentage.

Results
Since 20.05.2006 to 31.08.2013 total 540 new patients were admitted. Out of 540 patients 348 were boys (64.44%) and remaining 35.56% were girls. Commonest age distribution is between 0 to <5 years (41%) and next common age group was more than >5 to 10 years (31%), 26% is >10 to 15 years and only two cases were more than 15 years age group. More than 80% of the patient’s residences are outside the Dhaka city. Majority of patients were admitted with fever, pain, moderate to severe pallor, bleeding manifestations, respiratory distress and vomiting. Most common malignancy observed was metastatic/advanced retinoblastoma 25% and acute lymphoblastic leukaemia was in second position 15%. Non-Hodgkin’s lymphoma was 11%. Children came with AML and recurrence case of Ewing’s Sarcoma represented the respectively 5% and 6%. Hodgkin’s disease relapse was 4%, osteosarcoma with lung metastasis accounted 3%. Advanced case of Rhabdomyosarcoma was 4%, Germcell tumour 3% and Wilm’s tumour with lung metastasis 4%. Metastatic neuroblastoma and Naspharyngeal carcinoma respectively 3% and 1%.

Conclusion:
The concept of pediatric palliative care in Bangladesh is limited. So establishment of pediatric palliative care unit at government hospitals will reduce sufferings of dying children with cancer and their parents. For optimum palliation to children cancer patients – it is the time to establish a strong network between the organizations and related disciplines who are working for cancer patients of all age group.

Applied workshop on pain (1)

O18. The Role of Nurses in the Management of Pain – Fowler-Kerry S. (Canada)

In Children’s Palliative Care, we cannot claim to protect the quantity of a child’s life. However, Children’s palliative care can claim to protect the quality of a child’s life, and of course to relieve suffering. In my opinion, there can be few things more important or more valuable in life than to relieve the suffering of a child and to help the child live the life they have as fully as possible. Nurses play a pivotal role in the management of pain. Today, globally nurses comprise the largest group of professionals working in the health care sector. Typically, nurses live and work in areas that are under-resourced or not resourced at all by medical doctors. As such, they are often the first point of contact for many families

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when they are seeking help. Research has provided unequivocal evidence the parents of children with Palliative Care needs are concerned their child will suffer unnecessarily from pain. The profession of nursing has both a moral and legal obligation to ensure that their patients’ young or old do not suffer unnecessarily from pain. The management of pain must be broader than just the medical management of disease and show more understanding of the importance of adequate analgesia and psychosocial and spiritual support. The purpose of this presentation will be to use research data to; 1) Explain basic mechanisms of pain; 2) Discuss the role of nurses in the administration of drugs; 3) Present, interventions nurses can utilize independent of drs. orders to enhance the efficacy of drugs; 4) Finally, stress the ethical obligation of nurses to advocate for adequate pain management.


Issues
To determine the most commonly occurring pain syndromes in children with ALL and to assess the most common type of pain (Causes) in children with ALL who are undergoing treatment at MNJ Institute of Oncology& RCC, Hyderabad

Description:
ALL is the most common cancer in children and pain is the most commonly experienced symptom in children with acute leukaemia. Pain in children with cancer can be divided into one or more of four basic etiologies: cancer related, treatment related (e.g. pain as a side-effect of chemotherapy and radiation), procedure-related (e.g. pain due to vein puncture, LP, BMA or postoperative pain), and pain of other aetiologies. Procedural pain is the most common pain syndrome, which is over looked and under treated. We conducted a survey on children who are undergoing treatment for acute leukaemias in our pediatric oncology department, MNJ.

Materials & Methods
A survey was done on children with ALL who came to the department of medical oncology for a period of one month. Severity of pain was scored using Numerical Rating Pain Scale consists of 0-10[0-no pain, 10 –worst possible pain] or the Severity Assessment Scale. The survey used a questionnaire for pain assessment and identified the most common pain syndrome.

Results:
Based on this result, there were 45 children with ALL in the sample population. Pain was the most common symptom identified and procedural pain (97.7%, i.e. 44 children) was most common type of pain. Second most common symptoms identified were – Arthralgia [15%], Headache [11.1%].The other common symptoms are mucositis [6%] ear pain and pain in the abdomen.

Conclusion
Pain is the most common symptom in children with Leukaemia. It is commonly under recognized and under treated in our population. Procedural pain is the most common pain
syndrome which can be prevented or minimized by using pharmacological and non-pharmacological management.

O20. The use of opioids in children – Cleary J. (USA)

The "WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses” includes the current evidence on the use of opioids in children. This presentation reviews the move from a three step to a two step ladder based on issues of drug metabolism. CYP2D6, an enzyme involved in the metabolism of codeine, hydrocodone, tramadol and oxycodone is not fully developed in young children. Morphine is confirmed as the primary opioid in children although the use of other opioids in children will be explored. Factors of renal and liver impairment will be reviewed.


Background
Pain control is the most prominent problem in pediatric palliative care, especially in the developing countries. Many attempts have been made to improve this situation by different organizations including the WHO in 2012 (“WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses”). However, there are many local country-specified barriers to successful implementation of the recommendations. The aim of the study was to evaluate how ICPCN could help to improve pain control in children over the world.

Methods
A task force (TF) of the ICPCN Scientific Committee (25 PPC professionals from 15 countries of all the continents) created a list with eight possible roles of ICPCN. Survey participants were asked to mark the top three priorities. The survey was conducted on-line.

80 participants from 32 countries completed the survey. Distributions of participants by continent are 35 from Africa (11 countries); 8 from America (4 countries); 10 from Asia (7 countries); 3 from Australia and 24 from Europe (9 countries). Distribution of participants by occupation are: doctors n=30, nurses n=29, administrative/officers n=10, social/supportive workers and missioner n=6, lecturers/researcher n=5.

Results
Issues selected “to start as soon as possible” were: Education and Training (80% of participants), Global needs Analysis (69%), Dialogue with Governments (60%) and Translation/Dissemination of WHO Guidelines (58%), Development of Simple Algorithms for pharmacological and non-pharmacological treatment (56%), and Research (47%). Issues selected as the ‘second priority’ were: Dialogue with WHO; Work with local society and internet sites. Most of participants did not select any roles as ‘third priority’.
Discussion
Gap in knowledge of the guidelines and pain management in general seems to be the main barrier for pain control in children. Progressing country-specific upgrade of needs in education, policy and drugs could be helpful to reveal local problems and advocate them for governments as well as to create both universal and actual for the country simple algorithms for pain management to implement them by country appropriate way.

Acknowledgements. We are grateful to members of the TF Pain Group from the ICPCN Scientific Committee who provided excellent guidance and all those who completed the survey.

Applied workshop on research

O22. Results and utilisation of a Delphi study to Identify Global Priorities for Research into Children’s Palliative Care – Downing J, Knapp C, (USA), Marston J, (South Africa) on behalf of the scientific committee (ICPCN)

Background
Over the past decade there has been an increase in research into children’s palliative care, however this tends to come from a few countries and as a developing field there is much research needed. The International Children’s Palliative Care Network (ICPCN) therefore undertook an international Delphi study to identify the global priorities for research in children’s palliative care (CPC). The aim was to use the results to inform the ICPCN & international CPC community of an international research agenda and provide the evidence base to justify proposed research.

Method
Following a review of the literature a research protocol was developed and IRB approval gained from Makerere University. The study took place between October 2012 and February 2013 and was divided into several phases: 1) Identification of possible research areas by a group of experts of different professional backgrounds, and 10 different countries; 2) identification of individuals involved in CPC from across the world to be involved in the Delphi rounds; 3) The Delphi process with two rounds being undertaken via a web-based questionnaire; 4) Analysis and finalisation of the list of research priorities.

Results
Areas for research identified in the base line list of priority areas from the international experts were reduced to 70 following content analysis. 153 people completed the first round of the Delphi process and 95 the second round. Participants came from across the world with just over 50% coming from Europe and sub-Saharan Africa. The majority of the priorities identified came under clinical care (41%). 26 areas for research reached consensus in terms of priorities. These covered a variety of psychological issues, clinical care, education, policies and procedures and education. Children’s understanding of death and dying and managing pain in children where there is no morphine were the top two priorities, with others including training needs, the need for CPC, and pain assessment and...
management. Challenges to undertaking the study have included IRB approval, identifying participants, & terminology.

Conclusion:
It is hoped that the results of this study will help in focusing researchers on the perceived priorities from across the world, and the ICPCN are in a unique position to collaborate on some of the identified priority research areas.


Background:
Reliable epidemiological data are essential to rational development of clinical services. The main obstacle is often clearly defining the population of children who need access to palliative care services. Our Directory sets out nearly 400 life-limiting conditions by ICD10 code.

Method:
We developed the Directory of Life-Limiting Conditions by a) collating diagnoses among children admitted to hospices or palliative care services in the UK b) adding conditions from death certificate data in Wales over a five-year period and c) removing diagnoses that could not, in our view, be described by any of the ACT/RCPCH categories. The Dictionary was then piloted by using it to interrogate two databases: death certificate data in Wales between 2002-2007 and the first three pollings of the Millennium Cohort Study.

Results:
The Directory contained 376 diagnoses. There were life-limiting conditions in every ICD10 chapter, showing that the range of conditions that can limit life in children is very wide and not limited to cancer. In pilot testing, the Directory worked well in interrogating death certificate data, though some causes of death that were LLC did not appear in the draft version. Its effectiveness was less in interrogating the MCS, because the MCS did not record ICD10 data in sufficient detail.

Conclusion:
The Directory is a useful tool for secondary analysis of existing data by defining precisely conditions that are life-limiting, but it can only be used where the database records diagnoses precisely, using disease label and/or ICD10 subheading. To be optimally effective, the Directory should be online and continually appended by clinicians so that the proportion of life-limiting conditions it encompasses is always increasing.
O24. Development of a methodology for estimating the need for Palliative Care – Connor S, (USA) Sisimayi C, (Zimbabwe), Downing J (ICPCN), King E (USA), Lim Ah Ken, (USA) Yates R (USA) and Marston J. (ICPCN)

UNICEF and the International Children’s Palliative Care Network undertook a joint analysis of the need for children’s palliative care (CPC) in three sub-Saharan countries: Zimbabwe, South Africa and Kenya to estimate the palliative care need amongst children as well as explore capacity to deliver (CPC) and key gaps in the response as there is growing concern that there are critical gaps in the capacity to deliver CPC.

This study used a cross-sectional design with a focus on estimating the need for palliative care amongst children (from birth to 19 years of age) and gaps at the country level. A mixed methods approach utilising both quantitative and qualitative data obtained from primary and secondary data sources was used. The estimation of the need for CPC was based on estimation techniques using the prevalence and mortality of the specific diseases known to require palliative care.

Cardiovascular disease, HIV and congenital anomalies are the greatest contributors to children’s mortality in the three countries. Other non-malignant but chronic conditions contribute significantly to the childhood morbidity and mortality in the countries. The need for children’s palliative care as a rate per 10,000 children was highest in Zimbabwe at 180/10,000. Kenya had the lowest at 120/10,000 with S. Africa at 152/10,000. Coverage for children’s palliative care was lowest in Kenya with S. Africa and Zimbabwe covering about 5% of the need.

This research is important in that it demonstrates a method that can be used in other countries to calculate the need and capacity to deliver palliative care thus demonstrating the major gap in access to palliative care for children. Recommendations on integration, education, demand creation, and funding are given.

Collaboration workshop

O25. CPC Project in Maharashtra: A Model to develop service delivery centres – Talawadekar P, Cardoz M, Nikam S. (India)

Background
This project aims to improve quality of life of children living with life-limiting illness and their families and lifting the burden of care from families by changing the policy environment and sensitizing Health professionals and the community.

Methods
The project has utilized the experience and expertise of ICPCN to strengthen National Association (IAPC) and the Expert Centre (Tata Memorial Centre) to mentor three model centres with different geographical conditions and patterns of service delivery by..

- Advocating for adoption of Palliative Care Policy by Government to develop CPC centres and include it into the curriculum
• Educating Health professionals and sensitizing policy makers, community and media to provide quality care
• Raising awareness about access to pain relieving medications like Morphine
• Empowering children and families to improve their Quality of Life

Results
1. The development of the CPC sites has motivated the Policymakers and Heads of the Institutes to expand the services to other beneficiaries. (LTMG Hospital has started CPC OPD and adult Palliative Care services. NRHM and NCD program has started Palliative Care services in 12 more districts)
2. State government officials of Integrated Child Protection scheme have added ‘children with life limiting conditions’ into the ambit of the scheme.
3. Tremendous change in the attitude of the Pediatricians who were not receptive to CPC Project initially
4. Government of Maharashtra has issued a GR to implement Palliative Care in the State.

Discussions
The project design ensures maximum impact with relatively low cost. By combining the expertise of the model CPC centre, advocacy knowledge of ICPCN and national association, the project has a multiplier effect to make a sustainable change. Mainstreaming palliative care within existing services and mentoring is more cost-effective than developing new stand-alone services.

Applied workshop on Communication & Spirituality (1)


Communication is defined by Oxford dictionaries (2011) as the imparting or exchanging of information by speaking, writing, or using some other medium. It is essential to use effective communication in clinical setting while speaking with children. In the said setting the goal of communication is to understand and acknowledge the concerns and needs of children with life limiting or threatening conditions. This is to help child and entire family who go through spectrum of emotions in such stressful condition. To encourage the child to explore his/her own thoughts need continuous engagement. Maintaining rapport by giving enough time and providing non-threatening atmosphere helps to initiate the open discussion. Emphasizing on the emotions of the child helps this progress fruitful. As per the age and understanding of child, the issues to be focused differ. Listening is a key factor in communication and assurance of confidentiality and privacy ease the process. Efforts towards involving child in discussion and decision making process is important and which is possible by using various play way methods such as drawing, painting, creative communication tools, games and so on. Appropriate usage of open ended questions to help the child express and using simple language and avoiding medical jargons to provide necessary information helps effectively. Paying attention to the body language, facial expressions, gestures and tone of child helps to understand unsaid words.
This workshop aims to address importance of enhancing communication skills to improve paediatric patient care.

**Day 2 – Breakout Sessions 13.30-14.45**

**Research**


**Background**
There is very little published empirical evidence examining the impact of out-of-home respite care for children with life-threatening conditions and their families. Very Special Kids commissioned The Centre for Palliative Care to examine the role of respite provided at Very Special Kids House, a purpose-built hospice for children with life-threatening conditions and their families, through a three part investigation with parents of children supported by Very Special Kids.

**Methods**
The study employed a multi-methods approach combining quantitative and qualitative research. Stage 1 evaluated, using standardized measures and a survey based pre-test and post-test study design, the effectiveness of out-of-home respite care on the psychosocial experience of parents of children with a life threatening condition. Stage 2 aimed to further understand the benefits, advantages, and disadvantages of respite care through a qualitative semi-structure interview technique. The third stage, a cross-sectional survey used a combination of standardized and purpose-designed measures, aimed to document the psychosocial profile of those who are eligible for but do not utilize out-of-home respite care.

**Results**
The major finding of Stage 1 was parent’s levels of distress, fatigue and mental health quality of life were significantly reduced following their child having respite. Another key finding from Stage 1 and 2 was parent’s mean scores on mental and physical health related quality of life scales were below average when compared to the normative population data of Australian adults. In addition carer’s qualitative reports indicated many faced considerable adversities in their life with health problems, financial pressure and relationship problems.

**Discussion**
The results of this study reveal the very significant beneficial effect of out-of-home respite upon the quality of life of parents of children with life-threatening conditions. The study also suggest that parents are at greater risk for mental and physical health problems and often face major life stressors suggesting the need for access to quality psychosocial support services.
O28. **Defining Quality of Life in Paediatric Palliative Care Patients – Gaab E, Wallander J. (USA)**

At present, there are no instruments available for measuring the quality of life in the pediatric palliative care (PPC) patient population. Though some policies and services have been developed to serve this population, research lags behind. Despite the goal of palliative care being the "achievement of the best quality of life for patients and their families" (WHO, 2007), we do not have a uniform way to assess this. Many authors and healthcare providers have recognized the need for studies assessing the quality of life in the pediatric palliative care population (Donaldson & Field, 1998).

Though several measures have been designed to test quality of life in healthy and disease-specific groups, this has not been done consistently in PPC populations in any country to our knowledge. This study aims to identify elements that define quality of life (QoL) / wellbeing in a sample of PPC patients in institutions in California, according to their primary caregivers, siblings and the patients themselves. Participants answer semi-structured focus group questions about the meaning of quality of life, factors that contribute to a good or poor QoL (in social, physical, mental and spiritual domains), and their perceptions of how to improve existing QoL scales.

This research is intended to increase knowledge and understanding of quality of life and wellbeing of children and adolescents receiving palliative care. Our specific aims are to define quality of life in PPC (as it is understood by patients and their families) and to create a tool that can be used to measure it across PPC patients.

Using lessons learned from working with the Pediatric Palliative Care team at Starship Children's Hospital (New Zealand) and advice from current collaborators at George Mark Children's House, Children's Hospital Oakland, and Children's Hospital Central California, we will share preliminary data and ideas for moving forward.


**Background**

Hospices, hospitals, community services and family are all involved in caring for children and young people (CYP) with life-limiting conditions and their families. In 2007 an independent review identified variation in availability of community based services and respite care. Estimates of the numbers of life limited CYP have also proved inconsistent. The Big Study is the first UK region-wide study of how well the needs of CYP and their families are being met. Researchers from five universities collaborated with the grant-holder, ACT, to conduct the study.

