
2nd CONGRESS ON PAEDIATRIC PALLIATIVE CARE - A GLOBAL GATHERING
Rome 19th - 21st November 2014



ABSTRACT BOOK

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Scientific Programme

Wednesday 19th November 2014

17.00

Opening Ceremony

Keynote Lecture: Hope in Paediatric palliative care

Chris Feudtner

Keynote lecture: The History of PPC - What we have learnt

Ann Goldman

Thursday 20th November 2014

08.30

Plenary Session: Symptom Control

Moderators: *Joanne Wolfe & Boris Zernikow*

- Neurological symptoms - *Julie Hauer*
- Respiratory symptoms - *Stephen Liben*
- Nutrition and anorexia - *Ross Drake*
- Psychosocial symptoms - *Rut Kiman*
- Conclusions

11.15

Oral presentation session (2 in parallel)

Working Session I – Epidemiology and Surveys

Moderators: *Finella Craig & Danai Papadatou*

- The Epidemiology of Dying for Children and Adolescents in a Country without Provision of Paediatric Palliative Care (Portugal, 1987-2011)
Ana Lacerda
- Identification, Categorisation and Mapping of Paediatric Palliative Care (PPC) Services in Europe: Results of the European Association for Palliative Care Survey
Ebun Abarshi
- Transferring Critically Ill Babies and Children Home to Die from Intensive Care Units: A National Survey Exploring the Experiences and Views of Health Care Professionals
Katy Morton
- Access to Opioids in Argentinean Children with Advanced Cancer: Practices and Social Representations about Opioid use and Prescription. Results from a National Mapping Study *María Bevilacqua*
- Closing remarks

Working Session II – Education and Training

Moderators: *Joan Marston & Domenica Taruscio*

- Seeking Excellence: A Baseline Study of the Clinical Learning Requirements of Staff within LauraLynn Ireland's First Children's Hospice
Claire Quinn
- An Exploration of Medical Student's Understanding of Paediatric Palliative Care and the Educational Value of a Short Teaching Programme in a Children's Hospice
Joanne Balfe
- The Education in Palliative and End of Life Care (EPEC) - Pediatrics: Behavior Change in Pediatric Palliative Care (PPC) through a "Train-the-Trainer" Curriculum
Stefan Friedrichsdorf
- Italian Core Curriculum in Pain Management and Pediatric Palliative Care
Lucia De Zen
- Closing remarks

12.30

Lunch and Poster visit

Scientific Programme



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- 14:00 **Special Plenary Session - No Pain for Children Award 1st Prize**
• Bereaved Siblings' Advice to Health Care Professionals Working with Children with Cancer and their Siblings - *Malin Lövgren*
- 14.15 **Plenary Session: Pathways In Special Situations**
Moderators: *Mary Ann Muckaden & Marcello Orzalesi*
- Perinatal - *Alexandra Mancini*
 - Cardiac disease - *Elizabeth Blume*
 - Neuromuscular disease - *Anita Simonds*
 - Conclusions
- 16.30 **Oral presentation session (2 in parallel)**
Working Session III – Research Issues
Moderators: *Julie Ling & Rut Kiman*
- Research for Beginners - A Workshop to Teach Basics in Paediatric Palliative Care Research
Julia Wager
 - Research Governance and Study Design in Palliative Care Research in Children with Cancer
Are We Learning from Ourselves?
Christopher Barton
 - Research Priorities in Pediatric Palliative Care: A Delphi Study
Justin Baker
 - What Do Families Say about Participating in a Randomized Controlled Trial in Pediatric Palliative Care?
Veronica Dussel
 - Participation of Terminally Ill Children with Cancer in Clinical Trials
Ivana van der Geest
 - Closing remarks
- Working Session IV – Parents and Siblings**
Moderators: *Anna Garchakova & Zipporah Ali*
- Bereaved Siblings' Experiences of the Brother's or Sister's Cancer Death: A Nationwide Follow up Study 2-9 Years Later
Malin Lövgren
 - The Burden of Home Care: Parent's Care in Children with Complex Physical Healthcare Needs Eligible for Paediatric Palliative Care
Barbara Schiavon
 - How Well do Serbian Parents of Children Suffering from Malignant Disease Understand what Pediatric Palliative Care is (PPC)?
Tamara Klikovac
 - Depression and Anxiety in Siblings of Children with a Chronic Illness: Child and Parents' Perspective
Alessandra De Gregorio
 - Measuring Stress in Parents of Medically Fragile Children at the Time of Referral for Home Care Services Using the Pediatric Inventory for Parents (PIP)
Andrea Postier
 - Closing remarks
- 18.00 **Keynote session:** End of life care: Psychosocial and Spiritual Aspects
Barbara Sourkes



