1ST EUROPEAN CONGRESS on
PAEDIATRIC PALLIATIVE CARE
ABSTRACT BOOK

Rome, 28-30 November 2012

Under the high patronage of
the President of the Italian Republic

EDIZIONI - MINERVA - MEDICA
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Rome, 28-30 November, 2012

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The commitment of the Maruzza Foundation

The mission of the Maruzza Lefebvre D’Ovidio Onlus Foundation (Maruzza Foundation) is to promote and support Palliative care (PC) at all levels, with special attention toward the most vulnerable of patients: children.

The Foundation’s important commitment to this mission is extensively documented by the numerous initiatives undertaken during the past few years, often in collaboration with the European Association for Palliative care (EAPC), the Italian Ministry of Health and other prestigious Institutions.

I am sure that many of you are familiar with several of the publications resulting from our joint-projects such as “IMPaCCT: standards for paediatric palliative care in Europe”, published in 2007 in the European Journal of Palliative Care (EJPC) and the Booklet “Palliative care for infants, children and young people”, translated into 5 languages and available on-line.

I am particularly proud of the significant role played by the Maruzza Foundation in the drafting of recently approved Italian legislation, (Law N° 38 of 2010), which stipulates precise criteria for the organization and implementation of pain management and PC in children (PPC) in our country.

The 1st European Congress on Paediatric Palliative Care (ECPPC), aimed at providing all those involved in the care of children with life-threatening and life-limiting illness with a unique opportunity for knowledge sharing at an international level, seemed a natural continuation of our efforts to improve child-specific palliative care throughout Europe and beyond.

The response to this event has been quite remarkable, both in the elevated number of registered participants and the distinguished speakers accepting to present their work and ideas.

The relevance and interest attributed to the Congress is also demonstrated by the large number of important institutions and organizations that have committed their patronage and support to this event, (including: the Head of the Italian Government, the Municipality of Rome, the Italian Ministry of Health, the National Institute of Health (ISS), the Italian Pediatric Society (SIP), the Italian Association for Pediatric Culture (ACP), the International Children’s Palliative Care network (ICPCN), the Italian Society of Palliative Care (SICP), the Italian Federation of Rare Diseases (Unitiamo Fimr Onlus), the Italian Federation of Palliative Care, the Gigi Ghirotti National Foundation, Together for Short Lives, the “Bambino Gesù” Pediatric Hospital) that I wish to sincerely thank for their support. I am also grateful to Recordati Pharmaceuticals and Silversea Cruises for their generous financial help in the organization of the Congress. My sincere appreciation goes also to all other supporters.

I would like to express my sincere gratitude to Franca Benini and Chantal Wood, respectively Chair and Co-Chair of this First ECPPC, to the Members of the Scientific Committee
and the panel of eminent Speakers for their valuable contribution. I would like to extend a special thank you to Elena Castelli, Chief Executive Officer of the Maruzza Foundation, and the staff of the Congress Secretariat for their hard work and dedication in making this Congress a success.

I am convinced that this event will provide a productive and stimulating atmosphere for a fruitful exchange of ideas and experiences that will be replicated in years to come. I would like to wish you a enjoyable stay in the Eternal City.

ELVIRA SILVIA LEFEBVRE D’OVIDIO

President

Fondazione Maruzza Lefebvre D’Ovidio Onlus
Dear Colleagues, Delegates, Ladies and Gentlemen,

We would like to welcome you to Rome and to the 1st European Congress on Paediatric Palliative Care.

Child-specific palliative care is a relatively new discipline that encompasses and involves many aspects of care for critically ill children and their families: medical, psychological, social, spiritual, organizational and financial. For this reason it is unique, complex and not always easy to deliver. This complexity is demonstrated by the variety of solutions that have been implemented in different centres in countries throughout Europe and worldwide.

Being directly involved in the development of palliative care services for children at a national and international level, we are very aware of the need to stimulate research and promote education, to establish benchmarks and broaden our understanding through the shared knowledge of experts working in the field of paediatric palliative care (PPC). We also appreciate the importance of sharing and comparing different experiences, of how we can learn from each other and how we can adapt and adopt successful solutions to best meet children's and parent's specific needs.

In the planning and organization of the congress we have attempted to take into consideration and include all of these important aspects. We have strived to involve experts in PPC from a broad scope of international backgrounds in the panel of invited speakers, the members of the Congress Faculty and the Scientific Committee. We have also engaged with representatives from national and international private or public funding organizations and governmental agencies to share their expertise in this important field of paediatric palliative care.

The response to this initiative has gone far beyond our expectations: international interest and participant registration is remarkably high. More than 150 abstracts were submitted from all over Europe and further afield. Of these, 125 have been selected through peer review for oral or poster presentations and are printed in this Abstract Book.

The efforts required in organizing and hosting this event have been extensive and we would like to take the opportunity to express our sincere gratitude to Silvia Lefebvre D’Ovidio, President of the Fondazione Maruzza Lefebvre D’Ovidio Onlus (Maruzza Foundation) for firmly believing in this ambitious initiative and supporting it from the beginning. We would like to extend this gratitude to the Foundation staff who have done an outstanding job in organizing every aspect of the Congress.

In an undertaking of this magnitude we must pay tribute to all the colleagues and associates who contributed in various ways to the success of the Congress. Our sincere appreciation goes to the members of the Scientific Committee for their exemplary contribution. A Special thank you goes to the institutions, partners, supporters, non-profit organizations,
families and friends (and all those who we may have overlooked) involved in this unique initiative.

Finally, we would like to thank the congress participants who have travelled from near and far afield to participate in the first edition of this event. We would like to thank you for supporting us in our endeavour. We earnestly hope that we succeed in attaining our goals and that this may become a regular appointment for the development and improvement of child-specific palliative care throughout Europe and beyond.

FRANCA BENINI MD,
Congress President

CHANTAL WOOD MD,
Congress Vice President
1ST EUROPEAN CONGRESS on PAEDIATRIC PALLIATIVE CARE
ROME, 28-30 November 2012

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Organizer
Fondazione Maruzza Lefebvre D’Ovidio Onlus
Via del Nuoto, 11 - 00135 – Rome Italy
Tel: (+39) 06 3290609 - Fax: (+39) 06 36292743
E-mail: ecppc@maruzza.org
segreteria@maruzza.org - www.maruzza.org

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ROME, 28-30 November 2012

Wednesday 28th November 2012

17.00-17.45 Institutional welcome address
— Silvia Lefebvre D’Ovidio – President of the Fondazione Maruzza Lefebvre D’Ovidio Onlus
— Renato Balduzzi – Italian Ministry of Health
— Gianni Alemanno – Mayor of Rome
— Francesca Ratti – Deputy Secretary-General of the European Parliament

17.45-19.30 Opening Ceremony
Intervengono: Dott. Gianni Letta, On. Livia Turco
— Franca Benini – Congress President
— Chantal Wood – Vice President
— Giuseppe Profiti – President of Bambino Gesù Children’s Hospital
— Franco De Conno – Honorary Director of the EAPC
— Alberto G. Ugazio – President of the Italian Paediatric Society
— Adriana Turbizzani – President of the Italian Palliative Care Society
— Omar Leone: A Family’s PPC experience
— Claudia Robustelli: Testimony of a young woman living with rare disease
— Richard Hain: Ethical issues

19.30-20.30 Welcome reception

Thursday 29th November 2012

09.00-10.00 “Eligibility criteria”
Modemators: Franca Benini and Guido Fanelli
Finella Craig: Documents and guidelines
Ricardo Martino Alba: From theory to practice
Open Discussion

10.00-10.30 Coffee Break

10.30-12.40 “Models”
Modemators: Joan Marston and Gianlorenzo Scaccabarozzi
— Anna Garchakova (Belarus)
— Chantal Wood (France)
— Benjamin Gronwald (Germany)
— Julie Ling (Ireland)

Friday 30th November 2012

09.00-10.30 “Symptoms management”
Modemators: Chantal Wood and Nicola Pirozzi
— Stefan J. Friedrichsdorf: Pain: new strategies for treatment
— Boris Zernikow: Sleep disturbance and daytime agitation in severe neurological conditions
— Joanne Wolfe: End of life management
Open Discussion

10.30-11.00 Coffee Break
11.00-13.00 “Specific needs”
Moderators: Marcello Orzalesi and Domenica Taruscio
— Umberto Simeoni: Needs in newborns
— Bruno Dallapiccola: Rare Diseases
— UNIAMO FIMR ONLUS - Eurordis
— Giancarlo La Marca: Neonatal screening in the Tuscany region
— Samantha Parker: Providing access to knowledge and training in rare diseases
— Open Discussion

13.00-14.00 Lunch and poster visit

14.00-15.30 “Support and research”
Moderators: Lizzie Chambers and Vito Ferri
— Ulrika Kriechergs: Communication and psychological support
— Danai Papadatou: Support for the care team
— Myra Bluebond-Langner: Research in PPC
— Open discussion

15.30-16.00 Coffee break

16.00-17.15 Working session 5
Moderator: Stefan J. Friedrichsdorf
— Presentations
— Open Discussion

17.15-17.45 Closing remarks
— Sheila Payne, Chairman EAPC
— Franca Benini, Congress President
Palliative care as children’s right
Foley K.

International and national laws contain important guarantees for the child’s right to health and protection from degrading conditions. There are several human rights treaties that enshrine the child’s right to the highest attainable standard of physical and mental health, including the International Convention on Economic, Social and Cultural Rights (ICESCR), the Convention on the Rights of the Child (CRC), and for example, regional charters like the African Charter on Human and Peoples’ Rights and the African Charter on the Rights and Welfare of the Child.

In the ICESCR, it is stated that the state ‘CANNOT UNDER ANY CIRCUMSTANCES WHATSOEVER JUSTIFY ITS NON-COMPLIANCE WITH CORE OBLIGATIONS … WHICH ARE NON DEROGABLE. The core obligations that are relevant to palliative care include: providing essential medicines; ensuring non-discriminatory access to health facilities, goods and services and adopting and implementing a national public health strategy and plan of action addressing the health concerns of the whole population with particular attention to all marginalized and vulnerable groups. The CRC as an international human rights treaty introduces the concept that children as subjects of rights with the same inherent value as adults. The CRC was adopted in 1989 and signed by 193 countries (except Somalia, South Sudan and the United States).

Within the charter there are four Articles that are relevant to the discussion of a rights based approach for pain relief and palliative care for children. They include Article 2 which is to protect the child from discrimination which means that children cannot be discriminated against on the basis of their age or health status. Thus children cannot be excluded from palliative care and pain services and access to essential medicines to treat their symptoms. Article 3 supports the concept of best interests for the child and clearly, avoidance of unnecessary suffering and family-centered care which is the goal of palliative care - is in the best interest of the child and the family. Article 6 - the right to survival and development - supports the concept that palliative care concurrent with active therapies to provide the child with the best opportunity for quality of life and options for access to curative therapies. This includes the child’s right to participate in healthcare and to have information. For example, palliative care requires good communication and decision-making about choices for treatments and establishing goals of care. Children’s views need to be sought out and understood as is emphasized in Article 12 where the child has the right to be listened to which also means that that their symptoms like pain need to be assessed and treated and that they be allowed participate in family discussions and decisions around their care.

Another international convention, the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment can apply to children as the denial of pain relief may violate the prohibition of cruel inhuman and degrading treatment in international law. This right to be free also includes a positive obligation of states to protect persons in their jurisdiction from such treatment. As part of the positive obligation, states must take steps to protect people from unnecessary suffering related to a health condition according to a joint letter from the UN Special Rapporteur on Torture and other Cruel Inhuman or Degrading Treatment or Punishment Manfred Nowak and UN Special Rapporteur on the Right to Health Anand Grover.

A family’s PPC experience
Leone O.

Missing abstract.

Testimony of a young woman living with rare disease
Robustelli C.

Missing abstract.

Ethical issues
Hain R.

Missing abstract.
Paediatric palliative care is a relatively new area of paediatrics. The scope of practice, services required and the skill mix and educational requirements of service providers are still being defined and developed. Globally, there is huge variability in the evidence base for population need, funding for services and guidelines for service planning and delivery. The 1997 the UK publication ‘A Guide to the Development of Children’s Palliative Care Services’ [1] produced by the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health, was one of the first publications to define which children could benefit from children’s palliative care services. Four main groups of eligible children and young people were identified and included those with potentially curable disease but for whom treatment may fail, as well as those living with life-limiting conditions. The document emphasised that palliative care could be provided alongside curative treatment or life-prolonging interventions and set the scene for people to consider palliative care in its broadest capacity, for those children and young people living with life-limiting or life-threatening illness, and not just for ‘terminal care’. These eligibility criteria were given further credibility in the 1998 publication of the WHO definition of paediatric palliative [2], which included the statement ‘it begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease’. The American Academy of Paediatrics followed in 2000 with the publication of ‘Palliative Care for Children and Adolescents’. This statement presented an integrated model for providing palliative care for children with a life-threatening or terminal condition and also promoted the broader eligibility criteria in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death. In March 2006, a group of healthcare professionals from Europe, Canada, Lebanon and the USA met in Trento, Italy to discuss the current situation of paediatric palliative care in Europe. The group was called the International Meeting for Palliative Care in Children, Trento (IMPaCCT) and became an EAPC task force in 2007. Paediatric palliative care eligibility was defined, adopting the previously published ACT criteria, best practices identified and minimum standards agreed. This resulted in a united document for Europe, published in 2007 defining and identifying standards of care for children and young people with life-limiting and terminal illness [4]. In 2009 ACT published ‘A neonatal pathway for babies with palliative care needs’ [5] that identified premature birth as an eligibility criteria for palliative care and highlighted that for some families, palliative care will begin in the antenatal period. Whilst this could be inferred from previous guidance, this document served to remove ambiguity around who or when to refer during the perinatal period. Subsequently, in 2010, The British Association of Perinatal Medicine defined 5 eligibility criteria for antenatal and neonatal palliative care [6]. Again, a broad definition for palliative care was adopted to ensure access was not restricted to those children and families where death was certain or where the child was considered terminal. It was the first major guideline published to clearly include the unborn child within palliative care eligibility criteria. The broader definition of palliative care, to include all children likely to be born with or living with a life-limiting or life-threatening condition has gained universal acceptance. It does not exclude those for whom curative or life prolonging treatments continue, or those who are ‘not yet dying’. It means that no child who would benefit from the physical, emotional, spiritual and developmental aspects of palliative care will be excluded.

References

1. A guide to the Development of children’s palliative care services. Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Heath (RCPCH), ACT 2003, UK.
5. A neonatal pathway for babies with palliative care needs. ACT 2009

From theory to the practice

Martino Alba R.
Pediatric Palliative Care Unit, Hospital Infantil Universitario Niño Jesús, Madrid, Spain

In 1997 the Association for Children’s Palliative Care (ACT) and the Royal College of Pediatrics and Child Health jointly published the first guide to categorize...
life limiting and threatening conditions in childhood. This system can theoretically accommodate any life limiting condition whose trajectory can plausibly be described by one or more categories.

The American Academy of Pediatrics published in 2000: "An infant or child will benefit from palliative care when no treatment has been shown to alter substantially the expected progression toward death." And based on the practice we can now add "or when dying is a possible outcome of the actual situation".

What means palliative care? Palliative care is a way of care based on the people. The patient, the family and the professionals, in this order, are the cornerstone of palliative scope. This way of care modus of care should be provided by each clinician in each clinical setting.

Classification criteria

The classification of a concrete patient depends on:
1) The diagnosis
2) Disease trajectories of the disease or condition
3) Actual clinical situation
4) Therapeutic options
5) Country social and sanitary circumstances
6) Pediatric palliative care availability

Therefore, everybody doesn’t receive the same categorization everywhere. Some examples can illustrate the possible variability:

— All patients suffering a life threatening situation (as a meningococcal sepsis, a severe cranial trauma, pneumococcal meningitis or a pertussis) could be benefit from a palliative care approach. This approach has to be provided by the pediatricians in the emergency department or the intensive care unit in the very first moment of attendance. They can live or die. These patients could belong to a group "Ib".

— The belonging of concrete patients to group 2 is determined by the availability of different therapies and it depends on the sanitary system. Patients who belong to Group 2 in developed countries (Cystic Fibrosis, HIV infection or Muscular Dystrophy) turn to Group 3 if some therapies are not available.

— Patients of Group 3 usually have a long evolution with progressive neurological impairment. Metastatic tumors without curative therapies are quite different in the clinical picture than metabolic diseases.

— Some brain tumors can be in Group 1 at diagnosis changing to Group 3 when they are submitted to palliative care. Also they could be part of Group 4 if the tumor is cured but the patient suffers a lot of sequelae because of the therapies applied.

— Otherwise, there are an important group of patients which don’t have a concrete diagnosis, but their clinical situation and progressive impairment make them suitable for pediatric palliative care.

Who decides or proposes a patient eligible for pediatric palliative care?

— The caregivers.

— The referral clinicians or specialist.

A patient can belong to one or other group only because of the timing of referring to pediatric palliative care. The primary pediatricians or the specialists should decide which is the right moment to consult the patient.

In the provision of pediatric palliative care there are three levels of care:
1) Palliative focus, palliative approach.
2) Basic or general pediatric palliative care.
3) Specialized palliative care.

The question is which patient needs specialized palliative care?

— If the patient clinical situation is changing or has changed in the last time; it supposes an increasing impairment and an objective evidence of irreversibility.

— If clinical problems are multiple, greater and difficult to control by primary or specialized pediatric services.

— If the patient becomes dependent of external devices to maintain or substitute two or more of the vital functions (breathing, feeding, mobility...).

— If the patient shows a "Frailty Syndrome Like". In the elderly this clinical picture identifies these without a unique severe condition but suffering deterioration of several organs or systems. Frailty is an extended process of increasing vulnerability, predisposing to functional decline and ultimately leading to death.

Which is the appropriate age to be eligible for pediatric palliative care?

In developed countries one third of dying people younger than 19 years die in the first month of life. Therefore, the field of palliative care comprises the prenatal period, perinatal and neonatal. Today it is possible to diagnose different illnesses in the prenatal period. Forty to eighty percent of the parents want to continue the pregnancy and waiting the birth of their sick baby. It is important to accompany and help this parents to bond their son and prepare them during the pregnancy to give the best care after the birth and premature death.

Adolescent patients can be treated by Pediatricians or adult Physicians. In pediatric palliative care what milestone (age of diagnosis or dying) defines the upper age limit? It depends on the sanitary system and the availability of pediatric palliative care resources.

In conclusion, a patient eligible for specialized pediatric palliative care is a multidimensional person suffering a life threatening condition or showing a frailty syndrome.

References


The development of children's palliative care in Belarus

Garchakova A.1
1The Belarusian Children's Hospice, Minsk, Belarus.

The Belarusian Children's Hospice (BCH) started its activity in October 1994 as a non-governmental organization, which initiated palliative care in Belarus for cancer children. Since 1996 the Hospice has expanded a focus on cancer patients to address the needs of non-cancer patients with the support of the Belarusian Research Center Pediatric Oncology and Hematology. Thanks to close collaboration with governmental bodies in 2007 new guidelines on palliative care were released by the Ministry of Health. The guidelines defined the notion 'palliative care' and distinguished 3 groups of children. The 1st group encompasses terminally-ill children (end-of-life care). The 2nd group includes children with life-limiting conditions (neurological, genetic and metabolic disorders). The 3rd – children who are in a risk group (trauma-accidental and non-accidental injuries). It also gave recommendations how to deliver palliative care, to open palliative care units and defined groups of children who need ventilation.

BCH renders services in 11 fields. Our main model of delivering palliative care is Home Palliative Care. There is an in-patient department with 4 beds and some units in hospitals. Today BCH provides care mostly for children with non-oncological conditions (78%) and with oncological conditions (22%). We estimate that there are approximately 1500 children in Belarus who would benefit from palliative care. We want to facilitate the increase of delivering palliative care in our country. Hence, we are building the Children's Palliative Care Center. We also run base palliative care courses for doctors and nurses in Belarus and in other countries. We are in the process of registering 'Association of children's palliative care in Eastern Europe', the core aim of which is to assist post-soviet countries to develop palliative care services.

Children's Palliative care in Ireland

Ling J.
Health Research Board Fellow, School of Nursing and Midwifery, University of Dublin, Trinity College, Dublin, Ireland

In Ireland children's palliative care services have been the subject of several government reports. In 2001 a government report on palliative care services highlighted the need for a review of children's palliative care services in Ireland.1 This was the catalyst for a children's palliative care needs assessment the findings of which were published in 2005.2 In keeping with needs assessments undertaken in other countries, home was recognised as the location of choice for children and their parents with adequate professional support and respite was identified as an essential component of children's palliative care. The report also found that key information on the number, location, diagnostic category and age range of children with life-limiting conditions was not available, however it was estimated that approximately 1400 children were living with a life-limiting condition in Ireland and that there were on average 350 deaths each year from life-limiting conditions in people under the age of 18 years. In 2010, a national palliative care policy for children was published. This report laid the foundations for the development of comprehensive palliative care services for children in Ireland.3 In line with this policy, Ireland's first Consultant in Paediatric Palliative Care was appointed along with a number of key children's palliative care nursing posts. Recently Ireland's first children's Hospice opened. However, despite the publication of these reports, the subsequent appointments and service developments services are not always available to all children with life-limiting conditions and their families and are often dependent on diagnosis and geographical location. This paper will give an overview of how children's palliative care is delivered in Ireland.

References

Organizational model in Italy

Benni F.
Medical Director of the Veneto Regional Center for Pain Management and Palliative Care in children, Padua University Hospital, Padua, Italy

Throughout the different Italian regions Pediatric Palliative Care (PPC) services are at various levels of planning and implementation.

A study of the prevalence of children (0-18) eligible for PPC has shown that, in Italy, there are about 12,000 potential users of PPC services, with a mortality rate of 1100 to 1200 patients per year.
During recent years, much attention has been paid to PPC in Italy both at the legislative and planning level and currently services for children with an incurable illness are being developed.

In 2007, the Ministry of Health together with the Italian Regions approved an agreement which laid the foundations for the implementation of activities and programs at a national level to ensure access to homogeneous PPC services for all children with incurable disease and their families. This gave rise to numerous regional studies that have shown, and are continuing to show, the effectiveness, efficiency and applicability of certain care models, in particular, those based on the organization of a service network. On the 15th of March 2010, legislation (Law 38) was introduced stipulating “measures to ensure access to palliative care and pain management”. This legislation provided indications for innovative interventions in the field of PPC at all levels.

Law 38 establishes the RIGHT of eligible children to access PPC services, programs and settings dedicated to the pediatric age. From an organizational point of view it proposes the organization of PPC networks covering large catchment areas (regional or supra-regional).

The PPC network consists of all structures/services within the healthcare system necessary for the management of children and their families. It integrates and works together with other existing networks (paediatric and non) in the area. At the centre of the PPC network is a central coordinating facility which, through the work of a specialised multidisciplinary team, coordinates and supports the various providers of the PPC network; hospital, primary, social, health and welfare services, by providing continuous expertise and support.

The network must provide, in a combined and continuous manner, both home-care and dedicated residential (children's hospice) solutions that can be accessed during the various stages of the illness according to the needs of each individual patient and their families.

The law allows for the 'contextualization' of the organization of the PPC network in each region (based on specific factors such as population density and/or a particular geographical situation), but provides fixed criteria for the services provided, such as the establishment of a central coordinating facility, the pediatric specificity, continuity of care and the provision of child-specific residential solutions (children's hospice) other than hospital acute care units.

The legislation also set out strategies for the implementation of basic and specialized training in PPC and establishes the need to raise the profile and awareness of PPC in the general public through specific public awareness campaigns.

Furthermore, in 2007, the Ministry of Health, in alliance with the Maruzza Lefebvre D'Ovidio Onlus, launched the “Children Project” whose goal is to create a child-specific, PPC network in each Italian region. This has led to Italy to a boost in attention and the implementation of actions in this area. Currently 7 of 20 regions have decreed the development of a PPC network: a network of integrated hospital and community services that is child-specific and is accessed, managed and supported through a central coordinating facility. In 3 regions the network is active, whilst, in 4, it is under construction.

In the remaining regions the solutions to PPC provision is still in the study and programming phase: there are some examples of in-home hospitalization where children receive continued care at home from a team from the local children's hospital. There are some examples of integration with adult PC services (especially in the case of adolescents) and integration with not-for-profit organizations.

In Italy, there are few child-specific residential structures (Pediatric Hospice) and, in most of the regions, PPC continues to be provided in hospital acute wards.

Therefore, currently in Italy there is a clear reference and model of care established by legislation, but local issues and the varying availability of resources influence the planning and organization nationally. There is still much to be done to provide access to adequate PPC services to all eligible children and their families.

References
1. Legge 15 marzo 2010 N° 38 “Disposizioni per garantire l’accesso alle cure palliative e alla terapia del dolore” www.parlamento.it/parlam/leggi/10038l.htm

**Palliative care for children in Brasov, Romania**

Birrar D.
Paediatrician Hospice Casa Sperantei Brasov, Romania

Hospice “Casa Sperantei” (HCS) Brasov was the first organisation to pioneer specialised PC in Romania. The adult services were started in 1992, and after gaining experience in this area, it’s started PC for children in 1996. We first started as a home care service, with one doc-
Synergy of Church and Government: a Church Activity adopted by the State
Tkachenko A.
Children’s Hospice CEO

Prehistory
On July 1, 2003, the “Children’s Hospice” Charity Fund was established. State health insurance did not pay for any palliative services. Since there were no governmental subsidies, the only way was to raise funds from benefactors. During the first years of work, Hospice care for the children included regular home visits and various outing activities. It was also necessary to organize medical care at home. For this purpose, the Medical Institution “Children’s Hospice” was established in 2006. The City recognized that the paediatric palliative care for seriously ill and dying children was not provided within the national health system. A decision was made to establish an appropriate city institution. In 2010, St. Petersburg Governmental Health Institution “Children’s Hospice” was established. Since Children’s Hospice already had formed a team, then this team was offered to enter into the state institution. Thus, church activities have been recognized and adopted by the City Government.

St. Petersburg Children’s Hospice is an institution of pediatric palliative care for children and adolescents under the age of 18 years, suffering from terminal illnesses in the terminal phase and having a short life expectancy, as well as children who suffer from potentially fatal diseases, whose life span can be many years. Children’s Hospice renders an active and comprehensive care, which includes the physical, psychological, emotional, social and spiritual spheres of aid.

Care Structure
1. Home-Based Care Service
2. Around-the-Clock Care Station
3. Day Care Center
4. Intensive Care Unit

Perspectives
St. Petersburg Children’s Hospice has grown into the national leader of pediatric palliative care. Children’s Hospice is still the only institution of its kind in Russia. Full functionality of this expensive project is a credit to the St. Petersburg Government. Other regions in Russia can not yet afford to finance such projects. Children’s Hospices in Russia will grow. Children’s Hospice has become a model for establishing similar health and social care services in Russia. But because of the lack of governmental support, in the near future they can be developed only on the basis of charity. There will be mostly palliative home-based services.

Palliative care in Spain
Quiroga Cantero E.

Missing abstract.

Current situation of Paediatric Palliative Care in Switzerland
Bergstrøm E.
Centre of Paediatric Palliative Care, University Children’s Hospital, Zurich, Switzerland

Aim. To provide an overview of the current situation of Paediatric Palliative Care (PPC) in Switzerland.

Methods. Analysis of mortality data of children in Switzerland; description of models of care and outlook on research activities in the field of PPC in Switzerland.

Results. Mortality data provide two important issues relevant for models of care and investigations in the field of PPC. From a total of 550-600 deaths among children aged 0-19 years every year, death during
infancy, particularly during the first four weeks of life, represents at least 50%. With respect to disease related death in childhood, children with life-limiting conditions of the nervous system as well as cardiac malformations constitute also numerically a highly important patient group that is comparable to children with incurable cancer diseases. As this has been nicely demonstrated by Feudtner et al., most of these children (4 of 5) have complex care needs and are often in need of medical technology, such as wheel chairs or feeding tubes.

In Switzerland, only two centres of specialised PPC exist so far (Lausanne and Zurich), both are connected to a tertiary care centre. A hospice initiative has been launched in the area of Basel. Despite of this scarce specialised PPC supply, PPC has already a clear position within the governmental national concept for palliative care in Switzerland. 🌐

Outlook. To organise a needs adapted PPC supply, a nationwide retrospective analysis of current practice of EOL care for children in Switzerland, who died in 2010 and 2011 having an oncological, cardiological, or neurological disease or who died during the neonatal period (from birth up to four weeks of life) has been initiated.

References

United Kingdom models of care: a summary
Gelb B.
Together for Short Lives, Bristol, England

There have been considerable developments in UK children’s palliative care services since Helen House, the world’s first children’s hospice was established in Oxford England in 1982. This presentation will address the development of children and young people’s palliative care services over the last 3 decades in the statutory and non government sectors, across all 4 nations within the United Kingdom. This will include Scotland, Wales, Northern Ireland and England following a series of devolution reforms in the UK since 1997.

An overview will be provided of statistics, funding models and a description of the respective government strategies for children’s palliative care in each of the 4 nations. The prevalent health and social care models, and organisation of services at sub-national levels will be described, recognising that the ideal children’s palliative care service should facilitate the drawing together of all players to deliver co-ordinated and individualised packages of care throughout a child’s journey. It will include an outline of the opportunities and challenges faced in ensuring service provision for up to 49,000 children and young people under 19 years in the UK living with a life-limiting or life-threatening condition that may require palliative care services. Reference will also be made to the role played by Together for Short Lives the national voice for children’s palliative care in bringing leadership to the sector.

FAMILIES

Moderators: Richard Hain and Bruno Marino

Grief and bereavement
Guarino A.1, Serantoni G.2
1Department of Dynamic and Clinical Psychology, SAPIENZA–University of Rome, Rome, Italy; 2Department of Psychology, SAPIENZA–University of Rome, Rome, Italy

For parents, losing a child is a deep trauma that requires a cognitive and emotional redefinition–more or less adaptive–of life functions and relationships (Two-Track Model of Bereavement®). The grief of a parent corresponds to distress and suffering related to loss, with individual differences in duration, intensity, expressions2,3,4,5: the natural feelings associated with grief include sadness, anger, helplessness, despair, denial, disbelief, shock and guilt2,3. Experiencing and elaborating the grief is fundamental for regaining emotional well-being and growing innerly2,3,4,5: the group psychotherapy – with its possibility of being therapist to the very members who make it up – is the most widely used therapeutic instrument for helping bereaved parents not to develop complicated grief2,3,4,5.

The psychotherapeutic group for bereaved parents which is held in Lefebvre D’Ovidio Foundation Onlus (Rome) is a psychodynamically oriented group (homogeneous by type of loss and heterogeneous by phase of mourning, with fortnightly two-hour sessions) that includes use of cognitive and interpersonal techniques. As shown by the part of process-outcome (for evaluating the effectiveness of the aforementioned psychotherapeutic groups for bereaved parents®) research’s results concerning the peculiar group processes activated by parents who have lost a child (due to illness or accident), the therapeutic factors detectable in group are: creation of solidarity, overcoming social isolation, mutual support and feedback; exchange and experimentation through vicarious families, increasing of hope, enhancement of reflective function. Particularly, fathers show higher levels of Personal Growth, Working Capacity and Awareness of Interpersonal Impact. Otherwise, mothers show stron-
ger Commitment and Instillation of Hope but, at the same time, feelings of Conflict.

The aim of this paper is presenting part results of the aforementioned research, concerning the changes in the level of symptoms related to the loss and in the outlook on life of 12 bereaved parents joining the group for four sessions held for 5 months (after the death). The group was composed of two women, 4 men; age: μ=57, s.d.=8,78; permanence in group (in month): μ=38,18, s.d.=19,78]. The selected measured variables and administered tests are: Grief (HGRC): Despair, Panic Behaviour, Blame and Anger, Disorganization, Detachment, Personal Growth;

Changes in outlook (CiOQ): Positive Changes in Outlook, Negative Changes in Outlook; Complicated grief (ICG): level of maladaptive symptoms of loss.

The analysis of mean differences point out, inter alia, higher levels of Personal Growth and lower levels of Blame and Anger in fathers and in parents who have a higher permanence in group.

In agreement with the international literature, a medium-high time spent in group seems to: protect, balancing the outlook on life and improving a Positive Changes in Outlook, parents with medium-high risk of complicated grief; allow an important improvement in symptoms of loss in parents with general risk of complicated grief.

References

Perspective and role of families in pediatric palliative care

Jankovic M. Pediatric Clinics, Hemato-Oncology Dept., MBBM Foundation, Hospital S. Gerardo, Monza, Italy

Background. A diagnosis of leukemia in a child is a profoundly challenging event for parents and other family members. While most families adjust well to the demands of an ill child, substantial distress is widely reported initially, especially depression and anxiety. Increasingly complex treatments and extended care of a sick child in the home can compel parents to shift their daily routine resulting in employment changes, difficulty caring for other siblings, and loss of social and personal time. The extended length of cancer treatment means these changes can be enduring and sometimes accompanied by employment instability, shifts in support networks, and financial challenges. Though distress is often reported, parents also exhibit resilience, find new meaning in life, experience appreciation for the help from friends and family for their child's care and support, and note personal benefits of the cancer experience, including increased self-confidence, renewed family closeness, and greater clarity about meaningful elements of their lives. Relatively stable families tend to remain stable during treatment despite its challenges.