**Methods**

- A minimum data set (MDS) of children known to services.
• Questionnaires to parents, bereaved parents, staff and service managers.
• Interviews and focus groups with children, young people and their parents.
• Interviews with service managers and professionals about the operation of the local Children’s Palliative Care Network.
• Comparison data from national statistics and NHS sources.
• Parent and professional advisory groups supported the researchers and contributed to Methods and analysis.

Results
21 services for children providing care to children with palliative care needs participated. They provided an MDS on 1313 children. 192 parents, 23 bereaved parents and 264 professionals completed a postal questionnaire. 41 parents and 18 CYP took part in interviews, focus groups and arts-based activities. 33 staff and service managers were interviewed about the operation of the local Children’s Palliative Care Network.

Discussion:
Ethical and practical issues and challenges included access to parents of children with uncertain prognosis, gaining permission from parents for collection of the MDS from services, timing of access to bereaved parents, access to non-English speaking parents and provision of appropriate interpreting services, and formation of a CYP advisory group. The presentation will discuss lessons learned from this five-university collaboration.

O30. Paediatric palliative care program in rural setting of Andhra Pradesh state – An Initiative of an NGO Pain Relief and Palliative Care – Palat G, Kumari P, Vineela R, Venkatesh, Yashoda, Dayaker. (India)

Introduction
Children with incurable illnesses experience pain of progressive disease, invasive procedures, treatment, and psychological distress. There is need for development of clinical policies and minimum standards that promote the welfare of infants and children living with life-threatening illnesses and their families. Only a small fraction of these children have access to adequate palliative health services and hence other children suffer from undue sufferings and harassment.

Paediatric palliative care is an emerging subspecialty that does not seek to cure but to improve the quality of life of children suffering with life limiting illnesses and their families and is recommended that is integral part of any paediatric health care system.

Paediatric palliative care requires a flexible, coordinated, multidisciplinary approach. Most families prefer that their child be cared for at home therefore primary care and community services are critical to the provision of paediatric palliative care services.

Method:
A Nongovernmental organization (NGO) Pain Relief and Palliative Care Society (PRPCS) has taken up the challenge of provision of comprehensive community based palliative health care services for children and their families suffering from incurable illnesses. It can be
delivered at limited cost both in community through home based care and at health care centres aiming at reducing physical, psychosocial and spiritual suffering. As an example of model demonstrative project Dameragidda village of Chevella mandal that is located 60kms from capital city of Hyderabad was selected for the study.

**Objectives**
- To administer need assessment survey questionnaire and identify children who needed palliative health care services.
- Training of community volunteers and health care workers.
- Conducting series of awareness sessions for various groups of the population like school children, youth, mahila groups, village panchayat members, etc.
- Mobilizing the community
- To network and strengthen linkages with local bodies, NGO’s.
- Continuity of care is ensured by regular assessment of the quality of life of children and their families by provision of counselling, home care and regular follow up
- End of life care/hospice care/bereavement support
- Rehabilitation and socio-economic support

**Result:**
Children suffering with incurable illnesses like cancer, developmental retarded, cardiac diseases, Para/quadriplegia, congenital disorders were identified. The project that was started in one village is now expanded to 9 villages.

**Conclusion:**
Continuous Palliative health care services provided for suffering children. The team effort has brought in a ray of light into the life of children and their families.

**Applied workshop on pain**


**Issues**
Recent advances in our understanding of complex pain suggest that there is an association with maladaptive functional and structural cortical changes. Therapeutic interventions that specifically target this maladaptive neuroplasticity can yield substantial improvements in pain and disability. This session will detail the neuroplastic signature of complex pain and provide an evidenced based overview of graded motor imagery (GMI) as an intervention to target the associated functional and structural cortical changes.

**Description**
GMI aims to engage the cortical networks that subserve the patient’s pain presentation without activating the protective response of pain. GMI is a three stage treatment based on the application of the principle of graded and progressive activity to the brain. The first stage, implicit motor imagery, consists of left and right discrimination tasks which activate the premotor areas of the brain. The second stage, explicit motor imagery, consists of imagined movements of the painful body part which has been shown to activate motor cortical areas in a manner similar to actual movement. The third and final stage, mirror
therapy, utilizes mirror visual feedback to provide the illusion of pain free movement of the painful body part. GMI has been shown to result in cortical reorganization and to reduce pain and disability.

Practical Application
The evidence and practical application of GMI will be discussed in the context of a 17 year old patient presenting with rhabdomyosarcoma with metastatic disease and complex regional pain syndrome type 1 of the left hand.

Session Outcomes
At the completion of this session, attendees will have a greater understanding of the maladaptive neuroplasticity associated with complex pain, the principles of GMI as a graded exercise approach to training the brain, and learn a framework for the practical application of this modality in the context of the persistent pain patient.

Applied workshop on education

O32. Enriching your program through Nursing education – Chrastek J. (USA)

Palliative care education and training makes for a strong and lasting team, but is not always easy or inexpensive. Nurses are essential palliative care providers yet often have little to no access to formal training in the field. This oral presentation discusses one model for education of large number of nurses though an established train the trainer model and ongoing mentoring. The End of Life Nursing Education Consortium (ELNEC) developed an international curriculum for a train the trainer workshops. This project is administered by the American Association of Colleges of Nursing (AACN), Washington, DC and the City of Hope, Los Angeles, California, USA and is supported by a national cadre of nursing leaders in palliative care. The nine-module curriculum provides didactic education and training in areas such as pain and symptom management, family centered care and cultural/spiritual issues. It can be translated into the local language, adapted to be regionally and culturally appropriate. The curriculum is updated every three years. This presentation will review key aspects of the curriculum, how to become a trainer and a sample implementation plan for lasting change to take place, education must be practical and ongoing, this is best done through mentorship. Learning to be a good mentor takes time and effort. Those who build trusting relationships with the learner can foster growth and lasting change. This presentation will review aspects of mentorship and provide some tips on learning how to be a mentor. It will also discuss lessons learned,

O33. What does the assessment of a paediatric palliative care course tell us? – Friedel-Castorini M (Belgium)

In Belgium exists since 2002 a law that allows in particular conditions active euthanasia for adults. 10 years later, political discussions are focused on the extension of this law to minors. In this context, we wanted to make another proposal by offering education in pediatric palliative care to strengthen health professionals working with children presenting life limiting conditions.
That is the reason why the first Belgian (French-speaking part of Belgium) interdisciplinary course in pediatric palliative care (86 hours) took place from December 2012 to April 2013 in Brussels.

A pedagogical team of 25 experts coming from 5 different Belgian hospitals or Belgian universities gave this course. An important effort was made to coordinate the contents of each professor, to standardize pedagogical objectives and to promote reflective teaching practices, with a specific focus on family-centered care.

The program content was conceived in accordance to the main key-ideas of IMPACCT (2007, EAPC).
12 students took part to the course (5 nurses, 5 nurses spec. in pediatrics and 2 physiotherapists).

This paper presents:
1) The whole work upstream (16 months of preparation) which permitted the implementation of this course in a sustainable way, making connections between different Belgian hospitals and universities.
2) The results of an questionnaire which analysed the educational needs and belongings of the students at the first hour of the course. (n=2 physiotherapists and n= 10 nurses/nurses spec. in pediatrics),
3) The results of the final assessment made by the students (n=7) about each professor and about the whole course followed.

The results highlighted various interesting points:
• Great enthusiasm and motivation expressed by the students to participate at the course thanks to their different backgrounds and the possibility to share during the lessons their own professional experiences.
• Importance to offer a well-balanced program content between theoretical facts of study and clinical situations to debate.
• Importance to consider and to adapt the programme contents to the different professional backgrounds of the students (nurses/physiotherapists).
• Perceived needs from the students to receive information about the different religions, cultures and beliefs in regard of life, illness and death.

Thanks to these results and the elements pointed in the White paper on core competences in palliative care developed by Gamondi, Larkin and Payne (2013) an improved second edition of the interdisciplinary course in pediatric palliative care will be offered in Brussels from December 2013 to March 2014.

O34. The EAPC Competencies for CPC – Downing J (Uganda/Serbia) Ling J (Ireland), Benini F (Italy), Payne S (United Kingdom), Papadatou (Greece)

Education is an essential component in the development of paediatric palliative care, thus all health and social care professionals need to be trained to provide high quality palliative
care for children and their families. This paper will discuss the new EAPC white paper on core competencies for paediatric palliative care training, which provides recommendations and guidelines for the ongoing development of initiatives in paediatric palliative care training and education for healthcare professionals.

Education programmes for paediatric palliative care should be aimed at: a) the acquisition of knowledge, b) the development of specific skills, c) the capacity of interdisciplinary thinking, d) the cultivation of attitudes that promote quality of life, and e) the ability for self-awareness and reflective practice. Programmes need to develop practitioners who are ‘fit for practice’ and ‘competent’ to provide children’s palliative care. Core competencies are identified within the three-tiered approach to education proposed by Gamondi et al (2013) i.e.: (1) The palliative care approach; (2) General palliative care; and (3) Specialist palliative care.

Basic education on the palliative care approach focuses on the general principles and practices of palliative care, highlighting the differences between paediatric and adult palliative care. General paediatric palliative care education is aimed at those who come from a paediatric background who need to learn about palliative care. Minimum competencies are identified under twelve domains e.g. Core aspects of paediatric palliative care and its application. For healthcare professionals requiring specialist paediatric palliative care education the competency framework is broader and encompasses competencies in areas such as collaborative practice, leadership, service development, research, education and professional practice.

Whilst a growing number of courses and curricula are available on paediatric palliative care, provision of courses does not meet the need, therefore it is important to extend education opportunities for everyone involved in paediatric palliative care.

**Applied workshop on leadership (2)**

**O35. Valuing Intergenerational Diversity in the Workplace – Wagner A (South Africa)**

Diversity is more than just tolerating differences. It is respecting, appreciating, and understanding the varying characteristics of individuals. Diversity management is the key to promoting dignity and respect in the workplace and a framework for positioning people as a necessary factor to organizational success. Diversity management is a strategic organizational goal and requires a shift in thinking. Diversity management requires a specific focus on personal and organizational culture, cultural differences, culture change, and cross-cultural relationships based on interdisciplinary knowledge. This presentation will focus on the following:

1. Overview and Understanding of Diversity.
2. Generational Diversity in Workplace.
5. Barriers to Valuing Diversity.
**O36. Debates, dilemmas and opportunities within children’s palliative care in the UK –**

*Gelb B (United Kingdom)*

**Issues**

In 1982 the world’s first children’s hospice opened its doors in England. Since then there have been tremendous developments in children’s palliative care in the UK. With advances in medical science, evolving models of care and funding, and changing service user expectations, our sector is now at a critical point as we work to ensure that we are fit for the future.

**Description**

The UK children’s palliative care sector now comprises nearly 50 non-governmental children’s hospice services, alongside a range of government services providing specialist and generalist palliative care. The presentation will highlight the work of Together for Short Lives, the organisation that is the UK voice for children’s palliative care, now and into the future as we facilitate the necessary debates and dilemmas to be addressed by the sector.

**Lessons learned**

Our work is informed by the outcome of a series of stakeholder events held right across all 4 UK countries providing important insights into the experiences of children and families, and also by the emerging findings of the Commission into the Future of Hospice Care in the UK. Key issues which we must now address include the need for effective care co-ordination; the low awareness of children’s palliative care amongst generalist professionals and the urgency for more services for young adults. The need for sustainability into the future requires that we attend to workforce development, and the use of volunteers, partnership working and the need for a robust evidence base.

**Recommendations**

Leaders and strategists across the sector must now lead the way in their organisations by stimulating debate at every level in order to explore the best way of preparing for future service delivery. It is the responsibility of all in the sector to engage in the debates as we prepare for the future.

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**O37. We are providing an excellent clinical service, but is that enough to sustain us –**

*Wagner A (South Africa)*

NPOs providing Palliative Care can play a pivotal role in health, community and social services if management, leadership, governance and other elements of organisational capacity is well developed and continuously strengthened to support the excellent clinical service provided. This is critical for attracting local and international donors who provide crucial running costs and relieves national, provincial and local government departments of the financial burden.
Leaders in Palliative Care are in a position to ensure that the clinical service provided is of the highest quality, but are not always able to ensure that supportive services keep up with clinical services. Clinical service delivery is dependent on a strong support service structure. Long term organisational sustainability requires the correct mix, interaction and use of people, capacity, resources and development as these are interdependent. This presentation will look at the successful use and application of the key components required for sustainable organisational development. The presentation will address the following:

1. Key strategies for developing organisational capacity
2. The effective use of people, capacity, resources and development to ensure organisational sustainability
3. Assessing organisational capacity
4. Organisational change elements
5. Organisational life cycle stages

**O38. The UK Square Table programme: An engagement tool for children's palliative care services – Gelb B (United Kingdom)**

**Issues**

It is estimated that 49000 children and young people are living with a life-limiting condition in the UK. Family carers are important partners in their child’s care, but often their voices are not heard in service development and design.

**Description**

During 2010-11, 41 Square Table events held across the UK. More than 1,500 people took part, including families of children with life-limiting conditions, young adults who have grown up using children’s palliative care services, health, social care and education professionals and other community leaders.

The Square Table programme aimed to:

- Deepen understanding of children’s palliative care within communities.
- Act as a catalyst for communities to work better together to meet the needs of children and families
- Stimulate service providers to develop their services

**Lessons learned**

The Square Table is a structured discussion, where all sides of the table are the same length to symbolise all views as equal in merit. The events were hosted by local services, enabling greater understanding of the needs of users and reach out into their communities.

The themes, which emerged, were:

1. Low awareness impacts negatively on access to services.
2. Greater coordination of services and partnerships is needed at all levels.
3. Key working is a necessity for helping families to navigate a complex system
4. Serious concerns about support for young people making the transition to adulthood.
5. The future sustainability of services is a concern, particularly given the fragile economy.

Progress has been made by services since the programme, particularly in:
- Widening family support services
- Improving partnership working and collaboration with the statutory sector
- Developing new services
- Improving communication

**Recommendations**
The Square Table concept is a valuable tool for services to engage more effectively with communities and in service development.

**Applied workshop on Communication & Spirituality (2) (Lecture Room 1 – HBB)**


Spirituality can be defined as whatever gives one a ‘Transcendent’ meaning in life. But many times this is expressed as religion or relationship with God. Spirituality and religion are so closely associated that the words are often used interchangeably. Most situations, particularly difficult ones that a person finds herself/himself in are attributed to God’s will or Karma. The meaning in life can also refer to other things like nature, energy, force, belief in the good of all, belief in the importance of family and community.

One's values, beliefs, experiences, motivations, dreams, thoughts can profoundly affect how a person copes with illness and with the treatment of illness. So, spiritual and religious factors play a prominent role in a patient's experience with terminal illness, the dying process and death.

Though the importance of Spirituality has been identified in dealing with children with life limiting conditions and their families, health care workers are not comfortable in dealing with this aspect of Palliative Care. Dealing with Spiritual Care differs with the cadre of the Health Care worker. They are not trained enough in this aspect. Those who have suffered a loss, are more comfortable in dealing with spiritual care. Many a time, they take the support of religion. The most important thing being the health care providers should identify her/his own spirituality and there has to be a valid and reliable tool specific for the population.

The objective of the workshop would be to discuss the meaning of Spirituality, clear the difference between religion and spirituality and spiritual help that can be provided throughout the continuum of Care.
Day 2 – Breakout Sessions 15.15-16.30

Education

O40. From Training to Integration: Paediatric Palliative Care in Hospitals and a Hospice – Thambo V, (Zambia) Lockwood N. (USA)

Issues
The Government of the Republic of Zambia (GRZ) does not currently support palliative care (PC) in Zambia. Subsequent lack of training in PC has perpetuated stigma and misconceptions around PC and hospice centres. As the majority of health care workers (HCWs) in the country lack familiarity with PC, they rarely refer patients who could benefit from PC to hospice centres and do not provide PC themselves.

Description
1. After attending a paediatric palliative care (PPC) training session in South Africa, the attendee (EGPAF staff) returned to Zambia and trained 25 people at Macha Mission Hospital in Southern Zambia.
2. When Zambia’s only in-patient PPC facility, Maluba House (supported by EGPAF, TTF and Our Lady’s Hospice), opened in June 2012, filling the beds presented as a challenge. After much education and advocacy from key stakeholders, health centers began referring patients. Now, the beds remain full.
3. In early 2013, 24 HCWs underwent a three-week PPC training-of-trainers (Tot) course. Later, a trainee taught 22 additional HCWs at Macha Mission Hospital.
4. The PPC-trained staff members at Macha Mission hospital are now working to integrate PPC into the care they deliver.

Lessons Learned
1. Tot sessions, based in theory, can efficiently increase the number of PPC-trained HCWs and the awareness around PPC. Subsequent trainings based on these sessions can provide trainees with the tools to further expand PPC delivery.
2. Referral systems in hospitals act as effective modes to sensitize people to PPC, as well-informed HCWs at these health system entry-points can dispel misconceptions.
3. Need to continue to advocate to Policy makers for recognition of PPC in Zambia.

Recommendations
Tot sessions on PPC should be expanded, as they can have multiplicative outcomes in terms of reaching HCWs. Further, hospice centres and PC organizations should partner with hospitals and other health centres. Doing so has the potential to increase access to PPC by dispelling misconceptions held by HCWs in regards to PPC and hospice care, so that they can sensitize their patients.

Issue
Peadiatric palliative care was practically invisible in Thailand until 6 years ago. In Thailand, there are around 1000 new cancer children each year, cared for by 60 oncologists in 25 centers, around 500 will relapse and need palliative care.