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Friday 21st November 2014

- 08.30 **Plenary Session: Emerging issues in Paediatric Palliative Care**
Moderators: *Joan Marston & Zipporah Ali*
- Disability - *Adriano Ferrari*
 - Cultural and ethnic diversity - *Şenay Kaldirim- Celik*
 - Assessing local needs - *Martha Mherekumombe*
 - Integrative Therapies in Paediatric Palliative Care: Hypnosis - *Stefan Friedrichsdorf*
 - Conclusions
- 11.15 **Oral presentation session (2 in parallel)**
- Working Session V – End-of-life Issues**
Moderators: *Finella Craig & Anna Garchakova*
- A Good Death? Factors Related to Bereaved Parental Perspective of End-of-Life Care and Quality of Death in Children with Advanced Heart Disease
Sonja Ziniel
 - The Way Parents of Children with Incurable Cancer Gain insight in and Attend to the “Voice of their Child” at the End of Life
Marijke Kars
 - Withdrawal of Mechanical Ventilation at “End of Life” beyond the Paediatric and Neonatal Intensive Care Unit (PICU & NICU) - What Really Happens?
Joanna Laddie
 - End of Life Care in Hospital: Scope for Paediatric Palliative Care Involvement?
Lynda Brook
 - Closing remarks
- Working Session VI – Communication, Ethics and Spirituality**
Moderators: *Danai Papadatou & Myra Bluebond Langner*
- Spiritual Interventions in Families of Southeast Asian Children with Cancer during Palliative Care
Issarang Nuchprayoon
 - The Dynamics of Interviewing in Research Studies with Parents of Children Receiving Palliative Care
Honor Nicholl
 - How Does the Belgian Law on Child Euthanasia Impact a Belgian PPC Course?
Marie Friedel Castorini
 - Resilience and Professional Quality of Life of Health Care Givers Working with Children in Severe Medical Conditions: The Role of Spirituality of Health Care Professionals in a Pediatric Cardiac Intensive Care Unit (PCIC)
Ulrike Schloderer
 - Closing remarks
- 12.30 Lunch and Poster visit
- 14:00 **Plenary Session: Research in Paediatric Palliative Care**
Moderators: *Myra Bluebond Langner & Julie Ling*
- Ethics - *Richard Hain*
 - Evaluation of services - *Monica Führer*
 - Patient outcomes - *Julia Downing*
 - Conclusions
- 16.00 **Oral presentation session (2 in parallel)**
- Working Session VII – New Tools and Strategies**
Moderators: *Domenica Taruscio & Stefan Friedrichsdorf*



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- The Changing Face of Children's Palliative Care - Children's Hospice an Option for Children with Complex Technological Needs in their Transition from Hospital to Home?
Jayne Price
- Implementing PICU Screening Criteria for Unmet Pediatric Palliative Care Needs:
A Novel Application of the IPAL-ICU Project
Jessica Turnbull
- The Impact of Introduction the Sleep Diaries and a Sleep Evaluation Questionnaire in the Clinical Practice of a PPC Service
Delia Birtar
- Debrief Meetings as an Evolving Tool for Evaluation & Development of a High Quality Paediatric Palliative Care Service
Pat Sartori
- To become an Artist during Hospital Days Linking Art and Health for Children with Life Limiting Conditions (LLC) in a Pediatric Palliative Care Unit (PPC)
Catalina León
- Closing remarks