Aim. The death of a child is devastating for parents and families. Although bereavement is a highly complex and delicate process affected by social, cultural, religious, and spiritual context, some common themes emerge. It is important to identify practices that are helpful to parents and families who experience this loss. Although an intervention to change the ultimate outcome might not exist, health care providers can have a profound impact on the framing of events for parents and families experiencing such a loss.

Compassionate, informative, and attentive health care staff can have an enormous impact on parents coping with this overwhelming situation.

Methods. Jankovic et al. described their 7-year experience with physicians contacting parents who lost their child secondary to leukemia. Physicians contacted the parents within the first few months after the death. Sixty-four of 72 couples (89%) agreed to a meeting. This study concluded that most parents needed to talk to their physician at least once as many of them still had unanswered questions. In addition, parents benefited from the reassurance that all that could be done for the child was done. This work suggests that the opportunity to speak with the attending staff should be routinely provided to these parents. Similarly, another Group suggested that closing sessions with the attending staff after the death of a child are beneficial, especially for mothers. In addition, closure talks with a psychologist or social worker involved in the child's care were found to provide the best support for mothers over the long term.

Conclusions. The physician cannot always care, but can always care.
References

30TH NOVEMBER 2012
FRIDAY

SYMPTOMS MANAGEMENT
Moderators:
CHANTAL WOOD AND NICOLA PIROZZI

Managing Pain in Children with Serious Diseases: Treatment Strategies in Pediatric Palliative Care
Friedrichsdorf S. J.
Medical Director, Department of Pain Medicine, Palliative Care and Integrative Medicine, Children’s Hospitals and Clinics of Minnesota, USA

The majority of children with serious diseases experience medium to severe pain, which may be disease or treatment- (including procedure/intervention) related somatic, visceral, neuropathic, and/or spiritual pain. Data reveals a significant undertreatment of pain in children with malignant and non-malignant life-threatening diseases in the developed world. However, children and parents expect pain to be relieved and parents’ greatest distress is failing to protect their child from pain. The younger children are, the less likely it is that they receive appropriate analgesia. State-of-the-art pain and symptom management requires that pharmacological management must be combined with integrative, non-pharmacological therapies to manage a child’s pain effectively. Rehabilitative and anesthetic intervention are often in integral part of the multi-modal or “Broad-spectrum analgesia” approach.

Many myths still remain and may be responsible for the inadequate pain management of many children in palliative care. In particular, infants and very young children as well as severely impaired children and teens often do not receive sufficient analgesia, because their discomfort is different from that of adults. It is fallacious to believe that children’s nervous systems are immature and therefore unable to perceive experience pain.

1) Providing a good pain management usually requires a holistic, interdisciplinary approach and the knowledge to apply appropriate analgesics drugs in combination with integrative non-drug therapies.
2) The large majority of children in palliative care would enjoy good to excellent pain management, if the four 2012 WHO principles would always be implemented.
3) Children in moderate–severe acute pain usually need strong pain medication, i.e. morphine or other strong opioids.
4) A dose-limiting side effect occurs in more than 10% of children and likely will require an opioid rotation of equianalgesic dose.
5) The use of codeine is not recommended.
6) Methadone is probably underutilized in pediatric palliative pain management, however it should not be prescribed by those unfamiliar with its use.
7) Evidence supports other routes of opioid application: transmucosal, transdermal, and intranasal opioid applications are well tolerated, effective, and safe.
8) A subgroup of children will benefit from the addition of adjuvant analgesia or invasive, anesthetic approaches.
9) Emerging evidence supports the opioid sparing properties especially of alpha-agonist (e.g. dexametadetamine), but also NMDA-channel blocker (e.g. ketamine) and sodium channel blockers (e.g. lidocaine).

Sleep disturbance and daytime agitation in severe neurological conditions
Zernikow B, Tietze AL, Hechler T, Michel E, Koh M, Schlüter B, Blankenbarg M.
Vodafone Foundation Chair for Children’s Pain Therapy and Paediatric Palliative Care, Witten/Herdecke University, Children’s Hospital Datteln, Datteln, Germany

Introduction. Although sleep disturbances in disabled children are of central clinical importance, there is little research on that topic. There are no data available on frequency, severity or etiology of sleep disturbances and related symptoms in this specific patient group.

Objective. To review the current state of research and outline future research objectives.

Methods. We searched international scientific databases for relevant publications from 1980-2009. From all papers qualifying for further analysis we retrieved systematic information on sample characteristics, sleep assessment tools and their test quality criteria, and core findings.

Results. 61 publications including 4392 patients were categorized as “mixed” (reporting on heterogeneous diagnoses), or “specified” papers (specific diagnoses) based on international classification of diseases (ICD) 10 classification. To assess sleep disturbances, most authors relied on subjective instru-
End of life management

Wolfe J. 1, 2, 3

1 Division Pediatric Palliative Care Service, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, USA; 2 Division of Hematology/Oncology, Department of Medicine, Boston Children’s Hospital, Boston, USA; 3 Harvard Medical School, Boston, USA

Aim. To present results from the Pediatric Quality of Life Evaluation of Symptom Technology (PediQUEST) Study on end of life symptoms in children with cancer and to review care of children at end of life and their families.

Methods. Children 2-18 years old with advanced cancer treated at three large cancer programs from 12/2004-06/2009 completed a computerized survey (PediQUEST) at least once a month and at most once a week, and were randomized either to receive summary reports that were fed back to providers and families or not. Presentation will include a review of patient-reported symptom and quality of life data among children with cancer who died during enrollment on the PediQUEST Study compared to those who survived. Following this, an approach to end-of-life child and family care, including attention to physical, emotional, social and spiritual needs, will be shared.

Results. There was no difference in the types of symptoms experienced by children who died on study compared to those who survived. However, the average number distressing symptoms for patients who died was 4.1(SD 3.4) as compared to 2.61 (SD 2.90), P<0.0001 among those who were alive at end of study. Importantly, when a child is dying, all care goals may not be uniformly focused on easing suffering. Recent studies affirm the common clinical experience that even when a child’s illness is said to be incurable, parents will hope for life-extension concurrent with ensuring comfort.1-3 Family values will differ, while some aspire for a peaceful end of life experience for their child, others value an approached eloquently stated by one father, “The battle with the dragon, or the intent and the need, or the struggle to come to grips with him, or just coexist with him even, threatened to consume our lives, in the sense that the battle against the illness and all the circumstances – logistical and practical, and medical, and financial, and interpersonal…that became all consuming, just like the dragon’s fiery breath…just like his fiery breath is understood to be all consuming, literally obliterating either an individual, or a number of individuals, or a whole village”.4 In other words, a fight to the bitter end. As clinicians, however, it is critical to remember that whatever the primary goal of care, and care setting, it should never be at the exclusion of ensuring comfort.

Conclusions. Children with cancer at end of life experience a myriad of symptoms resulting in significant suffering. Greater attention to holistic care of the entire family is needed.

References:

SPECIFIC NEEDS

Moderators:
MARCELLO ORZALESI AND DOMENICA TARUSCIO

Neonatal palliative care

Simeoni U., Desrobert C.
Department of Neonatology, AP-HM & Aix-Marseille University, Marseille, France

The emergence of palliative care in neonatal medicine is recent. Neonatal palliative care came after several decades of reflection by perinatal health care professionals, which long crystallized upon the debate opposing extensive intervention on the one hand, especially in terms of neonatal intensive care, sometimes hampered by futility, and limitations of care, withholding or withdrawing life support, and sometimes even euthanasia (better defined, for neonates, as active and deliberate ending of life) on the other hand. While the concept of palliative care to newborns is not fundamentally different from what is understood under this terms in other patients, the perinatal context, however, is highly specific.
First, newborn infants are particularly vulnerable patients. They are furthermore absolutely depend-ent beings, in terms of autonomy, in particular in decision making processes. Parents and care providers usually act as their surrogates. Neonates are the most numerous pediatric patients affected by critical disease today in children’s hospitals; still, when such poor vital or functional (neurological) short or long term prognosis is known, they often are not in an end of life situation. Their consciousness is often preserved even in the presence of extremely severe enough brain damage, leading to questioning the sense of pursuing intensive, or even simply curative care. These characteristics are all accentuated in the particular, but frequent situation of preterm birth. Perinatal medicine and neonatal intensive care allow today an increasing number of extremely preterm infants to survive, while important questions are still open about their expected, future quality of life. The symbolic threshold of birth, at which these patients are perceived to be, and the proximity of the fetal condition, which allows completely different medical decisions about life or end of life in many countries, explain that emotions, believes and extreme attitudes, even in opposite directions are widely observed. Subjective feelings by doctors, nurses, parents and the society considerably influence medical decisions.

It is thus not surprising that, when the concept of palliative care reached the neonatal units, neonatal care professionals welcomed it not only thanks to its aims and to the benefits it provides to the patients, but also as a brand new resource which would allow them to avoid or solve the usual dilemma raised in neonatal intensive care units: offering intensive care to save many lives, but also accepting having to accept the cost of survival with major sequels in some cases, despite the already liberal approach of intensive care withdrawing or withholding, which characterized many of the neonatal deaths, in many neonatal intensive care units. Indeed, neonatal brain diseases are characterized by the fact that they, or their comorbidity, frequently induce a need for intensive care in an early phase, but also that, when their prognosis secondarily reveals itself (especially through brain imaging techniques), the patients are not dependent anymore on intensive care, typically on the ventilator. The re-orientation of care towards palliative care allows them to survive with comfort. But they survive in a context where the decision of withdrawing intensive care has been taken because survival was just undesired, due to terrific conditions affecting the future life. This limitation in the understanding of what neonatal palliative care could and could not offer has been understood only later. However, the huge benefits of palliative care programs to the patients, their parents, and to care providers remain today, and are usually considered as one of the major advances in modern neonatal medicine.

Neonatal palliative care has brought even more humanity and benevolence in neonatal care units and helps considerably in many unbearable situations. However, a thorough understanding of the neonatal and perinatal specifics of the dilemmas raised by care to perinates is absolutely needed to limit as far as possible any misunderstandings.

**Rare diseases**

Dallapiccola B.

*Bambino Gesù Children’s Hospital, IRCCS, Rome, Italy*

There are about 7,000 to 8,000 known Rare Diseases, which concern children in about 70% of the cases. According to the European definition, Rare Diseases affect less than 5 per 10,000 people, implying that the number of patients in each disease category is small or very small. As a consequence, these persons are isolated and marginalised within society and within the health system.

Because of rarity and complexity, scientific knowledge on Rare Diseases is scarce and fragmented. Lack of knowledge on pathogenesis makes it difficult the development of diagnostic and therapeutic tools, increasing vulnerability and disadvantage for the Rare Disease patients. Frequently, the diagnosis is delayed and life expectancy are often reduced. Many Rare Diseases are chronic and models for transition from paediatric to adult healthcare services have not been developed.

The success of Rare Diseases management requires a multidisciplinary and coordinated approach, by combining complementary expertise, creating European structures of excellences, and rethinking health and social care within a wider complex system in which patients and families also act as major protagonists.

An additional requirement is a supranational response across Europe and beyond. Centres of Expertise should contribute to make the best use of experts and patients panels at national level, and need to be coordinated at supranational level through European Reference Networks. In addition, it is essential to optimise resources, including registries, databases, diagnostic laboratories, and pharmacovigilance systems.

Differently from basic and fundamental research, clinical and translational researches in Rare Diseases are jeopardized by the perceived lack of their attractiveness. The major bottlenecks to the development of new therapies include little knowledge about the causes, pathogenesis, and natural history of diseases; scarce availability of animal models, which make it difficult to perform preclinical studies; lack of validated markers for monitoring diseases’ progression and response to therapy; limited investments of pharmaceutical companies in this area; need to develop multinational clinical trials; low return of investment due to very small markets; short-term limited funding availability and the need for public health funds to bridge the gap in Rare Disease research; historical hiatus between the research world and industry sector in Europe.

The cost of non-investment in research must also be considered. Diagnostic delays and errors in Rare
Diseases are costly, procrastinate access to accurate treatments, and waste resources for healthcare and social systems. Improvement of diagnosis and understanding of Rare Diseases reduce the costs for healthcare systems. A properly treated Rare Disease patient stops to be a consumer of inappropriate and irrelevant tests, or ineffective treatments or superfluous hospital admissions. Thus, unawareness can be more expensive than research aimed at improving knowledge.

A better knowledge of Rare Diseases also improves the understanding of mechanisms of common disorders. In fact, technologies for the treatment of Rare Diseases can be used for developing treatments for more frequent conditions. Rare Diseases are also at the forefront of personalised medicine, basically by applying the individual genetic information to tailor treatment and medical care to individual needs. Centres of Expertise are expected to bring to patients high value innovations, and to optimise medical solutions. Their multidisciplinary expertise, merged into the European Reference Networks, will pursue new research avenues, develop social care guidelines and improve standards for diagnosis and care. This new public health model could be a prototype for innovative approaches to more common diseases. Thus, the emerging Rare Disease health care model could pioneer new optimised use of existing healthcare resources to the benefit of all citizens. However, since many Rare Diseases will not benefit from any medical treatment for many years, it is important also to invest in social care and research. This strategy is horizontal since it will advantage all individuals affected by Rare Diseases and also generate valuable data for assessing the added value of treatments for Rare Diseases and launching clinical trials. Research in social care of Rare Diseases may open innovative avenues which benefit society at large. Although the development of social response targeted to the specific needs of Rare Disease patients and families is likely to have an initial higher cost, in the long term it will improve the patients’ conditions, which in turn reduce the hospitalisation costs and potential non-effective therapies and treatments.

**UNIAMO FIMR ONLUS - Eurodis**

Missing abstract.

**Neonatal screening in the Tuscany region**

La Marca G.

*Dipartimento di Farmacologia Clinica e Preclinica, Università degli Studi di Firenze, UO Diagnostica Malattie Sistema Nervoso e del Metabolismo, Clinica di Neurologia Pediatria, AOU A. Meyer, Firenze*

Aim. The use of mass spectrometry in clinical laboratories is very much increased on the outset of the 21th century. This development is obviously due to great advances in mass spectrometry applications in the last fifteen years. Mass spectrometry permits a very rapid measurement of different metabolites in different biological specimens using filter paper spots or directly in different biological fluids. Because of its high sensitivity, this technique can be used for qualitative and quantitative analysis of many analytes such as amino acids and acylcarnitines, homocysteine, orotic acid, purines and pyrimidines etc., with appropriate internal standards. Amino acids and acylcarnitines profiles allow the identification of inborn errors of metabolism such as organic acidurias, fatty acid β-oxidation defects and amino acids diseases. This is a report of the Tuscany Region 11 years experience as paediatric clinical laboratory especially in newborn screening by tandem mass spectrometry.

**Methods.** See references 1, 2 and 3

**Results.** During the period of activity (October 2001-September 2012), we screened about 370,000 newborns. We have identified among aminoacid/protein metabolism defects 65 patients with hyperphenylalaninaemia (15 PKU), 64 organic acidurias, 26 β-Oxidation Fatty Acid Defects, 9 Urea Cycle Defects, other defects 8 and 21 Biotinidase Deficiencies.

Out of the 34000 infants born annually in Tuscany and about 9000 in Umbria, the expanded newborn screening program diagnoses one metabolic disorder for roughly every 1800 births. One of the major problems in an expanded newborn screening program is the high rate of false-positive. False positive results are costly for Public Health Resources and causes unnecessary parental stress. We report an update on the latest developments in the expanded newborn screening programs.

Propionylcarnitine is one of the analytes most frequently responsible for false-positive results. We developed a rapid LC-MS/MS method that identifies free methylmalonic and 3-OH propionic acids in blood spots thus reducing false-positive rates due to C3 during expanded newborn screening programs. Analytical method consists of chromatographic separation on a C6-Phenyl column of an extracted 3.2 mm dried blood spot and injection into triple quadrupole mass spectrometer equipped with a Turbo Ion Spray Ionization Source. No derivatization is required and total analysis time is 5 minutes per sample. The application of this method as second tier test allows leading the positive predictive value to 100% for C3 recalls.

On the other hand, many false-negative cases of Tyrosinemia type I have been reported by several newborn screening laboratories. In some cases, newborns with tyrosinemia type I shows tyrosine levels lower than cut off. We describe a method for inclusion, in expanded newborn screening programs, of succinylacetone, the specific marker of Tyrosinemia type I in order to avoid false negatives. Traditional screening method was modified by adding dioxyoc-tanoid acid as an internal standard to the methanolic
solution of deuterated acylcarnitines and amino acids. A hydrazine solution was added to the mixture. The times of extraction, butylation and drying were only slightly prolonged. Specific Multiple Reaction Monitoring for derivatized dioxo-octanoic acid was carried out.

Conclusions. New and better strategies should be developed to provide additional testing on initial specimen that, applied to NBS programs, minimize the number of false positives while reducing the risk of missing an affected newborn. Moreover new strategies will be applied to extend newborn screening panel to additional diseases such as lysosomal storage disorders (LSDs) and SCID (Severe Combined Immunodeficiency).

References

Providing access to knowledge and training in rare diseases
Parker S.
External Affairs and Rare Disease Partnerships, Orphan Europe, Paris, France

Aim. Orphan Europe Recordati group has set up an academy for training healthcare professionals in the area of rare disease. Rare diseases (RD) affect approximately 30 million Europeans (one in 17 people). The 6000-7000 rare diseases span all areas of medicine, collectively resulting in a major public health, economic and societal impact. Most rare diseases are severely debilitating, chronic and affect children (30% of children with a RD die before the age of 5 years). The rarity of patients and the high phenotypic heterogeneity of RD, combined with the lack of knowledge, information and training about these diseases result in frequent delays in correct diagnosis and installation of appropriate care and treatment. This impacts survival and quality of life. RD are a priority area for action in the EU Public and research health Programmes. The overall intended impact of the academy is to improve access to rapid diagnosis and care for patients and families affected by rare disease.

Methods. Orphan Europe Academy provides unconditional grants for the development of tailored solutions in training and educational activities for healthcare professionals involved in the diagnosis and management of patients affected by rare diseases. The Academy is governed by a programme committee composed of scientific experts who have responsibility for the overall strategy, proposing new courses and appointing a scientific course programme committee to develop specific courses. All courses apply for EACCE European CME accreditation points. Academy programme committee:
— Prof. Bruno Dallapiccola, Bambino Gesù Children's Hospital, Rome Italy
— Prof. Georg F. Hoffmann, University Children's Hospital for Childhood and adolescent Medicine, Heidelberg, Germany
— Prof. Jean-Marie Saudubray, Pitié-Salpêtrière Hospital, Paris, France
— Dr. Frederic Sedel, Pitié-Salpêtrière Hospital, Paris, France
— Prof. Jan A.M. Smeitink, Radboud University Nijmegen Medical Center, Nijmegen, the Netherlands
— Dr. John Walter, Willink Biochemical Genetics Unit, Manchester, UK

Courses are restricted to a maximum of 30 – 50 participants plus faculty. Courses include lectures, practical based learning, laboratory training and case reports. Training courses last from two to five days.

Results. Nearly fifty courses have been organised over the last 12 years and the Academy has gained a reputation for its high-quality, innovative science education. The academy has partnered with different public health and research networks including the European network and registry for intoxication type metabolic disorders www.e-imd.org

We have developed e-learning modules to provide physicians world-wide with clinically useful and most up-to-date information concerning the current knowledge and management strategies.

Conclusions. There is high variability and inequality in accessing training between centres and countries. Biochemical and molecular investigations grow in complexity and it is increasingly important not to miss a treatable disorder. As a result there is an urgent need for training and education in rare diseases. The Orphan Europe Academy Recordati Group has made significant progress in educating healthcare professionals in rare disease.
The World Health Organization’s (WHO) definition of Palliative Care for Children entails not only active total care of the child's body, mind and spirit but also support to the child’s family. Support requires communication which is important in all types of health care and probably even more so in the transition from curative to palliative care. Delivering bad news is a complex task, mostly assigned to physicians. Not knowing the right thing to say has been reported a barrier for advanced care discussions in children with life-threatening conditions.1 Not only what is said matters, how it is said impacts the likelihood for parents to grasp the devastating information that their child has no realistic chance for cure.2 To whom such information should be given is not always obvious; to the parents only, and or the ill child together with all family members. In a Swedish study of parents whose child had died from cancer it was found that it was more common that the child was present when information about diagnosis was given than that about the transition to palliative care.2 It is unclear to what extent this practice reflects the child’s choice or that made by others. International guidelines emphasize openness of information to children and family members.3 Not to be forgotten are the siblings, often referred to as “the invisible”. Most decisions concerning the seriously ill child’s care are based on information given by health care professionals. However, neither the seriously ill child nor its family members may be able to understand the information, or to clearly express themselves verbally. This makes communication in Pediatric Palliative Care even more challenging.

Support requires communication which is important in all types of health care and probably even more so in the transition from curative to palliative care. Delivering bad news is a complex task, mostly assigned to physicians. Not knowing the right thing to say has been reported a barrier for advanced care discussions in children with life-threatening conditions.1 Not only what is said matters, how it is said impacts the likelihood for parents to grasp the devastating information that their child has no realistic chance for cure.2 To whom such information should be given is not always obvious; to the parents only, and or the ill child together with all family members. In a Swedish study of parents whose child had died from cancer it was found that it was more common that the child was present when information about diagnosis was given than that about the transition to palliative care.2 It is unclear to what extent this practice reflects the child’s choice or that made by others. International guidelines emphasize openness of information to children and family members.3 Not to be forgotten are the siblings, often referred to as “the invisible”. Most decisions concerning the seriously ill child’s care are based on information given by health care professionals. However, neither the seriously ill child nor its family members may be able to understand the information, or to clearly express themselves verbally. This makes communication in Pediatric Palliative Care even more challenging.

Is not well described what type of support that should be given to family members according to WHO. It could be psychological, emotional, social, financial etc. What type, how often and to whom should such support be expected from health care professionals? A family of a seriously ill child may vary from a single parent to a large family including siblings, grandparents and other relatives. Moreover, Palliative Care for Children can be provided at many different locations ranging from specialized facilities such as pediatric hospices to the child’s home depending on resources available, quality of care needed and family preferences. Obviously, this may also impact the range of options of support for family members. Yet, it remains unclear what type of support and to what extent it impacts the well-being of family members in the short and long-term.

In our study of parents several years following the loss of their child, we found that those who had had someone to share their problems and worries with during the child’s illness had resolved their grief to a greater extent than others. The same was true for parents who had access to psychological support during the last month of their child’s life and following the loss. However, not only professional support mattered, social support by a partner, friend or family member also facilitated the grieving process for the bereaved parents in our study.4 This may be true also for siblings. Recent preliminary data of bereaved siblings who lost their brother or sister to cancer suggests that their access to social support during before and after the loss improved their long-term well-being.

Further research should address the significance of communication and support for the seriously ill child and his or her family based on interventionist studies.

References

Support for the team: the challenge of transforming suffering into resilience

Papadatou D.
Faculty of Nursing, University of Athens, Athens, Greece. “Merimna” – Society for the care of Children and Families in the Face of Illness and Death, Athens, Greece.

Background. The provision of palliative care to children with life-threatening illness and to their families, evokes in professionals a suffering that is often disenfranchised. Some aspects of this suffering – usually associated to burnout, compassion fatigue, or vicarious traumatization- affect the well-being of professionals and lead to impairment. Other aspects, however, reflect a suffering that is adaptive unavoidable and integral to the care of children who die which is often reflected in manifestations of compassion stress, existential distress, and/or grieving. Understanding how professionals affect and are being affected by their relationships with children and families, has received limited attention in pediatric palliative care. The family-centered approach adopted in this field focuses almost exclusively on the...
physical, psychosocial and spiritual needs of patients and families, thus, restricting our view of what actually unfolds in caregiving relationships and how these are affected by the psychology of care providers and teams.

**Aim.** The purpose this presentation is threefold: first, it aims to propose a relationship-centered approach (or relational approach) to the care of seriously ill children and families, which highlights the reciprocal influence among those receiving and those providing care. This approach focuses on the subjective worlds of the sick child and family members, as well as on the subjective world of care providers whose responses are illuminated in the context of the team they belong to, and the organization they represent.\(^1\)

Second, it aims to describe how teams control the anxiety and regulate the suffering of their members by defining explicit or implicit rules that dictate how professionals are expected to feel, think, and cope with their suffering. Teams that acknowledge professionals’ distress, grief, and suffering, adopt rules that promote mutual support, develop rituals that facilitate sharing among colleagues, and provide supervision that enables professionals to explore their experiences. By contrast, teams that adopt rules which forbid the display of suffering, expect professionals to be strong, to suppress their suffering, and get ‘used to’ childhood dying or death, and parental bereavement. Not infrequently such teams resort to dysfunctional coping patterns in their striving to avoid rather than confront the anxiety and suffering of their staff members. Dysfunctional patterns may comprise the systematic fragmentation of care to avoid intimate relationships, the idealization of care that prevents any review of the team’s mode of operation out of fear it may uncover collective vulnerabilities and traumas, the pervasive display of aggressive patterns against patients who are forgotten, depersonalized or treated as clinical cases or room numbers, a striving to displace suffering through the scapegoating of a ‘difficult’ child, an ‘ungrateful’ family, an ‘insensitive’ colleague, or through splits and the formation of cliques among team members, etc. Common to all dysfunctional pattern is a reciprocal influence which highlights our responsibility towards self-care and team-care.

Finally, the presentation aims to discuss the significance of cultivating a culture of care which is based on the belief that the extent to which professionals are emotionally held by their team and organization, affects their ability to hold patients and families in similar ways. In such a culture, staff support becomes a shared responsibility, among staff members, team and organizational leaders. Support measures are not imposed, but co-designed in order to meet individual and team needs. Rather than being limited to stress management courses, staff rotations for burnt-out professionals, and referrals to an Assistance Employee Program, these measures are carefully identified, implemented, and evaluated.

**Conclusions.** Suffering as well as resilience stem from relationships. To define them in relational terms broadens our view on the process of caregiving, and highlights our responsibility towards self-care and team care.

**References**


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**Research in Paediatric Palliative Care: Considerations in Theory, Method and Implementation**

Blucbond-Langner M.

*Louis Dundas Centre for Children’s Palliative Care, University College London- Institute of Child Health, London, England*

We have come a long way in both our conceptualization and practice of paediatric palliative care from care at the end-of-life, care of the dying child to a new view and approach that calls for comprehensive, holistic care for children with life-threatening illnesses and life-limiting conditions over the entire course of the illness and in the case of surviving parents and siblings on through bereavement (ACT 2009). This perspective makes sense for several reasons, including: (1) the ever increasing life expectancy for children with life threatening and life limiting illnesses, (2) variability of trajectories where often the most aggressive disease directed therapy (e.g. heart-lung transplant) may come at the end (3) continuing advances in medical knowledge, technology, care and treatment (4) growth in both the number and kinds of institutions providing palliative care services (e.g. hospices, hospital based palliative care services, community teams) (5) needs and desires of children and families.

The development of the field of paediatric palliative care has however outpaced research [the development of the evidence base for practice], as well as the capacity of the current workforce to carry on both the research and clinical work necessary to deliver the highest standard of care for children with life limiting illness and their families.

In this presentation I consider what we need to do address this situation. Attention is given to the areas of research most in need of development including:
better understanding of children and families experience of the illness, decision making regarding care and treatment, pain and symptom management and service delivery as well as the theoretical and methodological frameworks best suited to drive the work forward. I take the position that our research needs to be informed by a theoretical perspective that recognizes the social nature of the illness experience and individuals responses to it. The impact of the illness needs to be grasped and approached in study as well as in practice in terms of a history which is both cyclic and progressive. Neither the impact of the illness on the family, nor the impact on any single individual can be captured in a few behavioural traits or measured by a few psychological or social scales. From this perspective comes a call for a closer examination of the theories which underlie our research and the methods that we use for study as well as for the design and evaluation of interventions and the formulation of practice guidance. This presentation draws on a number of prospective ethnographic research studies conducted over the last 40 years with children with life limiting illnesses, their parents and well siblings as well as mixed-method processual evaluation projects in paediatric palliative care with health care professionals and systematic reviews of the literature on place of care and place of death in children and young people with life threatening illnesses and life-limiting illnesses and recruitment to studies in paediatric palliative care.

References

Architecture and Design and for the Paediatric Hospice
Ferrante T.
DATE (Design Technology Architecture, Land and Environment) Department, “Sapienza” University of Rome, Italy

Aim. In Italy, the approval of Law No. of 15 March 2010 and the agreement signed this year between the State, Regions and Autonomous Provinces will finally allow for the establishment of a network of Paediatric Palliative Care where the paediatric hospice has an important role. The paediatric hospice envisages the merging of a collection highly complex healthcare activities that represent an alternative to the home when managing the disease becomes too burdensome. The paediatric hospice can provide the necessary health, psychological, social and spiritual support to the patient and his/her family for brief periods of time. The objective of the study is to identify the main features of innovation in the field of paediatric hospice architecture, with the aim of proposing more appropriate criteria and planning tools.

Methods. Some paediatric hospices operating abroad and in Italy at least for the past fifteen years have been selected from international literature as a sample for this study. Research has made use of questionnaires addressed to non-profit organizations and associations working in the sector, in addition to interviews with experts, meetings with designers and visits to the facilities.

Results. The study has developed a set of guidelines relevant to programming and design (texts, tables, layouts, exemplifying images) illustrated in the book entitled “Architecture and Design for the Paediatric Hospice” currently being published.

Conclusions. All the contexts taken into consideration have indicated that the paediatric hospice (through qualified architecture and design of its indoor and outdoor spaces) takes on an important supporting role. This supporting function is addressed to the patient and his/her family, collaborating with them in a significant manner towards a “better quality of life”.

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Impact of the end-of-life period and the death of a child on siblings

von Lützau P., Otto M., Zernikow B.
Paediatric Palliative Care Center and German Paediatric Pain Center, Children's and Adolescent's Hospital Datteln, Witten/Herdecke University, Datteln, Germany

Background and aims. Each year, about 500 children die due to a cancer disease in Germany. Siblings of these children suffer due to the death of their brother/sister. The aim of this study was to determine the effect of the end-of-life period and death of the child on the wellbeing of the siblings.

Methods. This analysis is part of the study “Retrospective parental interviews regarding paediatric care quality and psychosocial aspects in children and adolescents with cancer in the end-of-life period- A Follow-up Study”. 48 parents of children who died of cancer in 2005/2006 treated in one of 16 departments for paediatric oncology in North Rhine-Westphalia, Germany, have been interviewed. For this analysis, 35 interviews with parents whose ill child had siblings were included. Besides descriptive analysis Fisher’s exact test was used for statistical comparisons. A p-value of ≤0.05 was considered significant.

Results. This study referred to 52 siblings (mean age 13.4 years; 60% female). According to their parents, in 21 families the siblings were involved in the end-of-life care of the ill child, independent of their age (Fishers exact test p=0.4). In 48% of the families the siblings did not receive any support during the end-of-life period of the ill child. In case siblings got support, they have often been supported by their own family. In 22 families, changes in siblings were observed. Most often changes in social behaviour (55%) and educational difficulties (50%) occurred. In 11 families at least one of the siblings received professional support or psychotherapy. A severe illness and death of a child have a great impact on the siblings' current life and possibly also on their future. Results point out that not only the ill child but also the whole family including siblings need professional support during the period of illness and especially during the end-of-life period. The study has been supported by the German Children’s Cancer Fund.

Conclusions. In health care encounters knowingness in mothers and unknowingness in others raises difficulties that impact on the child, mother and family in both the short and long term that warrant attention in planning effective care services.
16 Hospital discharge: parents’ experience with a child with a neurological life-limiting condition in Ireland
McEnerney N.
The Children’s Sunshine Home, Dublin, Ireland

Background and aims. Discharge from hospital with a child with a neurological life-limiting condition can present daunting challenges for parents. Their child may be technology-dependent and require continuous monitoring and care. The aim of this study was to explore parents’ experiences of discharge from hospital in Ireland. The objectives of the study were to identify and describe these experiences and to develop an understanding of the issues involved.

Methods. A qualitative methodology was adopted using in-depth, semi-structured interviews with purposeful sampling to identify suitable parents. Meleis’ transition framework provided theoretical structure and underpinned the interview guide. Following a literature review, Morse & Fields (1996) data analysis framework based on comprehension, synthesis, theorizing and recontextualising was employed to analyze the data. A constant comparison method was used where data was systematically compared within and between parents.

Results. The findings revealed three main themes, the range of emotional responses experienced, communication with healthcare professionals, lack of appropriate community services and the alternating roles of parents when coping during this period. While the findings mirror international experiences, the issue of poor communication was repeatedly emphasised by parents throughout the study as being inadequate.

Conclusions. The findings highlight the need for review of present discharge procedures, the development of effective discharge planning and enhanced community services. Increased awareness of poor communication practices, for all healthcare professionals, also requires addressing through education and mentoring. The findings of this study highlight the areas that require improvement if the goal of a seamless service is to be reached for this vulnerable group.

76 Familial perspectives on end of life conversations on the special care baby unit
Jones K.S., Families
Peninsula College of Medicine and Dentistry, University of Exeter, Peninsula National Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC), Exeter, United Kingdom

Background. The admission of an infant to the neonatal intensive care unit represents for many parents, an unexpected and challenging event, particularly following birth. Neo natal nurses are often involved with patient’s families during difficult times when death is anticipated due to the clinical condition of the baby and withdrawal of artificial ventilation at the end of life. For many parents communication and the support that nurses and clinicians provide, can mediate parental responses to their infant’s death. There is an opportunity to forge a relationship of trust necessary to provide optimal care for patients and parents. A vital aspect of this care is the recognition of the significance of the death of the infant.