Description
To expand the workforce on PPC, we organized several education events for pediatricians and nursing communities in Thailand the past 5 years. Two End-of-Life care for Nursing Education Course (ELNEC) was offered in 2009 and 2010, co-organized with The Pediatric Nurse Society of Thailand with 100 participants from nursing schools and hospital centers. These events led to development of a nursing guideline for by the Nursing council of Thailand in 2011.

Pediatrician educational conference in palliative care was first introduced in 2007, and then repeated in collaboration with the Royal Society of Pediatrician of Thailand in 2011, where it was held in conjunction with the 22nd Children’s Hospice International World Congress. We have observed participation from over 100 pediatrician and nurses from all over Thailand, as well as Southeast Asia. From 2012, we visited several hospital centers in Thailand to organize one-day educational conference on pediatric palliative care (PPC) for their physician and staffs. Of 7 centers we have visited, the attendance varies from 50-150.

Lesson learned:
Through these educational efforts, we observed that there were few pediatricians and nurses in each center who would attend a centralized conference. But they will be the key persons who coordinate PPC education in each center, where overworked professionals who would otherwise have not gone to conferences were exposed to palliative care concept, inspired them to include PPC as part of a good oncology care, and enable their PPC champions to do the work with support from their colleagues and administrator.

Recommendation:
PPC education need to be presented to each treatment center.


Issues
Palliative care (PC) services in Serbia are at early stages in development with the focus being on the development of services for adults. However, the National Strategy for PC set out the need for PC service provision for both adults and children, thus it was important to explore the need for children’s PC within the country, and provide training as appropriate.

Description
A situational analysis was undertaken to highlight children’s PC needs as part of the EU funded project ‘Development of PC Services in Serbia’. Following a desk review, data
gathered from different sources and informal interviews were conducted with key informants. Following this an initial training programme on children’s PC was conducted for 40 participants (doctors, nurses, social workers and psychologists), and e-learning materials made available in Serbian.

Lessons learned:
There is a good foundation upon which children’s PC services can be developed. There are 200-300 new cases of child malignant disease annually (70% treatable) with rates of other life-limiting conditions unknown. Many children die in hospital although increasingly children are dying at home, and there is a well-established free healthcare system for children and excellent paediatric specialist services. The training aimed at enhancing understanding of the general principles and practice of children’s PC and was conducted for those working in tertiary level children’s services and social institutions. 100% of participants rated the course as very good, with 97.7% saying how useful it was to their practice. Pain assessment and management, along with communicating with children and their parents were seen as the most helpful topics in the course.

Recommendations
There is a need for children’s PC, and health and social care professionals are keen to learn more. With adequate resource allocation and education, children’s PC services could be successfully integrated into paediatric health care in Serbia.

Applied workshop on Pain (3)

043. Hypnosis for Pain and Palliative Care – Wood C (France)

Hypnosis is a psychological state of heightened awareness and focused attention, in which critical faculties are reduced and susceptibility and receptiveness to ideas is greatly enhanced. Children have blurred boundaries between fantasy and reality, a factor that makes them ideal candidates for hypnotic interventions.

In this workshop, the way hypnosis acts on the neuromatrix of the brain will be developed. Then the use of hypnosis shall be developed for procedural and chronic pain, and for palliative care. Many studies have shown that hypnosis is effective in reducing pain and anxiety during medical procedures such as lumbar punctures, bone marrow aspirations, and venipuncture’s...

During a procedure, the child is already focused on his anxiety and his pain. He is already in some sort of trance. The goal of the management is to make him focus on something else, something different than the medical procedure. The techniques that are used will be different according to the age of the child. For smaller children, distraction techniques, or physical interaction (with bubbles, or games with the fingers...) can be used. For older children, different hypnotic analgesic techniques can be used for acute and chronic pain management including direct suggestions such as pain displacement, symptom substitution, time distortion, topical anesthesia, glove anesthesia, and dissociation. One can also use indirect suggestions such as therapeutic stories and metaphors. They can be taught these
techniques and learn to practice self-hypnosis. Hypnosis can be used alone but can also be associated to medication such as anxiolytics, analgesics, EMLA cream, and Nitrous oxide 50/50 making the technique much more efficient.

Hypnosis is also a very useful tool in the context of palliative care. The child learns not only to reduce his pain, but also learns to go to a safe place, is able to find energy and strength to face his incurable disease. Hypnosis is a very useful technique in helping children to cope with their disease and their undergoing procedures. It helps create a therapeutic alliance between the child, the family and the therapist. The parents become part of the team, as they actively help the child in practicing and using this coping strategy, and in such a way, gain a sense of control over the pain.

Programme Development

**O44.** Preparing the soil, planting the seeds, and nourishing growth: developing your pediatric palliative care program – *Chrastek J (USA)*

Fully integrated and long lasting palliative care programs like gardens, must be carefully prepared, seeded and tended. This presentation will provide a working example of a template to walk learners through a collaborative development process. At the beginning of the workshop the attendees will be provided with work sheets to complete at intervals during the presentation. They will use the lecture material and discussions to develop a personal plan to improve care in their work place. The presentation will provide an overview of mission alignment, needs assessment, grass roots network building and collaborative team building across disciplines and specialties. The need for data collection, measurements and education will also be addressed. Community collaboration, education and relationship building are woven through the presentation as they are essential for successful implementation of palliative care. After each section the participants will develop a personal action plan to move their program forward. These plans may be small or large, but each step towards improving care, when coordinated with others, will bring about change. The participants will be invited to share their action steps to inspire others at the workshop and later in their own institutions. They will be encouraged to take the template and replicate it for program growth. Mistakes made by other program developers, pitfalls to avoid and lessons learned will be discussed. Small group discussions of challenges and solutions to encourage networking will be an important part of the workshop time. At the end of the workshop the learner will have a completed plan, a template they can replicate and have built a new network of contacts in pediatric palliative care. They will find like many others success comes when you start small build relationships and plan for long term commitment.

**O45.** Allocation of short-break care to children and families with palliative care needs – *Hughes E, Kauffmann L. (United Kingdom)*

Short breaks are important both in improving quality of life (embracing physical, emotional, social and spiritual needs) and providing support and respite. Through a literature review and interviews with service users and providers (including members of the paediatric
palliative care team, healthcare commissioners and social care sector workers, as well as hospices and foster carers) from across Greater Manchester, I found that allocation of short breaks is often inadequate and random, frequently not meeting needs. A tool that focuses on the child, primary carer(s) and sibling(s) can be used as a guide to short break care allocation. The child’s needs are assessed according to mobility, continence, eating/drinking, communication, seizures, sleeping, breathing, tissue viability, medication/procedures, dressing/washing, school, behaviour and hospital appointments. Primary carer(s) are assessed according to partner support, extended family/other support, occupation/study commitments, own health (physical and mental) and competency. Total number of siblings, including number not in full-time education is also taken account of, alongside health and behavioural needs of siblings. The tool provides a score that can be used to equate a monthly time allocation to the family's need. This allocation is neither prescriptive nor static but serves as a flexible guide alongside extensive discussions with the family. Should there be insufficient short breaks available to meet demand, the tool assists in prioritising those with the highest unmet needs. It also goes some way towards differentiating between health and social needs, thus aiming to resolve all-too-frequent disputes between sectors over where responsibility lies for short break provision. Weighting of variables still needs to be pursued. Nevertheless, following revisions suggested by preliminary trials with four families, the tool is promising in terms of its face validity and interrater reliability. We hope to see the tool being further tested and put into action soon.

O46. Developing Paediatric palliative Care in Western Kenya Region, a Tool to relieve suffering – Were PA (Kenya)

Introduction
More than 80% of children with cancer live in resource limited countries where access to medical care is poor. Parents of children who died on a pediatric oncology service reported that despite treatment at the end of life, their children's suffering was not adequately relieved. Pediatric oncology programs deliver inadequate palliation to children with cancer; with sporadic availability of oral morphine and strict administration regulations, uncontrolled pain is a major cause of suffering in these children. This paper highlights the introduction of Pediatric palliative care services, which provides psychosocial and pain management to children with life-threatening conditions and their families in the Western Kenya region.

Method
Two health facilities have been selected for pilot study; the implementing team comprises palliative care nurses, a pediatrician and a surgeon who make fortnight visits to these facilities. Activities include advocacy on early detection and role of chemotherapy in children’s malignancies, provision of psychosocial care and pain management.

Results
Two clinic visits have been carried out at each site with 22 children turning up for the visit. Relief of distressing symptoms has been reported in 80% of these patients.
Conclusion
A model that incorporates palliative services into the mainstream of medical therapy should be emphasized as a standard for the care of all children with significant life-threatening or life limiting conditions. Challenges of improving survival and prognosis include first presentation at an advanced stage failure to start or adhere to treatment and lack of trained HCP’s in children’s palliative care.

O47. The Development of PPC in Norway – Pederson N (Norway)

Background
Until 2009, Paediatric Palliative Care (PPC) for children with life limiting (LLC) and life threatening conditions in Norway had been given no attention. In almost four years, this field now has a huge amount of political and social attention and has led to active actions in several areas. The founding of the first organization working for PPC and advocating for this, has contributed to this development and attention to this field. In December 2011, the Committee on Health and Care Services acknowledged the need for improving the provisions made for children in need of PPC, and a unanimous Parliamentary group, who represents the ultimate expression of the sovereignty of the Norwegian people, decided that Norway should create national guidelines on PPC. Then in February 2011, the Norwegian Ministry of Health and Care Services gave the Norwegian Directorate of Health the mission to create them.

Methods:
Social media, media, collaboration with political parties and politicians and other health professional organizations - international and national, article’s in different journals, and a conference. Giving statements to several public hearings to parliament.

Results and Achievements:
The creating of the guidelines; the first conference on PPC in the Nordic countries; increased attention, both political and educational. Political advocacy and influence. The way forward is to fulfil the need to get PPC in the education system and to ensure that the standards for paediatric palliative care in Norway apply the principles of WHO’s definition of paediatric palliative care. And that the Government needs to commit to sustained and adequate funding to provide holistic, multidisciplinary palliative care in a variety of settings, including homes, schools, hospitals, respite care settings and to meet this need in the future.

Conclusions:
How advocacy, strategy and collaboration can ensure a multidisciplinary standard for a seamless PPC service to children. And how a small organization can make a difference and an impact on the development of PPC in a country.
Workshop

O48. Walking the halls of influence in global palliative care – Connor S and Cleary J (USA)

Recent events in international palliative care advocacy have resulted in some major successes and advances for the field. The World Health Organization just accepted a report on global palliative care progress and unanimously passed a resolution calling on member states to advance palliative care for adults and children. This report and resolution were informed by a joint publication from WHO and the Worldwide Palliative Care Alliance titled: The Global Atlas of Palliative Care at the End of Life. Plans are moving ahead to have this resolution presented and approved at the next WHO World Health Assembly in May in Geneva. In parallel, efforts continue to improve access to opioids through the UN Commission on Narcotic Drugs and the UN office of Drugs and Crime. Participants in this workshop will have a chance to learn about these recent developments from two of the main international advocates for hospice and palliative care with a special focus on how these developments can be used to promote children’s palliative care.

Clinical care

O49. Treatment of Fungal Keratitis by Topical Application of Fluconazole – Becker S, von Reuss, Fiedler H, Hornke I. (Germany)

Issues

Although immunosuppression besides antecedent trauma is known to predispose to fungal infections of the eye, this disease is rarely reported in palliative patients and only few is known about therapeutic strategies especially in children. We want to report the clinical course of a 5 9/12 yrs old boy with advanced cerebral cancer of the pons who suffered from fungal keratitis of both eyes.

Description

When the patient developed pruritus of both eyes and conjunctivitis with some smear we first assumed bacterial infection and started treatment with gentamycin, followed by azithromycin, both without success. Few days later, the parents reported large white deposits in the mouth typical for candidiasis. Due to difficulties in dispensing amphomoronal in the mouth, oral therapy had to be changed to diflucan. Clinical diagnosis of fungal keratitis was made when hypopyon and geographical corneal infiltration occurred. Additional local therapy with fluconazole eye drops (manufactored from the iv-solution) resulted in reduction of the conjunctivale injection, and the hypopyon and pruritus improved.

Lessons learned

1. Especially in patients with risk factors like immunosuppression (e.g. in our patient cancer, corticoidtreatment, keratitis sicca due to reduced eyelid movement) and candidiasis infection in other parts of the body, ceratomycosis should be taken into account as diagnosis.
2. Fluconazole eye drops offer a good treatment opportunity in candidas albicans infections in palliative patients as much higher concentrations in the eye can be achieved by eye drops compared to oral administration. Further, due to its low molecular weight fluconazole penetrates through the cornea into aqueous fluid.

**Recommendation:**
Take into account fungal eye infection in palliative patients with risk factors. Fluconazole eye-drops are effective in keratitis due to candida albicans infection. However, in non-candida-albicans infections, voriconazole should be considered.

**O50. The role of palliative care and ARV's in children with advanced HIV disease – Brits H (South Africa)**

**Background:**
Although treatment exists for HIV and AIDS, it remains a chronic life limiting and life threatening disease where palliative care can play an important role in the holistic approach of these patients. Palliative care offers assessment and management of the patient’s body, mind and spirit throughout the course of the disease, as well as support to the parents and caregivers.

**Aim:**
To assess the outcomes of children with advanced HIV initiated on ARV’s after 48 months on treatment.

**Methods:**
A cohort of all children in the Sunflower Children’s Hospice programme initiated on ARV’s from September 2006 till February 2007 and followed for 48 months. Data were collected from the patients’ ARV files situated at the hospital and verified from the patients’ retained records and hospice files to ensure accurate data.

**Results:**
A total of 37 children were initiated on ARV’s in the Sunflower Children’s Hospice programme. Eighteen children were followed up for the 48 month duration of the study, seven died, six were transferred to other programmes and six were lost to follow-up. The oldest and youngest child initiated on treatment died and the child with the highest initial viral load survived. Academic performances and social adaptability varied and between all the survivors.

**Discussion:**
Despite advanced HIV disease the outcomes varied considerably between individual children and some predictors for better outcome were identified. Therefore every child deserves the right to ARV’s and palliative care to develop to their own full potential.
**O51. Communication Challenges in Paediatric Palliative Care – A Practical Approach – Herbert A, Bluebond-Langner M (Australia)**

This presentation will be interactive and facilitative in nature. The participants will receive detailed narratives describing the experience of and care provided to three patients of different ages (cancer and non-cancer diagnoses). The workshop participants will identify themes relating to the issues of communication. Small groups within the workshop will then discuss the identified themes in detail, using their own experience and practical knowledge to contribute to the whole group’s broader understanding of communication issues in paediatric palliative care. A summation of each small group’s understanding of the various issues will help to conceptualize the key issues of each case. Depending on time constraints, 1 - 3 cases may be completed. Likely themes to emerge include cultural issues, understanding of treatment, and impacts on the family, communicating with the child, and schooling amongst others.

**O52. Management of respiratory distress in the palliative care setting – Drew D (Australia)**

Optimising quality care at end of life is paramount. Understanding the basic principles of palliative care assists in managing the challenging situations that arise during this phase of the illness journey.

This interactive session will discuss the issue of breathlessness in paediatric palliative care. Discussion will focus on causes of dyspnoea and common symptoms in the end of life setting. Pharmacological and non-pharmacological interventions will be highlighted with clinical vignettes woven throughout the discussion.

This session will share lessons learnt from the medical, nursing, patient and family perspective. The patient’s description of the experience of breathlessness will be shared.

**Day 3 – Breakout Sessions 11.00-12.15**

**Applied workshop on advocacy**


This is a workshop where participants will gain new skills in advocacy for palliative care in the region. In this session attendees will learn a variety of skills including 8 steps to good advocacy, use of advocacy data and reports such as the Global Atlas & UNICEF research reports, use of the WPCA advocacy toolkit. We will also work in small groups to identify goals for children’s palliative care advocacy in different parts of the world. This workshop will prepare participants to develop a plan for advocacy in the next session.
Research

O54. Observational Insights through a Counsellors Lens – Sunita J (India)

Introduction
Children and Adolescent population occupy a special place in the context of Indian families. And hence they form the core of any family. Diagnosis of life threatening illness like cancer presents a great deal of distress to the patients and their caregivers. In particular the distress of the adolescent patients gets compounded with the issues of their physical and psychological development and this can pose a real challenge to the service providers.

Aim and objective
This qualitative paper aims to capture a decade’s journey of Paediatric Palliative Care at Tata Memorial Hospital highlighting the progress which began as a unique service and emerged to be a need of the time helping Indian Families Cope with the potential loss of losing the child/adolescent.

Methodology:
Observational insight through a Counsellor’s Lens engaged in Paediatric Palliative since inception

Results
The unique service only of its kind than in the country began in 2002 in a tertiary hospital of international repute in an unstructured pattern in a small room of a consultant has entered the pubertal phase and is establishing independent identity. This service has passed through the developmental phase as children do. Paediatric Palliative Care has not only helped parents and patients but it has polished skills of all those engaged in counselling as the learning process matched the development phase. The amazing learning process and apprehensions of the professionals on how could one communicate best with parents without hurting them and yet reach to them to inform about bad prognosis and failure in treatment sometimes in a couple of sessions or at times in minutes.

O55. Providing respite care at home for children with life-limiting conditions:
Unravelling the issues – Ling J, McCarron M, Payne S, Conniare K. (Ireland)

Background
Respite care is of importance to the parents of children with life-limiting conditions. A myriad of factors influence whether parents utilise respite for their child and untangling these interwoven and interconnecting factors is challenging.