Working Session VIII – Models and Local Experiences

Moderators: *Mary Ann Muckaden & Zipporah Ali*

- Neonatal Palliative Care: The Experience of a Portuguese Program
Joana Mendes
- Children's Palliative Care (CPC) Project in Developing Country: Lessons Learnt
Pradnya Talawadekar
- Can Perinatal Palliative Care Be Improved by a Pathway? A Pilot Scheme to Assess will Be Discussed
Patrick Carragher
- An Evaluation of Models of Children's Palliative Care in sub-Saharan Africa
Julia Downing
- Pediatric Palliative Care (PPC) and Domiciliary Long-term Mechanical Ventilation (DLTMV): The Experience of the Veneto Regional PPC Network (RPPCN)
Francesca Rusalen
- Closing remarks

17.30 **Keynote session:** The Rights of the Dying Child
Kathy Foley & Marcello Orzalesi

18.00 **Conclusions and Closing Remarks**
Joanne Wolfe & Franca Benini



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Compassionate Confrontations: Integrating Hopes, Emotions, and Duties when Confronting Serious Illness

Feudtner C.

The Children's Hospital of Philadelphia, Philadelphia, PA, United States

This lecture will address two questions: 1) How are major medical decisions made by parents of a child with serious life-threatening illness? 2) How can clinicians better support parents in the process of making these decisions?

The main argument has five components. First, parents both feel as well as think their way forward when they are making major medical decisions for their children, and that they do so under the influence of relationships that they have with their child and with people around them. The emotional skills of recognizing the mixture of feelings that one has, and having sufficient trust in others to reveal these emotions, are essential challenges for parents of children with serious illness.¹ The skills of collaborative communication and relationship building can facilitate the thinking-feeling-relating process of decision-making for parents.²

Second, parents of children with serious illness experience both strongly positive and strongly negative emotions, and often have both types of emotions weaving together throughout the course of even a single conversation about decision-making. How these emotions mix and combined to influence decision-making is influenced by parents' levels of hopeful patterns of thinking, with parents who have higher levels of hopeful patterns of thinking having greater optimistic cognitive flexibility to adapt to and cope with the challenging situations, problems, and decisions that a child living with serious illness presents.³

Third, central to medical decision-making for children with serious illness is the process of regoaling: that is, the process that unfolds over time of shifting from emphasizing one primary goal (such as cure of illness) to another primary goal (such as being comfortable or staying at home). The regoaling process is powered in large part by emotions, with negative emotions causing one to reevaluate and potentially want to change the status quo and the original goal, and with positive emotions enabling one to have a sufficient level of energy and motivation to seek or create a new goal. Hopeful patterns of thinking further facilitate regoaling by enhancing the generation of new goals, which empowers people to deemphasize former goals while embracing new goals.⁴

Fourth, parents' self-perceptions of their own duties, what they believe they must do to be a "good parent", also likely influences the process of regoaling and decision-making. Parents have markedly different notions of what they must do to be a good parent in their own eyes, with some parents emphasizing that they need to make sure that their child feels loved while others emphasize that they must advocate for their child's medical needs and yet other parents are focused chiefly on their child's spiritual wellbeing. Despite these different notions of what parents state they feel they must do to be a good parent, clinicians rarely ask parents to share this information, instead focusing decision-making discussions almost exclusively on the child's medical situation.⁵

Fifth, clinicians can better support the process of regoaling and decision-making by being aware of and working thoughtfully and compassionately with these influential factors. Techniques such as inviting partnership, offering promises regarding how we will conduct ourselves, requesting permission to raise difficult topics of conversation⁶, asking what parents are hoping for or what they feel they need to do to be a good parent, exploring their thoughts and feelings about their hopes (which are likely to include several hopes) and how they can move towards them⁷ - all of these techniques can better support parents of children with serious illness confront the challenges of problem-solving and decision-making on behalf of their child.

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Guest Speaker



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The History of Paediatric Palliative Care – What Have We Learnt?

Goldman A

All over the world and across all time children have lived with and died from life threatening illnesses; their families and communities have cared for them and grieved their loss in ways that have fitted their time and culture.

These last 3 decades have seen palliative care for these children and their families develop from a novel and radical concept to a thriving, growing and accepted speciality.

In this talk I will look at 3 questions.