Aims. This research raises important issues around the lived experiences of parents on the neonatal unit, particularly at the end of an infant’s life.

Methods. This is a qualitative collective case study sample of 30 parents who were recruited from the southwest and north of England. Parents were at least 18 years of age, English speaking and had experienced the death of their baby more than 12 months prior. A voice centred relational method was employed to analyse data from 30 semi structured interviews and six focus group discussions with parents as framed by Brown and Gilligan (1993) at Harvard University.

Results. Parents identified several domains which were deemed to be highly salient and influential to the care received prior to and around the time of the death of the infant. These included relationship building, demonstration of effort and competence, information exchange and level of parental involvement.

Conclusions. This research suggests that the care received by parents during the hospitalisation of their child and around the time of their death can have a profound impact upon their experience of care.

Funding. This research was funded by the University of Bristol, UK.

113 Families’ views on children’s hospice support during childhood, transition and beyond
Kirk S., Fraser C.
University of Manchester, School of Nursing, Midwifery and Social Work, Manchester, United Kingdom

Background and aims. Although hospices are an important component of children’s palliative care provision little research has examined how families experience the support they provide or how they should respond to the increasing life expectancy of young people requiring palliative care. Service transition in relation to children/young people with life-limiting conditions and the support of young adults has been under-researched. Study aims were to identify how parents (bereaved/non-bereaved) and young people perceived their need for hospice support during childhood, adolescence and young adulthood and identify how support could be improved.

Methods. The presentation will report the findings from two UK studies. In one study a mixed-method approach was used (postal survey and in-depth qual-
Cancer is the leading non-feelings, fears, anger, self-image, identity, my family, right to speak. Sessions have structured themes, e.g. Children sit or lie in a circle and respect each other’s therapeutic, educational and provide peer support.

Methods. Families were highly satisfied with hospice support in terms of quality of care, interpersonal relationships, family-focused approach, hospice environment and decision-making involvement. For young people social opportunities and peer support were important. For parents the most important aspect of hospice support was the provision of a break from caring. During transition to adult health/social care services the hospice provided stability and continuity for families. However, there was uncertainty amongst parents of young adults about their access to hospice support. In addition some parents found it difficult to encourage their child’s independence.

Conclusions. Families value the family-focused support that hospices provide. However, how this is re-conceptualised in response to an increasingly older population of users needs consideration in order to support young adults, parents and siblings appropriately.

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Conclusions. Families value the family-focused support that hospices provide. However, how this is re-conceptualised in response to an increasingly older population of users needs consideration in order to support young adults, parents and siblings appropriately.

49 Development of integrated, holistic pediatric palliative care in Serbia: creation of psychosocial support groups (PSG)
Klikovac T.1, Steinhorn D.M.2
1Institute for Oncology and Radiology of Serbia, Faculty of Philosophy, Department for Psychology, Belgrade, Serbia, 2Northwestern University Feinberg School of Medicine, Pediatrics, Chicago, IL, United States

Background. Pediatric medical care in Serbia is traditional and biologically-focused without adequate resources for multidisciplinary care of the dying child and his family. Children often die at home without relief of suffering or in ICUs with parents excluded from the bedside by ICU policy. Psychosocial/spiritual aspects of suffering are not understood by most healthcare providers. Isolation and desperation are common in families of children with fatal conditions.

Aim. To develop psychosocial support groups (PSG) for children with incurable disease and their family.

Methods. We developed patient and family support groups for inpatients (5-10 yrs & 11-17 yrs) at the National Institute for Oncology. The PSGs are psycho-therapeutic, educational and provide peer support. Children sit or lie in a circle and respect each other’s right to speak. Sessions have structured themes, e.g. feelings, fears, anger, self-image, identity, my family, my pets, my favorite things, good and bad experiences, death/dying and debriefing when a child dies in hospital. Verbal and non-verbal (drawing, mime) methods are used as appropriate.

Results. PSGs stimulate pleasant feelings and positive thinking, alleviate stressful and traumatic experiences, contribute to a pleasant atmosphere on the ward, stimulate exchange and communication between children, influence development of creative thinking, provide diversion and relaxation, enhance social competence, self-image, identity and information seeking. Parental PSGs enhance parental processing of fears, anxieties and facilitate expression of feelings as well as debriefing when children die.

Conclusions. PSGs facilitate free expression of thoughts and recognition of feelings, encourage group cohesion, social identity and community spirit, provide opportunities to help others and learn to solve conflict peacefully. They help children to accept and cope with traumatic experiences of cancer and treatment. Parental PSGs enhance emotional processing.

64 Palliative care and death in children with cancer. Experience of a local program
Portuguese Institute of Oncology - Lisbon, Pediatrics, Lisboa, Portugal

Background and aim. Cancer is the leading non-accidental cause of death in paediatrics. In adults it is known that home is the preferred place of care and death, achieved by a minority in southern Europe. We planned to evaluate place of death of our patients and impact of enrolment on our palliative care (PC) program. The Department (Dept) treats about 150 children 0-16yo yearly, living in the south of Portugal, Azores and Madeira, as well as children from African Portuguese speaking countries (PALOP).

Methods. Retrospective review of the charts of children that died in the past 5 years (2007-11), identified through search of our database.

Results. 160 children died (56% male), at a median age of 9.2y (0-24y). Diagnosis: 45% solid tumors (ST), 31% CNS, 24% hematologic (H), 17% had a toxic death and are excluded from further analysis. 133 died of disease progression (DP) in the Dept (56%), in other hospitals (24%), at home (19%) and unknown (1%). In the Dept they were admitted an average of 12.3 (0-75) days (d) before death; for those enrolled in the PC program the average was 6.4d (0-24) and for the others 15.6d (0-75). Enrolment in the program increased the odds of dying at home 2.1x (31.9 vs 8.5%). 22% of H, 20% of ST and 16% of CNS patients died at home. Psychological support was 1.6 times more likely to be given to children and families enrolled in the PC program, especially when it concerned the mother (90 vs 58%), most times the main caregiver. Children from PALOP were more likely to
die of DP (90%) and in hospital (85%), for lack of social and economical support.

Conclusions. Enrolment in our PC program (detailed holistic plan involving the community) doubled the chance of dying at home and extended home-based care, significantly decreasing the length of admission to our Dept before death. Other children were cared for and died closer to home and family, in their local hospital.

73 Palliative care in children with spinal muscular atrophy

García-Salido A. 1, Montelón-Luque M. 2, Del Rincón-Fernández C. 2, García-De Paso M. 2, Martino-Alba R. 2

1Hospital Infantil Universitario Niño Jesús, Pediatric Palliative Care, Pediatric Intensive Care, Madrid, Spain, 2Hospital Infantil Universitario Niño Jesús, Pediatric Palliative Care, Madrid, Spain

Background. Spinal muscular atrophy (SMA) is the most common childhood neurodegenerative disease. It is necessary a pediatric palliative focus in the care of the children with SMA. There are no reviews about this topic.

Objective. To describe the clinical and demographic profile of children with SMA referred to a pediatric palliative care team (PPCT) in Madrid, Spain.

Methods. Retrospective chart review of eight consecutive patients affected by SMA (2010-2012).

Results. Five males and three women were admitted to PPCT before 6 months of life; median time of attention of 75 days (range 1-150); the patient attended only one day was managed in the hospital. The rest of them received domiciliary attention constituted principally by respiratory care (oxygentherapy by nasal cannulas, airway suction and nebulizer equipments). One required domiciliary mechanical ventilation by tracheotomy (SMA with respiratory distress); this patient was the only who needed bladder catheterization. In all cases a nasogastric tube (NT) was indicated because of swallowing difficulties. As end-of-life care 7 of them required morphine to manage the dyspnea; 3 patients of swallowing difficulties. As end-of-life care 7 of them required morphine to manage the dyspnea; 3 patients required CSI also received benzodiazepines. It was not necessary to acquire intravenous line in any patient. All the patients died at home except the one attended in the hospital. Palliative care team was positioned at the moment of death in 50% of cases. While they were attended by the PPCT none of the patients required hospital admission.

Conclusions.

— Domiciliary attention of patients with SMA is possible even receiving invasive ventilation.

— Nutrition and hydration of these patients could be achieved by nasogastric tube.

— Oral or subcutaneal morphine is useful to manage the dyspnea.

— Palliative sedation by benzodiazepines is not always necessary.

130 Paediatric palliative care as a transmurale liaison model: experience of 10 years of paediatric palliative care for “all” children

Renard M., Ruysseveldt I., Van den Eynde G.

University Hospitals Leuven, Paediatric Palliative Home Care Team, Leuven, Belgium

Background. Twenty years ago, a PPC program was started on the paediatric hemato-oncology department in the university hospital Leuven. Fundaments of the project were holistic care for patient and family, as described by the WHO, emphasis on symptom and pain control, 24 hour availability to support families and primary care takers, organise care at home. After 10 years of PPC in paediatric hemato-oncological patients, the program was extended to “all” children, meaning that children with complex chronic and life limiting conditions could benefit from the offered care. An import element in the philosophy of the project is that the primary treating paediatric specialist maintains the responsibility for the child. This should overcome one of the barriers to transfer children to palliative care.

Methods. 3 FTE nurses, 1 FTE coordinator, 0.50 FTE secretary and a 0.50 FTE paediatrician form a team to offer this care in close collaboration with the referring multidisciplinary team.

Results. Between 2002 and 2011 442 patients were enrolled, 185 patients died (median 18/ year), 128 at home, 45 in hospital and 13 elsewhere. Children were referred from different disciplines: hemato-oncology (148), neonatology (15), neurology (146), cardiology (32), nephrology (2), gastroenterology (3), hematology (7), pneumology (32), metabolic diseases (55) and other disciplines (2). The type of care is laborious and promoting communication between different care takers is the main goal e.g. 2597 visits at home were undertaken, 8335 contacts by telephone to advise parents, 941 telephone contacts to general practitioners, and 1680 to home care nurses. Furthermore, there was communication with pharmacists, physiotherapists etc.

Conclusions. To build integrating PPC service is challenging. Starting from a palliative care team in the paediatric hemato-oncological setting we were able to expand this kind of care to children with complex chronic and live limiting diseases.

160 Improving palliative care in children and adolescents by a multi professional, trans-institutional service - Concept and implementation of the Munich coordination centre for pediatric palliative care

Führer M. 1, Durox A. 1, Grassler M. 1, Klein B. 3, Nicklóay C. 1, Elbauer C. 1, Rümmelein N. 1, Beger E. 3, Kinast K. 1, Stiehl T. 3, Kyber C. 1, Schmittgen S. 1, Borasio G. D. 1

1Dr. von Haunersches Kinderspital, Ludwig-Maximilians-University Munich, Coordination center for Pediatric Palliative Care, Munich, Germany, 2Centre Hospitalier Universitaire Vaudois, Service de Soins Palliatifs, Lausanne, Switzerland
Background. In Bavaria every year about 600 children and adolescents die from life-limiting diseases. Although most of them wish to spend as much time as possible together with their families at home, still the majority dies in hospital. The Munich Coordination Centre for Pediatric Palliative Care (CPPC) was founded 2004 to improve inpatient palliative care and to establish a specialized pediatric outpatient palliative care service to support families at home.

Project description and methods. The multiprofessional CPPC team is working in the following main areas: Physician and team counselling in end-of-life decisions and palliative symptom management, coordination and provision of palliative care at home, patient/parent and home-team counselling, education and teaching in pediatric palliative care (PPC) for all professions involved. The characteristics and outcomes in patients of the CPPC were analysed retrospectively.

Results. Between 3/04 and 5/12 the CPPC took care for a total of 294 patients with a median age of 4.5 y (range 5 d - 43y), 179 pts. died so far. In 11 families prenatal palliative care was provided. Most children suffered from congenital malformations or chromosomal abnormalities (26%), neurological diseases (23%), neoplasms (22%) or inborn errors of metabolism (18%). In the majority of pts (72%) the CPPC team was recommended by pediatric specialists in the hospital. The leading symptoms were pain and dyspnoea. Of all children cared for at home by the CPPCs can improve the quality of pediatric palliative care, optimize the utilisation of existing resources and enhance the dissemination of knowledge. Management of advanced pediatric illness is challenging and requires teamwork and coordination between different disciplines and organizations. The aim of our work was to improve home care assistance into a paediatric palliative care program and home assistance in Pordenone (North-East Italy)

De Zen L1, Gerarduzzi T1, Minotto M1, Bagolin A1, Casini M1, Chittaro M1, Mascarin M1, Benini F2, Dall’Amico R1

1Azienda Ospedaliera S. Maria degli Angeli, Pediatric, Pordenone, Italy, 2ASS 6 Friuli Occidentale, Direzione Sanitaria, Pordenone, Italy, 3IRCSS CRO, Area Giovani, Aviano, Italy, 4University of Padova, PPC Regional Service, Padova, Italy

Background and aims. Home care assistance, particularly for children affected by cancer, is rarely practiced in our Country, even if international literature underlined undoubted advantages for child, family and social system. The aim of our work was to improve home care assistance into a paediatric palliative care program.

Methods. We recruited in our project all the figures involved in child assistance program (specialists, local hospital, district, family paediatrician, social assistance, voluntary organization, school...). Eligible children were from 0 to 18 years old, affected by life-limiting and life-threatening illness. For each patient a plan was drawn according to health, social, psychological, familial needs as to perform a global approach. Moreover an educational program for health carriers (doctors, nurses, parents) was instituted. Financial support was provided by Region and Province institutions and by voluntary organizations.

Results. From June 2011 to May 2012 27 patients were included in the project. Eight (25%) were affected by cancer (leukemias, lymphomas, solid tumors) and 19 (75%) from other disease (perinatal, metabolic, congenital, immunological diseases). The median age was 5.9 years (range 0.1-16.8). The starting point for each palliative program was a meeting with all figures involved in the assistance. The median time care period was 164 days/patient. Four hundred and fifty-seven home visits were made. The performances at home were devices medications (n=274), visits (n=288), blood samples (n=122), antibiotic therapies (n=17), chemotherapies (n=85), vital signs monitoring (n=58), others (n= 57). Our activities avoided 28 days of hospitalization and 151 outpatient clinics.

Conclusions. By this project, we implemented also in our Region the home care program in children eligible for palliative care, with a very good cooperation of the different figures involved. Moreover we demonstrated an economical advantages in home assistance.

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Organization of a pediatric palliative care program and home assistance in Pordenone (North-East Italy)

De Zen L1, Gerarduzzi T1, Minotto M1, Bagolin A1, Casini M1, Chittaro M1, Mascarin M1, Benini F2, Dall’Amico R1

1Azienda Ospedaliera S. Maria degli Angeli, Pediatric, Pordenone, Italy, 2ASS 6 Friuli Occidentale, Direzione Sanitaria, Pordenone, Italy, 3IRCSS CRO, Area Giovani, Aviano, Italy, 4University of Padova, PPC Regional Service, Padova, Italy

Background and aims. Home care assistance, particularly for children affected by cancer, is rarely practiced in our Country, even if international literature underlined undoubted advantages for child, family and social system. The aim of our work was to improve home care assistance into a paediatric palliative care program.
Methods. Eighty-nine parents of 59 children who died of cancer between 2000 and 2005 participated in a retrospective cross-sectional study and completed a set of questionnaires measuring grief (Inventory of Traumatic Grief), parents’ experiences of care (communication, continuity of care and parental involvement) and severity and control of the child’s symptoms. Statements on care were rated on a 5-point Likert scale (1=disagree; 5=agree). Univariate and multivariate regression analyses were performed.

Results. Parents were very satisfied with aspects of care, specifically communication (4.7±0.6), continuity of care (4.3±0.7) and parental involvement (4.6±0.8). Fatigue (75%) and pain (74%) were frequently reported physical symptoms, while anxiety to be alone (52%) and anger (48%) were frequently reported psychological symptoms. Univariate analyses showed that decreased parental satisfaction with communication (B=-8.93, p=0.03) and continuity of care (B=-10.91, p=0.01) and the severity of dyspnoea (B=-3.11, p=0.03), anxiety to be alone (B=4.50, p<0.01), anxiety about the future (B=4.83, p<0.01), anger (B=4.99, p<0.01) and uncontrolled pain (B=6.52, p<0.01) were associated with both care and symptom management on long-term parental grief.

Conclusions. Care was rated highly, and together with symptoms was associated with long-term levels of grief. The study highlights the importance of care, adequate symptom management and attention to the child’s psychological symptoms.

27 Spirituality and sources of coping in parents of children with cancer at the end of life
van der Geest I.M.M.1, Darlington A.-S.E.2, van den Heuvel-Eibrink M.M.1
1Erasmus MC-Sophia Children’s Hospital, Department of Paediatric Oncology/Haematology, Rotterdam, Netherlands, 2University of Southampton, School of Health Sciences, Southampton, United Kingdom

Background and aims. Spirituality is an important aspect of paediatric palliative care, however the number of studies using a survey to investigate aspects of spirituality is limited. The aims of this study were to develop better insights into what extent spirituality is important for parents in the palliative phase, and its influence on long-term traumatic grief and depression in parents.

Methods. Eighty-nine parents of 59 children who died between 2000 and 2005 participated in a Dutch retrospective cross-sectional study. Parents completed a set of questionnaires measuring grief (Inventory of Traumatic Grief), depression (Brief Symptom Inventory), factors that helped parents cope and aspects of spirituality, specifically faith and hope and whether parents discussed spirituality with health care professionals. Descriptive analyses and unadjusted logistic regression analyses were performed.

Results. For 19 parents (21%) faith was important and the majority of parents remained hopeful: hope for a meaningful time with their child (n=68, 76%), hope for a pain-free death (n=58, 65%), and hope for their child to be cured (n=50, 34%). Parents indicated that their child (n=70, 79%), health care professionals (n=46, 52%) and family and friends (n=45, 51%) helped them cope. Thirty-four parents (38%) disagreed that they had enough opportunity to discuss spirituality with health care professionals. Faith (OR=0.92, p=0.67; OR=0.93, p=0.55) and hope for cure (OR=1.14, p=0.49; OR=1.04, p=0.77) were not associated with long-term levels of traumatic grief and depression.

Conclusions. Faith seemed to be important in a small subset of parents and the majority of parents retained hope during the paediatric palliative phase. The child, health care professionals and family and friends were central as sources of coping. Aspects of spirituality did not predict long-term traumatic grief and depression in parents who have lost a child to cancer.

29 Rebuilding family life. Rites of reincorporation following the death of their child
Price J.1, Jordan J.1, Prior L.4, Parkes J.4
1Queen’s University Belfast, School of Nursing and Midwifery, Belfast, United Kingdom, 2None, Belfast, United Kingdom, 3Queen’s University Belfast, Sociology, Belfast, United Kingdom, 4Queen’s University Belfast, Nursing and Midwifery, Belfast, United Kingdom

Background and aim. The PATCH study used an interpretive qualitative approach to examine bereaved mothers and fathers’ experiences. Their stories charted an often protracted always painful journey which chimed with Van Gennep’s transition typology and their reintegration into society in a new social status, that of bereaved parent.

Methods. One off in-depth interviews were used as a potent means of gaining insights into the experiences of bereaved parents (n=25). A sequential approach to data analysis which involved thematic and narrative approach to data analysis was used.

Results. Amidst the chaos, grief and life shattering nature of the loss of a child the overarching concept which captured parents’ experiences of the passage of reincorporation was “rebuilding family life”. This marked the period where parents attempted to cope with “the tremendous void” brought about by their child’s death whilst searching for “connection amidst loss”. Parents were aware such a reincorporation into society after the death of their child, indicating how they were viewed as different, but also that they felt different. With the child’s funeral, reincorporation publicly had commenced but rebuilding family life was an ongoing process for parents and one that for many would never end.
Conclusions. The work of Van Gennep gave shape to parents’ experiences serving as a useful conceptual framework for understanding parents’ journey through the death of their child. In the analytically defined period “Rebuilding family life” increased social support was received by parents from friends and family, particularly in the period immediately following their child’s death. However, this support tended to fall away as parents were embarking upon the process of rebuilding their family life in the (physical) absence of their dead child. Professional support and services can aid reduction of parental stress and promote coping, especially in the context of parents’ sense of “abandonment” by others.

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The prognostic approach to non-compliant families and their unreasonable refusal of curative therapy of children with cancer

Polevichenko E.V.
Federal Scientific Clinical Center of Pediatric Hematology, Oncology and Immunology, Pediatric Department, Moscow, Russian Federation

Background and aims. Among children suffering from cancer and receiving palliative care (PC) according to the decision of their parents, the difficult problems are associated with patients (pts) from non-compliance families. In spite of the fact that the possibility of a 5-year event-free survival (pEFS) > 40% to 50% is not an absolute indication for the beginning of the PC, non-compliant parents take such a decision. The aim of the study was to determine the factors correlated with unreasonable parental refusal of curative program chemotherapy (PCT) and the beginning of the PC.

Methods. Retrospective analysis of medico-social data on 76 pts (1-14 years old) with leukemia/lymphoma (n=37;48,6%) and solid tumors (n=39;51,8%), received PC only, included 12 pts (15,8%) with unreasonable parental refusal of PCT.

Results. Correlation analysis by Spearman showed that the presence of unreasonable parental refusal of PCT and the parental decision about the beginning of PC does not significantly correlates with the type of diagnosis, the loss of one of the parents, the membership of the small ethnic groups, the number of siblings, the educational level of both parents, as well as the type of place of residence and its remote-ness from the oncohematological Center. However, there was revealed the significant direct correlation between the presence of unreasonable parental refusal of PCT and the duration of the previous medica- l observation of the patient in the oncohematological Center (ρ=0,36; p=0,001).

Conclusions. Long-term treatment of children with cancer can be regarded as the main predictor of unreasonable parental refusal of PCT. We recommend to apply the risk-based monitoring of the psychosocial status of the family and the application of strategies to improve the compliance in the later stages of the PCT to reduce the number of children, who begins PC without sufficient referral oncologic criteria. There is no conflict of interest with any financial organization.

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Mothers’ experience of bereavement support following the death of a child with a life-limiting condition

Jennings V.
University of Dublin Trinity College, Dublin, Ireland

Children’s palliative care is rapidly developing as a worldwide specialist area. Bereavement support is an integral component of children’s palliative care. However, to date little research has addressed bereavement support from an Irish perspective. Similarly much of the existing theoretical literature fails to capture the many conceptual nuances of parental loss. The aim of this research study was to explore mothers’ experience of bereavement support following the death of their child with a life-limiting condition. The use of a descriptive qualitative design and unstructured interviews allowed the ten mothers interviewed to share their personal experience of bereavement support. NVivo 9 was used to code and manage the data, and conventional content analysis utilised during data analysis. The researcher focused on three main themes where mothers illustrated their utilisation of bereavement supports. The three themes included keeping the memory of the deceased child alive, helping mothers feel understood and helping to reduce mothers feeling of guilt. The findings indicated that mothers relied on a combination of informal and formal bereavement support. In addition mothers described ability to self-support. This study is then discussed in relation to empirical and other literature. Implications for the future development of bereavement support for mothers following the death of a child with a life-limiting condition are discussed along with research and education implications.

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Call me if you need me: the roles of parents and professionals in early identification, assessment and treatment at home of symptoms of terminal cancer among children

Kars M.C., Grypdonck M.G., de Korte-Verhoef M.C., Bierings M.J., van Delden J.J.M.

1UMCUtrecht, Nursing Science/Medical Humanities, Utrecht, Netherlands, 2UMCUtrecht, Nursing Science, Utrecht, Netherlands, 3UMCUtrecht/Wilhelmina Children's Hospital, Pediatric Oncology, Utrecht, Netherlands, 4UMCUtrecht, Medical Humanities, Utrecht, Netherlands

Background and aims. A child’s suffering from symptoms is a major concern at the end of life (EOL). Symptom treatment among children with incurable
cancer is still insufficient, while today many children do die at home. We do not fully understand how symptom treatment actually takes place amidst the interplay between parents and professionals. The study aim was to gain insight into the roles of both parents and professionals, how they interact and what are its consequences for symptom treatment of children receiving EOL care at home.

**Methods.** A multi-centre study, using qualitative interpretative methods, was undertaken during the EOL phase. One-time or repeated face-to-face in-depth interviews were conducted with 44 parents and 39 professional caregivers of 23 children.

**Results.** During the stages of deterioration and dying, the early identification, assessment and treatment of symptoms among children cared for at home depends on the responsibilities taken both by the parents and the professionals, their intentions, and their skills, knowledge and expertise. We found professionals often adopted a “reactive” attitude, thus shifting responsibility towards the parents. Parents in turn experienced symptom treatment as being a factor in the child’s death and therefore showed reluctance to begin treatments that have consequences they perceive as losses. This often resulted in symptoms not being properly treated. Parents felt helped by professionals who took full responsibility for the child’s symptom treatment, provided that they remained perfectly aware of the parents’ perception. Starting a dialogue aimed at the child’s best interests, while preserving the parents’ sense of control, appeared to be the most fruitful approach.

**Conclusions.** An early and accurate assessment and adequate treatment requires an understanding of the parent’s perspective and a dialogue aimed at lessening the child’s suffering, just as much as professional knowledge and technical skills.

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**Working session IV**

**Room 2**

**PSYCHOLOGY - EMOTION - QUALITY**

**10**

**Emotional impact of delivering remote and rural paediatric palliative care - what are the support needs for adult trained nurses?**

Reid F.

* NHS Highland, Paediatrics, Inverness, United Kingdom

**Background and aims.** The death of a child is a rare phenomenon in the western world, being a highly emotive and subjectively distressing event. There are misconceptions surrounding the level of nursing expertise and degree of emotional work required to undertake the delivery of end-of-life care to children and young people (CYP), with a paucity of literature on the topic. This research is important because exposure to emotional stress influences nurses’ grief, coping, decision-making, professionalism, personal health and quality of care delivery. It aims to determine the emotional demands, and support needs, of adult nurses delivering palliative care to CYP in rural community settings.

**Methods.** After ethics approval, a qualitative phenomenological design method was used, involving indirect, but purposive sampling of relevant nurses from one rural Health Board in the UK. Ten one-on-one semi-structured interviews were conducted. Data analysis involved a coding and distillation approach with extrapolation of 4 defined main themes.

**Results.** Service delivery: comprehension of services, timing of referral, discharge planning, communication pathways. Self-efficacy: attitudes, knowledge, emotional and communication skills, educational opportunities. Rurality: geography/demography, balancing dual relationships, confidentiality and anonymity, grief ramifications.

Support systems: internal, peer, specialist nurses, clinical supervision, managerial.

**Conclusions.** The delivery of palliative care to children and young people in rural locations is complex and multifaceted. This unique research provides insight into nurses’ previously undocumented feelings surrounding the private, professional and work-related variables that impact on their coping. It presents new findings, and recommendations for further research, shaping changes to policy and practice regarding the comprehension of rural healthcare ethics, challenges and available support systems for nurses working in this field.

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**Acceptance and effectiveness of specialized palliative home care in children and their parents**

Groh G.1, Eihauer C.1, Nickolay C.1, Rümmelein N.1, Kyber C.1, Schmittgen S.1, Berger E.1, Borasio G.D.2, Führer M.1

1 Dr. von Haunersches Kinderhospital, Ludwig-Maximilians-University Munich, Coordination Center for Pediatric Palliative Care, München, Germany, 2 Centre Hospitalier Universitaire Vaudois, Service de Soins Palliatifs, Lausanne, Switzerland

**Background and aims.** Since 2007, German patients with severe, advanced, life-limiting diseases are eligible for Specialized Outpatient Palliative Care (SOPC). We are currently conducting a study to assess the acceptance and effectiveness of SOPC in children with life limiting diseases and their parents. The layout and interim analysis of the study will be presented after the inclusion of 80% of projected patients.

**Methods.** All consecutive patients treated by the pediatric SOPC team are eligible for the prospective non-randomized study. Exclusion criteria are patient or parent refusal, and inappropriate language knowledge, age or intellectual ability to understand the questionnaire. Two questionnaires were developed to assess the patient and parent situation before and during the care by the SOPC-team. Main topics
were the assessment of pain and other symptoms, the QOL in patients and parents and the burden of patient care for the parents.

**Results.** Between April 2011 and March 2012 30 pediatric patients (median age 5.5 y, 53% male, 77% non-oncologic diseases) were included. In 28/30 only the parents could be interviewed. The median interval between the first and second interview was 6.3 weeks. The QOL in parents as rated by the parents and the QOL in parents (QOLLIT-F 92 to 116) increased, and the burden of care decreased (HPS 17 to 7) significantly after SOPC. In addition the parent questionnaires also show significantly improved symptom control, better psychological support and every day assistance, and facilitated communication with the child and within the professional support system.

**Conclusions.** The preliminary result of this ongoing study show that pediatric SOPC teams can provide effective help to patients and families, improve QOL in patients and parents and lower the burden of palliative home care in the families of severely ill and dying children.

57 Changing the language: integration of “allow natural death” into the National Children’s Hospital in New Zealand

Bycroft K., Jameson J.

**Starship Children’s Hospital, Paediatric Palliative Care, Auckland, New Zealand**

**Background and aims.** Communicating with children and their families about end of life care places significant challenges on practitioners to maintain supportive relationships while acknowledging the vulnerability and suffering for all involved. Families hear the negative term “do not” or “not for” in “Do Not Resuscitate” or “Not for Resuscitation”. The aim was to remove the negative terms to allow emphasis on what can be done to support children and their families.

**Methods.** Health professionals from a range of specialist services met regularly over 1 year to develop an “Allow Natural Death” policy and an End of Life Care Plan for use in advanced care planning at Starship Children’s Hospital. Due to the commitment of biculturalism in New Zealand participation of Maori leadership was sought. Integration of the policy and plan into services occurred mostly through members of the Paediatric Palliative Care Service participating in or leading family meetings.

**Results.** Initially health professionals outside of Pediatric Palliative care were reluctant to integrate the policy and plan into practice. However, as the Pediatric Palliative Care Service worked alongside specialist services the awareness and use of the policy has increased. Terminology considered “negative” has been replaced with a term that aims to reduce suffering and promote comfort, quality and dignity. New Zealand Maori have gifted a new name – Te Wa Aroha (a time of love) and a new way of communication.

**Conclusions.** Te Wa Aroha or “Allow Natural Death” has been integrated and is the only term used by health professionals discussing end of life care with families at Starship Children’s Hospital. Health professionals are initiating and using the End of Life Care Plan independently of the Paediatric Palliative Care Service. It is likely these difficult discussions are occurring earlier in the illness trajectory therefore, earlier involvement of the Paediatric Palliative Care Service.

89 «Do teddy-bears go to heaven?» A French movie to approach some questions regarding end of life during childhood

(Access http://www.youtube.com/watch?v=htz6TFxgBf8)

Avruignon A. 1, Vialle G. 2, Pouveroux M. 3, dal Molin M.-B. 3, Michon J. 4

1Hôpital Armand Trousseau, Oncologie Hémato logie, Paris, France; 2RIFFHOP-PALIPED, Paris, France; 3Advita Productions, Grenoble, France; 4Institut Curie, Paris, France

**Purpose.** Pediatric Palliative Care in France has been recently structured: Regional Resources Teams in Pediatric Palliative Care currently exist in each French region. The main objectives of these teams are to acculturate classical pediatric hospitals to a palliative approach, to raise awareness of the adult palliative care teams on pediatric specificities, to contribute to clinical research in pediatric palliative care and to make sure that patients and their families are given efficient support.

**Methods.** PALIPED, the Regional Resource Team in Pediatric Palliative Care for Paris Region organized, in February 2009, a training day on the topic “Accompanying a child at the end of life, at home or at the hospital?”. Two parents, having lost their child treated for cancer, gave their testimonies. After that day, PALIPED decided to make a movie that could help to think about the delicate question regarding the choice of the place where the child will die: at home or in the hospital?

**Results.** A 52 mn documentary movie, was realized in 2010 around the story of 4 families having accompanied their child. Around every route, parents, brothers, sisters, teachers, classmates and also nurses from the hospital and from the city, were able to express their questioning and how they felt about this difficult question. The movie was shown for the first time in Paris on the 1st March 2011 and then already on 27 occasions to pediatric or other medical teams but also during parents associations meetings. This movie is obviously a good tool for initiating dialogue and for training of medical teams.

**Conclusions.** Using this documentary, PALIPED was able to reach its objectives: disseminating the pediatric palliative approach and supporting families. We realized an English version and propose a wider distribution.
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Does telemedicine influences quality of life of caregiver and patient with respiratory chronic failure?
Risso C., Veljkovic A., Ellena M., Goia M., Esposito I., Bignamini E.
OIRM, S.C. Pneumologia, Turin, Italy

Background and aims. The growing prevalence of chronic diseases and home-based treatments has led to the introduction of a large number of instruments for assessing the caregiving-related problems associated with specific diseases. Our Centre started a program of telemedicine (nocturnal satsirmetry, respiratory trace, questionnaires, telephone call) for patients with respiratory failure, in 2009. The purpose of our study was to evaluate the level of anxiety and depression in monitoring patients and his caregivers and to investigate the subjective perception of emotional burden and problems in social involvement, the management of the disease and experience of not knowing enough about it, the satisfaction with family relationships, thoughts related to the possible death of the patient. Informed consent and ethical committee approval was obtained.