Aim:
Presentation of findings on the factors that influence parent’s decisions to utilise respite
Methods
Utilising multiple, qualitative case study design, parents caring for a child with a life-limiting condition were recruited to a study to explore their respite needs and experiences. Multiple, in-depth interviews were undertaken with parents identified by a children’s palliative care team. Viewed through the theoretical lens of family systems theory in-depth interviews were also conducted with others identified by parents as having a role in the provision of respite. All data gathered were analysed using thematic analysis. Each individual case consists of a whole study. Cross-case comparison was also conducted.

Results
Nine families were recruited and followed for up to two years. Home was the preferred location for care. Whilst acknowledging the essential role of respite in the care of their child parents also identified a number of factors that influenced such services. Parents were concerned about issues such as: the skills and experience of carers or nurses; availability and flexibility of the service; the impact on the family of having a stranger in the family home; and concerns regarding the flexibility of arrangements for respite. Participants involved in providing care raised concerns regarding providing care. Parents found their own way to navigate the system to ensure that their child received respite services.

Conclusion:
Respite is an important component of children’s palliative care but is only acceptable when it is provided in a format and location that meets parents’ needs and expectations. A number of factors influence parental decisions to utilise respite.

O56. Audit of resuscitation planning at a tertiary children's hospital – Herbert A, Kelly J. (Australia)

Background
Resuscitation planning is a marker of good quality end of life care and the role of paediatricians in broaching this difficult topic is increasingly acknowledged.

Method
A retrospective review of case notes of children at the Royal Children’s Hospital who died over a 12-month period was performed.

Results
Of 62 patients’ records available, 51 patients had a severe life limiting condition. Of these 51 records, 35 (68.6%) contained a documented resuscitation plan (RP). Of the 11 patients who did not have a significant premorbid illness, 5 (45.4 %) had a RP. The average time from documentation of a RP to the patients’ death was 50.46 days (SD = 100.9). Referral to palliative care services (PCS) was associated with a statistically significant increase in the time from resuscitation planning to death. Furthermore, a large number of patients who had been referred to PCS (n=18) died in their own home. The resuscitation plan was easily identified in the medical record in just 12.5 % of cases, suggesting one area of practice, which could be improved.
Discussion
In addressing the difficult issue of end of life care, the family and patient (where appropriate) are afforded the opportunity to express their wishes. This allows some choice in areas such as location of care. Guidelines documented in resuscitation plans should be clear, unambiguous and easily identified in medical charts.

O57. ‘Double Grief’ - The experiences of grandparents of children with cancer: "It seems so unfair to see little ones suffer" – Drew D, Wakefield C, Ellis S, Doolan E, MMcLoone J, Cohn P. (Australia)

Objectives
During a child’s cancer treatment, grandparents are often relied upon for the provision of practical and emotional support. Most grandparents last raised a child several decades earlier and have no experience in children’s oncology. This study explored grandparents’ experiences of grand parenting in the paediatric oncology context across the disease trajectory focusing on the perceived impact of cancer on grandparent-parent - patient, and –sibling relationships.

Method
Grandparents of children with cancer (treated at three paediatric oncology centres) completed a self-report questionnaire. Open-ended responses regarding their grand parenting experiences were coded line-by-line and categorized using QSRv8.

Findings
Eighty-eight grandparents participated (mean age 65 years [range 46-81]; 31% male). Many described improved relationships with the ill child (n=27), their siblings (n=10) and the children’s parents (n=25). Grandparents reported increased feelings of anxiety and protectiveness for all family members. Grandparents described being challenged by parents’ emotional outbursts (including encountering anger directed toward them). They also experienced uncertainty about how to provide support and advice without over-stepping parents’ authority. Five grandparents of the 88 had a grandchild who had relapsed, was receiving palliative care or who had died. The grandparents of these children appeared to have the highest need for information regarding relapse (100%), palliative care (80%) and “special issues for grandparents if grandchild dies” (80%), compared to grandparents of non-relapsed/deceased children (89%, 53%, 54% respectively).

Conclusion
The diagnosis and impact of a life threatening illness for a grandchild on grandparents is under-studied. Grandparents are often called on to provide co-parenting support for the family in crisis, often without benefit of the knowledge imparted by the treating team to the child’s parents. The unique context of grand parenting during childhood cancer treatment across the disease trajectory places a considerable burden on this aging group.
Programme Development

O58. Helping communities to help bereaved children – Hunt J (Zimbabwe)

The nine-cell bereavement table was originally developed to raise awareness of the needs of the bereaved in a culturally diverse environment. By completing a table through a group work methodology, participants explore their personal and professional bereavement experiences. Then, looking at their feelings over time in relation to what is socially acceptable, and comparing their real needs with the kinds of support offered in their communities, participants can themselves develop strategies to help bereaved people more effectively and raise bereavement awareness locally. The tool is flexible enough to have a specific focus on bereaved children, and the same technique is used with a lens on the needs of bereaved children of all ages. An external evaluation has yet to be undertaken but according to anecdotal evidence, the nine cell tool has potential to significantly improve community support for bereaved children.

O59. Integration of Palliative Care into the Comprehensive Paediatric Oncology Programme of a Tertiary Cancer Hospital – Rapelli V, Venkatesh P, Reddy AJ, Palat G, Sinha S, Kannan T (India)

Background

MNJ Institute of Oncology is a 350-bedded tertiary care hospital for the state of Andhra Pradesh, India (population of 65 million). Every year the hospital sees more than 1000 new children diagnosed with cancer. Most children require long, intensive curative treatment. Painful procedures, various symptoms and the emotional trauma of facing a potentially life threatening illness, all cause enormous suffering. Many children develop severe anxiety, depression and become withdrawn and incommunicative. Families often travel long distances and stay in the hospital for weeks together. We realized the dire need for an effective palliative care program for children suffering from cancer and their families aimed at their physical, psychosocial and spiritual well-being. MNJIO Pain Relief and Palliative Care Program, a collaboration of the International Network for Cancer Treatment and Research (INCTR) and Pallium India with MNJIO, added paediatric palliative care to their service in the year 2007.

Methods

Palliative and supportive care was introduced to every child coming for treatment to MNJIO right from the time of diagnosis. Regular weekly support group meetings were conducted to elicit their concerns about the disease, treatment and to provide psychosocial, spiritual and emotional support. The families were prepared & educated to comply with treatment to ensure cure. The services offered with the help of interdisciplinary team were supportive care during active curative treatment, palliative and end of life care issues, pain relief protocol for procedural pain, continuity of care like providing home based and hospice care, bereavement support even after the death of child and 24 hour phone consultation.
Results
Achieving zero tolerance to pain and continuity of care right from the diagnosis and extending to palliative and end of life care and bereavement support. Government supported by offering children public insurance coverage for palliative and supportive care.

Outcome
Decreased treatment abandonment resulting in improved cure rate, awareness and education among the health professionals about palliative care, improve quality of life of children with cancer and Government awareness and involvement

O60. Introduction of Quality Measurements in a Child Hospice Organisation – Kraft S (Germany)

In Germany, child hospice movement has made great advances since it’s first child hospice opened its doors 15 years ago. All organisations are depending on donations to a great part although much has been reached so far. The landscape of the uprising organisations differs widely, and existing organisations might feel endangered by the might of some new initiatives that conquer the donation market. There is a conflict for the National Association of Child Hospices, because not to integrate new initiatives means not to share experience and good practice. While at the same time, these new initiatives might lack quality and professionalism. Therefore, the members of the BVKH (National Association of Child Hospice) have worked on developing quality proof measurements for their work. After three years collecting data and documents, a handbook has been distributed to members and non-members to help introduce a quality measurement system in child hospice organisations - one for purpose built hospices and one for the German Volunteer Hospice at Home service. In 2012 the first hospice reached the PROOF - the Quality Seal 'proofed Child Hospice' which is a seal given out by the internationally known DIN ISO certification organisation, the TÜV. The process of developing a seal has been very enriching for the participating organisations and the outcome of the first certifications is amazing, although critics say there is no way that volunteer work, which is a core element of German Hospice Work, can be put under DIN ISO norms. Well - it can - and in this presentation I would like to show the way to come to norms and the way a quality seal introduction enriches the organisations.

O61. Hummingbird House – A collaborative international hospice model transforming children’s palliative care – Quilliam P, Quilliam G (Australia)

Using ‘for profit’ business thinking, to stand out in a crowded not for profit sector, Queensland Kids (QK) has developed an innovative hybrid business model that connects clinical expertise with business acumen transforming children’s palliative care in Australia. QK believes this model can be translated into international settings within culturally appropriate contexts.

As Cofounders of QK, Paul and Gabrielle Quilliam recognised a gap in services after struggling to find adequate care for the complex medical needs of the children they
fostered. They have passionately translated their ideas into action providing the over 3,700 affected children and families with Hummingbird House, the only children’s hospice in Queensland.

QK was faced with a hostile stakeholder group due to the closure of a similar service 18 months prior to the incorporation of QK. Using the Chinese paradigm known as ‘Guanxi’, the re-engagement of clinicians and consumers was paramount while simultaneous systematic due diligence ensured lessons were learnt to de-risk the project.

Leveraging networks within QUT’s Executive MBA program and examining structures of similar facilities around the globe, QK has applied strategic commercial thinking to a community based project that sparked the interest of both the Queensland State and Australian Federal Government as well as the corporate sector; resulting in a landmark financial support commitment for children’s palliative care in Australia.

Lessons learnt would be shared on the benefits of collaboration, knowledge sharing and the power that comes from the pursuit of excellence in practice. By leading with authenticity and integrity, QK is creating Hummingbird House – a place where children and their families who have become disenfranchised members of the community, can gain a sense of belonging, knowing that they matter and they will be supported in an intimately unique way that will truly inform the transformation of children’s palliative care in Australia.

Clinical Care

O62. Invisible Unpaid Female Caregivers – Fowler-Kerry S (Canada)

Aim
The role of mother as caregiver follows logically from the historical position women have assumed as healers. Florence Nightingale herself felt that every woman was a nurse, a profound statement that captures the reality in North America where over 80% of workers in the health care system are women. There is now a considerable literature replete with documentation demonstrating that the care for children with life-limiting/threatening illnesses rests on a vast network of informal female caregivers, the growing invisible army of unpaid workers.

Methodology
The purpose of the Critical ethnography was to describe and interpret the constructed realities of mothers, who were living or have lived with a child with a life-limiting/threatening illness.

Results
For each mother in this study, there was only one option, to assume the role of caregiver and follow the historical tradition of women as healers. While the decision to be the caregiver was made willingly, the effect was frequently described as having a profound impact on every dimension of family life; emotional, physical, financial and spiritual. The full extent of these positions was never out rightly comprehended, and now, having lived the reality, all explained that the effect was more profound than ever imagined.
Conclusion
Often described as ‘wounded healers’ it was noteworthy that at no point in the study did any mothers voice any qualms about assuming the role of caregiver. The results of this study will be discussed in terms of transforming paper rights into lived rights embedded in policies.

O63. For the Child to Hear: Developmental Considerations for Palliative Care – Desai K, Chrastek J (USA)

“What to tell the children?” is a common question in pediatric palliative care. It is a complex question, requiring attention to a multitude of factors, including developmental trajectory and cultural context. This interactive workshop will increase personal awareness and comfort level for communicating medical information with children of different ages in a culturally sensitive and developmentally appropriate manner.

The presentation will introduce this topic using video segments or case vignettes followed by small group activities to identify current practices in different regions. Thought questions will be provided to facilitate group conversation. Following this, a didactic presentation wills overview the literature on cognitive, emotional, and spiritual development to provide a context for conversations with children. Participants will return to small groups to complete a rubric to facilitate age specific communication with children. Focusing on one developmentally based age range, groups will identify the key developmental considerations for that age, create a list of example phrases to use, and identify appropriate communication tools/methods. To contextualize this activity, participants will be provided with the same case example and will be asked to role-play the conversation. Using the same case for each group will allow participants to observe how language can be adapted for different age groups. To promote use of this information after the conference, participants will be asked to identify two colleagues or trainees with whom they would like to share the rubric and one current patient with whom they could use a new form of communication.

O64. The sexuality of life-limited young(er) people in the UK – Blackburn M (United Kingdom)

Background and Discussion
Previously children and young people with life-limiting illnesses were not expected to live until adulthood. As a result of advances in medicine and technology, there are a growing number of children surviving into adulthood who cannot always access appropriate, specialist palliative care services as adults (Fraser et al, 2011; Fraser et al, 2012). Some children’s and young people’s hospices in the UK and Australasia have made significant progress in developing transitional services for young adults whilst others are assessing what support maybe required and how best and where to deliver this care (Blackburn, 2010). What is less clear, is how intimacy and the sexuality of young people at the end-of-life should be addressed, given that sexuality may represent different things to people and that young people’s sexual needs at the end-of-life are often ignored (Triangle, 2011). Palliative care aims to be holistic, yet evidence suggests that sexuality is often overlooked.
when assessing care needs (Blagborough, 2010). As sexuality and intimacy are important components of quality of life until death, increasingly palliative care teams are seeking advice and information about addressing the relationship needs of young people with life-limiting conditions. Young people with life-limiting illnesses and their carers should be able to access information and be included in any discussions about sexuality and intimacy throughout their lives (De Vocht, et al 2011). This has not always been the case.

Drawing on the international sexuality and disability literature, my previous work and current research, this session will address:
- My current sexuality research with The Open University, UK
- What sexuality means to people with life-limiting illnesses in different cultures
- Young People’s choices about intimacy at the end-of-life
- Ethical and methodological issues in conducting research about sex

Methods
During late 2013 and early 2014, qualitative, semi-structured interviews will be undertaken with 10 adults with cystic fibrosis (CF) and Duchene muscular dystrophy (DMD) or spinal muscular atrophy (SMA) over 16 years, as well as carers and professionals supporting people with life-limited condition.

Results and analysis
These will be considered in 2014 but I am unable to report these at this stage


FHSSA, (which began as the Foundation for Hospices in Sub-Saharan Africa), an affiliate of the U.S.-based National Hospice and Palliative Care Organization, and the ICPCN (International Children’s Palliative Care Network) partnered together to assess effective and successful models of paediatric palliative care in Africa. This presentation will provide an overview of survey findings to help other paediatric palliative care programmes in underserved countries with their programme development.

Workshop

O66. Impact of Palliative Care Services on the Quality of Life of Children living with HIV – Manglani M, Talawadekar P, Gabhale Y, Mansukhani K, More D, Lilani M. (India)

Background
Pediatric HIV Clinic was established in 1997 at LTMG Hospital, Mumbai. The Antiretroviral Therapy (ART) Centre was started in 2005. The Centre was declared as ‘Pediatric Centre of Excellence (PCoE)’ in 2011. A total of 2163 children have been enrolled at the centre till date, of which 719 children are on ART. Children’s Palliative Care (CPC) Project was initiated in July 2011 in collaboration with Tata Memorial Centre under the auspices of Help the Hospices, UK, Indian Association of Palliative Care and International Child Palliative Care
Network. The aim of the study was to evaluate the impact of the intervention of palliative care counselling on the quality of life of children with HIV infection.

Methods
The existing Multidisciplinary team at the PCOE was trained by the mentors of the Project, i.e. ICPCN and Tata Memorial Centre to deliver holistic care.
The inclusion criteria were: HIV-infected children below the age of 18 years registered at our centre and diagnosed with one of the following: 1st line ART failure, Opportunistic infections, Malignancy, Terminally ill, Poor adherence, Psychosocial problems and Orphans. All these children and their caregivers were given holistic care and provided Palliative care counselling. Focused group discussions, Support group meetings, adolescent trainings were organised to empower the beneficiaries. The impact of the services was assessed by administering ‘Quality of Life’ standard questionnaire in 100 children.

Results
The analysis showed that there was a remarkable reduction in the difficulties in Emotional Functioning (75.75% to 58.45%) of the children, followed by Social (66.6% to 58.2%), physical (46.97% to 40.44%) and school functioning (54.55% to 52.11%) of the children, thus suggesting that holistic care including palliative care counselling with support group meetings, motivational and awareness activities are helpful for the beneficiaries to cope with the situation.

Discussion
This is the first model centre for Children’s Palliative Care in Pediatric HIV. It envisages the expansion of the services to children suffering with other life limiting conditions.

Day 3 – Breakout Sessions 13.30-14.15

Applied workshop on advocacy

O67. Advocacy Action for CPC – Baxter S (Canada) and Connor S (USA)

This is part two of a workshop where participants will continue to gain new skills in advocacy for palliative care in the region. Building on the first session we will review the teaching done in session one, review the goals established for advocacy in India and Asia for children’s palliative care, and then we will work in small groups to have participants actually develop an action plan to achieve the identified advocacy goals.

Discussion and workshop on Transition

O68. Crossing the great divide: caring for families following the death of a child from cancer. – Kurth L, Wakefoeld C, Cohn R, Russell V. (Australia)

Background
Most children diagnosed with cancer in Australia or New Zealand are referred to one of ten paediatric oncology units based in capital cities. For many families, this means travelling vast
distances from home for treatment, separation of family members for extended periods of time and for children where there exist no more curative options, often the return home for palliative and end of life care. At the very time families need the familiarity and professionalism of the paediatric oncology team – on returning home many bereaved parents describe feeling abandoned and isolated and suffer a dual loss - that of their child, and that of the healthcare team.

Methods
Rationale
This study explores three questions:
1. How do parents describe the experience of their child’s palliation and end of life care and their family’s transition into bereavement?
2. What are the personal, practical and professional resources parents draw on, or would access if available, throughout these various time points.
3. What is the impact of important demographic and medical factors on parents’ bereavement experience?