Why is palliative care the model of care that seems to respond to children's and families' needs today?

I will trace some of the circumstances, both medical and in society, which came together in the late 1970s and resulted in the development of children's palliative care.

What have we learnt from the practice of palliative care for children over the last 3 decades?

Different countries with different geography, cultures, resources and healthcare systems have given us a wide variety of services today, and these are still evolving. Exploring some of these different approaches gives us the opportunity to highlight the successful strategies and also to recognise the problems we face in achieving the goals of palliative care for children and families. We can identify some of the essential skills we have learnt as clinicians, and also some of the mistakes we have made.

What are the challenges for the next decade?

We have travelled along way in quite a short time and can be proud of the support and care we have given to many children and families. We have the opportunity now to learn from our experience so we can strengthen our foundations and bring palliative care to all those children and families who need it.

Change is inevitable and we will need to respond to the new situations we face; in the scope of palliative care in emerging fields, in the changing patterns of diseases and treatments and in the expectations of our patients and families. There is a huge need for research to explore new ideas and to give us a solid evidence base for our work. In clinical care we still have much work to do to achieve integrated care and equality of access, for all the children and their families, including those in the developing countries across the world.

Guest Speaker



Neurological Symptoms (Non-Cancer)

Hauer, J

Division of General Pediatrics, Complex Care Service, Boston Children's Hospital, Harvard Medical School, Boston, USA

Neurological symptoms occur when there is impairment that alters the function of the central nervous system. Neurological problems encountered include spasticity, autonomic dysfunction, dystonia, myoclonus, and seizures. Less commonly recognized yet well described in adults is central neuropathic pain.

Treatment of such problems is challenged by the significant overlap in the presenting features observed with each, making it difficult to prioritize the potential problem to treat. As an example, muscle spasms are associated with spasticity and are also frequently seen with pain from any cause in such children. In addition, impairment of the central nervous system that results in such problems places such a child at risk for more than one problem to co-exist.

This presentation will provide an organized strategy to guide empiric medication trials for this group of symptoms. Evidence related to pharmacologic interventions will be summarized. Medication categories include: anti-epileptic drugs including gabapentinoids, tricyclic antidepressants, alpha-2 agonists, benzodiazepines, baclofen, and opioids.

In addition, non-pharmacologic strategies will be highlighted. Such strategies recognize that any neurological symptom can worsen as a result of discomfort, illness, constipation, disrupted sleep, and medication toxicity. Beneficial interventions include regular sleep, a calm environment, and an effective bowel regimen. Other effective strategies include swaddling, rocking, repositioning, massage, music, physical therapy, supportive cushions, vibrating mat, weighted blanket, a cool fan, and water baths.

Finally, children with impairment of the central nervous system that is global and severe are at risk for such problems to remain intractable, best described with seizures. By recognizing and acknowledging this risk when symptoms persist after multiple interventions, parents can make informed decisions on behalf of their child. Palliative care clinicians and teams are well suited to maximize management of such problems while guiding families throughout their child's journey.

Problem	Comments	Treatment options	
Autonomic dysfunction (Dysautonomia, Autonomic storms)	Suggested by: sweating, flushing of the skin, hyperthermia, bowel dysmotility, pain localized to the GI tract, tachycardia, agitation, arching, and stiffening	Scheduled Intermittent (autonomic storms)	gabapentinoid, alpha-2 agonist alpha-2 agonist, morphine sulfate, benzodiazepine
Central neuropathic pain	Suggested by: sudden "out of the blue" bursts of pain and pain localized to the GI tract, including pain triggered by distention of the GI tract (such as pain associated with tube feedings or intestinal gas, with relief following a bowel movement or passing gas)	Gabapentinoid, tricyclic antidepressant Adjust tube feeds and maximize bowel management so as to minimize distention of the GI tract	
Spasticity Muscle spasms	Spasticity: velocity-dependent increase in muscle tone that results in muscles that are resistant to movement; spasticity is often not painful Muscle spasms: sudden involuntary contraction of a muscle or group of muscles; muscle spasms can be painful and pain can trigger muscle spasms	Botulinum toxin for focal spasticity, intrathecal baclofen pump for generalized spasticity Empiric pain treatment	