Material and methods. Questionnaires:
— The Family Strain Questionnaire (FSQ)
— Disease Impact On Caregiver (DIOC)
— Hospital Anxiety and Depression Scale (HADS)

Questionnaires were rielaborated after 1 year and after 2 years.

Results. Thirty patients was monitored: 17 with Cystic Fibrosis (CF) and 13 with Neuromuscular Disease (ND). 57 subjects responded on the questionnaires: 6 patients, 30 mothers and 21 fathers of patients. The mean age of patients was 10.56 years (min 2 max 24); 20 female and 10 male. The mean level of anxiety in total population was 7.38 (clinical relevance >7) and there was no significant difference between FC and NM group. The mean level of depression in total population was 4.12 (clinical relevance >7) and the NM group resulted much more depressed (5.09 vs. 3.51 p=0.08). Over time anxiety of NM patients parents decrease (8.66 vs. 7.86 after two years; p=0.01).

Conclusions. Telemedicine does not very symptom of anxiety and depression in patients ant they parents, but the decrease anxiety in NM patients/parent. Further studies are needed to confirm these data.

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Paediatric therapeutic needs in the treatment of pain: how to address them and be successful
Ceci A.1, Mangiarini L.2, Catapano M.3, Manfredi C.4, Felisi M.3, Knibbe C.A.5, Neubert A.6, Tibboel D.7, Della Pasqua O.8, Benini F.8
1Universita degli Studi di Bari, Bari, Italy, 2PHARM srl, Lodi, Italy, 3OIST - Gruppo Italiano per gli Studi di Farmacocono- nomic, Pavia, Italy, 4Consorzio per Valutazioni Biologiche e Farmacologiche, Pavia, Italy, 5University of Leiden, Leiden/Amster- dam Center for Drug Research, Leiden, Netherlands, 6University Hospital Erlangen, Department of Paediatric and Adolescents Medicine, Erlangen, Germany, 7Sophia Children’s Hospital, Rotterdam, Netherlands, 8Azienda Ospedalieri di Padova, Diparti- mento di Pediatría, Padova, Italy

Background. Paediatric pain remains under-treated because of insufficient information on efficacy and safety of analgesics, and lack of age appropriate formulations.

Results. TEDDY (Task-force for Drug Development for the Young) Network of Excellence’s analysis in paediatric pain shows that: none of the 142 paediatric drugs approved by European Medicines Agency (EMA) are authorised for paediatric pain; only 14 drugs are authorised for pain in the national market (6 EU Countries) and many differences exist in terms of authorised age groups and approved indications; very few studies supporting the paediatric use are included in the marketing authorisation documentation or are derived from academic research. Particularly lacking are a) preterm and term neonate studies, b) dose-finding paediatric studies, c) inter-individual and inter age groups variability in response data, d) long-term treatment data on choice and dose (adjustments) of analgesics during long term opioid-use; while 17 analgesics were included in EMA Therapeutic needs and Priority Lists, only for 2 products a paediatric investigation plan was approved by the Paediatric Committee and studies are now ongoing.

Conclusions. Several issues currently hamper the development of analgesics for children. Even the WHO guidance for pain treatment includes only three agents (tramadol, diclofenac, morphine) that are approved from 6 months or 1 year of age onwards, while other agents are authorised for older age groups. The Paediatric Regulation, ruling for mandatory paediatric development, is slowly increasing the availability of drugs for paediatric use. The set-up of large research Consortiums, including paediatricians and experts in paediatric drug development and ethics, should be promoted allowing the conduction of randomised controlled trials, with innovative designs using PK/PD modelling and simulation techniques and PB-PKPD approaches for predictions and extrapolations when applicable.

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Experience, knowledge and attitudes of medical students in Kuwait towards palliative care
McCulloch R.1,2, Comac M.3, Adekile A.5
1Bayt Abdullah Children’s Hospice, Kuwait City, Kuwait, 2Great Ormond Street Hospital, London, United Kingdom, 3Kuwait Uni- versity, Paediatric Haematology, Kuwait City, Kuwait

Background. The first palliative care service in Kuwait is within Paediatrics. The educational needs of medical students were studied as part of a national needs assessment.

Aims. To assess Kuwait medical students: 1) experience and education in palliative care; 2) knowledge of symptom management and end-of-life care; 3) attitude towards dying patients.

Methods. A total of 201 Year 6 and 7 medical students at Kuwait University Medical School received
a questionnaire prior to an educational program in paediatric palliative care; 179 completed it (response rate 89%). Students were asked to rate 21 items using a 4-point Likert scale.

**Results.** 96% of students were Muslim Arabs. 58% had “none” or “little” prior knowledge of the specialty. 59% rated their education about “end-of-life care” as “poor”, with 79% having never cared for a dying patient. Students reported receiving “no” (60%) or “a little” (31%) teaching about end-of-life care in clinical attachments. The majority felt unprepared about clinical practice issues (94%) and dealing with cultural problems (83%) at the end of life. 61% felt “helpless” caring for dying patients and 57% found it “depressing”. Students were more confident about managing nausea and vomiting rather than pain. In contrast to similar Western studies, 83% rated their own religious beliefs “important” to clinical actions. 72% agreed that working with dying patients is a rewarding experience and most students (95%) thought attention should be given to education in end-of-life care.

**Conclusions.** This is the first study to show palliative care experience, knowledge and attitude of medical students in the Middle East. The data strongly suggests that more attention should be paid to palliative care education and clinical training in Kuwait. Further information regarding the impact of religious beliefs upon the care of palliative care patients is required in order to develop a culturally appropriate palliative care education programme.

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**ORGANIZATION - EPIDEMIOLOGY**

**Health Related Quality of Life (HRQoL) constructs and measurement in children with cancer during palliative care - A systematic review**

Barton C.*, Brook L.*

*1 Alder Hey Children’s Hospital, Department of Paediatric Oncology, Liverpool, United Kingdom, 2 Alder Hey Children’s Hospital, Department of Paediatric Palliative Care, Liverpool, United Kingdom

**Aims.** To systematically identify published research describing instruments used to measure HRQoL in children with cancer receiving palliative care, and explore the HRQoL domains considered.

**Methods.** A literature search was performed via The Cochrane Library and The Cochrane Database of Clinical Reviews, and the NHS Evidence Portal to search the MEDLINE, EMBASE, CINAHL, PsychINFO and Pubmed databases.

**Results.** Of 6703 articles identified, a systematic exclusion process was followed to generate a final list of 18. No instruments were identified to measure HRQoL as primary outcomes in the management of children with cancer in the palliative phase. The research identified was predominantly qualitative in nature, including semi-structured, closed and open interview strategies, postal and telephone surveys. Two randomised control trials were identified, and one focus group. Physical, emotional, social, psychosocial and schooling (education) were the most frequently mentioned quality of life (QOL) domains, with differences in priorities at different ages. Psychological symptoms were consistently identified as having the most significant effect on HRQoL, with pain, fatigue and dyspnoea among the most frequently described, alongside GI disturbance and anorexia. Parental or proxy reporting was most common, with little self-report by children themselves.

**Conclusions.** This systematic review highlights the established difficulties of conducting research in children in the palliative phase of treatment, the challenge of self-reporting in the paediatric population, and the different QOL priorities of children of different ages during palliation for cancer. Further work is necessary to develop validated (especially psychologically validated) tools and.

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**Children discharged from maternity in need of pediatric palliative care - Epidemiologic study**

Bernadá M.M., Carrerou R., Guadalupe A. *Universidad de la República, Pediatrics Department - School of Medicine, Montevideo, Uruguay

**Introduction.** EAPC said: “Information relative to number, diagnosis, age range and location of children with life limiting or life threatening conditions is fundamental to the organization of PPC”. A National palliative care program is starting. Recently, PPC has been developed in the country. The number of children in need of it, is unknown. In the neonatal period, in addition to children that clearly fulfill definition for PPC, others probably may need PC. This is the first survey in the country of children in need of PC discharged from the largest and reference maternity.

**Objectives.** To describe the incidence and main characteristics of children in need of PPC discharged from the maternity.

**Methodology.** Descriptive, observational and retrospective study between 1/1 to 31/12/2011. Children included were: a) clearly in need of PPC, according to ACT; categories b) “probably in need” of PPC: children with: extreme prematurity without clear neurological sequelae, severe neonatal depression; post resuscitation.
Results. 236/7665 children discharged (30.6 %) were included. 44% were clearly in need of PPC and 56% were probably in need of PPC. Conditions for which children were included, according to ACT categories were: group I: 9; group II: 42; group III: 8; group IV: 45. Conditions for what children were probably in need of PPC were: extreme prematurity: 102, severe neonatal depression: 29. Malformative pathology was prenatally diagnosed in 21%. 27% of children clearly in need of PPC and 20% that probably need PPC died during hospitalization. Average hospitalization: 84 days. 86% were discharged to home and 14% to other hospitals. Average mother age: 24 years old. 26% of mothers were adolescents (13-18 years old).

Discussion. A PPC team situated in the maternity is needed in order to early start comprehensive care of children and families. Health authorities need this information to develop a PPC network according to national characteristics.

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Developing beacon centres to expand palliative care in Sub-Saharan Africa: a model for developing countries

Marston J.M.

International Children’s Palliative Care Network, Management, Bloemfontein, South Africa

Background and aims. Sub-Saharan Africa has the highest burden of childhood mortality yet only 8 countries have any paediatric palliative care programmes. The aim of the project is to increase access to paediatric palliative care through developing educational programmes and centres of excellence in 3 countries as resource centres for the sub-Saharan region.

Methods. Three countries were selected, Tanzania, Uganda and South Africa, for the development of Beacon Centres for Paediatric Palliative care, and education of professionals providing care. Two trainers, one psycho-social and one clinical professional designated as Navigators were selected for each country. A new textbook for palliative care for children in Africa was published and a certificate level multi-professional course developed. The centres selected were developed into Beacon Centres in line with identified criteria. In Tanzania and Uganda the Beacon centres were single large HIV organisations. In South Africa, where the Hospice Palliative Care Association has developed a country-wide network of services, the national association became the Beacon Centre with a web-based Virtual Resource Centre as an educational and informational resource. Professionals from hospitals, hospices and other organisations received training at certificate and introductory level. In Uganda the course has been developed into a diploma for East Africa.

Results. Across 3 countries 220 professionals have qualified in paediatric palliative care. A diploma has been developed for East African countries. Three Beacon Centres established for experiential learning. Baobab Virtual Resource Centre is a resource for Africa. Training extended to other African countries. National palliative care associations now interested in supporting paediatric palliative care. Increase in children receiving palliative care.

Conclusions. High quality, effective professional paediatric palliative care can be developed in poorly resourced countries.

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When numbers are high and resources are low: how do we provide sustainable palliative care for children?

Meiring M.A.1,2

1University of Cape Town, Paediatrics, Cape Town, South Africa, 2The Bigshoes Foundation, Paediatric Palliative Care, Cape Town, South Africa

Background and aims. Palliative care for children has its origins in the modern hospice movement started in the United Kingdom. Model respite centres developed for small numbers of children in countries with a relatively well functioning health care systems have been duplicated with donor support across the world including in some resource constrained countries. In resource constrained settings with high numbers of children in need of palliative care how do we meet this need in a manner that is sustainable? This study aims to demonstrate the potential cost per patient of different models of palliative care using a sample of paediatric patients with life limiting conditions attending a tertiary level hospital in South Africa over one month.

Methods. A sample of children with life limiting illnesses attending four large out-patient clinics (Oncology, HIV, Neurology and Cardiology) in a busy tertiary care centre in South Africa over one month was obtained from clinic attendance records. A subset of children most likely to need palliative care was determined from retrospective file review of the children seen over the study month who had either advanced disease, a high documented symptom burden or psycho-social stressors was selected. The cost of providing independant donor funded in-patient hospice services or professional home based care support was calculated for this sample population over a year.

Results and conclusions. The cost of parallel donor funded services to address the palliative care needs of large numbers of children in resource constrained settings is prohibitive and unsustainable. Paediatric Palliative care in resource constrained settings will only be sustainable if integrated into the public health care system with donor funded projects providing limited cost efficient complementary services whose primary aim is to upskill existing government funded services. More time should be spent on
advocacy and training to empower existing primary care teams.

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Mapping of palliative care services for infants, children and adolescents in Europe  
Lynch T.1, Benini F.2, Kreiebergs U.3, Wood C.4, Bergstrasser E.3, Craig F.5, Marston J.7, Martino Alba R.8  
1International Observatory on End of Life Care, Lancaster, United Kingdom, 2Clinica Pediatrica dell’Università di Padova, Padua, Italy, 3Department of Women’s and Children’s Health, Karolinska Institute, Stockholm, Sweden, 4Hôpital Robert Debré, Paris, France, 5University Children’s Hospital, Zurich, Switzerland, 6Great Ormond Street Hospital, London, United Kingdom, 7International Children’s Palliative Care Network, Assagay, South Africa, 8Niño Jesús University Hospital for Children, Madrid, Spain

Background. In many European countries, epidemiological data on the need for pediatric palliative care (PPC), the type and form of services available and the number of children that utilise them is not widely available. The EAPC Taskforce for the Mapping of palliative care services for infants, children and adolescents in Europe - a sub-group of the European Steering Committee for Palliative Care in Children created by the Fondazione Maruza Lefebvre D’Ovidio Onlus (FMLDO) - is undertaking a quantitative survey mapping the development of PPC services in the European region.

Aim. Explore, assess and summarize the current state of palliative care provision for children in Europe in relation to estimated need.

Methods. A list of “key persons” from each country has been compiled and a quantitative survey will be sent to them for completion. The questionnaire requests information about the number/type of PPC services that are provided, legislation/policy, education/training and opioid availability; a typology of PPC services will be included to assist with standardisation and definition of terminology. An attachment to the questionnaire will request contact details of PPC services in each respective country; a second questionnaire will then be sent to those organisations requesting more detailed and comprehensive information about the services that are provided.

Results. The data collected will be presented as a map of PPC services at the EAPC Conference in Prague, 2013. Comparative analysis of the development of PPC services makes it possible to witness the degree of progression or regression in each respective country and also functions as a benchmark to enable governments and policymakers to ascertain the degree to which their situation compares with others in the region; this will, in turn, have a positive impact upon providers of palliative care services in a direct, practical way through improvement in the development of policy and practice and future service design.

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Transition to home of technology-dependent children for End-of-Life Care (EOLC)  
Mullaney E.1, Steinborn D.M.2  
1Ann & Robert H. Lurie Children’s Hospital of Chicago, Palliative Care, Chicago, IL, United States, 2Northwestern University Feinberg School of Medicine, Pediatrics, Chicago, IL, United States

Background and aims. Medical technology has led to the survival of many children from previously fatal conditions. Technology has also changed the place of death for adults and children from the home to the hospital, often occurring in the ICU. Many professionals feel that death should optimally take place at home when possible, but the use of mechanical ventilators makes it difficult and uncomfortable to achieve that goal. Additionally, ICU resources are often limited and costly and demand wise allocation.

Methods. ICU patients whose parents were motivated to allow death to occur at home were transported by a senior ICU physician (in partnership with the palliative care team) for removal of technology support at home with subsequent hand-off of care to the home hospice team. Preparations included: Setting parental expectations, discussion of events occurring at the time of death, preparing siblings, preparing the ambulance team, preparing home hospice, selection of medications to alleviate suffering and distress in the patients, discussion of risks of death during transport, creating as much peace and comfort for the patient throughout the process. Patients on vaso-pressors were not considered candidates.

Results. 7 technology-dependent children have received EOLC at home using this approach. Diagnoses include: SMA, metastatic cancer with malignant pleural effusions, neurodegenerative disease, CNS malignancy, inborn metabolic errors. As needed to maintain stability, patients were transported with oral endotracheal tube/mechanical ventilator or on face mask BIPAP. Medications provided during transport included narcotics and benzodiazepines, as needed. There were no episodes of additional discomfort nor deaths during transport. Families expressed gratitude for this care.

Conclusions. Taking technology-dependent children home for EOLC is feasible, frees up ICU resources, and can be done safely and comfortably with appropriate, skilled staff. Parental acceptance was good.

82  
Transition of young people with life-limiting conditions from child to adult healthcare services  
Maguire H.  
Northern Ireland Children’s Hospice, Community Services, Newtownabbey, United Kingdom

Aim. To encourage a regional response to issues facing young people with life-limiting conditions at tran-
sition from child to adult health services, by bringing young people, parents and service providers/commis-
sioners together to agree issues and required actions.

**Methods.** Initially a young people’s focus group was hosted to identify concerns and inform the themes for two workshops for senior health/social care pro-
viders/commissioners, parents and young people to develop a regional response to four significant transi-
tion issues: information and mode of delivery; com-
missioning care packages, medical issues and adult
workforce education.

**Results.** Delegates agreed future actions as: Forma-
tion of multi-agency transition group with meaning-
ful participation from professionals and young peo-
ples/families. Development of an electronic Health
Passport/record. Review of medical interface be-
tween acute child and adult health. Review poten-
tial role of medical lead/coordinator for transition/
young people. Dedicated hospital beds for use by
adolescents. Agreed age of transition for transfer
from child to adult acute healthcare services. Re-
evew of child and adult commissioning to identify meth-
ods of transitioning budgets. Develop an education/
training module for professionals. In response to the
workshops, a regional interagency transition group
has been established to prioritise and implement ac-
tions. Young people are represented and chair some
of the sub groups.

**Conclusions.** The workshops have successfully
highlighted and prompted action around the difficul-
ties young people face. Current key areas of attention
are the development of an electronic health passport,
rationalisation of transition age in acute hospitals and
development of a training course for adult healthcare
professionals. None of this would have been achieved
without the powerful voice of the young people.

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**Use of intravenous titratable agents for refractory symptoms in children with ad-
vanced cancer: a single center experience**

Okhuysen-Cawley R.S., Mauricio R.S., Mejia R.E., Cortes J.A.,
Samuel S.

University of Texas MD Anderson Cancer Center, Pediatrics,
Houston, TX, United States

Refractory symptoms such as intractable pain (IP) or
dyspnea (DY) may develop despite implementation of
pharmacologic and non-pharmacologic measures,
and are devastating to children and families. We de-
scribe the use of intravenous titratable agents (ITA)
for palliation in 13 children 3 to 19 years of age with
metastatic solid tumors, 8 with IP and 5 with DY as
their predominant symptom.

The 8 children with IP had failed aggressive contin-
uous intravenous opioid titration. 5 had evidence of
opioid-induced hyperalgesia (OIH) or neurotoxicity,
and 3 had failed epidural catheters or cordotomy.

**Background.** The ICPCN developed a pilot web-
based program linked to the new WHO guidelines for persisting pain in children. The aims of the pro-
gram were to: improve the management of pain in
children with palliative care needs; increase partici-
pants knowledge of pain assessment and manage-
ment in children; and familiarise participants to the
new WHO guidelines for persisting pain.

**Methods.** The pilot program was conducted from
October 2011 to March 2012. Invitations were sent
to all ICPCN members and it was available on the
ICPCN website. Following completion, participants
were invited to complete an evaluation form. The eval-
uation of the programme was based on the data
available from the VLE, which included demographic
information on users, data on user access and use of
the course materials, data on the course assessment
and data from the users evaluation forms.

**Results.** Course access and use: 186 individuals ac-
cessed the course with 26% of them completing it.
In the general context of internet marketing where con-
version rates are 5-10%, these represent very high con-
Psychological burden and meaning in life in parents with children in palliative home care

Antretter B.1, Fegg M.2, Kögler M.2, Borasio G.D.3, Führer M.1

1Dr. von Haunersches Kinderspital, Ludwig-Maximilians-University Munich, Coordination Center for Pediatric Palliative Care, Munich, Germany. 2Ludwig-Maximilians University Munich, Interdisciplinary Center for Palliative Medicine, Munich, Germany. 3Centre Hospitalier Universitaire Vaudois, Service de Soins Palliatifs, Lausanne, Switzerland

Background. "Meaning in life" (MiL) was identified as an important coping factor for patients in palliative care (PC). Also parents of children in PC name MiL as a source for solace and strength. The aim of this study was to investigate psychological burden and to identify the main sources of MiL in parents of children in PC, and to compare these findings with a sample of adult patients in PC and a representative sample of healthy Germans.

Methods. Parents completed the "Schedule for Meaning in Life Evaluation" (SMiLE) and took part in a semi-structured interview. In the SMiLE participants list individual areas of meaning and weight the current level of importance and satisfaction with each area. Overall indices of weighting (IoW, range 0-100), satisfaction (IoS, range 0-100), and weighted satisfaction (IoWS, range 0-100) were calculated. The interviews were tape recorded, transcribed and analyzed according to Mayring. The "Brief Symptom Inventory" (BSI) was used to evaluate psychological burden.

Results. 17 parents participated. Overall they show only a slightly increased psychological distress (GSI 59.2±11.1) in the BSI. When compared to healthy individuals and PC patients, parents list less meaning-relevant areas (median 13 vs. 9), with a focus on family, partner and friends. For satisfaction and weighted satisfaction parents scored in the same range as PC patients (IoS 75.3±16.3 vs. 73.9±18.4; IoWS 76.0±17.1 vs.75.3±18.2), but lower in all indices compared to healthy individuals (IoW 79.6±13.1 vs. 85.5±12.3, IoS 82.8±14.7, IoWS 83.3±14.8). In the interviews support by family and professionals, relationship, profession, spirituality and personal growth were identified as additional sources of MiL.

Conclusions. In the SMiLE parents show less satisfaction with important areas of their MiL than healthy individuals. Interviews deepened the understanding of MiL. These findings might be useful to develop tailored meaning based interventions for parents of children in PC.
7
Reflecting on a child's life and death. How the use of syringe drivers in Irish children's palliative care can facilitate symptom management at home
Quinn C.M.1,2
1 National University of Ireland Galway, School of Nursing and Midwifery, Galway, Ireland, 2 Lauralynn Children's Hospice, Dublin, Ireland

Background and aims. The recent evolution of children's palliative care as a speciality in its own right, has prompted greater enquiry into symptom management and parental partnership in the community setting (DoHC/ IHF 2005; Hannon and Gibson 2008, Quinn and Bailey 2011).

Methods. By framing a Irish child and family story within the reflective model by Mc Neilly et al (2006) the presenter will critically examine and discuss recent literature around the challenges often faced by families who wish to access symptom management by virtue of certain therapeutic interventions in the home setting.

Results of literature review. The aspirations of Irish parents for home based palliative and symptom management (DoHC/ IHF 2005) do not appear to be often fulfilled. Indeed, anecdotal evidence indicates the place of palliative care for many children continues to be hospital although there is ambivalence why this occurs (Quinn and Bailey 2011, IHF 2011). Syringe drivers (Continuous Subcutaneous Infusion- CSCI). The use of Syringe Drivers or Continuous Subcutaneous Infusion (CSCI) to control difficult symptoms with medication, is detailed within the literature (Graham and Clark 2005; Mc Neilly et al 2006, Costello et al 2008). However, the benefits of syringe drivers as a "therapeutic intervention" can in some situations actually promote and enhance quality of life. (Mc Neilly et al 2004).


Conclusions and recommendations. The literature highlights the aspirations of parents to care for children at home whilst at the same time ensuring optimal symptom management via a syringe driver.

15
Palliative care needs in Juvenile Huntington's Disease
Harrop E., Parks H.
Helen and Douglas House Hospices, Paediatric Palliative Medicine, Oxford, United Kingdom

Background. Huntington's disease is an autosomal dominant progressive neurodegenerative disorder with a frequency of 4-10 per 100,000. In 1-10% of sufferers, onset occurs before the age of 20, leading to a label of Juvenile Huntington's Disease (JHD), which has a poorly understood and aggressive course with death occurring by early adulthood.

Aims. To better describe the complex and poorly defined symptom burden in the JHD population (questionnaire). To better understand the needs of JHD patients and their families at the end of life (case studies).

Methods. Data was collected within a hospice for children & young adults privileged to have had a cohort of five cases. A Likert scale was used to examine the nature & severity of symptoms. Case reports were prepared about the end of life care of the two patients who died during the study. Approval was sought from the institutional ethics committee.

Results. All patients reported low mood, involuntary movements, difficulty managing secretions and pain. In contrast to adult patients they also reported significant rates of dystonia, tonic-clonic seizure, neuropathic phenomena, and episodes of reduced consciousness. Unexpected symptoms are easily confused with drug adverse events, occasionally leading to needless reductions in beneficial medication. Two patients died during the study, both from pneumonia in the face of disease progression, one of whom also suffered refractory seizures.

Conclusions. The symptoms experienced in JHD appear to differ qualitatively & quantitatively from the adult disease. JHD patients have wider ranging & more aggressive manifestations. These patients represent an orphan disease group with significant and prolonged palliative care needs. This paper highlights the need for a more significant study. Due to the rare nature of JHD, such a study would need to be conducted within a research network.

18
Care team: end-of-life care on a Neonatal and Paediatric Intensive Care Unit
Naji S., Bergstrasser E.
University Children's Hospital Zurich, Zurich, Switzerland

Background and aims. Annually, there are 35-50 paediatric deaths on the intensive care units (NICU and PICU) of the University Children's Hospital Zurich. Most of these children's are admitted to PICU/ NICU due to life-threatening conditions. Critically ill or dying children need intensive technical and medical support and care. Thereby, parents often do not receive the attention they would need in these distressing circumstances. Various parental needs are known, including the active participation in the decision-making process with the need of ongoing honest and compassionate communication on their child's condition as well as being involved in their
child's care through death. To cope with this highly burdened situation, they need attendance and support which should continue beyond the death of a child. The aim of this project is to support families that they can spend the most precious last hours with their child according to their cultural and spiritual needs. At the same time it may provide assistance and relief for the attending teams, so they can care for the critically ill children.

**Results.** The care team of the University Children's Hospital Zurich exists since more than 10 years and supports the attending teams and cares for families and dying children. Events during this time may have an impact on the grieving process of both, parents and siblings. So far, informal feedbacks from family members confirmed the high value of this particular end-of-life care by the care team.

**Conclusions.** We believe, that this kind of caring should be offered on PICUs and NICUs to enable parents and siblings to spend the remaining life time of their child according to their needs and wishes.

**Outlook.** The next step of this project will be a mixed methods study to evaluate the experiences and perceptions from parents and health care providers who had access the care team's support.

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21 Ultrasound guided nerve blocks in pediatric palliative care

Zanon C.

Ospedale Pediatrico Bambino Gesù, Anestesia e Rianimazione, Roma, Italy

**Background and aims.** Pain is the most treated symptom at the end of life in children. When pain control remains inadequate with systemic opioids and when pain occurs in the territory of peripheral nerves, peripheral nerve blocks (PNBs) can be used. Continuous PNBs are increasingly used for pain control at the end of life in adults but there is limited experience for the same treatment in children. Here we describe our experience with ultrasound PNBs for pain management during and after orthopaedic surgery and for explain that this technique could be an important method for palliative treatment of chronic pain arising from pathologies of the upper and lower limbs, and usually does not preclude death at the preferred location. Little has been published about efficacy and safety of ultrasound-guided blocks (USGbs) in children, thus we report our undergoing experience to propose that this is a suitable technique of patients with terminal cancer also.

**Methods.** 25 children was selected to test the efficacy of ultrasound-guided supraclavicular, popliteal, sciatic and femoral nerve blocks to provide intra and postoperative analgesia. We use 1-2 ml/kg ropivacaine 0.2% in single-shot. The procedure time, establishment time, duration of analgesia and any complication were related.

**Conclusions.** We want extend our study for the next four months. Temporary result has demonstrate the efficacy and safety of USGbs in children: no complication related no block failed. We will report all patients' data at the end of the study. The same technique may be used for continuous peripheral nerve blocks (CPNBs). Our findings indicate that CPNBs can reduce pain scores and intravenous opioid requirements and that the efficacy and safety of this technique may be integrated in hospice-care or home-care programs and that CPNBs in paediatric palliative care programs can improve the quality of life of children.

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23 A model for transition to palliative care at home

Jespersen B.A.1, Bonderup A.1, Hjort A.2, Bjerregaard M.2, Neergaard M.A.1, Clausen N.2

1Aarhus University Hospital, Department of Oncology, Palliative Home Care Team, Aarhus C, Denmark; 2Aarhus University Hospital, Pediatric Department, Aarhus N, Denmark

**Background and aim.** In the Pediatric Department (PD), Arhus University Hospital (AUH), Denmark (DK), approximately ten children are dying from cancer annually. Previously, they died in hospital. Until 2008, the palliative specialist team (PST), AUH assisted PD with pain treatment. However, the need for specialist pediatric palliative care was evident, especially if the family preferred to stay at home. The aim of this study was to investigate if structured collaboration between PD and PST could improve collaboration in the trajectory helping children to stay at home in end-of-life.

**Methods.** In 2008 an agreement was made between PD and PST: When treatment of a child with cancer became palliative, a PST doctor and nurse attended a multidisciplinary conference to plan future palliative care. After discharge, the PST doctor and nurse met with the general practitioner (GP) and community nurse (CN) in the child's home with the aim to work closely in the palliative trajectory. After the child's death the involved professionals met at the hospital with the parents, who got the opportunity to ask questions and say goodbye to the professionals. Data were retrieved from the Danish Palliative Database.

**Results.** In 2010 and 2011, six boys and one girl were presented at the multidisciplinary conference and subsequently followed by PST (Median age: 12 years (range: 2-13)). The diagnoses were neuroblastoma (3), Ewing sarcoma (2), lymphangiosarcoma (1) and non-Hodgkin lymphoma (1). The children were followed by PST for a median of eight weeks (range: 2-88) until death. In all cases both CN and GP played a significant role. Five children died at home while two children died in hospital.

**Conclusions.** The results indicate that it is possible to optimize pediatric palliative home care through structured collaboration. The multidisciplinary team conference is an important “changing gears” and the
shared meeting in the child’s home seems to improve collaboration between professionals.

26 Staff debriefing; a method to cope when a child dies
Hjort A.
Department of Paediatrics, Aarhus University Hospital A 4, Aarhus N, Denmark

Background. Health care staff is competent in palliative care for children and their families but little attention has been focused on the need for support and reflection among health care staff working with this patient group. Debriefing is a collective support method where participants can express and share thoughts and feelings in relation to an event. No explanations are requested. In 2007, debriefing was integrated as a method in the Department of Paediatrics, Aarhus University Hospital.

Aims. To use the debriefing method to support each individual staff member to develop professional and personal skills to cope after the death of a patient connected to the department.

Methods. A debriefing coordinator summons internal and external collaborators to a debriefing session no later than 14 days after the death of a child. Debriefing is scheduled to last one hour. Patient confidentiality is mandatory. In 2008, a questionnaire was sent out to the multidisciplinary team to evaluate the concept of debriefing in the department.

Results. The questionnaires revealed that health care staff was satisfied with the concept of debriefing. Ethical and professional reflections within the multidisciplinary team were reported to be fruitful to all parties involved. Use of debriefing has considerably improved palliative care and procedures around patients and families in a difficult situation.

33 Which needs in paediatric palliative care?
Identify them to orientate the services
Vignola V.1, Dioni S.1, Franceschini C.2, Gasparini I.3, Nucci S.3, Scarpone D.3, Sornante C.6
1A.O.U. di Parma, U.O. Pediatria e Oncologia Pediatrica, Parma, Italy, 2Fondazione Hospice M. T. C. Seragnoli, Bologna, Italy, 3AUSL Reggio Emilia, Reggio Emilia, Italy, 4AUSL Rimini, Rimini, Italy, 5A.O.U. S.Orsola-Malpighi Bologna, Bologna, Italy, 6CD SIPO Emilia Romagna, Bologna, Italy

Introduction. In our experience, thank to the definition of WHO and in compliance with the L.38/2010, it is important to connect the expressed and unexpressed needs of hospitalized chronic or oncological children and their families to identify an efficient clinical model of care. The Emilia Romagna Region is involved in the project for Paediatric Palliative Care Network (Hospitals, Hospice and Territory); the Italian Society of Psycho-Oncology (SIPO), Emilia Romagna Section, intends to contribute to the development of dedicated psycho-social Services, through a research focused on the children and their families point of view.

Aim. The aim of the study is to give back to Emilia Romagna Region (Work Table of Paediatric Palliative Care) an exhaustive cross section of the main needs of patients and families, during the long and difficult experience of desease, able to orientate the clinical assistance from the Regional Paediatric Palliative Care Projects.

Objectives and methods. SIPO proposes an action research to explore “the needs of patients and their families”, in different moments of illness history. At first, 3 Paediatric Hospitals (Parma, Bologna and Rimini) specialized in the care and clinical assistance of chronic and oncohaematological diseases, will be involved. In a second step the research will be extended to other units. With the contribution of SIPO psychologist facilitators, will be identified 15 clinical situations: 5 cases, at the moment of diagnosis; 5 cases, of chronic illness; 5 cases of progression or relapse. Two types of tools, related to the chronological and developing age of the patient, specially created for this research, are suggested: Semi-structured interview for the patients (children and adolescents), administered by the psychologists of the centres, during a clinical interview; Semi-structured interview for the care-givers of little children (under six years old).