Study design
Phase 1: a pilot study of 10 parents exploring their experience of participating in bereavement research
Phase 2: a site audit of health care professionals responsible for follow up of bereaved families at each of the ten paediatric oncology centres
Phase 3: a mixed method study inviting parents to participate in a questionnaire and/or semi-structured telephone interview

Endorsements
This study has been endorsed by ANZCHOG (Australia New Zealand Children's Haematology Oncology Group) and all ten paediatric oncology sites have been invited to participate.

Discussion
This paper will describe parental perceptions of participating in bereavement research (phase 1), provide an overview of current bereavement care practices in Australia and Zealand paediatric oncology centres (phase 2), and present initial findings describing the experience and needs of parents whose child has died from cancer. We anticipate this study will further contribute to the development of guidelines for best practice bereavement support following the death of a child from a life-limiting or life-threatening medical condition.

O69. Establishing a Taskforce for Transition – Chambers L (United Kingdom)

Issues
Recent research from Leeds University shows there is a far greater number of young people in the UK who would benefit from palliative care, than previously believed. The study shows that the number of young people aged 16-19 with life-limiting conditions is growing and has increased by 44.8% over the past 10 years. Services do not currently serve this growing population of young people and their families well. The Transition Taskforce aims to make a
real and tangible difference to the experience of young people with life-limiting conditions as they outgrow children’s palliative care and make the transition to adult services.

**Description**

Building on the growing evidence base, in particular findings from the STEPP Research Project, the project has adopted a two-pronged action-focused approach to putting research and policy into practice:

- At national level, developing guidance, raising awareness, providing training and support for adult providers ensuring that the ‘push’ from children’s services is balanced by a ‘pull’ from adult services.
- At local/regional level, supporting the development of services and partnerships between children’s and adult services, so that the research and good practice that exists is implemented on the ground and disseminated nationally.

**Lessons learned**

Services, such as housing, education and the adult hospice sector provide services that can meet the needs of young people with life-limiting conditions, but need support and training from children’s palliative care providers to enable them to better meet the needs of these young adults.

**Recommendations:**

- Young people and their families should have a central role in shaping services to meet their needs so they have more choice and control to make informed decisions about their lives.
- Children’s and adult services must work together to support young people through Transition.

**Workshop**

**O70. Lessons learnt from the ICPCN 2-country project – Malawi and India – Tauzie J, (Malawi) Talawadekar P (India) Marston J. (ICPCN)**

This Workshop will describe a project to develop palliative care for children in Malawi and the Maharashtra Region of India, through the development of a strategy to replicate a successful model in both countries in three new hospital settings, education of professionals and community-based workers; mentorship; involvement of the national hospice palliative care associations; support for the voices of children and families to be heard; and advocacy for increased government support and inclusion in national or regional policy.

The 5 year project was designed by the ICPCN and funded by DFID through Help the Hospices (UK). The primary objective of the project is to improve quality of life of children facing life-limiting illness through training, mentorship, programme development, advocacy with government and educational institutions, and supporting children to express their needs. The workshop will provide for a description of the project development in both countries, including factors that have led the increase in access to palliative care and opioids for children, identifying common successes and challenges. Lessons learned that could
benefit development in other countries will be shared. The format of the Workshop will be both formal presentations and open discussions.

**Neonatal Palliative Care**

071. **Ensuring the care of babies expected to die too soon: developing neonatal palliative care** – McNamara K (United Kingdom)

**Issues**
Worldwide deaths in the first month of life account for 40 per cent of all deaths among children under five years of age. This presentation will describe the current situation in relation to neonatal palliative care in the UK.

**Description**
Every year over 80,000 babies are admitted to a specialist neonatal unit for care in the UK, we know that some of these babies require palliative care. Currently about 98% of infants with palliative care needs die in hospital units in UK.
In 2009 a Care Pathway for neonates with life-limiting conditions was published in the UK, followed by the publication of A Framework for Clinical Practice in Perinatal Medicine.

**Lessons learned**
Key learning from sessions promoting the roll-out of the care pathway to neonatal services included a need for workforce development; a need to explore specific aspects of care such as how to get babies home and care for them; and how to improve working between services. These lessons were integrated into more recent developments in Scotland, building a partnership between palliative care and neonatal services, the work aims to support the high quality care delivered to infants and their families through a partnership approach. This work has taken the Care Pathway and the Framework and has developed guidance to provide an individualized care approach for the baby and family. The resulting model aims to ensure that there are recognized pathways of care, within and between neonatal units and other services for every baby who has a life-limiting or life-threatening condition within a designated geographical area.

**Recommendations**
Everyone working across the children’s palliative care sector has a role to play in developing and delivering neonatal palliative care to ensure that all babies who die too soon have access to the best quality care they require.

**Presentations**

072. **Social Organisation – making project management and fundraising your day-to-day business** – Kraft S (Germany)

Talking about pediatric palliative care means talking about social entrepreneurship. In Germany, purpose built children’s hospices receive less than half the budget by public support. The culture of financing social projects is not as traditional as e.g. in America or even UK. Most of the funds come from private donors. How can a small organization reach
sustainability? And where are the challenges and chances? Is it possible at all to ever reach sustainability?

This presentation is for people getting started with a social project. Small initiatives do not have the funds to invest into a professional fundraising. So how can they get by? How professionalize. Depending on the number of participants this workshop will try to practically support with the development of a personal project plan for the own initiative. Starting from scratch, touching the environment analysis up to developing an activity plan. We will look at the first steps of building up a legal entity - from the perspective of people coming together for a common social goal. Then we will look at different ways of establishing a fundraising culture in the organization and collect creative ideas to overcome the start-up role developing into a professional social business.

In this presentation I will introduce methods of project management and show how an organization depending on donors must reach a donor oriented culture while it may not lose its purpose out of sight. You may sell nearly anything but not your soul.

O73. Denied Pill of the Soul: A Health System’s Error or Ignorance – Nkosi B (South Africa)

Introduction
Bereavement counselling is still not commonly available in black South African communities, despite a high mortality rate made worse by the HIV/AIDS epidemic. Many caregivers of children orphaned by AIDS, especially grandmothers, have experienced multiple losses without any form of bereavement counselling, an important psychosocial component of palliative care. In South Africa, palliative care is mainly provided by hospices, community based organizations and very few public hospitals.

Method
A survey was carried out in three provinces of South Africa. Community and myself health workers administered a questionnaire of ten questions from a local hospice. Respondents were 69 primary caregivers of children who were clients of two children’s organizations: Cotlands and CHOC, who had lost daughters, sons or partners between 2003 and 2013.

Results
Out of the 69 respondents, only 19 had received bereavement counselling. Fourteen had received some type of counselling from various sources and five received counselling in the form of prayers provided by their church members.

Conclusion
Most South Africans receive health care from the public health care system. The results of this survey confirm a known deficiency in its health care service - poor psychosocial care. South Africa therefore needs a national policy to integrate palliative care into the public health care system. This will enable consumers of health care to benefit from a holistic health care package, particularly psycho -social and good end of life care.
Clinical Care


Background
Consider the atmosphere within which the Preverbal Oncologic Child has been living since the diagnosis day |Acute Lymphoblastic Leukaemia|: Who thinks of his thoughts, his perceptions, his feelings, his emotions, his sensations, millisecondly? Every Preverbal Oncologic Child is closed within his pain, and it's urgent to enter his Inner Nature, his Inner World, his Self in definition. The Action in Clinical Care for the Preverbal Oncologic Child, in the Non-Pharmacological Care, is the participation inside his There-Being. Fully and wholly.

Methods
The power of sweet, soft, serene voice is light, breathing, smell, sound, tactile atmosphere, sweet taste. Listening to, observing, interpreting, translating, considering, speaking directly to the Child and only to that Child in a way of wording created just for him in that moment, millisecond, second and minute. Created because motivated by his feelings, emotions, perceptions and sensations. Sitting down in his There-Being, living-and-participating him. Filling up his time and space with our Presence, a Presence called In-Presence. The tissue within which all that is possible are Donald Zolan's painting-videos, http://donaldzolanvideos.

Results
Delicateness, pureness and sweetness are the soul of those paintings wherein Children are painted within a context of outdooring and indooring nature. Not only Children are painted, but also their feelings-and-thoughts, emotions-sensations-and-perceptions, and that is called 'discrepancy' (Gernot Bohme, 2001), a new and positive atmosphere created for the Preverbal Oncologic Child in Pain: windows opened before him and inside him.

Discussion
This study in the concreteness, Constance and substance of word said to the Preverbal Oncologic Child, interpreting those paintings, is effective in reducing ‘fear, anxiety, despair, disdain, disgust, distress and pain' (Paul Holinger, 2012). Let the Preverbal Oncologic Child feel understood, tailoring new atmospheres devoted to his Individuality, Personality, Singularity.

P2. Islamic beliefs about childhood death and bereavement – Perspectives of paediatric hospice staff in Kuwait – Dighe M (Kuwait)

Background
Religion affects people’s understanding and experience of death and their ability to cope with loss. (1) Pediatric hospice staff need proper understanding of religious beliefs of their patients' families.
**Methods**
This study was carried out in a Pediatric hospice in Kuwait- 97.8% clinical staff is expatriating, non-Muslim (93.5%). Majority of patients served are Muslims.

**Aim**
To elicits perspectives of Islamic staff around Islamic beliefs about childhood death. All Islamic members of clinical team interviewed using semi structured format. Interviews were audio- recorded, transcribed; emergent themes identified.

**Results**
Demographics- n=3; male-1, mean age 28 years.
Themes
1. Respect in death- Central to all post-death rituals, irrespective of deceased person’s age
2. Acceptance- of loss as will of Allah. Excessive emotional expressions of grief inappropriate.
3. Finding meaning in death- as release from suffering or test of faith for which parents rewarded in afterlife.
4. Social support through mourning customs - Obligation of family/ friends to visit provides support through mourning. Mourning etiquette, using appropriate religious expressions of sympathy emphasized.
5. Coping with loss- Religious practices and beliefs generally facilitate coping.

**Discussion**
Islam guides bereaved parents to channelize their emotional responses into religious modes of mourning through a belief system that helps to find meaning and solace. Religion also increases perception of receiving greater social support. Themes emerging from our study indicate that Islam helps bereaved families to cope. However, further research is needed.

**P3. Towards child friendly drug formulations in palliative care – Wata D (Kenya)**

**Introduction**
Solid dosage forms present problems for younger children who have difficulty swallowing whole tablets or capsules. When medicines are not licensed for children, it is unlikely that there will be a suitable, licensed liquid formulation and so extemporaneous liquid preparations. Standardized extemporaneous preparations are not available for all drugs with stability and storage data. The drugs may also have palatability issues. Some drugs do have commercial liquid preparations but these are not available in the developing countries.

**Objective**
The objective of the study was to find out the availability of child friendly formulations of the drugs used palliative care, within and without of the IAHPC essential drug list.
Methods
The following information was searched: availability of liquid dosage form, other licensed dosage forms and extemporaneous preparation data, dose recommendation for IAHPC indications and availability in Kenya.

Results and discussion
33 drugs were analyzed, 63.6% have liquid oral formulations, 21.2% do not have any liquid formulation and 18.1% have a special or extemporaneous form available. 63% had recommended paediatric dosages, 12.1% had dose recommendations only above certain age, 12.1% had no dose recommendation in children and 12.1 % had dose recommendations for a different indication other than for palliative care or for a palliative care symptom. 12.1% of the drugs were not licensed for use in children. 72.7% do not have a commercial liquid preparation available in Kenya and 27.3% do have a liquid preparation available in Kenya. 87.8% have data on extemporaneous preparation including excipients, storage conditions and stability studies. Some of the ingredients required for these are locally available and the pharmacist is now using this information in our institution to prepare some drugs in suitable liquid formulation for use in children for palliative care according to the dose recommendation.

P4. Quality of life in a patient with beta-Thalassemia Major (bTM) – a case report –Damani A, Ghoshal A (India)

Background
According to multicenter study in 2013, prevalence of bTM in India varies in different communities ranging from 0-10.5%. Patients with bTM are likely to survive till adulthood with proper treatment; it becomes important to provide productive life to them and improve their overall quality of life.

Methods and Results
Case description: A 7 year 6 months old male, Muslim child, born of non-consanguineous marriage, with uneventful perinatal period. At the age of 2month child presented with recurrent chest infections, paleness, yellowing of eyes and urine, lethargy and irritability. He was referred to tertiary care centre and diagnosed with bTM and started with blood transfusions on monthly basis. No other significant past medical or surgical illness. No developmental delay. National Immunization schedule was followed. Both parents were diagnosed as bT-trait. Patient is youngest child in family, apart from him there are eight members in family. Two siblings expired at age of 2months with similar complaints but remained undiagnosed. There are 2 earning members with total monthly family income of Rs.3000. Parents and patient were unaware of disease trajectory and prognosis of child. Regular counselling sessions were conducted for the patient and care-givers at three consecutive visits which helped to explore their psychosocial issues, concerns, aspirations, educate them about disease and prognosis, associated complications and empowered them make goal-setting about the future of child and family possible.
Discussion:
bTM is chronic condition. In resource-poor nations like India where it is difficult to offer curative options like BMT, gene therapy or stem cell transplantation to all thalassemics, disease condition also leads to lot of psychosocial morbidity apart from physical. So it is important to create awareness, educate and address issues and do periodic psychosocial assessment, counselling to provide continuous support to patients and families.

P5. Stress releasing and confidence building activities to address Emotional and Coping issues in Palliative Care of Pediatric Oncology Patients – Warty R (India)

Delhi branch of Cancer Patients Aid Association (CPAA) was started in 1979 and since then working through All India Institute of Medical Sciences (AIIMS), Delhi. As part of its work, CPAA supports poor & needy Pediatric Oncology patients from Northern India. CPAA adopts such patients and provides Chemotherapy and other support in kind till remittance. CPAA runs play rooms for the children coming in for their Chemotherapy in the Day Care Centre at AIIMS.

It has been identified that to counter the physical as well as the emotional pain and trauma suffered during the treatment, palliative care in the form of activities to build continued confidence and moral strength to cope with the treatment are helpful.

Methods
1. Informal education through worksheets for different age groups.
2. Group therapy through interactive games.
3. Indoor activities
   a. Art workshops
   b. Drawing competitions
   c. Celebrations of National days & festivals
4. Outdoor activities
   a. Dance & skit event
   b. Visits to amusement parks and recreational centres for children
   c. One to one interaction with Dignitaries like President/Prime Minister/ Celebrities
5. Parents’ Forum

Results
1. Interviews to assess the impact showed that there was a remarkable improvement in the Emotional, as well as Social and physical functioning of the child and family which can lead to better adherence to treatment.
2. Discussions during Parents’ Forums have brought out need to create awareness on various important aspects such as hygiene, nutrition, network of NGOs/Trusts and avenues of financial help.
3. Group activities create bonding amongst patients and families and encourage forming of support group.
P6. Clinical Issues and Profile of $^{131}$I-Metaiodobenzylguanidine (MIBG) therapy in Neural Crest Tumours in Paediatric Population: Experience gained in an Indian Setting – Basu S, Ranade R, Chinnaswamy G (India)

Background and Aims
To identify and define the major clinical issues that can be encountered in the practice of $^{131}$I-MIBG therapy in paediatric patient population.

Materials and Methods
For this, available data from a total of 101 patients who had undergone $^{131}$I-MIBG therapy over the last 5 years for different indications were analyzed especially with regard to the major issues that were encountered to evolve a sound practice regimen.

Results
Amongst the total 102 therapeutic MIBG procedures, 41 belonged to paediatric group: (i) 35 were cases of pediatric neuroblastoma (34.31 %) and (ii) 6 procedures for patients of juvenile pheochromocytoma (5.88%). Four issues were identified for debating the practice: (a) Defining the precise clinical indications of $^{131}$I-MIBG therapy in the background of evolution of peptide receptor radionuclide therapy (PRRT) with $^{177}$Lu-DOTATATE: we observed avid MIBG concentration in all of the referred patients for considering MIBG therapy. Considering all our paediatric neuroblastoma patients were already pre-treated with high dose chemotherapy, MIBG was a preferable option both by the Nuclear Medicine Physician and the referring paediatric oncologist. (b) Dose fractionation regimen to be employed in paediatric population; we observed with a dose of up to 12 mCi/kg, there was no acute episode of bone marrow depression (followed up to 2 months of therapy) in any of our treated patients (in all of them a normal and stable blood counts and a normal renal function was a mandatory prerequisite for treatment). With this regimen, repeatability of the therapy after 3 months was never an issue in any of the patients. The symptomatic improvement was obvious in majority of the patients. (c) The practice of myeloablative therapy with stem cell rescue: this was minimal and the requirement of enhancing them was felt. (d) Typical profile of patients were those who had been refractory to standard chemotherapy and not in an upfront-multimodality setting.

Conclusion
MIBG therapy continues to be the procedure of choice in paediatric population compared to the PRRT. The need for considering them upfront in Indian setting or earlier in the treatment cascade and adopting the myeloablative therapy with stem cell rescue regimen needs to be strongly considered for bettering overall patient outcome.


Purpose
To evaluate the clinical efficacy and response of serial transarterial embolization in giant cell tumors of the sacrum.
Material and Methods
Seventeen patients with biopsy-proven sacral GCTs received initial primary treatment with serial arterial embolization between January 2009 and December 2013. Patients underwent serial embolization using particulate embolic material at 6–8-week intervals. Patients were assessed by clinical evaluation and imaging (CT/MRI) for response evaluation. Visual analogue pain scale and quality of life questionnaires (EORTC-QLQ, version 3) were used for assessing clinical benefits.