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Dystonia	Involuntary sustained or intermittent muscle contractions cause twisting and repetitive movements, abnormal postures, or both; pain can trigger and worsen features of dystonia	Limited studies of various drugs: benzodiazepines, anticholinergics (trihexyphenidyl, benztropine), baclofen, dopaminergic agents (bromocriptine, levodopa), dopamine depletor and blocker (tetraabenazine) Empiric pain treatment
Myoclonus	Brief, abrupt, shocklike, nonsuppressible, involuntary movements due to sudden contraction or relaxation of one or more muscles; pain can trigger and worsen myoclonus	Valproic acid, clonazepam, levetiracetam, piracetam Empiric pain treatment

GI: gastrointestinal



“I Can’t Breathe” - Dyspnea in Pediatric Palliative Care

Liben S.

McGill University, Pediatrics, Montreal, QC, Canada

“Sooner or later, whether from panic or in our final hour, each of us will find ourselves breathless.”

M Rosenbaum

What we call “our life” is what happens between the beginning of the first in-breath at birth and the end of expiration at death. What could be more foundational to each person’s lived experience than the sensation of breathing? What could be more distressing than the experienced sensation of not being able to breath, to “lack air”, to be breathless?

This presentation will explore some aspects of the meaning of breathlessness (dyspnea) as construed by different points of view (e.g. psychological, cultural, religious, spiritual) and how it it reflects both on our patients and on ourselves as caregivers. A core aspiration of palliative care clinicians is the alleviation of one of the most distressing symptoms imaginable - that of being unable to breath without distress. Dyspnea results in powerful sensations that can quickly lead to both thought amplification and proliferation that then worsens dyspnea in a self reinforcing loop of thoughts feelings and sensations that is felt as “panic”. How might clinicians respond to such intense and often life-ending symptoms without over-medicalizing and over medicating as an unhelpful reaction to their own rather than their patients’ distress? What qualities of the caregiver might be helpful in reducing the panic-cycle of the patient and the secondary distress of caregivers and loved ones who bear witness? This presentation will explore some of these questions from one clinician’s point of view.



Nutrition and Anorexia - Beyond the Withdraw/Withhold Paradigm

Drake R.

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

Anorexia or loss of appetite is a relatively common symptom reported to be present in, as high as, 80% of children requiring palliative care regardless of the condition [1-4] and more likely to increase toward the end of life becoming more problematic. [3] Similarly, there has been consistent reporting of this symptom being relatively resistant to treatment [3,4] although the scant therapeutic data has focussed on children with an associated, even more difficult to treat symptom; cachexia, "a complex metabolic syndrome associated with underlying illness and characterized by loss of muscle with or without loss of fat mass". [5] Megestrol trialled in small numbers of children with cancer, cystic fibrosis and HIV disease [6-10] and cyproheptadine [11] in cancer have been reported to improve nutritional status by increasing appetite and weight. Adverse effects with megestrol use were significant with children developing adrenal suppression and one child manifesting clinical hypoadrenalism with haemodynamic collapse requiring inotropic support. [7]

In the region of 80% of the children who could benefit from involvement of a children's palliative care service have a non malignant condition [12,13] and many are already receiving some form of medically assisted nutrition such as nasogastric or percutaneous endoscopic gastrostomy feeding. [12] However, anorexia can be the precipitant for referral and coincide with contemplation for medically assisted nutrition. This frequently puts children's palliative care into the decision-making process around nutrition.

The orthodox view of palliative care is that it advocates for withholding or withdrawing such measures which is, arguably, contentious and challenging to convey to colleagues, let alone children and their families. This is because offering nutrition is a basic human interaction synonymous with giving life and comfort. Yet, confronting the issue is much less of a trial when the futility of such an approach is obvious or causing more distress than benefit which can be seen in neurologically devastated children, children with total and irreversible intestinal failure, or actively dying children.