34 Open communication at end of life care for adolescents: time to bridge gaps between cultural barriers and palliative care principles
Aldiri I.A.1,2, Moubaied H.3, Hasan H.1, Atta E.1
1NBK Children’s Hospital, Palliative Care Department, Kuwait, Kuwait, 2AUSL Rimini, Palliative Care Department, Rimini, Italy

Background. There has been an increasing effort in Kuwait during the last few years to improve end of life care for pediatric cancer patients, particularly the adolescents, a vulnerable group whom their needs are usually neglected by families and medical professionals.

Objective. In the two case reports of adolescent patients with advanced cancer who were treated in our cancer institute, we will illustrate on the challenges palliative care physicians are facing in providing end of life care in our culture, and the way to overcome such barriers by using open and culturally sensitive communication and adequate symptom management.

Methods. We will demonstrate and analyze our balanced management of the two cases, we initiated an open and empathic communication which respect
family values without dinging patient's autonomy, supported by a good symptom control which aimed to improve quality of life of both patients and their families rather than to prolong patient’s life at any cost.

**Results.** With our respect of adolescent’s capacity and involving him in decision making without ignoring family opinion, with effective and sensitive communication, we managed to discuss some culturally sensitive issues such as death and dying, withholding life sustaining measures, and terminal sedation. We succeeded to bridge the gap between our medical principles and our cultural values, and provide a good quality of care and dignified death.

**Conclusions.** Even in a rich culture like middle east one where cultural beliefs and values play a significant role in people’s life, palliative care physicians can overcome different barriers and improve end of life care for their patients by providing effective symptom control and using open, empathic, and sensitive communication with the adolescents and their families.

### 35

**"We are not alone" - The value of an international education initiative children’s palliative care**

Price J.1, Heywood M.2, McNeilly P.3, Hynson J.4, Quinn K.5

1Queen’s University Belfast, Nursing and Midwifery, Belfast, United Kingdom, 2The Royal Children’s Hospital Melbourne, Melbourne, Australia, 3Queens University Belfast, Belfast, United Kingdom, 4Royal Children’s Hospital Melbourne, Melbourne, Australia, 5Centre of Palliative Care, Melbourne, Australia

**Background and aims.** Policy across countries suggest education is central to future development within Children’s Palliative Care. Numbers of professionals involved in children’s palliative care are fewer than those caring for the adult population. Thus generating numbers to make education programs viable can be difficult. On line learning offers unique learning opportunities to larger number of students. This paper explores an international on line student discussion forum and its impact on learning.

**Methods.** A virtual learning environment for professionals undertaking a postgraduate educational programme in children's palliative care was created, whereby students in Australia and a part of the United Kingdom could learn with and from each other. The moderated discussion forum enabled students to explore current models of care/service provision across the 2 countries. Evaluations were carried out with all students and drew on students views on this type of forum as a means of learning. Ethics committees in both education institutions approved the initiative.

**Results.** A total of 14 students from a range of professions were enrolled on the programmes. Evaluations were positive regarding this teaching method, citing particularly that it enabled a broader perspective of models of care/service and associated challenges in another country much more so than for example reading a paper. Interestingly the challenges experienced across countries and professional groupings were highlighted as similar.

**Conclusions.** High quality palliative and end-of-life care for children is dependent on the availability of a highly skilled, knowledgeable and competent multi-disciplinary team. Educators are therefore charged with the responsibility to ensure a variety of multimodal approaches are used to stimulate meaningful learning experiences, and as such an on line international discussion forum proved its worth. The possibility of further expanding this forum is being explored.

### 37

**Bridging the gap in home care services - The specialist nursing services provided to children with life-limiting neurological disorders in Ireland**

Moran S.1, Nolan S.M.1, Thomas C.1, Ni Mhuchú E.1, Nicholl H.2

1The Jack & Jill Foundation, Naas, Co Kildare, Ireland, 2Trinity College, Dublin, School of Nursing & Midwifery, Dublin, Ireland

**Introduction.** The Jack and Jill Children’s Foundation is the only voluntary organisation in Ireland that provides home specialist nursing care for children under the age of four years who have life limiting severe neurodevelopmental problems and non-oncology palliative care conditions. In this presentation the experiences of expert specialist children’s nurses who provide this nationwide service will discuss the services they have provided to children over the past five years and the challenges faced when doing so. This includes data on the service need and service delivery to the children and their families.

**Methods.** Based on an analysis of organisational statistics the numbers of children who have received care, their gender and diagnosis will be described. This will contextualise the specialist community services required by pre-school children in Ireland who have life limiting and rare disorders.

**Results.** Over the past five years 715 children were referred to the Jack & Jill service. The children had a range of rare inherited genetic and chromosomal disorders and acquired neurological conditions. Over 100 separate diagnoses were identified in the children who received services which indicates the complex nature of providing individualised care and the variation in families needs. Sadly 25% of these children have died, 34% in hospital and over 60% at home with the support of the Foundation. The majority of children passed away in the 1st year of life (n=64%).

**Conclusions.** The services provided to children with complex needs in Ireland and their families will be explored. The need for clear criteria for service provision, clear referral pathways and the development
of a rapidly responsive service to meet the needs of very sick children who may have a short and difficult disease trajectory as a result of a rare diagnosis will be examined.

38
Sleep tight! - Assessment and multimodal palliative care of sleep disturbances and daytime restlessness in children with complex neurological diseases
Otto M., Wager J., Freker M., Garske D., Grumbach-Wendt M., Frerker M., Zernikow B., Chair of Children's Pain Therapy and Paediatric Palliative Care
Paediatric Palliative Care Unit, Children's and Adolescents' Hospital, Witten/Herdecke University, Datteln, Germany

Children with severe neurological diseases in palliative care (PC) often experience persistent sleep disturbances as well as indiscriminate behavioral problems and anxiety during the day. The high prevalence and severity of these bothersome and complex symptoms have an adverse impact on the clinical picture of the underlying disease and impairment of quality of life for all family members. The study “Sleep tight!” was planned to get a better insight on sleep disturbances in this group of children. It is conducted on a paediatric palliative care unit (PPCU) and has three goals: (a) to analyze the sleep behavior of children and their families, (b) to describe the multimodal palliative care at the PPCU and (c) to examine the social factors of families. All children and their parents admitted to the PPCU between April 2012 and March 2013 on are included in the study.

Different survey instruments were employed on three levels: (a) sleep behavior of the children and their parents were assessed by the Sleep questionnaire for neurologic and other complex encumbrance (SNAKE), the Sleep questionnaire for parents of children with complex diseases (SEEK), a 24-hour protocol and the Paediatric Pain Profile (PPP). (b) palliative care, treatment information was gathered from the children’s charts. (c) social factors of the families were assessed by the Questionnaire on the social orientation of parents of disabled children (SOEBEK) and Questionnaire on life satisfaction (FLZ). The measurement will be used at different times: for (a) and (c) at admission and 3 weeks after their discharge; for (b) during the inpatient stay. Due to the clinical relevance, first results of the study can provide guidance for clinical practice. Study results may help to recognize and evaluate the specific needs and symptoms of the children more precisely. Effective modules of the multi-professional PC can be adapted individually and families’ resources can be specifically used for therapy.

40
Professional stress: empathy fatigue in pediatric vs adult oncology staff in Serbia
Klikovac T.1, Steinhorn D.M.2
1Institute for Oncology and Radiology of Serbia, Faculty of Philosophy, Department for Psychology, Belgrade, Serbia, 2Northwestern University Feinberg School of Medicine, Pediatrics, Chicago, IL, United States

Background and aims. Palliative Care is a new and evolving field of medicine in Serbia. Pediatric palliative care is in a very early phase of formal development even as the national agenda for adult palliative care is being currently developed. Health care professionals in oncology are widely believed to be at a greater risk of work-related burnout involving emotional exhaustion, depersonalization and a reduced sense of accomplishment. Our aim was to examine the amount of professional stress and burn-out in pediatric vs adult oncology staff oncology staff.

Methods. Professional stress was estimated with the 25-item Perceived Stress Scale (PSS- Cohen S et al 1983). Burnout was assessed using the Maslach Burnout Inventory/Human Services Survey (MBI-HSS- Maslach C. 1996). Empathy was estimated using the 28-item Interpersonal Reactivity Index (IRI - Davis, H 1983). Additional information was obtained regarding demographic and staff knowledge, education and perceived need for education about burnout, cope with it, communication skills and empathy. To analyze differences between groups regarding ordinal data, the Mann-Whitney U-test or Kruskal-Wallis test was conducted. To determine differences between groups regarding their mean, an analysis of variance (ANOVA) was computed.

Results. 125 women and 11 men (107 nurses/29 physicians) respondents from 3 children’s hospitals in Belgrade and one adult hospital were analyzed. Staff working with adults had the highest level of stress (p<0.01). From the MBI-HSS, staff working with adults also had a higher level of emotional exhaustion and depersonalization compared to staff working with children. Both adult and pediatric oncology workers demonstrated similar empathy. 92% of all respondents were unaware of burn-out or coping skills. 98% had no education in stress management at the workplace.

Conclusions. High levels of stress are present in Serbian oncology staff (adult>pediatric). Staff desire education in burn-out and stress management.

42
“It’s a balancing act”: delivering an interprofessional children’s palliative care programme in Ireland
Nicholl H.1, Tracey C.1, Nic Philibin C.1, Corroon A.M.1, Doyle C.1, Hayes A.1, Malone H.1, Connaire K.2, Price J.3
1Trinity College Dublin, School of Nursing & Midwifery, Dublin, Ireland, 2St Francis Hospice, Centre for Education, Dublin, Ireland, 3Queen’s University Belfast, School of Nursing & Midwifery, Belfast, United Kingdom

The need for education in children’s palliative care is recognised internationally as the requirements for
service delivery for children with life limiting diseases are increasing. In response to national and international directives in palliative care education an innovative modular programme in children's palliative care was implemented in an Irish University.

**Methods.** Ethical approval was obtained to undertake a course evaluation from the multiple perspectives of students, lecturers, stakeholders and employers. Data were collected by formative and summative questionnaires and focus group interviews.

**Findings.** Based on the evaluation of this unique MSc level nine programme it is evident that there is a balance to be struck during its delivery between the expectations of the participants, the course lecturers and course funders. The educational, clinical and professional needs of individuals undertaking the programme also need to be balanced against meeting the needs of the majority of students who may represent a single professional group, usually nurses. In planning teaching there is tension for educationalists between what "needs to be taught" to meet curriculum requirements and what can be "discovered" by using the participant's experiences to focus on their unique learning needs and expectations of course outcomes. In addition a balance needs to be struck in the amount and nature of content as to what constitutes "specialist" children's palliative care and "generalist" palliative care as this is not well defined. In addition the findings indicate that there is a tension between meeting the academic and clinical demands of the programme at this level and the demands of maintaining employment and family life for student participants.

**Conclusions.** Using the research findings the strategies that were implemented to ensure that an effective balance was maintained during the delivery of this programme will be discussed.

### 43

**Outpatient parenteral antibiotic therapy (OPAT) administered by parents to chronic patients**

Madrid A.1, Pelaez M.J.1, Rivera M.2, Escobosa O.1, Aguiar C.1, Leiva I.1, Ramon Y.1, Corripio A.1, Tundidor B.1, Sanchez M.1, Urdà A.1

1Hospital Regional Carlos Haya, UGC Pediatric, Málaga, Spain
2Hospital Comarcal Axarquia, Pediatrics, Vélez-Málaga, Spain

**Introduction and objectives.** Outpatient Parenteral Antibiotic Therapy (OPAT) is defined as the integral treatment of the infectious disease at patients' home. Our study evaluates the characteristics of chronic pediatric patients admitted to the Pediatric Home Health Care Unit of a tertiary hospital in order to determine whether they are eligible for receiving intravenous antibiotic treatment by their parents at home.

**Materials and methods.** A retrospective, descriptive study of patients admitted to HADO (Home Health Care) for outpatient intravenous antibiotic from January, 2000 to December, 2011.

**Results.** There have been 154 admissions for OPAT with an average age of 11.1 years. The average stay at the Unit was 11.8 days. The basal conditions of the admitted children were: 112 cases of cystic fibrosis (72.7%) and 31 cases of tumoral conditions (20.1%). 107 patients (69.5%) have received antibiotics through a peripherally inserted catheter. 251 antibiotics were used, as well as 7 antivirals and 4 antifungal agents. In 97 cases (63%), two antibiotics were used, and three antibiotics were used in 6 cases (3.9%). The most widely used antibiotics were amikacin (41 cases), cefepime (37 cases), and cefazidime (37 cases). Thirteen patients had to be readmitted to hospital; 12 cases were due to clinical worsening, and two of them required surgical procedures. The following incidences were found: 12 cases of phlebitis, 1 broken infusion pump, 1 administration mistake (system not purged), and 1 case of allergy to imipenem.

**Conclusions.** Certain chronic pediatric conditions require multiple and prolonged hospitalizations. Some of these admissions are due to acute exacerbations of infections. OPAT represents a safe alternative to hospitalization; and in our setting, Home Health Care is the adequate healthcare resource for its implementation. Training parents correctly will ensure a better quality of life for these children and their families.

### 44

**Main Caregiver's support in paediatrics palliative care**


Hospital Regional Carlos Haya, UGC Pediatría, Málaga, Spain

**Introduction.** The primary caregiver is the foundation in palliative care. It is important to ensure psycho-emotional support, encouraging the participation of all the family and the social network in the planning and child care with palliative care to avoid extra stress being placed on the family. The work of health personnel is based on the coordination of care, designed to develop independence and autonomy of the child and family, or to supplement the care needed to satisfy their needs.

**Objectives.** 1) Detection of diagnostic and/or problems of the primary caregiver. 2) Resolution of diagnoses and/or problems using standardized interventions and established performance criteria.

**Material and methods.** A review of the cases included in our Paediatric palliative and oncology care follow up clinic between May 2010 and May 2012. An interview assessment of the main caregiver to find the problems encountered - Nursing diagnoses to elaborate the care plan. The methods used are the NANDA Nursing diagnosis taxonomy, NIC Nursing interventions classifications and NOC Nursing outcomes classifications.
Results. During the period described above we provided palliative care to 13 children with oncology disease. On the Nursing process we detected the following Nursing Diagnoses: NANDA
00061: 7/13 cases; 00147: 5/13; 00062: 2/13; 00074: 1/13; 00069: 1/13; 00126: 2/13
We made the following Nursing Interventions:
NOC 7040; 7110; 5440; 6485; 5602; 8100; 8020; 7370; 8190
And we had the following outcomes
NOC 2508; 1307; 2604; 1302; 1813
Conclusions. It is important to assess the caregiver’s strains as they are an essential role in the palliative holistic care plan of the child, and that the condition of the main caregiver has to be addressed independently. To conclude, it is necessary to assess and to predict that caregivers are susceptible of nursing care as part of the Nursing process.

45 Students and lecturers views on the importance of “real world experience” when delivering children’s palliative care education
Nicholl H.1, Connaire K.2, Tracey C.3, Price J.3, Doyle C.1, Nic Philbin C.1, Corroon A.M.1, Hayes A.1, Malone H.1
1Trinity College Dublin, School of Nursing & Midwifery, Dublin, Ireland, 2St Francis Hospice, Centre for Education, Dublin, Ireland, 3Queen’s University Belfast, School of Nursing & Midwifery, Dublin, United Kingdom

Credibility and experience are recognised in the educational literature as tenets of quality when teaching students. However within children’s palliative care education little is known about the need for experience in this subspecialty and its importance in underpinning an effective learning situation. In Ireland an interdisciplinary children’s palliative care programme comprising three 30 hour modules focused on the philosophy, principles and practice of children’s palliative care; on pain and symptom management and psychosocial and spiritual issues were developed. This specialist level programme, delivered at Master’s level for professionals involved in palliative care delivery, and taught by a range of interdisciplinary experts, has been completed by 15 students. Having obtained ethical approval to research and evaluate the programme initial findings indicate that both students and lecturers have expectations about the level of real world clinical expertise in children’s palliative care required to effectively deliver this type of programme. In this presentation the qualitative and quantitative outcomes from focus groups (n=4) with lecturers and questionnaire data from students (n=10) will be examined and discussed. The findings from this evaluation have implications for all those involved in children’s palliative care education. These include the need to locate appropriate professionals with current and relevant expertise in children’s palliative care and to ensure that the clinical expertise of the students is valued in the learning process.

Conclusions. The challenges of delivering specialist children’s palliative care programmes will be described and solutions provided to the difficulties that educationalists can face when planning and implementing “niche” programmes of this type.

46 Home care of children with cancer: review of last 12 years of medical attendance
Hospital Regional Carlos Haya, UGC Pediatría, Málaga, Spain

Introduction. Paediatric Home-Care Units arose as an alternative way of medical attendance which offers a complete care to patients with chronic diseases in their homes, improving the attendance quality and promoting recovery in their environment. We report home attendance provided to patients with cancer at our Paediatric Home-Care Unit (PHCU) for the last 12 years.

Material and methods. This is a descriptive retrospective study of all paediatric patients with cancer treated at our PHCU from January 2000 until December 2011.

Results. We had 258 admissions at our Unit (average: 21.5 per year) from 72 different patients. Ages ranged from 6 months to 18 years (average: 7.7 years) in 7 different care programs: home chemotherapy (83), symptoms control (63), home enteral nutrition (57), palliative care (44), home antibiotherapy (31), home parenteral nutrition (1) and heparinization of central vein devices (10). Most frequent diseases were histiocytosis (59 admissions, 22.9%), meduloblastoma (29 admissions, 11.2%), Ewing’s sarcoma (26 admissions, 10%), neuroblastoma (20 admissions), osteosarcoma (13), rhabdomyosarcoma (13) and brain-stem tumours (11). 145 blood samples were taken at home. During the period of the survey we report 87 re-admissions in hospital, most of which were due to deterioration of the patient’s health or to receive a more intensive chemotherapy regimen. 154 discharges of our unit were given when the therapy was finished. Nine patients died in their homes.

Conclusions. Children with cancer are the main beneficiary of home care, because of their long-lasting disease and multidisciplinary needs. Shortening admission in hospital improves their life expectancy and allows them to spend more time with their families. We don’t report any increase of adverse events, on the contrary we noticed higher patient and family satisfaction and parents got more easily and deeply involved in children’s care.
47 Enhancing the potential of school communities as partners in the provision of paediatric palliative care support
Craig F.1, Boden C.2, Samuel J.3
1Great Ormond Street Hospital for Children NHS Foundation Trust, The Louis Dundas Centre for Paediatric Palliative Care, London, United Kingdom, 2The Latymer School, Head of Learning Support, Unit A, United Kingdom, 3The Child Bereavement Charity, Founder Patron, Buckinghamshire, United Kingdom

Background and aims. In order to provide holistic, patient focused, palliative care, health care professionals must acknowledge the role of a school in the life of a young person, however ill they are, and the role of that young person in the school. Continued attendance and/or involvement in the school community helps young people maintain a sense of their identity and value, as well as facilitating continued access to a peer group and to trusted adults trained and experienced in supporting young people. Poor communication between health care providers and schools means that many young people miss out on this important aspect of their lives and on the support that can be provided through their school community. This project aimed to develop a program for health professionals and school staff, to facilitate the provision of palliative care support through schools.

Methods. Through literature review and work with individual schools and families, key themes were identified that facilitate continued involvement of young people within the school community and optimise the provision of appropriate support.

Results. Key themes identified: 1) Developing Personal Health Care Plans to facilitate school access. 2) Sharing information with staff, students and within the wider school community. 3) Education, training and support for school staff, that enables them to support the student, and other students, in school and during school absence. 4) Preparation of the young person, other students and staff for bereavement and the provision of bereavement support in school. 5) Assistance to identify appropriate support pathways for staff and students

Conclusions. By addressing the key themes, schools can contribute significantly to the delivery of palliative care for young people, enabling them to maintain a valued role within, and receive support from, their school community. Authors posts are funded by education services and NHS. Ethics approval not required.

48 Advance care planning in pediatrics - A systematic review
Lotz J.1, Jox R.J.2, Borasio G.D.3, Fuehrer M.1
1Ludwig-Maximilians University Munich, Coordination Centre for Palliative Care, Children's University Hospital, Munich, Germany, 2Ludwig-Maximilians University Munich, Institute for Ethics, History and Theory of Medicine, Munich, Germany, 3Centre Hospitalier Universitaire Vaudois, Service de Soins Palliatifs, Lausanne, Switzerland

Research question. Relevance of pediatric advance care planning (pACP) is increasing. Adult programs, however, cannot be simply applied to children and adolescents. Complicating factors include prognostic uncertainty, reluctance to address the issue, legal incompetence and social complexity. Our aim was to assess current practices and outcomes of pACP.

Methods. We conducted a systematic review, following the PRISMA requirements. We searched PubMed, BELIT and PSYClino for empirical literature on pACP, published 1991-2012. Titles, abstracts and full texts were screened by three independent reviewers for studies reporting measures on pACP. The evidence level of the studies was assessed. Relevant study outcomes were retrieved according to theoretically defined and pilot tested questions.

Results. We included six qualitative and seven quantitative studies. Only three pACP programs were identified, all from the U.S. Two of them were informed by adult programs. Major pACP-features are: Formal sessions with the families meeting with a trained facilitator, an ethicist or an interdisciplinary team, and advance directives. A chaplain, an ethics committee and other providers may be referred to if required. Programs vary in how well they are implemented and evaluated, with only one randomized controlled trial. Preliminary data suggests that pACP can successfully be implemented and is perceived as helpful by families and patients. Positive effects include facilitation of communication and decision-making, and emotional relief. Problems reported are negative reactions from schools, the community and emergency services. Elements of pACP are not very common in regular pediatric care.

Conclusions. There are few systematic pACP programs worldwide and none in Europe. Future research has to investigate the needs of all stakeholders: patients, families, facilitators of pACP and recipients of advance directives. Particularly, the perspective of professionals has been totally neglected.

50 End of life pathways: an audit of compliance and its implications
Ryance K.1,2, Smith H.3, Mayer A.4
1Sheffield Children's Hospital NHS Foundation Trust, C/O Aunton Mayer - PCCU, Sheffield, United Kingdom, 2Royal Hospital for Children, Sheffield, United Kingdom, 3Sheffield Children's Hospital NHS Foundation Trust, PCCU, Sheffield, United Kingdom

Background. Development of paediatric end of life care pathways (EOLP) have led to improvements in care and greater understanding of end of life management. Following introduction of a paediatric EOLP (2009) in our Trust a previous audit found standards eg pre-emptive prescribing were not being met. Since appointment of a palliative care consultant, EOLPs have become increasingly used. By audit we aimed to reassess the standards of completion and possible implications for non-completion of an EOLP within our region.

Methods. All patients with an EOLP who died at hospital, local hospice, and in community (Jan 2010-Feb 2012) were eligible. The EOLP, medical notes, and pharmacy records were reviewed against a pro-
The place of death was hospice in 61% of cases, hospital in 21% of cases and in the community in 18%. Children were on EOLP for a median time of 6.5 days, and a limitation of treatment agreement (LOTA) for a median time of 12.5 days. Communication with GP was reasonable but requires improvement (93% GPs informed of death, 82% informed of EOLP). Pre-emptive prescription improved (93%) and non-essential discontinuations (96%). Poor recording of Diagnosis on EOLP (50%). Finally, encouragingly, the issuing of a Palliative care drug box was facilitated (100%).

Conclusions. EOLP are increasingly widely used. Previous audit identified poor pre-emptive prescribing, and this audit has shown improvement. Some aspects of the EOLP remain poorly completed although it is unclear whether this reflects care delivered. Improvements could be made to the layout/structure of EOLP to encourage better completion. Further education is required to teach people throughout the region the importance of EOLP and their completion.

52 The Charon myth: should we, as doctors, be the ones to put the coin in our patient’s mouth?

Villa M., Bengoechea C., López J., García M., Cilla C., Soriano M., López-Íbor B.

Hospital Universitario Madrid Montepríncipe, Pediatric Oncology, Madrid, Spain

Purpose. The purpose of this poster is to show how some of the incurable and hopeless patients coming to our pediatric oncology unit seeking care, may survive the time needed for their family to accept dying or they might just survive, in spite of having been sentenced.

Methods. The charts of 15 patients (5–19 yo) coming to our pediatric oncology unit from 2003 to 2012 seeking for care under palliative conditions were reviewed.

Results. Diagnosis were: 11 BT, 2 ALL, 1 stageM NB and 1 disseminated Ewing tumor. 8 have DOD, one died in CR from influenza A infection, and 7 are alive, 3 in CR, 2 with SD and 2 in PR. 5 were asymptomatic when first admitted, 6 had moderate to severe neurological sequelae from previous treatment at their reference hospital, one was septic, one had pleuritic pain and 3 came with terminal sedation. The main reason for parents to come to our unit was the feeling of being abandoned by their previous doctors, being all aware of the theoretically end-stage disease status. Treatment included surgery, radiation, chemotherapy or monoclonal antibodies. Upon the 8 patients that eventually died, mean time to death was 14 months (1-39m). Among the 7 patients surviving, mean time is 121 months (1-60 m). HRQOL adapted PQOL 4.0 scale was used to measure QOL. Phisical, educational, social and spiritual needs of patients and their families were taken care of by a team of professionals. Parents are followed systematically after their children’s death in specifically designed parent’s groups.

Conclusions. When we are faced with a child with an incurable disease at his/her theoretical end-stage status, we are due to listen and to act. Our main objective is to fulfill the children and their families needs. They are certainly the judges of our work as doctors at the end of the line.

53 Music and medicine in palliative care: music therapy as facilitators of communication in the dying process of adolescents with cancer

Bengoechea C., Soriano M., Hernández A., Lopez-íbor B.

Hospital Universitario Madrid Montepríncipe, Pediatric Oncology, Madrid, Spain

Aims. In palliative care the child and the family need to say goodbye, feel, experience, share and set free the emotions that this process produces in them. Symbols, images and music perform a very important role in this moment. They help the child to identify, project and experience what they usually cannot or find difficult to say with words. This presentation shows how music therapy helps two adolescents in palliative care in a paediatric oncology unit. In both cases we could do a previous work on Music Therapy using active techniques such as improvisation, instrumental practice, song writing, as well as receptive techniques such as relaxation or listening to diverse music styles and translate them into some art project or guide imagery and music. The first case is a 17 years-old girl diagnosed with osteosarcoma, who started with palliative care after two years of treatment. Music therapy sessions allowed her to experience imagery and project scenes that helped her to face her real situation and talk about it as well as understand and share it. Furthermore, it allowed the patient to get through her most relevant needs facing her death. Ultimately music therapy techniques offered the patient the opportunity of living her own dying process in a more functional way. The second case is a 15 years-old girl with a brain stem tumour, who lost mobility along the illness process and eventually lost speech until she even had no speech. The progression of the illness allowed the girl a better psychological and emotional approach to palliative care phase. Nevertheless we had to face the fact that she could not talk about nor express her feelings. In this case music therapy enabled the patient to name and feel what she could not name in any other language but was perfectly aware of.

Conclusions. Music therapy we used in both cases as well as its usefulness to encourage deep communication processes within the work of paediatrics palliative care.
54 Challenges on European Pediatric Palliative Care
Santos M.J.1, Mendes J.2
1Atlantica University, Lisbon, Portugal, 2São Francisco Xavier Hospital, Lisbon, Portugal

Background and aims. Reflect about the state of pediatric palliative care across Europe and identify some of the main challenges to move pediatric palliative care forward.

Methods. Personal reflection based on the experience from the first and second International Multi-professional Pediatric Palliative Care Course (held on Germany 2009 and 2012) and bibliographic research.

Results. Pediatric palliative care (PCC) development is quite different depending on the country and the patient setting (Oncology, Pediatric Intensive Care, Neonatology). Nevertheless we can identify some of the common challenges such as: 1. Misunderstood of the concept of pediatric palliative care in the medical and social culture; 2. Different eligible criteria, ally to a small numbers of patients and a big geographic dispersion of families; 3. Few healthcare professionals and teams with specific competencies and training on PCC; 4. Lack of community resources that can help families when they are discharged home; 5. Global economic crises that increases difficulties in getting fundraising PPC projects; 6. Need assessment of each country is required; 7. Few research developed and internationally published in PPC; 8. Few pre and pos graduate training programs available for health care professionals (diversity of programs across Europe).

Conclusions. Although the diversity of cultural, social, political, technological and scientific scenarios across Europe, pediatric palliative care challenges can be transversal to each country. In our opinion, in order to developed European PPC, EAPC pediatric task force, should encourage the development of an international, strong and consistent network. This network could enhance synergies between experts from different settings promoting research, problem sharing and problem solving that could help moving pediatric palliative care forward in their countries in a common European language.

58 Paediatric palliative care: pilot project in the Balearic Islands
Tavera A.1, Fullana R.M.1, Daviu A.M.1, Salinas J.A.1, Guibalalde M.1, Benito E.1, Flaquer N.3, Joan F.1
1Hospital Universitario Son Espases, Palma, Spain, 2Estrategia Balear de Cuidados Paliativos, Palma, Spain, 3Hospital San Juan de Dios, Palma, Spain

The number of life-threatening diseases in the paediatric population has increased in the last decades. In Spain, there are only two multidisciplinary teams (in Hospital Niño Jesús of Madrid and in Hospital San Joan de Déu of Barcelona) attending to the needs of the children with life-threatening diseases and their families. In the Balearic Islands we only have a palliative care programme for adults. In January 2012 we started a pilot project on paediatric palliative care in Mallorca with the duration of 1 year. The aim of this project is to evaluate the real need, viability and efficacy of a specific paediatric palliative care team in Mallorca. With this communication we want to share the development of this project and the results from the first 5 months. The project is carried out by a multidisciplinary team consisting of a paediatrician, a nurse and a psychologist. This team works as a hospital-based team and attends the physical, psychological and social needs of the patients and their families.

Results. From January to May 2012 we registered 23 patients, of whom we attended 17. The diagnoses were: 5 (22%) diseases of the nervous system (2 spinal muscle atrophy, I muscular dystrophy and 2 neurodegenerative diseases), 5 (22%) sequelae of prematurity, 4 (17.3%) congenital malformations, 3 (13%) heart diseases, 3 (13%) neoplasms, 1 (4.3%) cystic fibrosis, 1 (4.3%) neonatal asphyxia and 1(4.3%) metabolic disease. Seven of these children died in the hospital (5 in neonatal intensive care unit, 1 in oncology department and 1 in his country). None of the children died at home.

Conclusions. This project reflects that there is an important amount of children in Mallorca that would benefit from the care of a specialised multidisciplinary team of paediatric palliative care. This team should grow in members in order to take care of all the children that need it, and also to attend the families 24 hours a day, 7 days a week and also to offer the possibility of home care.

60 Evolution of a paediatric palliative care unit (PPCU)
Ortiz J.1, Navarro S.1, Palomares M.1, Albert M.2, Badosa R.3, Solé A.4, Cuerva A.5, Escobar M.R.1
1Hospital Sant Joan de Déu, Paediatric Palliative Care Unit, Barcelona, Spain, 2Hospital Sant Joan de Déu, Psychiatry, Barcelona, Spain, 3Hospital Sant Joan de Déu, Social Work, Barcelona, Spain, 4Hospital Sant Joan de Déu, Spiritual Support Department, Barcelona, Spain, 5Hospital Sant Joan de Déu, Head of Special Care Area, Barcelona, Spain

Introduction. Although the increasing interest in paediatric palliative care (PCC), important deficiencies exist if we compare it with PC provided to adults. There are few specific PPCU and taboos surrounding children death still influence both society and medical community. The aims of this study are to expose the evolution of a PPCU unit after 21 years, to describe the influence of the national and international advances in PPC and to identify the principal improvements achieved.

Methods. Descriptive retrospective study based on the records of activity of the PPCU of a tertiary care hospital.

Results. The PPCU of our hospital was founded in
Assessing the need for a community-based pediatric palliative care team in Moscow. The mobile palliative service

Kumirova E.1,2, Sonkin A.1

Background. In 2011 a service to provide multidisciplinary home-based palliative care to children with nonmalignant life-limiting diseases in Moscow was created. The study was conducted to assess the need of these children in Moscow for community palliative care based on the Service's experience.

Materials and methods. From December 2011 to May 2012 the service was accessed by 42 patients (1 to 21 years old), 35% (15) had mucopolisaccharidosis (types 1,2,3,6), 26% (11) - severe cerebral palsy, 19% (8) - Duchenne muscular dystrophy, 12% (12) - spinal muscular atrophy (types 1 and 2), 7% (3) - other. The services offered included a nurse (1-2 visits per month), social worker (2 visits per month) and physician and psychologist consultations as needed. The team consists of nurses, physicians, social workers, a psychologist and an administrator. During 5 months of the service's functioning there were 205 visits by all the team members. 82 telephone consultations were given. A questionnaire was developed that assessed the need for various elements of palliative care and satisfaction with current service provision. 68% of respondents experience a need for home-care nursing, 61% feel a lack of psychosocial support, 61% experience financial difficulties, 61% need legal support, 67% answered they would welcome a 24-hour telephone line, 78% don't want to talk about advance planning and would avoid difficult conversations.

Results. The results show that there are various unprovided needs in families of patients with life-limiting conditions in Russia, part of which are not specific to palliative care (community nursing, financial difficulties). This might mean that apart from palliative care there are general health care needs that are not available in Russia. Further analysis of reasons for visits/consultations can show whether and how the deficits in general health-care affect how patients and families acknowledge their need for palliative care and are ready to accept it.