Results
The mean follow-up duration in this series was 22.8 months (range: - 3-52 months). All seventeen patients demonstrated substantial pain relief and improvement in quality of life after arterial embolization. Preprocedural visual analogue pain score was 5–9 with mean of 6.8, whereas mean pain score after embolization was 1.2. Three patients underwent surgical intervention after arterial embolization. Disease stabilization was noted in 12 of the remaining 14 cases. Two patients showed tumor progression on follow-up and required alternate treatment. Two patients developed urinary retention after the procedure, which improved over a 2–3-week period with no long-term sequelae.

Conclusion
Serial arterial embolization can be a useful primary treatment option for sacral GCTs, given its promising results and safety profile coupled with potential morbidities associated with alternative treatment options available. Further research and long-term follow-up is required for substantiating long-term benefits of serial arterial embolization in this subset of patients.


Aim:
To demonstrate the safety of percutaneous radiofrequency ablation (RFA) of osteoid osteoma and evaluate the clinical outcomes of the patients treated with it.

Materials and Methods:
A retrospective analysis of twenty cases which on clinical and imaging findings were suspected to have osteoid osteoma and were treated with RF ablation at our institute from Jan 2006 to December 2013. Informed consent was taken from all the patients. The procedure was done using computed tomography for guidance using radiofrequency ablation electrode. The entire procedure was done under general anaesthesia. Lesion characteristics were determined from imaging studies obtained prior to the procedure. Pain being the most common presenting symptoms, was assessed before, 24 hours and 6 weeks after the procedure. Pre and post procedure PET CT was done in every case to confirm complete ablation of the lesions. Minimum 6 months follow up is available.
Results:
None of the patients showed residual FDG uptake on post procedure PET CT scan. Significant relief of symptoms was noted on the immediate post procedure day. Minimal analgesics were required for seven days after the procedure. All the patients had complete relief of symptoms with no need of any medical or surgical intervention at 6 weeks follow-up. No major procedure related complications were noted. Mean follow-up was one year.

Conclusion:
Percutaneous Radiofrequency ablation has proved to be a safe and effective modality for osteoid osteoma both clinically and on imaging. The technique is minimally invasive and can be done on OPD basis as an alternative to surgery.

P9. Patient Case Report: The role of metronomic chemotherapy in the control of pain in children with Esthesioneuroblastoma – Arora RD (India)

Introduction and Objective
Metronomic Chemotherapy which is intended to prevent tumor angiogenesis is based on more frequent and low dose drug administration compared with conventional chemotherapy. This case report attempts to explore the role of metronomic chemotherapy in control of pain and improvement of quality of life in a paediatric patient with Esthesioneuroblastoma.

Case Presentation
Reported herein is a case of 17 year old male diagnosed with Esthesioneuroblastoma, who underwent surgical resection followed by adjuvant radiotherapy, subsequently developed nodal metastasis which was treated surgically following which the patient was started on oral metronomic chemotherapy. The Metronomic chemotherapy was discontinued after the patient developed chemotherapy associated complications. The patient received re-irradiation to the Face and Neck for palliation of bleeding from the external ear and pain control. At present the patient has undergone a biopsy of mass in the right external auditory canal and awaits a histopathological confirmation of tumor recurrence versus a chronic inflammatory change.

Discussion
The role of adjuvant chemotherapy in the management of Esthesioneuroblastoma is generally not clearly justified. Feasibilty of metronomic chemotherapy has been assessed in the palliative care setting in patients with oral cavity cancers where it was found that use of metronomic chemotherapy seems promising and well tolerated. However, in this particular patient, a better control of symptoms and overall quality of life as reported by the parents, was documented with the use of radiotherapy and pharmacological intervention.

Conclusion
Benefits of oral metronomic chemotherapy in the improvement of the patients overall quality of life in the palliative care setting needs to be evaluated further.
P10. Mother’s lived experiences when a child is diagnosed with cancer – Thelly AS (India)

Introduction
A cancer diagnosis challenges the belief that our lives will be long and happy. When a child is ill with cancer, this affects the whole family especially mother for long periods. Childhood cancer and its treatment result in many challenges that impact the entire family.

Methodology
An in-depth interview process was utilized. Colazzi method of analysis was used.

Results
The phenomenological data analysis process transformed the combined set of 5 mothers’ narrative transcripts. The themes identified for the mothers were: insecurity and uncertainty, feeling of helplessness, concern about other children, feeling of over stressed, fear of death and loss, struggling to make child comfort, wish to be with own family, developing trust in god’s plan, questioning God, feeling of added responsibility, confrontation, inappropriate emotional outbreaks, inability to feel happiness, fear of outcome, always alert. These themes gave a structure presenting the essence: balancing a changed life situation in fear and uncertainty.

Conclusion
The results of this study challenge nurses to be conscious of the nature and difficulties that not only patients face but also family members are encountering. The study can increase the understanding of what it is like to have cancer in its advanced stage. These findings also indicate


Background
Kaposi’s sarcoma (KS) is one of the two major malignancies associated with HIV infection in African children. However, there is limited data on treatment outcomes of HIV infected children with KS. Within the provision of palliative care, the treatment of malignancies such as KS and the palliative of symptoms associated with it are important aspects of care.

Methodology
A chart review of 10 children with HIV/AIDS and KS at Hospice Africa Uganda was carried out. All the children had been on programme for at least a month prior to review.

Results
Of the children reviewed, 6 (60%) were male and 4 (40%) female, the age of the children ranged from 3 to 15 years with the mean age being 9.4 years. In reviewing their histology, the most common presentation was lymphadenopathic KS. 5 of the children were receiving treatment in terms of both chemotherapy and ARVs whereas 5 of the children were unable to start either treatment. Three out of the 5 children receiving chemotherapy had earlier
shown signs of clinical improvement but following treatment default, they had presented with rapidly progressing symptomatology. These three children fared poorly on retreatment courses of chemotherapy with one fatality.

**Conclusion**
Children commonly get lymphadenopathic KS and this is more common in the older children. Although this review is small in scale, it does seem to suggest that combination of therapy with chemotherapy and ARVs is beneficial. On the other side, treatment default can lead to rapidly progressing symptomatology, poor response to retreatment regimens and possibilities of high fatality rates. Within the provision of palliative care, this has implications for both management of KS but also for the palliation of symptoms associated with both treatments for the disease as it progresses. Bigger studies are recommended in the pediatric population to study this in more depth.

**P12. Role of Haemostatic Radiotherapy as a Palliative measure to control hemorrhage in PNET – A Case Report – Ostwal S, Muckaden MA, Deodhar J, Salins N. (India)**
Ewing sarcoma/primitive neuroectodermal tumor (ES/PNET) is the most frequent malignant tumor of the chest wall in children and young adults and bleeding is one of the known common complications.

14 year old girl a case of recurrent primitive neuroectodermal tumor (PNET) presented to palliative medicine outpatients with 9x7 cm fungating bleeding mass over the right scapular and infrascapular region. She underwent surgery on 3 occasions at the same site and had defaulted on other forms of treatment.

She had torrential bleed from the mass which was not controlled with local haemostatic measures such as adrenaline soaked compression, local Ethamsylate, Botropase and Sucralfate. She was also started on IV Tranexamic acid. She failed to respond to these measures a surgical oncology opinion was taken and sutures were applied as an attempt to arrest bleeding. However as bleeding persisted a radiation oncology opinion was sought to consider haemostatic RT.

Patient received 3 fractions of 6Gy/# as haemostatic RT. Post RT bleeding was well controlled. Patient was discharged home on oral metronomic chemotherapy, analgesics and other supportive care treatment.

Haemostatic RT should be considered as an important measure to control active bleeding in cancer patients.

**P13. Nutrition in Paediatric Palliative Care – Nair A (India)**

**Background:**
Palliative Care is a programme of active compassionate care devised for ill children, primarily directed towards improving the quality of life.
Methods:
Nutritional support forms a one of the essential adjustments along with other measures of palliative care. It is essential to think of some home based feeds of improved digestibility and textures which can be of better nutritional support. Emphasis can be laid on malted cereals and legumes (low cost Enteral feeds) which in comparison to commercial product also provide dense nutrition. 100 gms. Of LCEF =395 calories, 16.4gm proteins. It is with low bulk and less viscous and can be easily prepared from foods material available at home.

Results:
In standard Nutrition therapy generally 8 feeds can be started on with 100-120 KCals/Kg/Day and Proteins of 1.5-2gms/kg/day. The food intake can be gradually increased over 1 week to help in patient to improve on weight as per present height. Slowly over 4-6 weeks, the child can be expected to consume expected Calories and Proteins for expected weight and height for his age.

Discussion:
As Children especially those who are ill need to be persuaded to eat, parents should be taught to prepare suitable diet depending on acceptability, affordability and appetite of the child. Frequent small energy dense foods should be encouraged eg. Milk-cereal mix, cereal pulse mix, sweet curds, besan/flour laddoos, suji, panjiri, mungdal sheera, egg flip, egg custard, etc. Once the child starts on and is able to start with some nutrition and achieve weight for height then the aim is to consolidate cure and prevent further nutritional problems.

Collaboration

P14. Let’s Do It Together – Mortlock D (Swaziland)

Everybody should be encouraged to do something to improve the life of a child suffering from a life limiting or a life threatening condition no matter the setting or the resources available.

Our natural response is to think that this is the domain of medical experts, yet palliative care is so much more than this and the opportunities for service to the child and family are limitless.

This has been clearly evident in every instance when we have had the privilege to respond to requests for assistance in our short time of being established. A doctor may call and ask us to pay for medicine, which is not stocked in their facility and is beyond the budget of the family. Or to pay for tests which are not conducted in Swaziland and need to be sent to South Africa. Or to supply orthopedic boots or funding for transport to attend physiotherapy or speech therapy. These are such small items yet they can hugely determine the outcome of a child’s future.

The best is that once we make these needs known in the community, they are met with generosity. This is especially the case when we are attempting to fulfil the wishes of a dying child.
Children have shown a remarkable interest and have been overwhelmingly accepting when asked to help their peers who are ill. They donate school books and stationery, readily accept them in the classroom if they are able to attend and write notes and cards when they are in isolation wards.

We have all heard that it takes a village to raise a child. What we need to appreciate is that it takes the same village to care for a child who may not reach adulthood. And that is what we at The Rocking Horse Project aim to do.

P15. A model of Family Engagement – Chambers L (United Kingdom)

Issues
Together for Short Lives’ has an overarching vision to ensure that every children or young person with a life-limiting condition has the best possible care and support. In order to achieve this we recognised that our strategy and all the information and support we offer should be based on the voiced needs of children, young people and families. As a national organisation in the UK representing these families, we have established mechanisms for engagement with families which underpin the whole organisation.

Description
We have developed a family engagement strategy to ensure that we engage with families at all levels of the organisation. Though our family membership, we have invited parents and carers to join our Family Reference Group. We have also established a Parent and Carer Advisory Group (PCAG), which has a key role in providing the team with the direct lived experience of families. We have also ensured parent representation both at Board level and on our other major sub-committees to ensure that parents and young people play a key role in shaping our work. Our work with children’s palliative care networks across the UK has included a focus on raising awareness of involving parents in their work.

Lessons learned
The participation of parents and young people in the development of children’s palliative care is vital. However it is also difficult and takes considerable time, particularly to ensure that engagement is meaningful and not tokenistic.

Recommendations
Across the UK we will continue to promote the inclusion of the ‘patient voice’ in health and other reforms. Through our work with children’s palliative care networks, we will support the strengthening of mechanisms to ensure that the parent and carer voice is heard by those commissioning and delivering services.


Introduction
The need for Palliative Care (PC) around the world is overwhelming and challenges us all to respond. With ever increasing disease burdens from communicable and non-communicable
diseases, traditional models of care are stretched. Spiritual care is a key domain of PC and faith based communities are uniquely placed to respond. For example, Christian organisations already contribute 40% of health care delivery in sub-Saharan Africa and over 10% in India.

Objectives
1. To engage the Christian faith based communities in the development and support of palliative care services.
2. Develop a resource that demonstrates the importance of PC and mobilises a response.

Method
1. Following a grant award from the Diana Princess of Wales Memorial Fund in 2012, EMMS International established a working group. Objectives and terms of reference were agreed with lead author & editorial group; publication reviewed followed by a launch at APCA conference 2013. On-going publicity and promotion to relevant communities from September 2013.

Results
A Handbook comprising the following: what is PC, role of the church, resources for inspiration, reflection, teaching, motivation and action, short stories, further reading and useful contacts.

Conclusion
Faith based communities are an essential and integral part of understanding and offering health care, and can offer a unique perspective and network for spiritual support and PC. The Handbook provides an excellent tool for inspiring, informing and challenging churches to respond that is

Education

P17. Efficacy of a training program for nurses at Bayt Abdullah Children’s Hospice – Asaaf F (Kuwait)

Background
Bayt Abdullah Children’s Hospice (BACCH) is a developing service for life-limited, life threatening children and their families in Kuwait. Our growing community service aims to provide high quality care to children and families anywhere they prefer to receive the care at. Training nurses to help support children and families is one of our goals.

Aims
To evaluate the efficacy of a training program directed towards the new nurses in BACCH.

Methods
The survey was performed using a rating scale questionnaire and results were analyzed and where appropriate to the need. The survey was distributed to 42 BACCH nurses from different clinical backgrounds where they were asked to rate their level of skill competency.
in generic skill areas as excellent, satisfactory or unsatisfactory, the same rating scale was repeated after 3 months of training respectively.

Results

- The general assessment the results were satisfactory in 30% vs. 84%, and unsatisfactory 50% vs. 16%.
- For the physical assessment the results were in 75% vs. 30%, and no answer 25% vs. 5%.
- For pediatric screening the results were satisfactory in 10% vs. 65%, unsatisfactory 75% vs. 20%, and no answer was the same 15%.
- For pain assessment on use of an assessment tool the results were unsatisfactory were 80% vs. 57%, 20% vs. 13% had no answer, with 30% were satisfactory vs. none.
- For pain definition results were satisfactory 10% vs. 82%, unsatisfactory 60% vs. 10%, and 30% had no answer vs. 8%.
- For non-pharmacological and pharmacological management the results were satisfactory in 15% vs. 45%, unsatisfactory 85% vs. 40%, and 15% had no answer.

Conclusions

The training program delivered to BACCH nurses showed improvement over the duration of 3 months. More training may further improve the results of training.

P18. NHPCO's Centre for Children – Sullivan G, Masterjohn J. (USA)

The National Hospice and Palliative Care Organization (NHPCO) has established the Center for Children to advance pediatric hospice and palliative care nationally and internationally. Meet staff and learn about the programs and resources available from NHPCO and the Center.

P19. Paediatric Palliative Care in my opinion: A residents view of Paediatric Palliative Care at a tertiary teaching centre in India – Ghoshal A, Damani A. (India)

Issues

I joined Palliative Medicine residency as fresh medical graduate. Naturally, when I tell people about it, I usually hear one or a combination of following: “What is that?”, “Why would you want to do that?”, “Is it something very different and new?”, “What is its present day status?” or “What is the scope in future?”

Description and lessons learned:

I get the same comments from medical professionals and lay people alike which bring out opportunities and challenges inherent in this branch, both as specialty field and within the realm of resident education in present day India.

‘What is that?’

WHO defines Pediatric Palliative Care as active total care of child's body, mind and spirit along with supporting family through a multidisciplinary approach.

‘Is it something very different and new?’
Though being a new subspecialty, the concept is centuries old. As physicians, we are all privileged to play an intimate role in care of children and their families as parents let us into their confidence in ways that few others are allowed. This is true for any pediatrician in any setup.

“What is its present day status?”
In present day India pediatric palliative care is experiencing a paradigm shift under mentorship of Tata Memorial Centre in Maharashtra since 2002. This includes site setup, training, strategic planning, and policy formulation. Morphine availability amendment act has been put under scrutiny.

“What is the scope in future?”
The future is full of challenges. Lack of awareness among healthcare workers, meagre budget, poverty, gender bias, illiteracy, ignorance, unemployment, addictions, superstitions and collusion are to mention a few.

Recommendations
The new generation of residents and pediatricians will stand to grow and will have an opportunity to care for children during full spectrum of health, illness, death or bereavement.

Ethics


Judeo-Christian concepts of the value of life have dominated Western culture for several thousand years. The intrinsic value of a child’s life has been a ‘given’ in most moral and legal frameworks. But over recent years this view has been increasingly questioned by modern utilitarian philosophers who ask the question “Why should a child’s life be of value?”

The Judeo-Christian view is characterised by some philosophers as archaic, rooted in a primitive understanding that can be of only minoritarian relevance in a post-religious age of reason and enlightenment. They argue that the intrinsic value of a child’s life is no more than a theological construct; rejecting religion themselves, they encourage others to reject any concept of the ‘sacredness of life’.

In this talk, I will set out three ways in which the Judeo-Christian tradition gives an account of the value of a child’s life and suggest that only one of them is dependent on the objective truth of its religious premise. Judeo-Christian understandings of the value of life can and should continue to inform ethical debate in end of life care in children, despite the current move away from formalised religious thinking.
Leadership

P21. The future of volunteering in the children’s hospice sector – Carling R, Gelb B. (United Kingdom)

Issues
Volunteers have a key role to play in children’s hospices in the UK. Over 17,000 volunteers give their time to work for children’s’ hospice in the UK. Volunteers give 57,722 hours of their time each week to children’s hospices; the annual value of this donated time is £35m using the average hourly wage. Volunteers are involved in a range of roles including, trustees, fundraising, hospice shops with a smaller number of volunteers supporting children and families.