Conversely, withdrawing and withholding medically assisted nutrition may not be appropriate. This could occur when the clarity around futility is murky and the benefit to harm balance is evenly poised, or too difficult to evaluate. In such situations the clinician must give careful deliberation to what is in the child's "best interest" and this reflection may dictate sound clinical practice requires promotion rather than opposition to medically assisted nutrition. Through case vignettes and a review of the literature these themes will be explored with the aim to stimulate contemplation of an open and considered attitude toward how nutrition is provided in the face of anorexia for children requiring palliative care.

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Psychosocial Symptoms (delirium)

Kimman R.J.^{1,2,3}

¹International Children Palliative Care Network, Bloemfontein, South Africa, ²Hospital Nacional Prof. A. Posadas, Pediatrics, Buenos Aires, Argentina, ³University of Buenos Aires, Department of Pediatrics, Buenos Aires, Argentina

Pediatric Palliative care improves the quality of life of children who are facing chronic, complex, advanced, or life-threatening conditions. These conditions are often associated with a significantly increased risk of psychosocial symptoms such as depression, anxiety, and delirium. Accurate diagnosis and appropriate treatment can be challenging.

The purpose of this presentation would be to provide an overview of delirium, its prevalence, key features, risk factors, subtypes, pathophysiology, assessment, and evidence-based interventions, both pharmacologic and nonpharmacologic.

Delirium is a common but frequently unrecognized syndrome among compromised children. Delirium is primarily a disturbance of consciousness. The hallmarks of delirium include an acute onset of a mental status change, impaired attention, fluctuation in the severity and presence of symptoms over time, change in level of consciousness, sleep-wake disturbance, restlessness, and psychotic symptoms.

Of the 3 subtypes of delirium (hypoactive, hyperactive, and mixed), hypoactive is frequently mistaken for depression. The degree to which these subtypes apply to pediatric populations has yet to be fully demonstrated. (Karnik 2007). The clinical manifestation between children and adults might differ, which may be due to their young age and developmental changes. Pediatric delirium shows a more distinct course with a more acute onset, less circadian variety in symptoms and fewer sleep-wake cycle disturbances, as compared to adults. Making the correct diagnosis is critical to providing appropriate treatment. Delirium carries a significant burden for increased mortality as well as for patient, family, and caregiver distress. (Creten 2011)

There are numerous theories to explain the cause of delirium, it is likely that the symptoms are the expression of different abnormalities that impact neurotransmitters and neurons in different areas of the brain. The leading one is decreased cholinergic activity accompanied by dopaminergic increase.

Delirium could be the result of a medical condition and can be caused by the illness itself (e.g., serious infection or neoplasm), by products of the illness (e.g., metabolic or endocrine dysfunction), or side-effects of the treatment (e.g., sedative drugs or drug withdrawal). There are also risk factors for the development of delirium like low serum albumin, elevated white count, proteinuria and dehydration (increased BUN/creatinine ratio). Also multiple precipitating factors have been identified: psychoactive medications, metabolic disturbances, dehydration, non-respiratory infection, hypoxic encephalopathy, and intracranial causes were among the factors noted.

A key factor in diagnosis is a high index of suspicion, underlying causes as 50% may be reversible. Expert consensus supports presentation of delirium in children over the age of two years as comparable to adult delirium, and clinical diagnosis, based on the DSM-IV criteria, has been found to be valid. Preverbal children under two years of age and developmentally delayed children may be very difficult to evaluate for alterations in awareness, consciousness, and cognition, leading some to question the validity of diagnosing delirium in this population. The presence of delirium can interfere in the assessment of symptoms.

Treatment of Pediatric Delirium exists in two components: psychosocial (restoring orientation and comfort) and pharmacological (antipsychotic) management. Treatment with neuroleptics can be considered the standard of care. Haloperidol is most often recommended because it has fewer anticholinergic side effects, is less sedating, has fewer active metabolites, and rarely causes orthostatic hypotension or cardiovascular side effects. In the case of hyperactive delirium, haloperidol may be more effective because of its narrower targeting of the dopamine D2 receptor. Because of their wider receptor effects, atypical antipsychotics may be more useful in mixed or hypoactive delirium.

Conclusion: Delirium is a common devastating complication of advanced disease and often a result of the medications we use to treat these patients.