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Provision of pediatric palliative care in Portugal

Lacerda A., Rodrigues F., Gaspar E., Pedrosa E.

Portuguese Institute of Oncology - Lisbon, Pediatrics, Lisboa, Portugal

A recent article (Sept11) by Knapp et al placed Portugal in level 1 of provision of Pediatric Palliative Care (PPC), the only western European country not a level 3/4. We aim to demonstrate that this is not the case, and that Portugal is clearly in level 2 (capacity building activity), if not a burgeoning level 3 (localized provision).

Since at least 2005 there a growing interest in training (mainly from nursing) and in developing service provision. Nationwide there have been 1-2 day courses/symposia on PPC. Some PC MSc’s and Post-Graduations have classes/modules on PPC. One of the author’s (AL) is an MSc student at KCL/CSI. In 2009 the Portuguese Catholic University of Oporto organized an International Congress - “Pediatric Palliative Care: Realities and Challenges”. The Portuguese Association of Palliative Care (APCP) regularly incorporates PPC workshops/conferences in its annual meeting. There are no pediatric hospices or specialized teams. Some tertiary Departments (mostly Pneumology and Neonatology) have teams that provide supportive care at home.

Our Pediatric Oncology Department has a formal PC program, focused on providing home-based and/or local care, integrated with the National Network for Continuous Care (GP’s) and local hospitals using existing resources in adult palliative care and community health providers; to our knowledge, it’s the only in the country. The main problems we face are communication issues (families and adolescents) and lack of psychological/spiritual support. The national parent’s association (ACREDITAR) is setting up a voluntary-at-home program. We have also put an effort into education of other professionals as well as fami-
lies, for whom we have written self-help booklets. Much of our training has been supported by grants from Gulbenkian Foundation. Maybe as a result of these efforts, the 2011-2013 Development Strategy for the National Palliative Care Program recognizes for the first time the need to develop pediatric services.

63 I don’t want to be an angel, I want to be a F-1-pilot... How to care for spiritual needs in pediatric palliative care. A web-based ontology of spirituality

Shieh T.1, Führer M.1, Borasio G.D.2, Kunzmann C.3, Schmidt A.3, Roser T.1

1Ludwig-Maximilians University Munich, Coordination Center for Palliative Care, Children's University Hospital, Munich, Germany, 2Centre Hospitalier Universitaire Vaudois, Service de Soins Palliatifs, Lausanne, Switzerland, 3FEZ Research Center for Information Technologies, Karlsruhe, Germany, 4Ludwig-Maximilians University Munich, Interdisciplinary Center for Palliative Care - Spiritual Care, Munich, Germany

Background. 73% of severely ill children’s parents name spirituality, religion, and religious rituals as most helpful in their situation (Robinson et al., Pediatrics 2006). This paper describes spiritual concepts and spiritual needs in a Specialized Outpatient Pediatric Palliative Care (SOPPC) service.

Data. We retrospectively analyzed 143 patient records of a German SOPPC service. Within these records, physicians, social workers, and chaplains documented contacts with children and their families (2004 to 2009). Sections: Sociodemographic data, Medical report, Nursing, Social work, and additional information. Although spiritual care is not addressed in a separate section, spiritual, religious, and cultural aspects could be found throughout the records.

Methods. The methodology was developed following an IT-based ontology. All data relevant for cultural, religious, and spiritual aspects are collected and structured, leading to a comprehensive concept of spirituality within the SOPPC team. (macro-level). On the micro-level individual case-studies can be described.

Results. 1. The spirituality of the child may differ from the spirituality of the family, also there can be different spiritual needs. Spiritual-care-interventions can address the child, the family or both. 2. Main topics concerned implicit spiritual needs (beyond faith) in issues of culture, concepts of “family”, understanding of death, quality of nursing, etc. 3. Explicit spiritual themes were: “Why?” (mostly combined with: “Who is guilty?”), almightiness/helplessness, transcendence, eternal love, eternity/finiteness. Analyzing cases based on this ontology helps focus spiritual-care-interventions to specific needs: ritual, pastoral counseling, meaningful silence, spiritual guidance.

Discussion. The ontology indicates how to create appropriate interventions within SOPPC. It provides a model to describe concepts of spirituality and to integrate spiritual care into pediatric palliative care.

65 Comorbidities and palliative care

Cora F.1, Buzoianu E.2, Cavache A.3, Moiceanu M.3, Iancu M.3, Hurduc V.4, Plesca D.A.3

1“Dr. Victor Gomoiu” Children’s Clinical Hospital, Pediatric Neurology, Bucharest, Romania, 2“Dr. Victor Gomoiu” Children’s Hospital, Pediatric Neurology, Bucharest, Romania

Aim. Children with medical conditions that are subject to palliative care (neurological diseases due to genetic or nongenetic causes) require often admission in our hospital with respiratory, digestive, renal, metabolic or neurological disorders. These cases often need prolonged hospitalization period because of various comorbidities, that are increasing the degree of difficulty in providing medical care for these children.

Methods. We have completed a retrospective descriptive study including 15 children with neurological diseases subjected to palliative care in “Saint Margaret ” Hospice, admitted in our hospital between June 2011 - May 2012 due to respiratory, urinary or digestive infections, dehydration, hydrolelectrolitic imbalance or seizures. We have calculated the average hospitalization length for each patient and compared this with the average hospitalization length for these conditions in children without neurologic condition. Also we have underlined comorbidities that are causing the increase in hospitalization length in each case.

Results. Malnutrition, uncontrolled epilepsy, neurologic swallowing disorders, excessive muscle spasticity, bone and joint deformities, prolonged sitting, mouth malformations, constipation are increasing the average hospitalization length and medical resources involved.

Conclusions. Comorbidities in children subjected to palliative care are increasing the difficulty of medical care.

67 Clinical presentation and management of recurring acute dyspnea with inspiratory stridor in pediatric patients with neurodegenerative diseases

Nickolay C., Eibauer C., Rümmelein N., Kyber C., Schnittgen S., Berger E., Führer M.

Dr. von Haunersches Kinderspital, Ludwig-Maximilians-University Munich, Coordination Center for Pediatric Palliative Care, München, Germany

Background and aim. One of the most distressing symptoms in children with severe progressing neurological disease is acute dyspnea with inspiratory stridor. We describe the clinical presentation and
management of acute dyspnea with stridor in four patients in an outpatient setting. **Methods.** We retrospectively analyzed the charts of four patients (age 5 months - 12 years) who presented with episodes of acute dyspnea accompanied by inspiratory stridor. The patients were treated by a Specialized Outpatient Palliative Care (SOPC) team for children. Two patients suffered from cytochrome -c-oxidase deficiency, one from unclassifiable leukodystrophy, and one from an unclassified neurodegenerative disease. **Results.** In the beginning dyspnea was present in all four patients only with effort but increasingly while at ease. There was no evidence of infection, chronic pulmonary disease or aspiration. Mild to severe spasticity was present in all patients. During the episodes of dyspnea the patients suffered from a transient upper airway blockage caused by a dystonic collapse of the larynx. Changing body position and jaw-thrust maneuver temporarily alleviated the symptoms. Benzodiazepines and morphine were effectively used in all patients to reduce respiratory distress. While beginning with oral or mucosal application of lorazepam or diazepam, all patients had to be switched to a continuous subcutaneous infusion of midazolam with on demand bolus application in addition to oral or subcutaneous morphine. Increasing dosages of midazolam were necessary for symptom control. Three patients were treated with baclofen with no apparent effect on dyspnea. **Conclusions.** Acute dyspnea with inspiratory stridor was successfully managed with continuous subcutaneous midazolam application in addition to morphine. Further studies are necessary to better describe and treat patients with obstructive dyspnea in neurodegenerative disease.

68 History, implementation and first results of a regional comprehensive concept for pediatric palliative care in Bavaria, Germany

Führer M.1, Duroux A.1, Grasser M.1, Borasio G.D.2, Scheurlen W.3, Working Group for Pediatric Palliative Care in Bavaria

1Dr. von Haunersches Kinderspital, Ludwig-Maximilians-University Munich, 2Center Hospitalier Universitaire Vaudois, Service de Soins Palliatifs, Lausanne, Switzerland, 3Cnopf’sche Kinderklinik, Nürnberg, Germany

**Background.** In Germany since 2007 patients with life limiting, advanced diseases and complex palliative care needs qualify for specialized outpatient palliative care (SOPC). However, there is still a lack of comprehensive concepts for pediatric palliative care (PPC). Most children with life-limiting diseases still die in hospital. To promote and implement PPC in Bavaria (12.5 million inhabitants), the Working Group (WG) for PPC in Bavaria was founded in 2006. **Project description.** In 2009 the WG developed the first German comprehensive concept on "Palliative Care in Children and Adolescents", which was adopted by the Bavarian Health Ministry. The concept was based on the 5 year experience of the Coordination Centre for PPC in Munich. The core of the concept is the implementation of 6 multi-professional PPC teams consisting of a minimum of two full time specialized pediatricians and pediatric nurses, and one health care coordination specialist. The PPC teams provide SOPC district wide and counselling in end-of-life decisions and PPC in the regional children’s hospitals. **Results.** Three years after introduction of the concept 4 PPC teams have been implemented and are funded by the statutory health insurances. Major challenges in the implementation of a spatially inclusive and comprehensive PPC were: lack of specialized staff, implementation of a 24/7 on call service, and long distances in rural areas. Strategies to overcome these challenges were: cooperation between the children’s hospitals of a local area to establish a joint PPC team, cooperation and coordination of local resources e.g. pediatricians in private practice and family doctors, regular meetings of the WG to exchange experience and provide continuing education in PPC. **Conclusions.** A regional WG on PPC can facilitate trans-institutional cooperation and coordination of resources to successfully implement and institutionalize PPC teams as a comprehensive structure within the health care system.

71 Role of emergency resuscitation plan (ERP) at a children’s hospice

Anderson A.-K.1,2, Menezes T.2

1Royal Marsden Hospital, Sutton, United Kingdom, 2Shooting Star Chase Hospice, Guildford, United Kingdom

Emergency resuscitation plans promote early discussions around resuscitation enable low level, as appropriate treatments and avoid inappropriate and invasive interventions. **Aim.** To consider the role of emergency resuscitation plans (ERP) in a children’s hospice setting. **Methods.** The medical records of all children and families under the care of a children’s hospice service referred between 1st May 1999 and 5th August 2010 were retrospectively reviewed. Cases where the child had either been discharged from the service or the child had died. We reviewed all the available medical records for the presence of ERP and the decision made at the final review. For the purposes of the study the children were allocated into cohort disease groups based on their primary diagnosis. **Results.** There were 875 children referred to the hospice during the review period; 585 closed cases. Of the 292 open cases, 45 medical records were not available. Of the 247 cases reviewed, 120 were female (age range:0- 22 yrs and 70 bereaved families). ERP were present 206 (83%) cases; 174 (70%) were
for full resuscitation (FR), 19 (8%) were not for full resuscitation (NFR). 24 (13.7%) children with FR had died (62.5% in hospital; 37.4% at home/hospice). 12 of 19 children with NFR had died (83.3% at home/hospice; 16.6% in hospital; statistically significant with p-value=0.032). In 25 of 41 cases where there was no ERP the child had died. Contemporaneous discussions about ERP were documented in the medical records.

**Conclusions.** Where NFR were in place it appeared to predict that the child was more like to die. Furthermore it was statistically more likely that the child would die in the community. ERP are effective tools for supporting families and hospice staff in planning place of care. From our review, the presence of NFR ERP may be a useful predictor of the last year of life and may affect the place of care at end of life.

**72 Engaging and sustaining a parental user group engagement in a paediatric palliative oncology service**

Anderson A.-K.
Royal Marsden Hospital, Sutton, United Kingdom

In 2009, a bereaved parent users group was established to guide a tertiary Paediatric Palliative Oncology care service (PPOC) on how to obtain formal feedback from families. The group's involvement and success in gaining valuable feedback from families, led to an expansion of its role into supporting other areas of the service.

**Aim.** We describe the process of engagement and sustenance of a Parental user group in a PPOC service.

**Methods.** An invitation letter at the inception of the group, was sent to parents already actively involved in a bereaved parents support group (12 active parent members). It was also sent to 2 parents who had expressed a desire to support the service. The group attended quarterly evening meetings at the tertiary centre. In early 2012 a further recruitment letter was written by the group and sent to bereaved parents whose children had died between 5 years and 15 months previously. Ten parents were excluded for various reasons.

**Results** Initially there were 8 parents. After 2 years, the core number dropped to 4 parents. In early 2012, 53 letters were sent out to parents. We received 11 (21%) replies. 3 parents wanted no further contact. One parent wanted to be involved but did not want to attend meetings. One parent, whose child had died 15 months before wanted to be involved but felt it was too soon. Six parents (11%) wanted to attend future meetings.

**Conclusions.** Timing and the communication approach is key to maximising engagement of parents. Invitation to join appeared to suggest a minimum of 18 months post-bereavement. Attrition is an issue with planned letters to parents bereaved 18 months to 2.5 years previously. Face to face meetings were appropriate for some parents and an email group has been set up to widen the participant group. A response rate of greater than 10% affirms the view that parents want user involvement palliative care services.

**74 Palliative care for children in Russia: from a dream to reality**

Vvedenskaia E.1,2, Sokolova E.2

1Nizhny Novgorod Society for Palliative Care, Nizhny Novgorod, Russian Federation, 2State Medical University, Nizhny Novgorod, Russian Federation

Palliative care in Russia is an emerging public health approach that focuses on achieving the best possible quality of life for children with life-limiting and life-threatening conditions and their families. The aim of our study was to describe palliative care for children state of art and the progress made in past 2 years as well as perspectives for its development. We adopted a multisession approach, which involves the synthesis of evidence from published literature, the Internet resources, local experts' interviews and personal communication. Data have been gathered from the following sources: 1) published articles in peer reviewed and professional journals; 2) books and monographs; 3) palliative care directories; 4) palliative care web sites; 5) grey literature and conference presentations; and 6) the experts' opinions. The data were analyzed using the typology's key elements and the country was allocated to the category: in transition from capacity building activity to localized provision (M. Wright et al, 2007). There is evidence of wide-ranging initiatives designed to create the organizational, workforce, and policy capacity for hospice-palliative care services for children to develop. Great progress has been made in the past 2 years - palliative care provision has been legalized on the national level and considered to be one of the main approaches of medical care by the Federal Law on Health in the Russian Federation for the first time in 2011. The Order on palliative care for children provision in the country is almost ready to be drafted by the Health Ministry and palliative care experts. Some good palliative care programmes for children are in progress and children's hospices and scheduled to be set up in 74 regions.

**79 Maluba House: model of Paediatric Palliative care in Sub-Saharan Africa**

Meade T.J.1, Kaonga W.2, Tiwari A.3, Eswaran H.3

1Tiny Tim and Friends Zambia, Lusaka, Zambia, 2Ministry of Health, Lusaka, Zambia, 3Our Lady's Hospice, Lusaka, Zambia

**Background and aims.** In Sub-Saharan Africa with its HIV epidemic, there has been a significant in-
crease in the occurrence of total childhood cancers, mostly due to a significant increase in paediatric Kapost's Infection. There are very few services offering basic paediatric palliative care in Zambia. Most children are sent home to deal with their pain, and offered very little psychosocial or medical support to manage their symptoms. Maluba House provides a pediatric palliative care model that links the acute care centre, paediatric palliative care (PPC) unit and community.

Methods. Maluba House works closely with the acute care centre, which refers children for pediatric palliative care. Children are admitted from the acute care hospital and holistic symptom control is addressed. Primary caregivers are trained in wound care, pain and symptom management, and are assessed by the team of psychosocial counselors. They are paired with a PPC-trained community caregiver and discharged to home. The community-caregivers work closely with children in their homes, ensuring that provision of palliative care does not end upon discharge from Maluba House. Maluba House also acts as a vital staging facility for children discharged from acute care but residing outside of the capital city, Lusaka.

Results. Since July 2011, over 70 children with life-limiting and life-threatening illnesses have been admitted to Maluba House for pediatric palliative care. One mother comments: "With pain control and wound care, my son was able to spend much of his last 6 months of life at home. At the time of his final re-admission to Maluba House and his death, we also felt at home with the Maluba House Family."

Conclusions. Maluba House model has been successful in that it has linked hospital to hospice to home-based care, allowing children and their families to spend more time at home without sacrificing pain or symptom management.

81 At what age do children understand death? Preliminary findings from the Czech Republic

Loucka M., Payne S., Brearley S., on behalf of EURO IMPACT

Lancaster University, The International Observatory on End-of-Life Care, Lancaster, United Kingdom

Background. The knowledge of how children understand death is important for discussion with paediatric patients, their siblings and parents. The literature suggests that the concept of death is usually fully developed around the age of 9 years.

Aim. The aim of this study was to assess the development of a children's concept of death and the influence of children's death anxiety, parental anxiety and communication about death in families.

Methods. 71 healthy school children aged 6-9 years were recruited to participate in a mixed methods study undertaken in the Czech Republic. A structured interview method measuring the development of a concept of death on a scale of 1 to 10 (Death Interview) was used. Data were also collected on children's death anxiety, parental anxiety and communication about death in families.

Results. Most children understood the concept of death very well (Mean 8.15, SD=1.154). There was no significant difference in the development of death concept between age groups in children. No significant relationships were found with other variables such as death anxiety or communication about death in families.

Conclusions. These results suggest that the age of acquisition of a concept of death is younger than previously reported in the literature. This may be attributable to increasing exposure to media and internet representation of death among children. This has implications for communication between professionals and paediatric patients and their families.

83 Management of patients in the terminal phase of disease. Experience of the Pediatric Oncology Unit at Istituto Nazionale dei Tumori in Milan

Polastri D., Catania S., Biasom V., Casanova M., Ferrari A., Lukusch R., Mezza C., Podda M., Schiavello E., Spreatico F., Terenzi M., Massimino M.

Fondazione IRCCS Istituto Nazionale dei Tumori, Milano, Italy

Introduction. We evaluate type of assistance performed in all case of died due to malignancy with the aim of verify the different ways of managing problems of patients in terminal phase of disease.

Patients and methods. At the Paediatric Unit of the National Cancer Institute of Milan in-patients and out-patients access for a new diagnosis of pediatric solid tumours are over 200 for year, most of them (about 60%) comes from Lombardy. During the triennium 2009-2011 133 of our patients entered in the end of life phase. 83 of them (62%) was resident in Lombardy and 50 in other regions. Data collected for this observational study are: age, diagnosis, principal place of care was our Unit, home for 37 patients (28%) and other Hospital for 15 patients (10%), 18 patients (14%) died in our Unit, 55 patients at home (41%), 48 at another Hospital (36%) and 12 at the hospice (9%). Patients followed by home health care system, few of them in cooperation with family physician, was 62/135 (47%). Principal symptoms was unknown for 8 patients, for the remain 125 pain was notice in 117 patients (94%) and dyspnoea in 30 patients (24%)

Conclusions. On one side we cannot intervene on clinical reasons (rapid worsening of clinical condi-
Family management when a child is undergoing palliative care at home

Bousso R.S., Misko M.D., Mendes-Castillo A.M.C., Rossato L.M., Santos M.R.D., Interdisciplinary Nucleus for Research in Loss and Bereavement - NIPPEL

University of Sao Paulo, Maternal and Child Nurses, Sao Paulo, Brazil

Palliative care settings in many countries acknowledge families as their prime focus of care, but in Brazil, to date, researchers have devoted scant attention to that practice setting. In this article, we report the findings of a study that explored how families define and manage their lives when they have a child undergoing palliative care at home. Data included individual semistructured interviews with 14 family members of 11 different families. Interviews were transcribed and the coding procedure featured qualitative content analysis methods. The deductive coding was based on the major components of the Family Management Style Framework and the eight dimensions comprising these components. The analysis provides insight into families’ daily practices and problems inherent in managing their everyday lives that are encountered when they have a child in palliative care. The article features discussion of implications for the palliative care related development of family nursing practice.

Everyday ethics in bereavement research

Bousso R.S., Rossato L.M., NIPPEL - Interdisciplinary Nucleus for Research in Loss and Bereavement

University of Sao Paulo, Maternal and Child Nursing, Sao Paulo, Brazil

Qualitative research with bereavement family members has been conducted. Challenges and ethical consideration should be discussed. This presentation will be a description of the experience of conducting family interviews in two studies. Both study procedures were completed in accordance with the protocol approved by the hospital’s Institutional Review Committee. The original studies used as a theoretical reference the Symbolic Interactionism, and the Grounded Theory methodology. The first study was developed in order to understand those families’ experience when their consent is asked for the donation of their child’s organs. Thirteen families, a total of 38 individuals, were interviewed. The second study explored how families define and manage their lives when they have a child undergoing palliative care at home. Data included individual semi-structured interviews with 14 family members of 11 different families. This paper presents and discusses ethical dilemmas about strategies for family recruitment, conduct of family interviews and family-level data analysis. Interviewing families with children in end of life presents many challenges. First, we recognized that participants in the study would be undergoing a period of considerable stress. In addition, we recognized that it was essential for family members to perceive the researcher as a knowledgeable and caring individual, someone who would respect participants’ privacy and ensure that they would be protected as far as possible from any adverse consequence of their participation. It was essential that interviewers had the expertise to conduct interviews in this manner. A person that is well qualified to do so, having a solid knowledge base in ethics decision making and family systems and a clinical specialization in end of life. Families with a child in end of life stage may experience periods of uncertainty that diminish their ability of foreseeing future life perspectives and thus making decisions.

Parents’ perceptions of quality of life in families having a child in palliative care at home

Bousso R.S.¹, Misko M.D.², Rossato L.M.², Santos M.R.D.²

¹University of Sao Paulo, Maternal and Child Nurses, Sao Paulo, Brazil, ²University of Sao Paulo, Maternal and Child Nursing, Sao Paulo, Brazil

The past few years have seen a growing appreciation of palliative care. Families of gravely ill children can feel abandoned and overwhelmed, often suffering emotional consequences for years to come. In Brazil, supports to children and families before and after death are woefully inadequate, and health care professionals themselves are often left without emotional support for the difficult work they do. As a prelude to establishing a Pediatric Palliative Care Program and for improving the quality of end-of-life care of families, we conducted this research about the families’ experience of having a child in palliative care at home. In this qualitative study, we examined the nature of quality of life for families with a child in palliative care. Interviews were undertaken with eleven families. Institutional Review Board approval was obtained for the study. Informed consent and assent were obtained from every parent who participated in the study. Participants were reminded they were free to withdraw from the study at any time. Data were analyzed using qualitative content analysis. Results indicated the factors that helped or hindered family members to deal with day by day life. The major factors that promote quality of life
News from the Netherlands: the first evidence based guideline for pediatric palliative care

It is widely known that the Netherlands was the first country in the world to legalize euthanasia in adults. Less well known, even among the Dutch, is the fact that in the Netherlands termination of life of severely defective newborns babies is also legal under very narrowly defined circumstances. Because of this development, it was widely argued, palliative care for children had not received much attention in the Netherlands in comparison to other developed countries. The Dutch Pediatric Association took the initiative in 2010 to develop the first evidence based guideline for pediatric palliative care, in cooperation with representatives of all specialties potentially involved, both in the home, hospice, institution and hospital setting.

Methods. Evidence from international and national guidelines and studies was systematically scored and analysed in order to make recommendations for decision making (medical, legal, ethical, and parental role), for symptomatic care and for organization of pediatric palliative care.

Results. A total of 69 recommendations were abstracted from the international guidelines and scored unanimously by our expert s as useful and important enough to include in the guideline. Recommendations for symptom care could not be based on RCTs but were mainly from small and often single-centre studies or expert opinions. Recommendations about the organization of pediatric palliative care were taken from a very large interactive multidisciplinary meeting, using the validates “open space” Methods.

Conclusions. The palliative care of the baby was care fully designed in the aim of holistic approach with multidisciplinary team taking part and the whole family involved. The team consisted of medical and non-medical stakeholders namely nurses, physician, psychologist, physiotherapist, music therapist, special needs teacher, conductor, speech therapist and social worker. The pathway was modified and adapted continuously to the needs of the family.

Background and aim. The purpose of the authors is to present a case study in perinatal palliative care, analyzing the theoretical and practical challenges for the families and the carers.

Methods. The palliative care of the baby was carefully designed in the aim of holistic approach with multidisciplinary team taking part and the whole family involved. The team consisted of medical and non-medical stakeholders namely nurses, physician, psychologist, physiotherapist, music therapist, special needs teacher, conductor, speech therapist and social worker. The pathway was modified and adapted continuously to the needs of the family.

Results. The presentation will describe the three month long period of end of life treatment smoothly changing in form and place between hospital, home and hospice house depending on best interest of the family valuing their short time given together. The different therapeutic approaches will be demonstrated as a part of the complexity in an end-of-life treatment.

Conclusions. The hospice care for children especially for babies is a new entity not only as a discipline of science but also as an integral part of the society as a whole. Our holistic approach, multidisciplinary involvement and interoperability can be revealed from the given case and has its lessons for the future of valuing short lives.

Holistic approach in the end of life care. A hospice house case study

Background. The publication of the Irish Palliative Care Needs Assessment for Children (2005) revealed home as the preferred place of care for the majority of Irish families. Yet, current statistics indicate that many children with life limiting illnesses (LLI) still do not receive appropriate services. Recent policy (2010) is working towards recommending several important initiatives. However, the need for an Irish children’s hospice has always been seen as a priority. Following an intensive fundraising effort the Lauralynn Irish Children’s Hospice was formally opened in September 2011. The organisation aims to provide a wide service encompassing respite, transitional care, symptom management and end of life care.
life care, initially on an inpatient basis to all Irish families regardless of geographical location. This new children’s hospice will continue to build on earlier initiatives and further develop outreach services. In line with national policy recommendations, currently the service is conducting an evaluation of the supportive requirements of families who care for children with LLI which will underpin organisational planning. This service evaluation will present evidence of the care demands reflecting the utilisation of this solitary national children’s hospice during the first year of its life. The presentation will evidence the dedicated response to families with varying LLI nationally.

Methods. Data regarding referrals and utilisation of services will be discussed in the context of qualitative evidence from child and family narratives.

Results. This presentation will give a brief overview of the evolution of Ireland first children’s hospice. Provisional feedback from the evaluation will be shared.

Conclusions. By illuminating the experiences of parents and children, the presentation will especially focus on the aspirations for children’s hospice both as inpatient and outreach nature and demonstrate the potential for this new service.

92 Coordination between pediatric palliative care team, primary care and adult palliative care teams

Navarro Vilarrubi S., Escobar Ramírez R., Palomares Delgado M., Vélez Delgado V., Ciprés Roig S., Cuerva Molina A., Ortiz Rodríguez J.

Hospital Sant Joan de Déu, Pediatric Palliative Care, Barcelona, Spain

Background. As a pediatric palliative care team (PPCT) we attend patients in serious illness or with a medical condition that may threaten or limit their life, in an interdisciplinary and holistic way. The geographic dispersion of patients in our area requires to balance the services to the needs, and sometimes it is essential to be coordinated with the primary care (PC) and the adult palliative care team (APCT).

Aims. To describe the course of patients treated together with pediatricians of PC and APCT’s. To describe the features of coordination between different teams.


Results. During the study period 113 patients were treated. In 46 cases (40.7%) were followed together with the area services. In 10 of them took part the APCT (4 in 2010 and 6 in 2011). APCT’s had little or no experience in pediatric patients so decisions were always made jointly. There were 63 deaths, 20 of them occurred at home. Twenty-seven cases had been followed together and 15 of these died at home. Thirty-six were treated exclusively by our team and 5 died at home.

Conclusions. Coordination with the area teams (PC and APCT) is particularly necessary in those patients who live far from our unit. This coordination improved the home care until the death occurred, if the child and his family wished so. It also allowed using the health care resources available in the different levels. One of the reasons that interfere with the relationship with the area services could be the close ties of family and patient to the hospital specialists. The APCTs had a very receptive attitude in the management of pediatric patients and mutual collaboration was enriching for all professionals.
Cannabinoids in severely multiple disabled children with pain and spasticity
Gronwald B, Gottschling S
Saarland University Hospital, Centre for Palliative Care and Paediatric Pain, Homburg/Saar, Germany

Introduction. Severely disabled children with therapy-refractory spasticity and pain are a major challenge for paediatric palliative physicians. Furthermore current medication for pain and spasticity including baclofen, benzodiazepines, anticonvulsants and analgesics are often associated with relevant side-effects. Cannabinoids offer a promising treatment option. Unfortunately no trials in children of higher quality have been performed so far. We present a paediatric case series of 15 patients.

Methods. 15 Children (age 6 months - 17 years, median 52 months, weight 6 - 56 kg, median 15 kg) with pain and tetra-spasticity (8 children with infantile cerebral palsy, 2 children with leucodystrophia, 3 children with metabolic disorders, 2 children with hypoxic encephalopathy) were treated in our center. 14 children received baclofen, 7 children were additionally under opioid and nonopioid analgesics (metamizole). All children received dronabinol in a daily dosage between 0,1 mg/kg and 1,1 mg/kg (median dosage 0,3 mg/kg/day).

Results. All children showed a relevant decrease in pain (pain was measured with the FLACC-R scale), reduction of spasticity (on a 0-10 NRS-spasticity-score as judged by the caregivers) and an improvement of sleeping disorders. In 5 children the opioid-comedication could be reduced despite further deterioration, in one child the analgesic medication could be stopped. In none of the children any dronabinol-associated side-effects occurred. 8 out of 15 children are currently alive and under longterm cannabinoid therapy. Therapy duration is between 8 weeks and 7 years (median 32 months).

Conclusions. In our case series the cannabinoid dronabinol had both analgesic and antispastic effects with an additional positive effect on sleeping disorders. No relevant side-effects occurred. Prospective data from other centers (preferably double-blinded placebo-controlled trials) would be highly needed.

Developing pediatric palliative care service in Moldova
Carafizi N.
Charity Foundation for Public Health Angelus Moldova, Hospice Angelus, Chisinau, Moldova, Republic of

Background. Palliative care is a concept which successfully works in many countries of the world, but in some states it is still a new field of the national healthcare systems, which makes first steps in its development. Pediatric palliative care is even more unexplored area and in many countries still remains neglected. Palliative care is a new domain in the Republic of Moldova both for the general public and medical society. It was initiated in 2000 by different non-governmental organisations. Currently, state services which can provide palliative care to different categories of incurable patients, including those with cancer, are only initiated.

Aims. To assess the activity of the Charity Foundation for Public Health "Angelus Moldova" in pediatric palliative care development in Moldova.

Methods. Information collected from the Charity Foundation for Public Health "Angelus Moldova" annual reports about pediatric palliative care development in Moldova.

Results. Charity Foundation for Public Health "Angelus-Moldova" is one of the non-governmental organisations that has been providing palliative care services to incurable cancer adult patients in the capital of the country since November 2001. Since November 2008 it also has been running a pediatric palliative care service for incurable cancer children, starting with 7 little patients in 2008 and gradually increasing number of children to 28 in 2009, 26 in 2010 and 36 in 2011. In addition to this, in October 2011 a pediatric palliative care service for incurable non-cancer children was initiated.

Conclusions. Despite the fact that medical legislation in regards of palliative care in the country, including adequate access to weak and strong opiates, import of their oral forms and pediatric doses of necessary medications is gradually changing, three year practice shows that qualified pediatric palliative care services can be provided until the state system can be well created and developed.
palliative care services. Yet, there is a great need for paediatric palliative care services as there is significant number of children requiring services. 

**Methods.** In 2010, Kenya Hospices and Palliative Care Association (KEHPCA), in partnership with International Children’s Palliative Care Network (ICPCN), trained the first team in Kenya on paediatric palliative care. Two paediatricians and a child pyschologist attended a two week training that included clinical placements in South Africa. The idea was to develop champions, who had an interest in paediatric palliative care and would be willing to work with KEHPCA to change the situation in the country. In 2011, 40 clinicians, including 2 paediatric consultants, 15 registrars in paediatrics and other clinicians, were trained for five days in Kenya through the support of ICPCN.

**Results.** As a result of the training and advocacy, paediatric palliative care services are now slowly being integrated in some government hospitals; there has been more interest and demand for more training of more clinicians, more children are now being referred for services.

**Conclusions.** Although there is some awareness on the need of integrating paediatric palliative care services, there is still more work that needs to be done. More clinicians need to be educated; paediatric palliative care should be integrated into medical and nursing curricula both at undergraduate and post-graduate level.

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**Confidence in skills and desire of attending palliative care training among medical students in Serbia**

Dokmanovic L,1,2, Krestovski N,3,4, Lazic J,1, Rodic P,1, Milosevic G,1, Jancic D,1,2,3

1University Children’s Hospital, Belgrade, Serbia, 2University of Belgrade, Faculty of Medicine, Belgrade, Serbia

**Background and aims.** To determine the confidence level of medical students after passing general paediatrics curriculm in providing paediatric palliative care and identify willingness to obtain training in paediatric palliative care and pain relief.

**Methods.** Surveys were given to all medical students during their final year of education at Faculty of Medicine, University of Belgrade, Serbia. The survey instrument included 5 demographic, training and practice items, 10 items designed to assess participant’s confidence in core palliative care skills and 3 items designed to assess interest in obtaining additional training. Students were asked to rate their confidence level to provide palliative care components on a 4-point scale for each item.