Description
In 2011, Together for Short Lives commissioned work on Volunteering in Children’s Hospices in UK. The work aimed to describe the current contribution and value of volunteering in relation to children’s hospice care and identify gaps and highlight current innovations in volunteering in children’s hospice care which could be built upon and replicated in response to children’s palliative care needs in the future.

Lessons learned
The work helped identify new ways in which volunteers could be used by children’s hospices in the future to meet such needs – drawing on the experience of the sector. The project also established the current picture of volunteering in children’s hospices, including the numbers of volunteers; roles; outputs in terms of hours of work; challenges to enabling effective volunteering and areas where it is perceived volunteers could be used. The project identified clear development potential for volunteers to become more involved in care roles.

Recommendations
There are a range of strategic options are available to children’s hospices around volunteering. It is recommended that services engage in discussion to explore the potential roles for volunteers in hospices in the future, the required strategies for their recruitment, training, involvement and ongoing support at strategic and operational levels and the impact of such developments on other components of children’s hospice care.

Programme Development

P22. Bereavement Support – Garchakova A (Belarus)

It is important to ensure meaningful support to a family for the first few weeks, months and even years following the death of a child. While guiding parents through bereavement it is necessary to recognize distinct differences in culture. Death is a taboo subject in Slavonic cultures, and that’s unfortunate because most people never speak about death. As a result parents are sure that it’s better to endure the pain and grief alone. It is good practice to offer consultations, art-therapy, joint activities (planting trees, decoupage, collage, releasing balloons with small angels and names on them in memory of their departed children,
organizing Memory Days). The Belarusian Children’s Hospice works with a bereaved family individually or in groups during a year. Sometimes experienced psychotherapists are invited to exceed the needs of families. All these events help them to recover from the death of their child.

P23. The Role of the Dietician in Paediatric Palliative Care – Al-Dabbous T, Comac M. (Kuwait)

Issues
There is no evidence base in Paediatric Palliative Care for the role of the dietician, it has recently been argued in the review of the Liverpool Care Pathway that more evidence is required in palliative care.[1] Much of the literature focuses on acute clinical pharmaceutical support in palliative care[2], rather than the contribution of the dieticians working within a multidisciplinary hospice team where the child, parents needs are addressed in a holistic manner.

Description
The development of a nutritional programme where individual diet plans are formulated which includes ‘Shakes, Meals and Tasters’ which are individually tailored to meet the child’s biomedical needs, which has a significant impact on the child’s and as important the family’s quality of life. Whereby the child is able to tolerate tasteful supplements, the foods are natural; the mothers are able to continue to provide nourishment for their child; enabling them to fulfil maternal instincts and family mealtimes and eating remains integral to family life [3].

Lessons Learnt
“You can give a child something to eat that they want, while making it suitable to their needs”
In practice, experience has shown the speaker that it is not the quantity of food in that the child is given; it is the method in which food can be tolerated and given to the child, throughout the disease trajectory.

Recommendations
Nutrition in paediatric palliative care is a much under researched area, where greater evidence is needed. Parents require a consensus of opinion and plan of care that is shared across the whole team, that can be adjusted as and when need dictates.

P24. Paediatric Palliative Care: Service development, referrals and outcomes over two years – Herbert A, Irving H, Pedersen I, Kurth I, Bradford N. (Australia)

Background and aims
Paediatric Palliative Care is an emerging specialty service within paediatrics. The aim of this study was to review and define the characteristics of the population referred to a new service over a two year time period.
Methods
A database was developed to document specific details of referrals and outcomes for individual patients. Descriptive statistics were used to describe variations in referrals between non-oncology and oncology diagnoses.

Results
150 patients were referred to the service during the time period (of which 117 died). The most common disease referral was cancer, representing 52 (35%) patients. Eight-seven (58%) children were from regional or remote locations. Children with cancer were more likely: to die at home (54% vs 31% p= 0.01); be over four years of age (90% vs 63% p=< 0.001); and to stay on the service for less than six months (8% vs 37% p = < 0.001). There were no differences in reasons for referral between the two groups e.g. for pain and symptom management or end of life care.

Discussion
This study identified some key differences for care requirements between cancer and non-cancer patients. Despite these differences, a consultative model of care has proved successful for both groups of patients. Additionally the service was able to support parents and health professionals across vast geographical distances, at a statewide level. The focus of this support is both on maximizing quality of life and providing end of life care, when necessary, for children with life limiting conditions.


Issue
Lampang hospital is a government tertiary care medical center in Northern Thailand, 557 miles North of Bangkok, serving a population of 2.1 million in 4 neighboring provinces. Lampang hospital started pediatric oncology service in 2006. Children in Northern Thailand was often referred from long distance, (up to 250 km from center). For children who relapsed, many have requested to die at home.

Description
Lampang hospital begun a pediatric palliative care service in 2009. Of 81 cancer children, 39 was diagnosed after 2009, 21 has relapsed and were provided palliative care, which includes home visits, 24 hr access to phone consultation, and fulfilling wishes. In addition, all cancer children were eligible to join an annual trip to the beach, therapeutic art at the center, and parent support group.

Lesson learned
We have identified wishes for 11 children; 7 wished to go to the beach, 2 wished for zoo visit, 1 wished to pay respect to a particular Buddhist monk. Through this conversation, we developed a close relationship with families, were able to fulfil the spiritually meaningful wishes in 10, and through which families accepted volunteer in their life's journey, empowered to consult volunteer and professionals and handle death at home. For each
family, we created individualized palliative care plan, provide phone coverage, and the occasional home visit were meaningful to the patient.

**Recommendation**
Identifying wishes for children is a useful introduction in palliative care service and set the stage for good memory and relationship.

**P26. Focus Group Discussion - A tool to understand parental concerns toward their HIV affected child** – *Marathe M, Muckaden M, Manglani M, Talawadeker P. (India)*

**Background**
Focus Group Discussion is used as one of the effective methods in qualitative research methodology in health research. It is essential to recognize needs and concerns of parents before creating model of care for these care givers. FGD is used as a planned intervention to determine feelings, perceptions and manner of thinking of parents regarding disease of their child. FGD does not expect homogeneous responses or agreement so participants can express their opinions freely. The strength of the FGD in health sector is that further intervention can be planned based on the expressed needs of beneficiaries.

**Methods**
22 parents of children registered with ART Centre of Municipal General hospital-Mumbai, having similar characteristics were called in 3 consecutive FGD-sessions by giving prior appointment. Discussion was initiated in non-threatening and permissive atmosphere after administrating written consent and respecting ethical rights of participants. Discussion facilitated by trained facilitator based on predetermined open ended questions was initiated by encouraging self disclosure.

**Results**
1) Parents expressed their worry and anticipated fear regarding the quality of life of the child.2) Limited personal resources such as finance, family support and experience of social stigma were articulated as stress provoking factors.3)they spoke about their discomfort while discussing disease related issues, disclosure of diagnosis and prognosis openly with child. 4) Material and non-material help, emotional support through counselling and free medication from the ART-Centre was considered as few of the factors to cope effectively with child’s disease.

**Discussion**
Parents need support to face the child’s life limiting condition. They experience spectrum of emotional, psychological, financial, spiritual and social issues. Health, anticipated future, overall wellbeing of child and quality of life are captured as parental concerns. As CPC acknowledges and understand these issues, can be recognized as support system for caregivers.
**P27.** Developing, setting up and managing a paediatric palliative care service model in a Government Paediatric Hospital by Dean Foundation. – Muthaiya D, Namboodripad KA, Jacob MC, Navis R. (India)

*The Vision*

All Children’s with a progressive life threatening illness and their families and carers will have access to a high quality service system which fosters innovation and provides coordinated care and support that is responsive to their needs.

1. Introduction: The need for such a service was communicated. Having no Palliative Care Policy in place, a strategy was drawn to identify stakeholders, sensitize them, implement the service by prioritizing treatment settings and options, and seamlessly integrate into the existing health care system.

2. Programme Evolution: The Need for Palliative Care services once acknowledged set forth a series of decisions. Setting up units in Major State Medical College Hospitals was conceived by DEAN Foundation. In the process – the paediatric Palliative Care service provision was opted for by DEAN Foundation

3. Setting the scene: Infrastructure, Resources and logistics that were needed to realize the vision was procured and streamlined. Once the need was established, a process was set-up – a model of care was devised.

4. Challenges: Lack of awareness .Difficulty in finding donors for the project. Staff retention. Lacks of space were overcome as they surfaced.

5. Recommendations: Cost efficiency of care. More educational efforts. Referrals from other hospitals could be improved.

6. Fulfilling the Mission: The DEAN FOUNDATION Model of advanced care planning and care coordination carries out the intent of paediatric palliative care to improve the quality of time left to the child and family. It is consistent with recommendations by the palliative care programs, education and research. While we cannot always save the life of the child, we can help the child live well and die peacefully. We can aid the family in parenting their child, managing the issues at the time of death, and moving through bereavement.

**P28.** Setting up child palliative care services in a Municipal tertiary care hospital in Mumbai – Experiences and Challenges – Chaturvedi RM, Srivastav M, Laad P, Mangalani MV. (India)

*Introduction*

Municipal hospitals in Mumbai deliver healthcare to a diversified population coming from different parts of India. It is one of the major referral centre for all sorts of terminally ill cases, including cancers. Establishing of child palliative care (CPC) OPD in a municipal set up has contributed to easing counselling and breaking bad news to the care taker of the ailing child.
Aim & Objectives
This study aims at studying the socio-demographic and clinical profile & challenges faced by the patients attending the CPC centre of a tertiary care municipal hospital at Mumbai.

Material & Methods
The study includes the profile of all patients catered to since the inception of CPC OPD in February 2013 to Dec 2013. Details related to socio-demographics and clinical profile were recorded using a semi-structured questionnaire. SPSS version 15 was used for data analysis.

Results
A total of 71 children attended the CPC since the inception in February up till December 2013. Majority (70%) were boys. Nearly 2/5th of the children were under-five, followed by 37% in 5 to 10 years and 23% in more than 10 years age group. More than half (54%) were Hindus. More than 2/3rd of the children belonged to poor socio-economic status. The reason for attending the CPC was mainly non-malignant disorders (73%) as compared to malignant disorders. Approximately 40% of the children had hematological involvement. Every fifth child had developmental delay of milestones. More than 1/5th of the children had malnutrition. Majority (73%) faced challenges of unknown prognosis. The main need identified was that of psychological support, required in nearly 70% of the cases.

Conclusion:
The CPC has played a great role in providing a holistic approach to the terminally ill patients, however this is just the beginning and has immense scope for expansion.

P29. Impact of palliative care for children at Sree Avittom Thirunnal Government Medical College Trivandrum in collaboration with Pallium India – Abraham B (India)

Introduction
Palliative care for children represents a special, albeit closely related field to adult palliative care. SAT paediatric palliative care clinic was on 08th December 2011 and it is in all Thursday 1pm to 5pm. Conducted by Dept: of Pediatrics, Dept: of Pediatric Neurology and Pallium India (WHO collaborating centre for training and policy on access to pain relief).

The team
Includes Pediatrician & palliative physician, Pediatric Neurologist, Psycho-social worker, Psychologist Physiotherapist, Staff nurse and four volunteers. The function of the team is:
- Medical illness studied in detail
  - Physical disabilities assessed (based on ADL) VSMS (SQ)
  - Hearing /vision
- Social/psychological/financial/spiritual aspects-studied in detail
- Immediate treatment modalities decided
- Long-term comprehensive rehabilitation of the family-discussed and planned
- Physiotherapy
  - Techniques taught to the care givers
o Physiatrist led team visit the house-decides on physical rehabilitation(selected patients)

- Periodic home visits for assessment and re-enforcement
- Drugs
  o All essential drugs are issued free of cost to the child.
  o Anti-epileptics/Analgesics/drugs for Chronic kidney disease; etc.:
  o Inj: Erythropoietin-given to children with CKD
- Other support
  o Educational support for child (if needed) and siblings
  o Travel expense for the family to attend the clinic
  o Food-kit for the needy
  o Re-imbursement/financial support for costly Counselling
  o investigations/special devices etc.:
  o Parental counselling to all
  o Counselling to children (in those who are old enough)
  o Home visit & social support
  o Vocational rehabilitation
    ▪ Training for caregivers
    ▪ Soap & soap solution
    ▪ Cattle rearing
    ▪ Sewing machine
    ▪ Rabbit rearing
- Family get together & parent support group

Impact
- Better understanding of the nature of disease of the child and methods of rehabilitation.
- Provision of free drugs, home physiotherapy, and educational support relieved the financial burden of the family to a great extent.
- The days of hospitalization were considerably reduced as the parents were taught to give medications for common ailments
- Improvement in the care of the child’s siblings

Conclusion
A lot of children with chronic non-malignant conditions need palliative care. In past two years, the Pediatric Palliative Care service caused a measurable improvement in the physical, social and emotional well-being of children and their families.


Background
Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family. Hospice Africa Uganda introduced the pediatric palliative care services on January 23, 2007. The emphasis was to provide total palliative care including but not limited to pain and symptom management, psychosocial and spiritual
care for children suffering from cancer and HIV/AIDS. The other focus was on provision of chemotherapy to children suffering from Burkett’s Lymphomas and other cancers. The current number of children on programme is 145. 62 of these have HIV/AIDS, 67 have different cancers and the remaining 16 have both HIV/AIDS and cancer. There is a children’s Palliative Care Team that is comprised of a Clinical Paediatric Care Nurse (CPCN) who acts as the overall Coordinator, play therapist and volunteers that support the children. This team from HAU works very closely with the Oncology team at Mulago-Uganda Cancer Institute.

**Services rendered**
Provision of total palliative care services to children with cancer and HIV/AIDS especially those that are in homes and hospitals. Daycare services: Children are collected from their beds and come to spend time in the house of hope, a hospice house at mulago hospital. They do all sorts of activities like playing, shading and storytelling about their illnesses. This helps them to cope with the illness. Others are collected every Tuesday to came and attend a day care at hospice. End of life counselling and bereavement support to the children and their care givers. Financial support to those in need – for investigations, buying equipment, etc.

**Challenges**
- Small team
- Limited financial resources: for programme support, chemotherapy, etc.
- Lack of formal infrastructure for service provision

**P31. Improving quality of life of a child with Osteogenic Sarcoma through Home Care Services – Dhumal S (India)**

**Background:**
Child, 19 years old, referred to Paediatric Palliative Care on 26th April, 2012, child was residing in Mumbai with family.

**Method:**
Improving quality of life child & rehabilitation of family through Home Care Service

**Results:**
Child was studying in 12th std; however due to treatment child was not able to continue with her studies. The child was hopeful that he would be able to join college after treatment. But the Doctor and Counsellor didn’t break this hope but explained the prognosis to the family.

The child cared a lot for all his family and friends. The child also came for the various patient support group programmes and enjoyed himself a lot with other children. During this time, his father got a paralysis attack, due to which he had to be taken to the Hospital, and he could not express himself any longer. Within few days the child began to get irritated as was not able to walk without support even at home, was bored sitting at home and was losing hope. The child expressed his wish for a computer, so the Home Care Team along with a Volunteer, also provided a Computer to the child to divert his mind; his friends used to visit. Because of the child’s deteriorating condition, and the child’s father who was also under
treatment, the family underwent a lot of emotional suffering. It was very difficult to for the mother and sister to manage so many issues all at once. The mother took the prime responsibility of caring for the child and her husband as well.

The child’s family was in continuous communication with the Local Doctor and Home Care Team for management of the child’s symptoms at home. Due to his worsening condition, the child was brought to the hospital with severe breathlessness but expired on 21st Jan, 2014. After the child’s death a bereavement call was done for the family. Family was able to cope. Sister was referred for Vocational training.

Discussion:
Home Care provided by Multi - Disciplinary team has showed improvement in quality of life of the child and his family.

P32. Paediatric palliative care: Barriers and facilitators towards implementation – Tilve P, Talawadekar P, Muckaden MA. (India)

Introduction
Children suffering from life limiting illnesses are under the care of paediatricians. They are not necessarily trained in palliative care, which results in lack of Holistic care including psychological support and rehabilitation. This is more so in rural set up.

Objective
To find out the current perceptions among pediatricians of Paediatric Palliative Care with a focus on identifying barriers and facilitators to implement the same.

Methods
261 paediatricians practicing in the state of Maharashtra were administered a semi structured questionnaire. Perceived barriers and facilitators towards implementation were marked on Likhert scale.

Results
53.6% respondents had prior experience with Palliative Care in form of symptom management, psychological support and rehabilitation. 86% of Paediatricians, showed disposition to implement Palliative Care principles into their routine practice. Busy schedule (54%) and need for documentation (61%) was seen as a major barrier for implementation. Non Availability of Morphine (50.9%) was also seen as a major hurdle. Major Facilitations perceived were availability of a consultant or team (52%), education in basic palliative care competence (43%) and training in communication skills (47%).

Conclusions
Training in Paediatric Palliative Care Competence and Communication skills was felt as the utmost need to incorporate Paediatric Palliative care principles into routine practice when dealing with life limiting conditions. For this, short courses and one day CMEs should be conducted. Need to improve networking of the Pediatricians who are willing to practice Palliative Care was felt.
Role of a multidisciplinary team in Pediatric Palliative Care Unit at Sree Avittam Thirunal, Medical College Hospital, Trivandrum, Kerala – Kalaricka J (India)

**Introduction**

Core of Palliative care is team work which takes care of four aspects of Palliative Care. The ideas generated from the team members can transform the whole life of the patients and the families. The team includes Pediatrician, Palliative Care Physician, nurse, social worker, physiotherapist, volunteers and patient support group (care givers). The pediatric palliative care is a joint venture of Pediatric department, Pediatric neurology department and Pallium India Trust, a famous national level Non-Governmental Organization working in the field of Palliative Care. Majority of the children are suffering from cerebral palsy, kidney diseases and genetical disorders.