Guest Speaker



Pathways in Special Situations: Perinatal

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Palliative care pathway- ‘ Practical guidance for the management of palliative care on neonatal units ‘

Despite advances in neonatal medicine, many infants will suffer from conditions that mean they will not survive longer than months, days or a few minutes. The goal of all involved in neonatal medicine is to sustain life and restore health, but when this is not possible, infants and their families should still receive the best possible care until the end of life. However long or short, care must always be tailored to individual needs of the infant and their family.

The purpose of the guidance is to equip professionals with a clear set of principles, to underpin the care they provide infants with life-limiting conditions and support their families through this difficult time whilst ensuring consistently high quality care.

This document aims to complement existing resources which are available in the UK.

The guidance document was developed by members of the neonatal team at Chelsea and Westminster Hospital that included doctors, a senior nurse, a psychologist and a hospital chaplain. It has been endorsed by the Royal College of Paediatrics and Child Health (RCPCH) after several rounds of national stakeholder consultation, including key organisations including Bliss, British Association of Perinatal Medicine, Child Bereavement UK (CBUK), Multiple Birth Foundation (MBF), Stillbirth and Neonatal Death Society (SANDS), and Together for Short Lives alongside professionals within the field of perinatal and paediatric palliative care. The development of the guidance was funded by the Department of Health and includes a foreword by Sir Bruce Keogh, National Medical Director for NHS England and real-life experiences of families whose babies have received such care.

This guidance has been developed following a systematic review of published literature. The Appraisal of Guidelines for Research and Evaluation II (AGREE Next Steps Consortium, May 2009) process was followed to synthesise evidence and formulate recommendations.

The guidance development group (GDG) undertook the systematic review and subsequent summary of the evidence. Where there was limited evidence to support recommendations for practice, these were based on the consensus of the GDG. It is acknowledged that there is a paucity of good quality research in this area.

Feedback and amendments can be viewed on the RCPCH website.

The views of parents and families in the development of the guidance was obtained by a combination of the review of the literature and by involving organisations that provide support to parents and families of the target population in the national rounds of stakeholder consultations.

Caroline, mother of baby Brigid, said: “Nothing can prepare you for the death of a child. It is vital that the staff who are caring for our babies and supporting us through this difficult time are trained and equipped to do so with an understanding of the procedures and protocols that will allow our babies to die with dignity, whilst ensuring that they do not suffer unnecessarily. It is also important that this is done within a framework that allows the families to have their concerns heard and their wishes considered.

I cannot stress enough the importance of having access to professionals who work as a team and put your baby at the forefront of their planning. Good training, guidance and support is essential to empowering them to do this and to reassure us, as parents, that we do not have to worry about the practical aspects of our babies’ condition and can concentrate on being the best parents we can be for whatever time we have left with our precious children.”

Hard copies of the guidance have been sent to all neonatal units in the country and it is also available to download, along with all of the supporting documents, from the Royal College of Paediatric and Child Health website. It is also available from a number of charity and stakeholder websites including Bliss, British Association of Perinatal Medicine, Chelsea and Westminster Foundation Trust, Child Bereavement UK, The Multiple Births Foundation, Stillbirth and Neonatal Death Charity and Together for Short Lives.

Guest Speaker



Pathways in Special Situations: Cardiac Disease

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(Adapted from "Palliative Care and Children with Advanced Heart Disease". American Academy of Pediatrics Section on Hospice and Palliative Medicine Quarterly newsletter, June 2014, pp3-4)

Despite dramatically improved short and long-term outcomes for infants and children with cardiac disease, advanced heart disease remains one of the leading causes of death in childhood. When infants and children with advanced heart disease (AHD) die in the current era, it is frequently in an ICU and from multi-system organ failure. [i] Although research exists related to the advancement of medical and surgical technologies to prolong the lives of children with AHD, much less is known about symptom control, suffering, and end-of-life decision making in this population.