**Results.** The response rate was 323 out of 368 (87.7%). The proportion of students who rate their ability to provide specified components of palliative care as confident ranged from 12% to 38.5%. The ability to provide therapy for pain control rated as confident in 9% of students. 80.8% of the students said that they would be willing to attend training in order to improve their ability in providing palliative care in children.

**Conclusions.** The lack of formal education during Medical faculty leads to insufficient confidence about students’ ability to provide paediatric palliative care. High proportion of students would like to attend additional training to improve their ability. Introduction of paediatric palliative care training courses into the curricula of Medical faculty should overcome this gap.

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**Development of the APCA African Children’s Palliative Outcome Scale: second phase pilot**

Powell R A,1, Qjing M A,1, Namisango E,3, Ali Z M,2, Marston J,1, Meiring M,1, Sseengooba J,2, Kiikute E S,1, Leng M,1, Williams S,1, Onyango J,1,2, Harding R,1,2

1African Palliative Care Association, Kampala, Uganda, 2Kenya Hospices and Palliative Care Association (KEHPCA), Nairobi, Kenya, 3International Children’s Palliative Care Network, Assagay, South Africa, 4Big Shoes Foundation, Cape Town, South Africa, 5Formerly with Hospice Africa Uganda, Kampala, Uganda, 6Formerly with MilderCare Centre Uganda, Kampala, Uganda, 7Makerere University Palliative Care Unit, Kampala, Uganda, 8Oxford Hospice, Harare, Zimbabwe, 9Kisumu Hospice, Kisumu, Kenya, 10Nyanza Regional Hospital, Kisumu, Kenya, 11Kings College London, London, United Kingdom

**Background and aims.** Showing improvements in palliative care outcomes among children in Africa is premised on culturally appropriate, validated measurement tools. This study aimed to develop a multi-dimensional tool (the APCA African Children’s Palliative Outcome Scale [POSI]), for children with life-threatening illnesses and their families.

**Methods.** An initial tool was developed, a first pilot conducted and changes made to the instrument for verbal and non-verbal children prior to second-phase piloting. The latter phase was a prospective longitudinal study in 8 sites across 5 African countries. Children aged 0-16 years new to a palliative care programme or presenting with a new problem or a new inpatient. 58% of children had a HIV primary diagnosis, 80% from urban settings, with 47% under homecare, 40% inpatient, 58% of children had a HIV primary diagnosis and 57% had cancer. Change was demonstrated across the tool domains, with most significant change between T1 and T2 (p< 0.05) for all comparisons. The mean time taken to complete the tool reduced from 23 minutes (SD 20) at visit 1, to 15 (SD 10.3) at visit 4, indicating good tool feasibility. Qualitative
feedback indicated the tool helped improve relationships between care providers and children.

Conclusions. Findings suggest the tool contains useful palliative care domains acceptable to children and their carers. A validation study of the finalised tool is ongoing to produce the first multidimensional palliative care outcome tool for children in Africa.

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Pain control in pediatric oncology with transdermal fentanyl: efficacy and feasibility

Clerico A., Reale G., Ferrara E., Mollace M.G., De Grazia A., Suraci S.
Sapienza University of Rome, Pediatric Oncology, Roma, Italy

Objectives. Transdermal fentanyl delivery system (TFDS) offers advantages if oral administration of opioids is difficult because of progressive disease or poor compliance, in cancer patients (pts). The current study was conducted to assess the efficacy and safety of TFDS in a pediatric cancer population.

Patients and methods. Twenty-seven pts were enrolled between June 2004 and December 2011. TFDS was applied if pts had pain under non opioids treatment, according to our step-by-step ‘pain protocol’. Starting dose of TFDS was decided considering the dose of the last non opioids drug used. Degree of pain was assessed using visual and numeric scales.

Results. Nineteen males and eight females were studied, median age was 10 years (range 2-23 years). They were affected by moderate to severe pain, because of progressive and/or metastatic disease. Median starting dose was 50 microg/h (range 6-100 microg/h). Highest reached dose was 300 microg/h. In 63% of pts, starting dose was adequate. Thus, pain total control was obtained in 96% of pts, with a median delay, from starting TFDS, of 33 hours (range 12-360 hours). Only in one patient pain control was not achieved with TFDS. No toxicity was observed but a moderate lethargy within the first 12 hours, in 26% of pts and moderate constipation in 40% of pts.

Conclusions. TFDS was found to be an effective and safe system to treat pain in pediatric cancer pts. All pts and their families showed high compliance with TFDS. It could be also taken in account for outpatient therapy.

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Nationwide paediatric palliative care education programme for paediatricians in Japan

Nagayama J.1, Tatara R.2, Fukuda Y.3, Hirai K.4, Matsuoka M.5, Ogata A.6, Okazaki S.7, Park M-J.7, Sasazuki M.8, Yokosuka T.9, Yoshida S.10, Kizawa Y.11

1Life Planning Center, Peace Clinic Nakai, Nakai, Japan, 2Osaka City General Hospital, Osaka, Japan, 3Machi-no-Nurse-Station Yachiyo, Yachiyo, Japan, 4Osaka University, Center for the Study of Communication-Design, Osaka, Japan, 5Kagawa National Children’s Hospital, Zentsuji, Japan, 6Hiroshima University, Graduate School of Education, Higashihiroshima, Japan, 7Gunma Children’s Medical Center, Shibukawa, Japan, 8Fukuhoka-Higashi Medical Center, Koga, Japan, 9Yokohama City University School of Medicine, Yokohama, Japan, 10National Cancer Center Hospital, Tokyo, Japan, 11University of Tsukuba, Faculty of Medicine, Division of Clinical Medicine, Tsukuba, Japan

Background. Despite the need for palliative care for children with life-threatening illnesses (LTI), paediatricians in Japan lack sufficient palliative care knowledge and appropriate behaviour in palliative care settings. Thus, palliative care approaches are limited for children with LTI in Japan.

Aim. To improve the knowledge and attitude of paediatricians towards paediatric palliative care, a nationwide education program on paediatric palliative care, the Care for Life-threatening Illnesses in Childhood (CLIC) programme, was developed and implemented.

Methods. With support from a Health Labour Sciences Research Grant provided by the Japanese Ministry of Health, Labour and Welfare, the CLIC programme was developed and workshops were implemented. The project team consisted of paediatricians, nurses and psychologists with profound knowledge of paediatric palliative care and LTI in childhood. The programme was designed as an educational workshop comprising three components: group discussion, role-play and video learning. The programme focuses on important elements of paediatric palliative care, pain assessment and management in children; symptom management in the terminal phase; communication in paediatric palliative care settings and discussion of ethical issues.

Results. CLIC workshops have been conducted four times in the last two years and have included 151 participants in various subspecialties, such as oncology, neonatology and neurology, from institutions all over the nation. These workshops will be conducted on a regular basis.

Conclusions. The CLIC education programme for paediatricians working with children with LTI should improve understanding of paediatric palliative care. To demonstrate the efficacy of the programme, development of tools to measure the participants’ knowledge of paediatric palliative care and attitude towards providing palliative care are required.

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Audit on the use of intravenous methadone in a paediatric palliative care service

Fernando R.A., Collins J.J.
The Children’s Hospital at Westmead, Pain and Palliative Care Service, Sydney, Australia

Background. Pain is a significant symptom at end of life. Intravenous (IV) methadone may be required to manage pain or opioid-induced side effects. Howev-
er, little literature exists on the use of IV methadone in paediatric palliative patients.

**Objective.** To describe experience with IV methadone in one paediatric palliative care service and increase understanding of its efficacy and safe prescription in the paediatric population.

**Methods.** All 10 patients who received IV methadone between 2006 and 2010 were included. Local ethics approval was granted for a retrospective audit of extracted de-identified data. Primary outcomes were the overall effect of IV methadone on pain (based on validated paediatric pain scales and documented observations), side effects experienced and calculations used when rotating to methadone.

**Results.** IV methadone provided substantial analgesia in 80% of patients, with 30% experiencing prolonged, substantial analgesia with minimal dose adjustments. 30% experienced significant adverse effects including sedation and myoclonus. There was no correlation between maximum daily IV methadone dose/Kg or the timing or size of the last dose increase with survival. The IV morphine:methadone conversion ratio was 10.6:1, which provided significant analgesia in 90% of patients in their first 2 days of therapy, with 50% requiring only minor, delayed or infrequent dose adjustments during methadone use. Using this ratio, 1 patient experienced significant sedation.

**Conclusions.** Pain at end of life can be challenging, often requiring opioid rotation and dose escalation for optimal analgesia. IV methadone in this setting is challenging due to high inter-patient pharmacokinetic variability. This unit’s practice of using an initial 10:1 morphine methadone ratio appears to be safe and effective. However, toxicity monitoring is required due to the complexity of individual disease processes, tolerances and susceptibilities.

**118 Using the narrative for actively involving children and adolescents suffering from life-limiting and life threatening conditions**

Lala R. 1, Lesmo I. 2,3, Nave E. 2,3,4, Goia M. 3

1 Regina Margherita Children’s Hospital of Turin, Città della Scienza e della Salute, Day Hospice, SS Endocrinologia, Turin, Italy, 2Università degli Studi Milano-Bicocca, Milan, Italy, 3Regina Margherita Children’s Hospital of Turin, Città della Scienza e della Salute, Direzione Sanitaria, Turin, Italy, 4Università degli Studi di Torino, Turin, Italy

**Backgrounds and aims.** The concept of “childhood”, according to which children would be unaware, dependent and incompetent people, was deconstructed by studies that underlined their socially active role. In clinical area children work out creative representations about health, disorder and therapy; the difference between them and the adults is the power they have for negotiating their own goals. This project collected the narratives of children suffering from life-threatening and life-limiting conditions, in order to promote their active involvement.

**Methods.** Creation of an interdisciplinary team (pediatric endocrinology, anthropology, bioethics)-involvement of 13 children/adolescents and their families in semi-structured interviews-analysis of the collected narratives, through analytical technique and interpretivist approach-synthesis, through dialectic narratives within the team.

**Results.** The analytical method showed that—the morality of an individual is elaborated through bodily experiences—children/adolescents with complex disease are less autonomous in their moral conception—clinical encounters do not encourage children/adolescents to be holders of autonomous choices—children/adolescents do not manifest any need of autonomy, but autonomy could be beneficial for them. The interpretivist approach showed that—most of the patients consider biomedical knowledge as an objective and an unquestionable knowledge—they do not expect to exercise decisional power in the therapeutic area—even though they are hushed up and disempowered, they work out their own interpretations and strategies—they pursue their goals through non verbal and indirect strategies.

**Conclusions.** Dialogical narratives within the team showed that children and adolescents with life-limiting and life-threatening conditions seem not to be interested in the choices about their health and their bodies, just because they are infantilized by adults. Anyway, they may be competent and moral subjects.

**120 Interdisciplinary narrative for the management of life-threatening and life-limiting conditions: experiences in a pediatric hospital**

Bignaminini E. 1, Fenocchio G. 2, Ferro G. 3, Lala R. 1, Lesmo I. 2,3, Goia M. 2, Levi P. 6, Morgando P. 7, Nave E. 2,8, Nave L. 9, Risso C. 2, Tinari C. 1

1 Regina Margherita Children’s Hospital of Turin, Città della Scienza e della Salute, Day Hospice, SS Pneumologia, Turin, Italy, 2 Regina Margherita Children’s Hospital of Turin, Città della Scienza e della Salute, Day Hospice, Turin, Italy, 3 Regina Margherita Children’s Hospital of Turin, Città della Scienza e della Salute, Direzione Sanitaria, Turin, Italy, 4 Regina Margherita Children’s Hospital of Turin, Città della Scienza e della Salute, Day Hospice, SS Endocrinologia, Turin, Italy, 5 Università degli Studi Milano-Bicocca, Milan, Italy, 6 ASL 1, Turin, Italy, 7 ASL 3, Turin, Italy, 8 Università degli Studi di Torino, Turin, Italy, 9 Society of Philosophical Counselling, Turin, Italy

**Background and aims.** This work shows how the interdisciplinary narrative can be used in a pediatric hospital, in order to manage the complexity of life-threatening and life-limiting conditions. Assuming that such conditions challenge the traditional ideas of “cure”, the working group established that appropriate therapeutic itineraries cannot disregard the perspectives, sometimes different or contrasting, of the various involved subjects. Re-narrating the disorder’s experiences from different points of view allowed to enrich the interpretation of those experiences, in order to devise creative and personalized solutions.
Methods. A team for clinical narration called The Tales Corner has been established within the hospital. It is composed by physicians, social workers, psychologists, a philosopher, a bioethicist and an anthropologist. Last year the team has been meeting twice monthly, in order to discuss some stories regarding paediatric patients with cystic fibrosis (CF), who are waiting for lung transplantation. Specific and inner meetings were dedicated to foreigner people with CF, in order to face experiences of more difficult comprehension, as witchcraft, evil eye or different ideas of family and person.

Results. Through the narrative, the team discusses about the imaginations, the fancies and the emotional impulses relevant in moulding clinical experiences. Usually considered not much relevant in therapeutic itineraries, these aspects are fundamental in the experience of subjects with CF: by exploring them through the narratives, they could be considered in the therapeutic planning, increasing the mutual comprehension, the knowledge and the competence of every involved subject.

Conclusions. The shared narrative was fundamental in order to devise interventions allowing the management of the complexity in life-threatening and life-limiting conditions and to personalize the therapeutic itineraries.

121 Ethical room: an experimental project for practising clinical ethics in the hospital

Bignamini E., Cordero di Montezemolo L., Corsi D., Ferro G., Goia M., Lala R., Lesmo I., Nave E., Saracco P.

Backgrounds and aims. Form clinical practise of health care professionals who face complex (life-limiting and life-threatening) pathologies the need of thinking and discussing about the ethical aspects related to care came out. Therefore, in a pediatric hospital Ethical Room was born: it is a project through which those who works in the hospital can confront each other about situations that raise ethical issues, in order to analyse single cases, to unravel moral problems and to purpose rationally justified and as much as possible shared solutions.

Methods. Among the different methods suggested by literature for analysing concrete cases of clinical practise, Ethical Room took into account:

— casuistry, new casuistry
— coherence/principilism
— ethic of care
— national review of principilism: ethical reasoning in the situation.

Results. The main functions of Ethical Room are cases analysis and the development of pertinent thinking; specific tasks are:

— providing advisory and not binding guidance about ethical issues
— helping the moral decision of health-care professionals
— elaborating pertinent remarks, considering the increased availability of diagnostic-therapeutic tools and the emancipation process of citizens
— preventing conflicts, by providing a mediation among the involved subjects
— training to practise ethical analysis
— promoting occasions for ethical thinking, information and awareness, in a context characterized by ethical and cultural pluralism.

Conclusions. The emerging of new ethical issues and the increasing of their complexity in life-limiting e life-threatening pathologies require an appropriate thinking about every single case. Ethical Room pays attention to ethical issues about complex situations, by considering ethical aspect as a moral need of each people, but also as the condition for a proper professional practice.

122 Childhood cancer: nursing care in the last days of life

Armstrong D.

Royal Belfast Hospital for Sick Children Belfast, Children’s Haematology & Oncology, Belfast, United Kingdom

This study was designed to explore professional nurse’s experiences of caring for children with cancer during the last days of life. Childhood cancers have the highest mortality rate of any childhood disease and care of the dying child is an inevitable part of the professional role of the Children’s Oncology Nurse. Nurses care for patients and their families, many of whom they have known and nursed over a period of months and years in every phase of treatment and disease progression, and at times of extreme vulnerability. Close relationships develop between the nurse, the child, and the family and death of the child has a significant impact on nurses, presenting a number of personal and professional challenges. The aim of this study was to explore the challenges of providing nursing care to a child with cancer during the last days of life in a U.K Children’s Hospital. A predominantly qualitative approach was utilised in this exploratory study. By utilization of a demographic questionnaire, unstructured interviews and focus group, data was collated from a cohort of eleven Children’s Oncology Nurses. The transcripts of their interviews/discussion were subject to a qualitative based content analysis using Burnard’s (1991)
framework. This exploratory study offers a previously unheard perspective of paediatric oncology nurses in relation to end-of-life care. Caring for the child dying of cancer has a major emotional impact on the nurse and nurses identified a need for availability of formal support. Nurses highlighted a distinct shift in care during the last days and playing a pivotal role in ensuring the child and family’s last hours and minutes together were precious. The imminence of death can be difficult to recognise and impacts on staff and family’s preparation for death. Knowledge and skills deficits identified in the study could be corrected through an increased emphasis on palliative care skills and education for nurses.

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Mixing curative and palliative care in brain tumors in children
Boeriu E.1,2, Cucuruz M.2, Arghirescu S.3, Serban M.2, Sarau I.2, Badescu E.3, Pienar C.3
1 „V. Babes“ University of Medicine and Pharmacy, Timisoara, Romania, 2 3rd Pediatric Clinic, „Louis Turcanu“ Emergency Hospital for Children, Timisoara, Romania

Introduction. Brain tumors (BT) are an important part of oncological pathology in children. We have witnessed an increase in the diagnosis and therapeutic accuracy of BT but some of these tumors have an unfavorable outcome and a palliative approach is necessary.

Objectives. We performed a retrospective analysis of the BT evaluated in the 3rd Pediatric Clinic, between 1997 and 2010, of the factors that influenced their evolution and prognosis.

Methods. The study group consisted of 23 children aged between 1 year, 9 months and 17 years - (12G/11B, 53% / 47%). Our evaluation was complete. The statistical analysis consisted of descriptive statistics and the Kaplan-Meier survival curve.

Results. The onset symptoms were: headache 82%, vomiting 43%, balance disorders 34%, movement and postural disorders 26%, blurred vision 26%, convulsions 25.9%. The distribution according to pathology was: 30.43% medulloblastoma, astrocytoma 30.43%, and an even distribution for glioblastoma, ependymoma, oligodendroglioma 8.69%. Treatment included surgery in 86.95% of patients, followed by chemotherapy in 73.9% and radiotherapy in 60.86%. Evolution was favorable in 5 cases (21%) and unfavorable, to exitus, in 52%. These patients and their families were approached in a holistic palliative manner (control of the symptoms, psycho-emotional and spiritual support). 4 cases (17%) were noncompliant to treatment. Relapse within 1 year of treatment occurred in 43.7% and palliative care continued until the end of life.

Conclusions. Onset symptoms of BT include headache, vomiting, impaired balance in a high percentage and we think more attention should be paid to such nonspecific symptoms. The unfavorable outcome is influenced by the time until diagnosis and the therapeutic response. Palliative care measurements were needed in inoperable cases from the onset and in all patients with unfavorable outcome.

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Role of nursing at the hospital home: the importance of health education
Barceló Escano M., Moreno Martínez A., García Quintero I., Martínez Lorenzo T., Fillol Cuadrado A., Martino Alba R.
Hospital Infantil Universitario Niño Jesús, Pediatric Palliative Care Unit, Madrid, Spain

Background. The most of the children treated in our Unit are under home care regime and require complex caring. Being at home, those cares are largely delegated to family members. Therefore, it’s necessary to analyze the main cares required by patients at home and the tools needed to ensure a good health education.

Aims. To identify which are the more frequent cares required by patients under home care.

Methods. Retrospective study of 123 patients who died.

Results. Out of the 123 children included in the study, 99% have been in home care regimen and had one or more devices at home. 70% died at home. 46% belonged to group 1, 2% to group 2, 24% to group 3 and 28% to group 4. A descriptive analysis of the type of care received by the children will be presented: the percentage of children who needed support oxygen therapy, airway suction, aerosol therapy, tracheotomy, cough assistant and/or ventilation support invasive or noninvasive, SNG of feeding or evacuation, and nutrition with enteral pumps, permanent or intermittent catheterization, portal-a-cath care, central lines of peripheral access, peripheral lines and/or subcutaneous infusion pumps, PCA and infusers and those who have received blood transfusions in home. In addition, those children who had skin problem, mainly UPP and tumor ulcers, will be analysed.

Conclusions. Most of the children had at least one device at home and most of them more than two, which makes the care complex. Being the caregivers the ones who are responsible for ensuring the continuity of caring at home, their training is what will mainly ensure the success of home care.

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Identify of complex factors in pediatric palliative care: needs and use of resources
García-Salido A., del Rincón C., García de Paso M., Cata E., González C., Martino R.
Hospital Infantil Universitario Niño Jesús, Pediatric Palliative Care Unit, Madrid, Spain

Background. The complexity of caring is the result of a balance between the identified needs and resources available for their care.
Aims. a) To explore the interdisciplinary attention of the palliative care needs; b) to describe the complexity found in our patients related to the number of visits; c) To identify patient factors predictive of key aspects of palliative care needs.

Methods. Retrospective study of 107 death patients.

Results. 60% boys with average age 7.7, 68% Spanish, 87% medium-low socioeconomical status. Descriptive analysis will be presented regarding: diagnosis, drugs used for treatment, enteral nutrition, hydration, use of blood products, oxygen therapy; aerosol therapy, airway suction; devices like portacath, subcutaneous infusers, and have skin problems. Psychiatric history of the child and caregiver, knowledge of clinical status, presence of previous bereavements, overload, family cohesion, communication style. Laboral difficulties and funeral expenses. Social support, social isolation, risk of giving in and coordination with social services. Doctor and nurse performed an average of 19 visits per patient [1-121], psychologist 5.7 [0-31] and social worker 4 [0-26]. Condolence visit 3.34 [0-20]. The predictors of activity was the use of gastrostomy, benzodiazepines, enteral nutrition, subcutaneous infusers, skin problems and hydration. Psychologist plays an important role in families with problems of cohesion, in families that avoid emotional communication and if the primary caregiver has previous psychiatric problems. Social worker has a role in mentally retarded children and families with financial difficulties and poor social family support.

Conclusions. Seen patients have highly complex factors according to criteria used in our environment: use of respiratory devices, carrier gastrostomy, blood products at home. We use the visits number as a measure of provision of resources that may help identify factors of complexity.

128 Gastrostomy in paediatric palliative care
García-Quintero I., Moreno A., Barceló M., Martínez T., Fillol A., Martino R.
Hospital Infantil Universitario Niño Jesús, Paediatric Palliative Care Unit, Madrid, Spain

Background. In Paediatric Palliative Care nutritional support is imperative. Sometimes Gastrostomy, ensures a correct nutrition, pharmacological treatment and decrease the risk of aspiration.

Aims. Identifying patients with gastrostomy and the complications. We describe the preventive care and complications treatment.

Methods. Retrospective study of patients in Paediatric Palliative Care Unit.

Results. We reviewed 190 patients: 123 died, 26 (21%) had gastrostomy, with an average age of 7 years [0-18], mostly girls (63%), ACT diagnosis was 8% group 1, 38% group 3 and 54% group 4. 11 (45%) of death patients with Gastrostomy suffered complications, 4 (15%) of them were seriously. There are other two groups: overcame patients (14) and active treatment patients (53). 7% of the overcome patients and 55% of the active treatment group have gastrostomy also.

Conclusions. Most of the patients of the active treatment group have gastrostomy. Most of the patients have neurological illness with swallowing disorders. Patients with gastrostomy survive more than three
months. Probably due to the improving in nutrition. Although complications are common in patients with gastrostomy, most of them can be managed at home. In order to show parents the best way of keeping safe and to avoid complications with gastrostomy the most important thing is the nursering health education.

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**Diagnostic radiology in paediatric palliative care**

Paiel P.1, Koh M.2, Carr L.3, Mc Hugh K.3  
1Great Ormond Street Hospital NHS Foundation Trust, Department of Radiology, London, United Kingdom, 2Great Ormond Street Hospital NHS Foundation Trust, Paediatric Palliative Medicine, London, United Kingdom, 3Great Ormond Street Hospital NHS Foundation Trust, Department of Neurosciences, London, United Kingdom

**Background and aims.** Patients receiving palliative care may have numerous radiological tests which radiologists traditionally categorise under organ systems rather than under the umbrella of palliative medicine. Moreover, because so many of our young patients are not able to express themselves or articulate their problems, imaging in evaluating the cause of symptoms and state of disease is valuable. In this review, we focussed on our experience at our institution, where radiology has proven to be an invaluable partner to palliative care. We will discuss examples of conditions commonly referred by the palliative care team, delineate the role of radiology in palliative care and recommend ways the two specialties can further collaborate.

**Methods.** Joint practice review by both specialties of the role of diagnostic radiological investigations in children with conditions in each of the 4 ACT (Association for Children’s Palliative Care) categories.

**Results and conclusions.** A sensible approach to the diagnostic radiological investigations is paramount, balancing the risk of the invasiveness, practicalities and potential for harm, of the imaging study against the potential benefit to the child. It is often too easy to repeatedly acquire excellent diagnostic images which are actually of no tangible benefit. Equally, the rights and comfort of the child need to be borne in mind such that the patient is not denied an appropriate test. Radiologists need to consider how to apply new techniques and skills in a practical way to benefit these vulnerable children. We have found good communication between radiology and the palliative care team has been improved by the recent introduction of a quarterly palliative care radiology meeting and we would encourage this collaborative approach. We also identified that the management of pain during radiological procedures needs to be better and more systematically addressed for all children in general and for palliative care patients in particular.

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**Children’s palliative care in Malawi**

Tazie J W., Thambo L F., Winga G.  
Palliative Care Association of Malawi, Lilongwe, Malawi

Malawi is one of the poorest countries in the world in the sub Saharan region with a population of about 14 million. One of the countries badly hit by HIV/AIDS and has about a million people living with HIV/AIDS and 120,000 are children between 1-14 years. In 2010, the palliative care association did a baseline survey in three main National referral hospitals to find out about children palliative care services. The survey revealed that very little is being offered to children who need the service. Through funding from an international organisation, the association is implementing a project to scale up children’s palliative care with the aim of improving quality of life of all children with life limiting and life threatening conditions through relief of pain and suffering. A total of 45 health care workers have been trained in Children’s palliative care and several sensitisation meetings with other health care workers on children’s palliative care have been conducted. Communities have also been sensitised through media. The project is currently involved in the process of developing a palliative care policy in which children’s issues have been included and in the process of integrating children palliative care chapter in the medical and nursing college’s curriculum so that whoever will be graduating from these colleges will already have the knowledge and skills to offer the services to the children. Advocacy materials such as fact sheets, calendars, stickers and Chichewa translated ICPNC charter of children rights have been printed and distributed. The project is also empowering children who have life limiting and life threatening conditions and their guardians to advocate for the services through awareness meetings, focus group discussions and rights awareness using the ICPNC charter of rights. Over 400 children with life threatening illnesses are now able to access the services. The project is funded by DFID.

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**Low dose morphine for treating respiratory distress in spinal muscular atrophy type 1**

Renard M., Ruyssenfeldt I., Massy W.  
University Hospitals Leuven, Paediatric Palliative Home Care Team, Leuven, Belgium

**Introduction.** Spinal Muscular Atrophy type 1, SMA1, is an autosomal recessive disorder, caused by degeneration of anterior horn cells of the spinal cord. Type 1 is characterized by progressive muscle weakness and atrophy, with extreme hypotonic and...
extreme respiratory distress. Most of these patients died in the first year of life. Cure is not possible, only supportive care. Comfort care is the major goal. Tracheotomy and artificial ventilation and non-invasive ventilation can be proposed, but these children developed soon severe complications.

Methods. Respiratory distress is a major cause of anxiety and discomfort in these children. We followed between 2003 and 2012 fourteen children with SMA 1. One child is treated by ventilation, from the age of 14 months, and is still alive at the age of 4 years and 6 months. All other 13 patients died between 3 and 21 months. When children were in respiratory distress, a low dose of Morphine was started: 0, 2 mg/kg/dose orally (nasogastric tube) 2 to 3 times a day, increased to 6 times a day. If comfort was not present, the dose was increased by a ¼, without dose limitation. If discomfort was still present, Benzodiazepine was associated (0,1 mg/kg intra recta).

Results. 10/13 children started on Morphine. No severe respiratory depression or severe drowsiness was noted, neither by starting, nor by increasing the dose. 4 children died of a pulmonary infection, one child died in an acute situation and 8 children died because of progressive muscle weakness. Time between starting Morphine and death was between 6 days and 3,5 months. There is no literature information concerning the use of Morphine as treatment of anxiety and distress in children with SMA 1.

Conclusions. Morphine in low dose is a good comfort treatment for children with severe respiratory distress and anxiety because of hypoxia. Morphine does not lead to respiratory depression or hastening of death.

133 Not too young for loss. Involving children and youngsters in palliative care
Ruysseveldt I.1, De Lust A.-M.2, Vanden Berghe P.3, Dillen L.4
1University Hospitals Leuven, Paediatric Palliative Home Care Team, Leuven, Belgium. 2Federation Palliative Care Flanders, Vilvoorde, Belgium

Introduction. Clinical practice and research show that the involvement of children and youngsters during the illness and the palliative process of a loved one is of upmost importance. A timely and adapted care for this (often) forgotten group is not only of essential importance for their grief process, but also for a healthy emotional development. Yet, involving children in this process is still a great taboo, even among professional caregivers. Therefore, the Federation of Palliative Care Flanders started a four-year project focused on the care for children and youngsters when a loved one is in palliation.

Aim. The aim is to build expertise among professional bedside caregivers in the psycho-emotional support of children and youngsters who are confronted with the imminent death of a loved one. This general aim falls apart in sensitization of, education of, and material development for professional caregivers.

Methods. The project consisted of two phases. A first phase focused on the state of the art regarding the theme by means of a comprehensive literature review, a stocktaking of existing initiatives in Flanders and the Netherlands, and a needs assessment in diverse settings of palliative care. Based on this stocktaking a mission statement was developed with a sensitization and information campaign, a website, a children's book, a symposium for professional caregivers, a brochure for parents and professional caregivers, a training package for professional caregivers, and workbooks for children and youngsters.

Conclusions. The project has resulted and still results in a slow but steady change in mentality and awareness of the importance to involve children as soon as possible when someone is ill. The success may be explained by the bedside origin of the project, the multidisciplinary composition of the workgroup, and the inclusion of the diverse palliative settings.

135 The lived experience of parents raising a child with a chronic and terminal disease
Moraiti A.
National & Kapodistrian University of Athens, School of Nursing, Athens, Greece

The aim of the study was to investigate the lived experience of parents raising a child suffering from a chronic and fatal disease, the Duchenne Muscular Dystrophy (DMD). The research questions were the following:

a) what meaning do parents attribute to their son's disease,
b) how do they perceive their parental role?,
c) what kind of relationship do they develop with their sick child under the certainty of his death and
d) how do they communicate in the family about the disease?

A two-phase qualitative study was undertaken in the Neuromuscular Unit of a pediatric hospital: during the pilot phase, two focus groups with 8 participants were conducted. The main themes that emerged from the analysis of the data led to the formulation of an interview guide, which was used for the conduction of the main study. The sample comprised 11 parents who were the main caregivers of a boy suffering from DMD. The data collection and analysis were guided by a phenomenological approach.

According to the findings, the theme that best describes the parents' overall experience is "living with a deadline". The child's illness is perceived a major rupture in their life story and evokes deep suffering. Their attempt to attribute meaning to their child's
disease and to their experience involves a long-term process which appears ongoing and incomplete. They invest their parental role with unrealistic expectations, which evoke guilt feelings, leading parents to a total and unconditional dedication to their sick child. The relationship they develop with that child is characterized by dependence and overprotection. Finally, their communication with their children is based on selective information, which in most families minimizes the severity of the illness. The above contribute to the formulation of specific guidelines for the healthcare professionals who seek to provide a support that meets the needs of families of children with DMD.

**136**

**Experience of a paediatric reference centre in home paediatric palliative care**

Annaloro N., Bocco L., Brandino D., Maggno A., Volpato M., Plumari G., Badalotti C., Scisciola R., Goia M., Bignamini E. OIRM, S.C. Pneumologia, Turin, Italy

Paediatric palliative care deals with medically complex and/or medically fragile children, many with intense medical needs resulting from multisystem disease states, technology dependence or complex medication regimens. Care of these patients includes an array of services that go beyond medical and nursing services and extend to rehabilitation, social and patient/family support services all of which could be ideally home centred.

From 2010, our Centre started with a home service aiming to improve quality of life of patient/family, reduce hospital scheduled control and improve coordination among clinicians, patients/family, community resources. Fifteen children with special health care needs, whose pathology is reported in Table I are included in this programme which is sustained by patients associations.

Centre pulmonologists and nurses, territorial paediatricians and nurses, patients and care givers are involved in the visit. These are performed every three months, for each patients, but vary on the base of illness severity and in the last phase of life.

The visit consists of: 1) meeting with family, territorial nurse, family paediatrician; 2) clinical visit; 3) mediogasanalysis; 4) check of ventilatory parameters; 5) check of gastrostomy and tracheostomy; 6) medical prescriptions; 7) monitoring of caregiver compliance. In our experience, this home program has given a substantial improvement of care satisfaction as reported by families which will be verified by specific questionnaire.

**References**


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**ICPCN’s elearning strategy. Development and the way forward**

Downing J.1, Marston J.2, Boucher S.3, ICPCN Scientific Committee

1International Children’s Palliative Care Network, Kent, United Kingdom, 2International Children’s Palliative Care Network, Bloemfontain, South Africa, 3International Children’s Palliative Care Network, Durban, South Africa

**Background.** Children and young people have very specific palliative care needs which are often different to those of adults. One of the ICPCN’s key objectives is to ensure the provision of education for children’s palliative care (CPC). ICPCN believe that education is the foundation for the development of CPC globally and that efforts need to be made to increase availability and accessibility of education programmes to all health professionals.