**Pediatrician:** The doctor does comprehensive assessment of physical symptoms. Pediatrician also checks the developmental milestone in the child. Talk to the parents of the child and explain about the medical conditions.

**Palliative Care Physician:** The doctor who is trained in Palliative Care. The Palliative Care physician also does comprehensive assessment of physical symptoms and plans the management for the child. The doctor is trained in Palliative Care is working in palliative care clinic. The doctor does comprehensive assessment of physical symptoms.

**Palliative Care Nurse:** The nurse who is working in the Palliative Care Unit is trained in Palliative Care. One who manage the symptoms with procedures and dispensing the prescribed medications to the Patients. Moreover, the nurse also does the follow up of treatment by regular telephonic calls.

**Physiotherapist:** The physiotherapist helps in the physical rehabilitation of the children in the palliative care unit. The physiotherapist also teaches the range of motion exercises to the parents of the children.

**Medical Social Worker:** Medical social worker does a complete assessment of the socio economic condition of the patient. Medical social Worker identifies the needs like financial, psychological support.

**Clinical Psychologist:** clinical psychologist do counselling for the parents and assess the mental ability with the special tools.

**Volunteer:** Volunteers listen to the parents of the children and identifies the need of the child and family. In addition to that, the volunteer act as bridge between the medical team and the family.

**Patient support group (care giver):** Patient support group at SAT is formed three months ago. This support group is formed by the parents of the children and mentored by the volunteers. This group plays a vital role in finding out the economical measures for the family by organizing and teaching rehabilitation measures. And also this group is known as...
**self-help group.** This idea of self-help group plays a very important role in rendering Palliative Care Services.

**Conclusion**
Pediatric Palliative care addresses the problems of the children with malignant and non-malignant condition. In this venture the multidisciplinary team and ideas generated from the team played a vital role in improving the quality of life children with chronic illness and their family.

**Research**

**P34.** The BiG Study - using the Measures of Processes of Care (MPOC) to evaluate parents’ and professionals’ perspectives on family-centred care – *Hunt A, Hacking S, Farman M.* (United Kingdom)

**Background**
There are limited measures to assess the effectiveness of children’s palliative care. An instrument, the MPOC-56 evaluates the extent to which parents consider the services they receive to be family-centred on each of five dimensions:

- Enabling and Partnership (EP)
- Providing General Information (PGI)
- Providing Specific Information about the Child (PSI)
- Coordinated and Comprehensive Care for the Child and Family (CCCF)
- Respectful and Supportive Care (RSC)

The MPOC-SP assesses whether organisations perceive themselves to be delivering family-centred care on four dimensions:

- Showing interpersonal sensitivity (SIS)
- Providing general information (PGI)
- Communicating specific information about the child (CSI)
- Treating people respectfully (TPR)

Items are scored on a scale of 1 'never' to 7 'a great extent'.

**Methods**

We used a slightly adapted 56-item Measures of Processes of Care (MPOC-56) for parents and 24-item MPOC for Service Providers (MPOC-SP) as part of the BiG Study evaluating services for children and young people (CYP) with life-limiting conditions (LLC) and their families. 21 services in the West Midlands distributed questionnaires including the instruments to staff and managers.

**Results**

Parent survey: 192 (12.5%) responded. Lowest scores for MPOC-56 were given for Factor ‘PGI’ (mean 4.2 SD 1.6) and highest for ‘RSC’ (mean 5.3 SD 1.4). Staff survey: 264 (52.4%) responded. Staff scored items ‘PGI’ (mean 4.3 SD 1.5) and ‘CSI’ (mean 4.1 SD 1.9) considerably lower than ‘TPR’ (mean 6.1 SD 0.6) and ‘SIS’ (mean 5.4 SD 0.9).
Discussion
Parents and staff agreed that provision of information to families was the least well met dimension. Parents report that they find it difficult to access information. Professionals may underestimate families’ needs for information or there may be lack of clarity about whose role it is. The MPOC proved useful for evaluating family and professional perceptions of family-centred care.


Little is published concerning the frequency and characteristics of pain in boys and young men with Duchenne Muscular Dystrophy (DMD) or how they manage their pain. The many and varied complications of DMD give high risks for experiencing pain of many types throughout the progression of the disease.

Methods
Face-to-face interviews with boys and young men with DMD incorporating assessments of
1. Pain (Body maps (developed for this study)), Color Analogue Scale and Numerical Scale (McGrath et al, 1996), and Faces Pain Scale-Revised (Hicks et al, 2001)
2. Pain coping - Pediatric Pain Coping Inventory-Teen version. (PPCI) (Varni et al., 1996),
3. Quality of life - Youth Quality of Life Scale (YQOL) (Edwards et al., 2002; Patrick et al., 2002).
4. Function – (completed by clinicians) Muscular Dystrophy Functional Rating Scale (MDFRS) (Liu et al., 2003).
5. Parent questionnaires included the Pediatric Pain Coping Inventory (Parents version). (PPCI) (Varni et al., 1996).

Results
Over a period of four years, 15 boys and young men (mean age 15; range 11 - 21) and their parents/carers were recruited, mainly through their hospital clinic. Most were interviewed at home, one at school. All but one asked for their parent/s to be present during the interview. Parents / carers of 14 boys completed their own questionnaire, occasionally with help from the researchers. Visits to the home lasted approximately 2 hours. Young men and their parents found the visit and interview enjoyable and had no complaints or additional suggestions. Qualitative and quantitative results will be presented.

Discussion
Due to the time taken to recruit participants to the feasibility study it is likely that a multi-centre study under the Medicines for Children Research Network and increased resources at the recruitment stage will be necessary for a larger study of pain in this group of young people.


Background
Annually 60 children of the Emma Children’s Hospital AMC die from life limiting diseases (LLD). To provide good end of life care, a pediatric palliative care team (Emma Home Team, (EHT)) was initiated. It bridges the gap between hospital and home in providing Advanced Case Care Management (ACCM). One year after the launch data were gathered to objectify the needs for care and to objectify the composition of the research-population.

Methods
Since the launch of the team data were gathered during one year. We reported patient demographics, nursing procedures, reasons for hospital visits and admissions. Results were compared within two groups; non-malignant versus malignant. The non-malignant disease group (NMDG) was divided in different subdivisions according to the ICD-10 code. We described the actual population receiving palliative care and to gain insight in provided care for the different subgroups.

Results
In one year 43 patients were included in the EHT. 22 had malignancies 21 had non-malignant LLD. The average time of care before death was longer for the malignant disease group (MDG) (median 99 days (5-267 days)) compared to the NMDG (median 72,5 days (5-211). Of this care in the MDG the majority was spent on homecare (median of 2,0 hours per patient). The NMDG had more days of admission (830 versus 121). Infections were the major cause of admission in the NMDG (42% vs 24,7% in MDG). Within the NMDG group the syndromic diseases caused the most admission days.

Discussion
One year after initiation of our pediatric palliative team the first results are evaluated and show that different patient subgroups have different profiles and need different types of care. The coming years we will prospectively evaluate the additional value of this team from a parental as well as a professional and cost-efficacy perspective in the PANDA study (Palliative Anticipated and Dedicated cAre).

P37. Patient controlled analgesia for children at home – Mherekumombe M (Australia)

Objectives
To survey the effectiveness of patient controlled analgesia (PCA) in the form of a portable Computerized Ambulatory Drug Delivery device (CADD) in the home environment and document the opioid consumed, reasons for prescription, doses required, side effects, adverse events or safety issues that may have occurred.

Method
A retrospective chart review was conducted on children discharged home with opioid infusions. Charts from 2008 to February 2012 were surveyed. There were 37 CADDs dispensed in that period.

**Results**
Thirty-three (89%) CADDs were prescribed for patients with cancer related pain. Majority of the children lived in metropolitan Sydney (86%). Approximately 33% of the CADDs were commenced at home and the rest in hospital prior to discharge. Almost all PCAs were utilised until death and fifty percent of the children died at home. Hydromorphone was the most commonly prescribed opioid. Majority of opioids prescribed were required for bone pain due to metastatic cancer. An opioid switch occurred in ten (27%) patients for severe pain. The average morphine equivalent dose was 26mg/kg/day (range 0.2 to 190mg/kg/day). Sixteen (43%) patients were readmitted to hospital from home and only 18% of these were related to pain. Patients with severe pain also required adjuvant therapy. The median duration on a CADD was 45 days (range 2 to 420 days). The audit found minimal reported side effects, adverse events and safety issues.

**Conclusion**
Patient controlled analgesia in the form of a CADD is an effective and safe way to manage pain at home. Several patients required an opioid switch and adjuvant therapy to effectively manage pain. The effectiveness of the use of PCA in the home environment is illustrated, including recommendations for improvement and further research. The use of PCA CADD infusions is also recommended in all palliative patients at home with severe pain and to manage end of life symptoms.

**P38. Parental decision making regarding end of life care – Neefjes V (United Kingdom)**

**Background**
When a child with cancer no longer has a realistic chance of cure, the parents are faced with a range of decisions; e.g. treatment options, place of care and place of death. However, little is known how parents make decisions at the end of their child's life. Better understanding of the parental decision making process could lead to more effective care as well as a better allocation of resources.

**Method**
This qualitative study used semi-structured interviews with four bereaved parents and subsequent analysis by IPA to describe the parental decision making process.

**Results**
During curative treatment, the child's consultant was regarded as the main decision maker regarding the treatment. At the end of life however, the interviewees felt that decisions regarding treatment were the parent's responsibility (none of the children in this study were informed of their impending death). The most important factor in deciding in favour of further treatment was a belief that further treatment could be successful, either to cure or prolong life. The principal argument against further treatment was a concern regarding the child's quality of life should the treatment succeed. In deciding the place of death it was
very important for parents to ensure continued involvement of family and friends who had been supportive during the treatment. After the death of the child, engagement in altruistic and reciprocal activities was described as helpful in bereavement. Importantly, all participants describe disagreements with their partner, especially with regards to medical treatment decisions. In all families, these disputes were resolved by the mother acting as the main decision maker.

Discussion
This retrospective pilot study allows some insight in the parental decision-making


Background
In contrast to the extensive expertise in palliative care for adults, expertise in care for children with a life-limiting or life-threatening disease is still in its infancy. Professionals have difficulties to timely recognize care needs and often lack skills to provide the required care. Moreover, for children that are taking care of at home, guidance is lacking due to a multiplicity of disciplines involved. Parents often feel that they have to rely on themselves while they already are in a stressful, insecure and vulnerable situation.

To improve palliative care for children in the Netherlands, a pilot project of Advanced Care Case Management (ACCM), called the Emma Home Team (EHT) was introduced in 2012i. This interdisciplinary and trans mural functioning team of case managers is responsible for the coordination, continuity and the substantive quality of palliative care and supervision of children with a life-limiting or life-threatening disease. This program provides the unique opportunity to research on the care needs of different involved actors (parents, children and professionals). In addition, we will assess the added value of the EHT from the perspective of these actors. This study is part of a greater research project called PANDA (Palliative Anticipated and Dedicated cAre).

Methods
Qualitative research methods provide the opportunity to shed light on the lived experience of actors involved in paediatric palliative care. The area of oncology as well as the less researched general paediatrics will be explored by doing interviews with parents, children and professionals. We aim to improve paediatric palliative care by illustrating experiences and perspectives to get a better understanding of how different actors manage. In addition, we evaluate the EHT and develop a care pathway.

Although our research is currently in its infancy, we would like to present the research design with special focus on the qualitative methods and additionally show some first results.
P40. Development of an End of Life Chart Review Tool for Paediatric Palliative Care – Doherty M, Vadeboncoeur C. (Canada)

Among children who are dying, symptoms of pain, fatigue and anorexia are common. However, these symptoms are often not recognized by health care providers, leading to potentially treatable suffering at end of life (EOL). Recent evidence from hospitalized adult patients shows that involvement of a palliative care team generates more recommendations regarding symptom management and advance care planning. Similarly, in the Neonatal Intensive Care setting, the involvement of a pediatric palliative care (PPC) team lead to more referrals to spiritual care providers, less days spend in Intensive Care, and fewer investigations at EOL. We sought to investigate the impact of a comprehensive multidisciplinary pediatric palliative care team on the quality of life in children who are dying through the development of a chart review tool. Following review of the relevant literature, we identified the following 6 domains of interest: symptoms, advanced care directives for resuscitation, invasive treatments or investigations, communication, psychosocial supports, and recommendations from a PPC team. We then developed a chart review tool consisting of 6 discrete modules to assess these domains. We further refined the tool through review by experts in PPC and a pilot chart review with patients who had died at our own institution. This tool will allow investigators to examine the quality of life for children who are dying and evaluate the differences in the care of children when a PPC team is involved. The development of a standardized tool will allow comparison of children cared for in different settings internationally.

P41. Investing in the Future: A Case Study of the Transition Experiences of Young Adults with Life Threatening Conditions – Cook K, Jack S, Siden H, Thabane L, Browne G. (Canada)

Change in all spheres of life is the hallmark of young adulthood: biological, social, developmental and cognitive. The impact of this change is described as being alternatively exhilarating, disconcerting, satisfying, frustrating, and terrifying. For young adults with pediatric life threatening conditions (pedLTC), the burdens of their condition, disabilities, and uncertain life trajectory have the potential to both limit and intensify their experiences. Advances in pediatric medicine and new technologies have created a generation of young adults with pedLTC surviving into adulthood; however appropriate services to support them in these young adult years have not paralleled their increasing life expectancy. At the pinnacle of their developmental changes from adolescence to adulthood, they leave behind comprehensive, supportive and coordinated health, social and education systems, and fall into an abyss of uncoordinated adult services not compatible with the purpose, quality or quantity of the resources provided in the pediatric systems. Consequently, these young adults must often construct a “new normal” for their journey forward. Using data gathered from an innovative bulletin board focus group, we describe the complex interplay of the health, education, and social service sectors in this transition. Our descriptions include system deficits and strengths and the young adults’ resilience and coping strategies to overcome those deficits and move forward with their lives. Young adults with pedLTC require knowledgeable providers, coordinated and accessible services, being respected and valued, and services and supports that promote independence. This paper describes the
monumental effort required to overcome system deficits that impact transition, and coping strategies young adults with pedLTC use to invest in their short futures. The input and voice of young adults in the development of these services are imperative to ensure that multisystem services support their needs and life goals.

P42. Identifying patterns of concerns expressed by an adolescent with life limiting illness: An audit of documented narrations of 10 adolescent patients – Pandya S (India)

Introduction
Adolescents with cancer form a distinct group of patients with special developmental, emotional, physical and psychosocial needs and counselling these patients needs special skills to identify these unique concerns. This is an audit of 10 documented narrations of adolescents with life limiting illness highlighting the concerns expressed.

Methods
10 case files of adolescent patients attending Pediatric Palliative Care at Tata Memorial Hospital outpatients from June 2013 to Dec 2013 were audited. Documented narrations were audited using a standard pro forma prepared for the study.

Results
The concerns expressed were stratified as a) disease specific concerns b) psychosocial / emotional / existential concerns. Among the disease specific concerns major concerns were regarding the poorly controlled symptoms and unreliability of diagnosis and need to reconfirm. The major social concerns expressed were being burden on the family, financial constraints, peer separation and isolation, stigma associated with illness, inability to attend school and difficulty in coping at home and in school environment. The major psychological concerns expressed were feeling of guilt and body image issues. Major emotional concern expressed was loss of hope and feeling helpless. Existential issues were not of a major concern. However, a couple of patients associated their current illness to bad past karmas and were worried about how things will unfold in future.

Conclusion
This audit demonstrates a wide spectrum of concerns ranging from disease related to psychological, social, emotional and existential. Hence it is important to acknowledge and understand these concerns in adolescents with life limiting illnesses.

Sustainability

P43. Challenges of Children’s Palliative Care Services Opened as a result of Governmental Policy Changing in Russia – Kumirova E, Savva N (Russia)

Issues
Governmental support (legislative and financial) is important for sustainable development of pediatric palliative care (PPC) services over the country. The aim of this abstract is to present the idea that the only administrative resource is insufficient to implement theory of PPC into the practice.
Description
Palliative care as a branch of health care system in Russia has been firstly defined in the Federal Law in 2011. Development of PPC governmental and non-governmental services has been approved by the Decree of the President and bylaw of the Government in 2012 as a priority of National Strategy for the period of 2012-2017. In 2012, Ministry of Health requested to open palliative care departments in hospitals for children over the country. In 2013, the first grant has been allocated by the Committee of Public Relation of Moscow Government to the Children’s Palliative Care Foundation for home care of children and young adults.

At the same time, neither basic nor postgraduate courses exist to educate specialists in PPC. There are a limited number of knowledgeable trainers to start educational process.

As a result, 390 PPC beds have been opened to date. In total, 26 services (governmental and charity) provide PPC at present. Of them, only ten have home care teams. Stationary beds mostly remain empty as parents prefer to care children at home, and specialists of PPC departments have problems with understanding which of the patients are eligible for PPC and what care is needed for them.

Lessons Learned
Development of legislative base is crucial but insufficient to organize PPC effectively.

Recommendation
By our experience, to escape existing challenges it would be reasonable to open multiple services already having educated multi-professional team and implemented standards of care.