**Methods.** An international strategy for elearning in CPC was developed, which included: Undertaking a training needs assessment (TNA) and analysis of programmes; Reviewing existing elearning programmes; Conducting a pilot elearning programme; Drafting the strategy and discussion of the way forward; and implementation of the strategy.

**Results.** A pilot elearning programme was conducted from October 2011 through to March 2012 via the ICPCN website. 186 people from 31 countries accessed the pilot, which was developed following the TNA and review of existing elearning materials. Results from the pilot were then fed into the development of the strategy. Key to the elearning strategy is ensuring that programmes are both available and accessible, particularly in places where training opportunities are limited such as Asia, Latin America and sub-Saharan Africa. Collaboration is key, and ICPCN hopes to collaborate with other regional organizations to provide the platform for the training, and subsequent modules will be developed by international experts working in the field, and available in different languages. Key to the ongoing elearning strategy is the identification and setting-up of clinical placement sites in different countries/ regions around the world.

**Conclusions.** The ICPCN’s elearning strategy is an important step forward to improving availability of and accessibility to, training on children’s palliative care around the world.
140 Developing the talent of clinical leaders to foster learning in paediatric palliative care: the tension between knowing that and knowing how

Duke S.1, Bennett H.2, Townsend K.1, Sepion B.3, Cullen J.3
1University of Southampton, Faculty of Health Sciences, Southampton, United Kingdom, 2Together for Short Lives, Bristol, United Kingdom

Background and aim. High quality education and leadership inspires staff, enhances quality of care and improves staff satisfaction and retention. This project aimed to enhance the confidence of clinical leaders to teach ethics, symptom management and communication skills in paediatric palliative care environments, needs identified from a regional training needs analysis.

Methods. We held an intensive two-day residential education summit, in which clinical leaders were exposed to “state of the art” master-classes and educational workshops, designed to enable them to plan and rehearse how to teach these issues in their clinical setting. The impact of this training was evaluated through a rating tool assessing confidence in caring for children at the end of life and of teaching others in this care, and inviting qualitative comments. The tool was administered before and after the summit.

Results. 25 practitioners completed the training. Overall confidence in the practice of caring for children and families at the end of life increased. However the important finding from the evaluation was the challenge faced by participants in making the shift between what is known (how to do something or what knowledge to use in decision making) to how to help this to be known to others - what Bernstein describes as the translation and transmission of knowledge. Participants tended to want to re-tell their knowledge (knowing that), rather than considering the education process that would enable learning by others (knowing how) and re-creating the knowledge to be applicable to their practice setting. The modelling of this process by the facilitators was considered important to understanding this process.

Conclusions. An intensive educational intervention is an effective way to enhance clinician’s ability to facilitate learning in practice but this requires modelling of how to transform knowledge and design educational processes.

141 Villa Indigo, a “Second Home” for seriously sick children

Dubois A.C., Develter S.
Villa Indigo, Brussels, Belgium

Background. Caring for a seriously ill child at home not only affects the child, but also the lives of family and friends. Parents frequently find themselves isolated and become exhausted. Until recently, those had no other alternative than the hospital to care for their child. However, in the absence of an acute illness, a stay in a hospital care unit does not properly address the needs of the child. It is specifically in response to a lack of appropriate structure that several respite house projects have sprung up in Belgium.

Description. Villa Indigo opened in Brussels in March 2011. It allows parents to entrust their child to caregivers specialized in pediatrics, in an effort to “fill the gap” in a close familial setting. Ten children aged 0-18 years can be accommodated for residential stays (up to 32 days per calendar year), including at the end of life. During the first year, many families have benefited from these services. From March 2011 to March 2012, 45 children with chronic medical problems were welcomed for varying durations. The activities of the Villa are growing steadily following our public information campaigns. Most children who have stayed at the Villa quickly arrange a second stay.

Outlook. To maximize the support provided to families, we plan to conduct a study among families whose children are cared for in a respite house. The results of this study will allow us to determine if the support provided to parents, children and siblings, gives them strength to continue their tough journey.

Conclusions. Our first year of operation was very positive. The Villa Indigo responded to the distress of families dealing with physical and emotional challenges. We believe the project met a real need. The acknowledgement of the importance of respite must continue to grow among both pediatricians and doctors who work with sick children and their families, as well as with the parents who deserve our support.

142 Situational analysis of the palliative care needs of children in Serbia

Cunningham C.1, Downing J.2, Stojanovic L.3
1Independent Palliative Care Consultant, Cork, Ireland, 2EU Funded Project “Development of Palliative Care Services in the Republic of Serbia”, Belgrade, Serbia, 3Consultant, Belgrade, Serbia

Background. Palliative care services in Serbia are at early stages in development and the recent National Palliative Care Strategy presents a good foundation for its ongoing development. A situational analysis was undertaken to identify and highlight children’s palliative care needs as part of the EU funded project “Development of Palliative Care Services in Serbia”.

Methods. A desk review was carried out and data gathered from different sources and informal interviews were conducted with key informants.

Results. There are approximately 7.5 million people in Serbia and 200-300 new cases of child malignant disease annually. 70% are treatable while 30% are not and efforts made to ensure the child’s comfort until death. Rates of other life-limiting conditions are un-
known. Many children die in hospital although increasingly children are dying in the home, however structures are not in place to support this. Serbia has a well-established free healthcare system for children from the age of 0-19. There is a highly skilled professional body of experts as well as excellent paediatric specialist services. In addition there are parent support groups that would benefit from education in palliative care so that parents are better able to cope with a child living and dying with a life-limiting condition. **Conclusions.** These findings provide a foundation upon which children’s palliative care services can be developed in Serbia. With adequate resource allocation and education, children’s palliative care services could be successfully integrated into paediatric health care in Serbia. The Ministry of Health in Serbia is committed to developing palliative care services and plans are being developed as to how best this can be done.

**144**
**Communicating with children about death through a wall of sunflowers**

Marston J.M.
International Children’s Palliative Care Network, Management, Bloemfontein, South Africa

**Background and aims.** Children with HIV in developing countries experience multiple losses through death and abandonment. Many children are orphaned and live in children’s homes and hospices for long periods of time. They experience the deaths of other children and express feelings of fear and uncertainty regarding their own mortality. A children’s hospice in South Africa established a sunflower wall of remembrance set up in the playground of the hospice. Each sunflower contains the name of a child who has died. The aim of having it in the playground is to assure children that death is a normal part of life and that they will always be remembered.

**Methods.** Children learn that the sunflowers contain the names of friends who have died. Speaking about the sunflowers leads to questions about death and meaning of life. Knowing their name will be in a sunflower assures the children they will not be forgotten. Chaplains and other spiritual supporters spend time with children when need spiritual support and more reassurance.

**Results.** Having the wall of remembrance in the playground children learn that death and life are connected and that they will be remembered after they have died. Children speak openly about their beliefs around death, and at times choose the flower that will contain their name. When children die in the hospice, other children participate in a remembrance activity and the placing of their names in a sunflower.

**Conclusions.** Children do not have to be protected from discussions around death. The assurance that they will be remembered helps children feel worthwhile and that their lives have meaning.

**145**
**Implementation in Moldova of palliative care services for children with non-oncological diseases**

Isac V., Ciobanu O., Miron R., Gutium-Hirciiala D.
The Charity Foundation for Public Health Angelus Moldova, Hospice Angelus, Chisinau, Moldova, Republic of

**Background and aims.** In Moldova palliative care services have been provided since 2000 in order to benefit adult patients with oncological diseases. 2008 was the first year of implementation of paediatric palliative care services in Moldova for children with oncological deseases. The next step was the Paediatric Palliative Care Project for children with non-oncological diseases, which began in 2011. The aim of this study is to optimize paediatric palliative home care services for children with non-oncological life-limiting diseases in Moldova.

**Methods.** Between October 2011 and June 2012 the number of patients included in the program was 24 children aged between 7 months and 17 years with non-oncology life-limiting diseases at varying stages of illness. The area service covers Chisinau city and the suburbs.

**Results.** Structure diseases, according to principal diagnosis, are the following: neurological diseases (13 patients) including cerebral palsy, hydrocephalus; genetic diseases (9 patients) including cystic fibrosis, neuronal ceroid lipofuscinoses, Down syndrome, Werdnig-Hoffman spinal myotrophy, Duchenne muscular dystrophy; congenital malformations (2 patients)- extrahepatic biliary atresia, multicystic dysplastic kidney. In all cases there is a collaboration with family doctors and hospitals for children.

**Conclusions.** Since 2011 in the Republic of Moldova paediatric palliative care also includes another category of beneficiaries: children with life-limiting non-oncological deseases. But this service currently covers only Chisinau and suburbs area, making it difficult for children who live in other regions of the country. Thus there is a necessity to consolidate the development and outreach for this category of patients.

**147**
**A seamless service: evaluation of an integrated model of delivering both palliative care and community oncology services to children and young people with life threatening and life limiting illnesses**

Dempster T.
Ellenborough Hospices, Children and Young People’s Service (CHYps), Canterbury, United Kingdom

**Aim.** To present an evaluation of an integrated model of palliative care that includes delivery of pallia-
tive care services to children and young people with cancer from point of diagnosis to either discharge or end of life care. Community based services are considered to play an important role in changing the way in which the UK health system operates. The introduction of palliative care services for some children can still be left until treatment or cure is no longer an option. At this difficult point in the child’s journey, new professionals are often introduced to the family and care transferred to another team.

In January 2011 Ellenor lions Hospices commissioned an independent review of its well established Children and Young Peoples Service (chYps). The aim of this review was to evaluate the integrated service model which chYps delivers to both palliative care and community oncology children.

Methods. Between January and June 2011 a team from Canterbury Christ Church University undertook a review of the chYps service. The project was conducted in 2 phases. In phase 1, an information review was undertaken and in phase 2 the effectiveness and usability of the service or service users and staff was analysed by qualitative methods. 10 families, 4 young people and 12 professional or support staff were either individually interviewed or invited to a focus group interview.

Conclusions. The data presented in the evaluation report concluded that the Ellenor lions chYps service was an integrated model, reflecting the best practice guidance within the ACT framework and had a number of unique features. The chYps team were able to demonstrate that the service model it delivered integrated both palliative and curative approaches and provided a good example of seamless care.

148 Whic kind of paediatric patients need respiratory palliative care?

Ellena M., Urbino R., Gregoretti C., Veljkovic A., Luccoli L., Goia M., Esposito I., Castello M., Bignamini E.

Introduction. In palliative care the number of children with or at risk of chronic respiratory failure (CRF) is increasing. The ability to aid these patients with mechanical ventilation invasive or non invasive, at home has been one of the major advances of respiratory medicine.

Objective. The aim of this study was to describe the population of patients affected with CRF and at risk of developing CRF treated in our Centre.

Methods. We surveyed all 502 patients attending our service for Chronic Respiratory Failure for home treatment between 2005 and 2011. These patients have been treated following the regional guidelines for pediatric chronic respiratory failure. We excluded from the description the patients who were >18 yrs old and those who had not attended the Centre for a period longer than three years.

Results. Causes of CRF were varied. Table 1 shows the details of the children with more common causes of CRF. Total number of children included in the study were 375. Mean age 8,53 yrs. 15 died (mean age of death 7,36 yrs. Male 204 (54,4%), Female 171. Patients in Telemedicine 31 (8,2%). Mean length of hospitalization 10,38 days. Patients treated with Fi- siokinesitherapy 161. Mean number of reacutization 1,35 per year. Patients treated with antibiotics in last year 142 (37,86%). Mean number of outpatients visits per year 2,71. Patients ventilated 59 (15,7%). Tracheotomy 38 (10,13%). PEG 36 (9,6%). Oxygen therapy 20 (5,3%).

Conclusions. As known, the overall prognosis is related to an early and constant care, both in hospital and at home. The regional guidelines foresee programmed visits, nocturnal dsaturations, emogasanalys is, nutritional, cardiological controls. These guidelines have shown to be efficient in reaching this aim. A rigorous follow-up of young patients affected by and at risk of CRF can contribute to terminate a better prognosis of the pathology. Sharing guidelines at regional level would be useful to guarantee this follow up.

149 The pediatric palliative care regional network in an Italian Region: an integrated model between home care, hospital and hospice

Marri E.1, Bravi M.2

1Regione Emilia Romagna, Servizio Presidi Ospedalieri Direzione Generale Sanità e Politiche Sociali, Bologna, Italy, 2Fondazione Isabella Seragoni, Bologna, Italy

Since the National regulation in palliative care, including pediatric area, has been actuated many Italian Regions organized its services provision Agenda accordingly. At the 1st Pediatric Palliative Care Congress it will be presented the work that an Italian Region accomplished in defining the Pediatric Palliative Care (PPC) network and how it will make it operative. The presentation will draw all the steps that led the Region to understanding the need of creating a regulated network in PPC avoiding the growth of models not fully appropriated to children and family needs. At the Congress it will be presented the goals achieved by the PPC Work Group in one year in defining the network. The final documentation approved by the Work Group includes the phenomenological analysis and the categories of patients that will be followed by professionals in the different settings. The Network of PPC will be composed by the Home Setting, the Hospital setting and the Hospice setting. There will be one 10 beds Hospice for all the region. The Hospice represents an innovation in
the Region and will be managed by a private non profit organization well-known for managing three Adult Hospices in the area. At the conference it will be presented the Hospice project defined upon the international guidelines and the most interesting experience of Children Hospices at the international level. The Hospice will be presented showing all the settings including consulence to other professionals in other settings, complementary activities and school services. The Group Work has already defined the training and research activities that will frame the regional PPC network and will be coordinated by the Hospice. The presentation will stress the importance, also considering the historical period of economical crisis, of setting up valuable and innovative projects with the successful collaboration between public institutions and private non profit organizations effective in the community.

**150 Academic education in pediatric palliative care in Italy: presentation and outcome of the university higher education course as a start-up project for specialist education defined by law 38**

Pession A.1, Bravi M.2

1Department of Paediatrics University of Bologna, Bologna, Italy. 2Fondazione Isabella Seràgnoli, Bologna, Italy

The outcomes of the university higher education course launched in 2011 will be presented at the 1st European Congress on Paediatric Palliative Care. The course has been acknowledged for its distinctive innovation, contents and faculty by many organizations and institutions including the Regional Authority for Health and Social Policies. The course has been co-launched by University and a national research and educational centre focused on palliative care courses (e.g. masters and ECM courses) and it has been acknowledged by the Faculty of Medicine within the Pediatric Department of the University. The students of the first edition come from different Italian Regions and are involved in the Pediatric sector with different backgrounds and roles. The course faculty has been defined following the need of combining education and experiences accordingly to the diffusion of the integrated multidisciplinary network model. The course modules have been adapted by the international core curriculum in pediatric palliative care and contextualized to the Italian sector and to the 38 law. The presentation will stress the need arisen by professional, in the Region and all over the country, to be properly trained in pediatric palliative care at all levels. In fact, due to the fact that effective structures and services networks of pediatric palliative care have been only recently created, the course has been drawn in consideration of the training need of professionals involved in the already existent health structures. Thus, the course has been launched basing on a strong advocating aspect that aims at diffusing the palliative care culture in all the health primary sectors in order to spur an early integration process between curing and caring. The positive experience will be the driver for the organization and the university that launched the course to setting up the recently required Master in Pediatric Palliative Care addressed to podiatrists.

**151 International developments in paediatric palliative care**

Boucher S.J.1, Marston J.M.2, Downing J.3

1International Children’s Palliative Care Network, Information, Hillcrest, South Africa, 2International Children’s Palliative Care Network, Chief Executive, Bloemfontein, South Africa, 3International Children's Palliative Care Network, Education and Research, Assagay, South Africa

In 2009 the International Children’s Palliative Care Network (ICPCN) undertook an exercise to map the levels and provision of palliative care worldwide. A marked increase in interest and awareness of children’s palliative care globally has taken place since then. While it is not possible to point to any one reason for this, it is worth noting that it coincides with the establishment and corresponding growth in membership and in project involvement of the ICPCN. The ICPCN not only freely shares information through its website and newsletters, but has evolved to include full or partial involvement in projects to bring training in paediatric palliative care to countries where previously there was little knowledge of the discipline. This involvement has included training and mentorship in Kenya, Zambia, Malawi, Tanzania and Brazil. This has in turn led to the piloting of an ICPCN online e-learning module on the new WHO pain guidelines, the first in a series. ICPCN’s original vision to showcase the research of others has also expanded to include a Scientific Committee whose members include top academics taking a leading role in identifying the gaps and carrying out their own research. Additionally the ICPCN has published a number of seminal documents, including the ICPCN Charter for Life Limited and Life Threatened Children, a Fact Book on Children’s Palliative Care addressed to podiatrists.

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153
Touching rainbows: finding the human face of paediatric palliative care
Boucher S.1, Marston J.M.2, Downing J.1
1International Children’s Palliative Care Network, Information, Hillcrest, South Africa, 2International Children’s Palliative Care Network, Information, Assagay, South Africa, International Children’s Palliative Care Network, Education and Research, Durban, South Africa

Patch Adams said "Transference is inevitable... Every human being has an impact on another. Why don’t we want that in a patient/doctor relationship? A doctor’s mission should not just be to prevent death but also to improve the quality of life. That’s why if you treat a disease...you win, you lose. If you treat a person...you win, no matter what the outcome.

With these simple but heartfelt words he captures the essence of palliative care. The same simple precept of children’s palliative care can be distilled from the stories found in the latest ICPCN publication "Touching Rainbows". These stories have been written in some instances by children or siblings and in others by those who care or cared for them while they were ill and through their death.

The book’s subtitle is ‘Acknowledging the child’s voice in children’s palliative care’ and has over 40 stories about children who have received or who are still receiving palliative care. Where possible these stories have been told by the child and/or siblings and in others by those who care or cared for them while they were ill and through their death.

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years and many more in the pipeline. This is due to the committed efforts of some professional and volunteer champions. The 4 centres in Mumbai, Delhi, Hyderabad and Kozhikode are caring for up to 2000 patients a year with a comprehensive care for children and their families. An urban centre for children with HIV and a rural centre for any child with a life-limiting condition has been possible with the help of ICPCN and HTH. There are 2 more centres coming up in Chennai and Calcutta. With a great emphasis on training of Paediatricians all over the country, theimpetus is gathering. Budgets are being found. There is a lot of good will being created for the children. Media and NGO’s help in this. Stories from the mouths of children are acting as a factual tool to convince Govt Officials to accept a Paediatric Palliative care policy for India where some budget will be set aside to provide care at every district in the country. The experiences in achieving this will be shared in this paper.

Conclusions. Challenges act as an impetus for rapid growth as has been shown with these experiences.

157 Specialist pediatric palliative home care in lower Saxony, Germany - Two years of care provision
Kremerike K.1,2, Sander A.2, Reinhardt D.2
1Netzwerk für die Versorgung Schwerkranker Kinder und Jugendlicher e.V., Hannover, Germany, 2Hannover Medical School, Hannover, Germany

Background and aims. In Lower Saxony, a federal state in the north-west of Germany with a low population density, a comprehensive specialist pediatric palliative home care (SPPHC) was implemented. The aim was to ensure an adequate care for children suffering from life-limiting conditions (LLC) in the context of low patient numbers and low numbers of specialists.

Methods. Potential home care providers (physicians, psycho-social specialists, nursing and hospice services) were evaluated to support number estimations. Since April 2010, a central office undertakes the coordination and administration, while different regional teams comprising medical, nursing and psycho-social specialists care for the children and adolescents suffering from complex conditions due to LLC. These teams closely cooperate with the regional primary health care and volunteer services. Additionally a central hotline service provides 24/7 specialist availability.

Results. The evaluation within Lower-Saxony confirmed the estimated numbers of children with LLC (n = 1630). About 163 children per year could be expected to have the right of specialized care. During the first two years of operation, the SPPHC providers were involved in the management of 82 children suffering from LLC. 43 of these children died in the same period. In total, 3278 hours of SPPHC were delivered, predominantly spent on joint patient care with regional health care providers (31%), driving time (22%) and coordination of care (13%).

Conclusions. The provision of a comprehensive SPPHC in a region of low population density is possible. Our data demonstrates that only a minority of patients and families exercise their right of SPPHC. The reasons might be the unwillingness to accept the incurable condition of the child or a lack of knowledge about the benefits from SPPHC. The results further demonstrate the high percentage of coordinative and logistic efforts to enable and ensure the SPPHC in each child and all areas.

159 Children dying with cancer: how well we care
Birtar D.M., Luca D., Corbu A.
Hospice “Casa Sperantei”, Paediatric Dep, Brasov, Romania

Aims. 1) To assess the frequency of the symptoms in advanced cancer in children being cared by Hospice Casa Sperantei. 2) To compare what was recorded in our files with what the parents recall regarding the most distressing symptom and the response to the treatment.

Methods. We review the medical records of all children who died of cancer between 1996 and 2008 in our service. In this period we had a total of 94 deaths in children, from which 51 died of cancer. Criteria for inclusion: to have at least one complete evaluation of symptoms. We also collected data from the parents referring the symptoms of the children in the last months of life, the response to the treatment, the quality of life and how much the CPC team intervention had helped. We analyzed all the symptoms using descriptive analysis with SPSS.

Results. 80% of children died at home. A number of 39 symptoms were identified. The most common symptoms were pain (100%), lack of appetite (87%), asthenia (87%), constipation (72.9%), nausea (70.8%), dyspnoea (60%), cough, irritability, and anxiety. Pain was controlled in 60% of our patients, better than dyspnoea (10%) and nausea (50%). Anorexia, fatigue, irritability were frequent rated in our survey, distressing a lot the parents, but we found out that not the same attention was given in the management of these symptoms.

The parents survey showed that the PC team intervention contributed a great deal to better symptom control and quality of life in children with advanced cancer. They especially appreciated that the child was able to be cared at home most of the time, giving the family the possibility to spend time together.

Conclusions. All the children experienced substantial suffering in the last period of life. Even if not all the symptoms could be controlled, the palliative care made possible for the majority of children to die at home and contributed a lot to the improvement of the quality of life for the children and their families.
161 Homecare Assistance (HA) for haematological children in terminal phase V
Leoni V., Decimi V., Adzic M., Meda A., Mandelli N., Jankovic M.
Milano Bicocca University - S Gerardo Hospital, Pediatric Haematology Department, Monza, Italy

In our Department the median number of childhood acute lymphoblastic/myeloid leukemias and lymphomas diagnosed is respectively of 50 and 10 cases a year.

Objective. To offer the best quality of life in palliative care for terminal children.

Key-points. 1) To consider a child terminal on the basis of a team decision (physicians and nurses). 2) To guarantee assistance continuity by the same equipe who followed the child during first-line treatment.

Methodology. HA is based on parents and children’s observations made during assistance and emerged in post-mortem interviews.

Results of 6 years’ experience. From little children we have realized their wish to stay at home, to play and perform their routine activities and not to be ospedalized. For adolescents, instead, day-hospital calls have been of great importance not to feel abandoned. The necessity of assistance continuity led us to administer HA by the same staff who had followed the child during his previous treatment in order to respect his wishes, priorities and attitudes. Parents’ anxiety has made us aware of the importance of 24 hours’ reperibility. When HA has been offered by other teams (for logistic problems as excessive distance from hospital) it showed a failure, with patients ospedalized in consequence of parents’ anxiety or management difficulties. During HA we have also learnt to respect the child’s will, following his time and wishes in visiting, in starting therapies and playing with him.

Project. 1) The equipe consists of 3 doctors and 7 nurses, the same who followed the child during his previous treatment. 2) The team cooperates with the family doctor, who can play an important role, and accept any person identified by the child. 3) Care is offered at home with daily/weekly visits and a few day-hospital calls. 4) The team assures 24 hours’ availability, specific treatments and psychological support. 5) A bed is reserved in hospital in case of management difficulties or when parents require hospitalization.

162 The experience of the family of a child/teenager requiring palliative care: fluctuating between hope and hopelessness in a world transformed by loss
Bousso R.S., Misko M.D.
University of Sao Paulo, Sao Paulo, Brazil

The present study aimed to understand the experience of the family of a child/adolescent requiring palliative care. This is a qualitative study using the Symbolic Interactionism and Grounded Theory as theoretical and methodological frameworks, respectively. The study was conducted at the Pain and Palliative Care Outpatient Clinic of a tertiary teaching and research hospital in the city of Sao Paulo. A total of fifteen families of children requiring palliative care took part in the protocol and data were obtained by means of participant observation, semi-structured interviews. Data comparative analysis made it possible to unveil the meaning of the family’s experience in the child’s palliative care process. The experience is made up of four sub-processes: “Having their lives shattered”; “Dealing with the new situation”; “Recognizing palliative care” and “Learning to live again”, which are continuously interrelated throughout the experience and are the challenges the family has to act upon and devise strategies in order to overcome them. Articulation among these sub-processes allowed the identification of the core category fluctuating between hope and hopelessness in a world transformed by loss, from which a theoretical model explaining the experience is proposed. The process shows the experience lived by the family, determined to offer the best quality of life they can to the child and to keep the family united before and after the child’s death. Hope, perseverance and spiritual beliefs are the elements guiding the family to keep fighting for their child’s life amidst uncertainties, anguish and suffering due to the losses lived during the process of their child’s illness. Knowing the family’s experience makes it possible for the health care professionals to identify and recognize the family’s weaknesses and strengths when coping with this process so that professionals can devise and implement intervention strategies to help families with children in need of palliative care.

168 Preparation of a psychological folder in pediatric palliative care and home care
Minetto M.1, Benini F.2, dall’Amico R.1, de Zen L.1, Gerarduzzi T.1, Bagolin A.1
1Azienda Ospedaliera Santa Maria degli Angeli, Pediatria, Padova, Italy. 2Centro Regionale Cure Palliative Pediatriche, Pordenone, Italy.

Introduction. Various professionals are involved in the child’s care pathway, able to work as a team is very difficult, because this individual skills can sometimes bring more than space.

Objectives. Create a folder that would gather all the psychological information to help the team a psychological palliative care and pediatric home care. The areas are: 1) UVO-UVD (evaluation unit home and hospital evaluation unit). 2) Knowledge interview/assessment with the family. 3) Talks accompanying the child and family.

Methods. The starting point was to perform a literature search but did not reveal any published work. The next step was to identify and contact centers of pedi-
Adherence to non invasive ventilatory support in children with spinal muscular atrophy type 1 and 2

Verrillo E., Salerno T., Pavone M., Chiariini Testa M.B., Soldini S., Piliero A.M., Cutrera R.

Children Hospital and Research Institute Bambino Gesù, Department of Pediatrics, Respiratory Unit, Rome, Italy

Introduction. Autosomal recessive Spinal Muscular Atrophy (SMA) is the most common fatal inherited disease in infants. The impaired respiratory function in these children is the main cause of the high mortality rate associated with these disorders; Non Invasive Ventilation (NIV) has reduced morbidity and mortality due to respiratory insufficiency and has a favourable impact on respiratory infectious complications.

Aim. To evaluate the necessary time and mode to achieve adaptation to NIV in SMA patients free from acute respiratory insufficiency.

Methods. We prospectively studied 28 consecutive patients with SMA type 1 and 2. Mean age was 19±23 months, M/F 10/18, 11 patients with SMA 1 and 17 patients with SMA 2. All these patients started NIV: 7 patients during acute respiratory exacerbation (3 SMA 1, 4 SMA 2). NIV was delivered via a nasal mask (86%) and nasal prongs (14%). Full face mask was used only in one child. NIV was administered with Pressure Support Ventilation mode (89%) and Assisted controlled pressure ventilation mode (11%). Mean Inspiratory Airways Pressure (IPAP) was 12±2.7 cm H2O while mean Inspiratory Airways Pressure (EPAP) was 3.9±0.74 cm H2O. Success was defined as the necessary time to accustom the SMA patient free from acute respiratory insufficiency to NIV and the mode to achieve acceptability of this tool.

Results. According to our success definition, all patients were considered as successfully ventilated, as all of them tolerated the mask and NIV with a mean adaptation time of 8±2 days. In our study NIV was effective and well tolerated in all patients, and no major complications were observed.

Conclusions. Our study demonstrates that NIV is well tolerated in children with SMA, and, probably, the high rate of success was obtained thanks to a standardized protocol of NIV initiation/administration, the proper parents education, a strict follow-up, the lack of major complications.

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Factors that influence families in deciding disclosure of death to dying children

Teo M.P., Rashid N.A.B.

KK Women’s and Children’s Hospital, Paediatric Palliative Care Service, Singapore, Singapore

Background and aims. It can be emotionally upsetting to broach the subject of death to children. Parents often struggle in deciding whether or not they should talk about death with their children and how much to disclose to them. Families are often involved in rituals and practices that acknowledge the threats of death although they may avoid addressing the topic of death directly. The International Society of Paediatric Oncology recommends that parents communicate honestly with their children about their imminent death. Studies have shown that children may benefit from talking about their imminent death but many at times parents would decide not to tell. Healthcare professionals in our hospital believe that the children should be given the honest and accurate information about their diagnosis, treatment plan and prognosis. However families often attempt to shelter their children from the news of their impending death. Therefore the aim of this study is to uncover the factors that influence families in disclosing imminent death directly with their children.

Methods. Semi structured interviews will be conducted. The participants will be families with children having a terminal illness and between ages of 7 to 16. These families will be identified from KKH Palliative Care Team database. This will be a qualitative study and the data from the interview will be analysed using a phenomenological approach.

Results. The results will be presented in the conference.

Conclusions. The outcome of the study may potentially help families decide whether or not to disclose the prognosis to their children who are dying of a terminal illness. Understanding the experiences of these families may also provide healthcare workers with the knowledge to facilitate communication of prognosis with the families and the dying children.
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Role of cancer-directed therapy in palliative care: case report in a child with advanced stage neuroblastoma

du Plessis J.

Universitas Hospital, Bloemfontein, South Africa

I will be presenting the case report of a child’s seven year battle against Advanced Stage Neuroblastoma and the lessons we learnt from his journey. The patient presented 7 years ago with unexplainable bone pain and the diagnosis of stage IV Neuroblastoma was made. In order to obtain first remission the first line chemotherapy protocol was extended with two cycles. His first remission lasted 18 months and due to his poor prognosis and time from completion of first line chemotherapy the same protocol was used to obtain second remission. Second remission lasted 15 months and this time oral etoposide was used as a palliative option (5/28 day cycle). The effects was pain control and good quality of life. The disease however continued to progress and regular transfusions was required due to the bone marrow infiltration. Later he developed propoasis, skull-and brain metastases and convulsions as a complication thereof. It was after one of these convulsion episodes that he recorded an inspiring testimony, which will be played during the presentation. Cranial irradiation was used as a palliative measure to relieve the pressure symptoms he experienced from the metastases. Unfortunately he passed away seven years after his initial diagnosis. During his journey we have learned that palliative cancer-directed treatment has a definite role in palliative care. Not only to extend life and relieve symptoms, but the lessons we can learn from our children/patients be life changing!

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Pediatric Palliative Care (PPC): how is it perceived by italians?

Benini F.1, Fabris M.2, Pace D.S.3, Orzalesi M.3

1University of Padua, Department of Pediatrics, Padua, Italy, 2Episteme srl, Milan, Italy, 3Maruzza Lefebvre D’Onofrio Onlus Foundation, Rome, Italy

Background. Palliative Care (PC) for children (PPC) is not sufficiently implemented in Italy, in spite of the presence of a special law. The correct and widespread knowledge of the nature and aims of PPC is necessary for its implementation and diffusion.

Aim of the study. To verify the level of knowledge and understanding of PPC among Italians.

Methods. We submitted 9 questions on PC and PPC to a sample of 1934 Italians, aged 18 to 74 years, representative of the entire population for gender, age, education and geographic area of residency.

Results. Less than 55% of the interviewed had heard, even vaguely, of PC. Even when helped with some definitions, 32% of them did not know how to answer or had a mistaken idea of the nature of PC. Only 7.1% of the interviewed believed that PC is applicable also to children. Furthermore, 78% did not know if in Italy there were children that had benefited of PPC. They thought that the major fear of an incurable child is the eradication from his/her family, friends and home (42%), followed by physical pain (16.7%), death (12.5%) and being abandoned (7.2%). Only 55.8% of the interviewed thought that a child perceives the burden of psychological (anxiety, fear, etc.) and social (loneliness, isolation, etc.) problems due to his/her illness, at any age, while 23% of them believed that this is not possible before 7 years of age. 65.6% believed that a child should be cared for at home, by his/her family (47.8%) or by external personnel (17.8%), while 9.1% would prefer a dedicated structure and 7.7% the hospital. The prevailing source of information on PC was television (32%), followed by relatives and friends (27,3%), by the family doctor or other health professionals (18,1%) and by the newspapers (10,4%). 57,9% had no idea if and to what extent the National Health System would provide adequate PPC.

Conclusions. In spite of the debate in the mass media on the proposal of a law for the right to PC, and even following the approval of such law, the knowledge of Italians on the nature of PC, and particularly of PPC, is still largely incomplete or even erroneous. A law is not sufficient to guarantee the access to PC, unless public knowledge is improved through an adequate and correct information; this could increase the demand and put pressure on the policy makers, thus facilitating the application of PC in the whole Country.
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