Some important aspects of the care of children with AHD population may contribute to the differences in end of life care and palliative care consult involvement, when compared to the oncology population. The focus on highly technological interventions and procedures; the variable and unpredictable progression of heart failure; and the culture of pediatric cardiology and intensive care, all have an impact. In the congenital heart disease population, most of the initial clinical encounters between parents and cardiologists, often prenatally, focus on immediate, life-saving management options. Even in cases in which staged palliative surgeries are planned, death is rarely imminent and the risk of significant morbidity years down the line is often minimized. The burden and risks of the procedure, however, must be balanced with the degree of predicted symptom relief.

The clinical course for children with heart failure is variable and highly unpredictable. Infants and children, similar to adults with heart failure, often experience episodes of life-threatening decline followed by days and months of stability, possibly even discharge to home. That cycle can repeat itself many times over. Each intermittent episode of acute decompensation may also lead to the introduction of new technologies that may possibly prolong life, including ECMO, ventricular assist devices, and heart transplantation. Many of those proposing these new technologies find it challenging to incorporate attention to quality of life, suffering, and end-of-life planning.

Lastly, the relationships that pediatric cardiologists and cardiac surgeons have with patients and families over time cultivates close relationships and trust. Introducing a second team to help "communicate" with the family or provide end-of-life care can at times be perceived as threatening that long term relationship between the patient and cardiology providers.

Our research has focused on how, where, and when children die of advanced heart disease and how parents and physicians perceive their prognosis, suffering and end-of-life care. We have found that parents realize that their child has no realistic chance for survival occurs, on average, one day prior to death.[ii] Nearly 50% of parents perceived suffering during the end-of-life period. Nearly three-quarters of parents described their child's overall quality of life in the last month of life as "poor" or "fair." At the same time, seventy percent of parents agreed that, given the circumstances, their child had experienced a "good death" and 84% reported the overall quality of care provided to be "very good" or "excellent." The parents made additional observations. We also compared parent and physician perceptions of suffering and end-of-life care in children with advanced heart disease.[iii] We found that physicians overestimated parent preparedness for their child's death and underestimated the degree to which they felt they had received conflicting information from various members of the child's care team.

A typical parent reported immense confidence in their cardiac surgeon, beyond all other caregivers. They were unlikely to accept poor outcomes as likely until the surgeon acknowledged that there was no way to stop the progression of the disease. This is further complicated by the view among the surgeons that "involving the palliative care team will send the message to the family that I have given up, and I have not given up..."

It will surprise no one that the world of pediatric AHD is a complex culture involving patients, families and providers. Palliative care providers can make important contributions but those contributions are best made with awareness of this culture. There is room for important collaboration between cardiologists and palliative care practitioners. Prospective studies are necessary to improve EOL care for children with AHD. Specifically, identifying risk factors or triggers that would allow discussions earlier may help inform parent decisions regarding interventions that may significantly impair quality of life, and aid in family preparedness for the possibility of patient mortality.

Guest Speaker



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Neuromuscular Disease

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Neuromuscular conditions are heterogeneous in cause and presentation. In conditions involving the respiratory muscles, respiratory complications are the commonest cause of death. In recent years breakthroughs in molecular genetics have aided classification and given a better understanding of natural history of these conditions. In addition, new approaches have improved outlook. For example in Duchenne muscular dystrophy life expectancy has more than doubled with the introduction of assisted non-invasive ventilation and around a third of young men with the condition live into their 30s and 40s. Even in Type 1 spinal muscular atrophy life expectancy can be extended with the use of ventilatory and nutritional support.

Many children with inherited neuromuscular disease are now surviving to adulthood – in our practice approximately 40% of children starting on non-invasive ventilation in childhood transition to adult care. But increased survival brings new problems and complications not seen when death occurs in early childhood. For many children with neuromuscular conditions palliative care is required alongside aspects of active care, with close attention paid to the best interests of the child. The use of palliative non-invasive ventilation to facilitate symptom management and care at home with the family will also be discussed.



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End of life Care: Psychosocial and Spiritual Aspects

Sourkes B.

As pediatric palliative care develops into a field of its own, we have a window of opportunity to define the parameters of optimal psychological and spiritual care for these children. In the same way as specialized medical and nursing assessments are carried out for children admitted to palliative care, so too should their psychological status and spiritual beliefs be evaluated by mental health and chaplaincy professionals who have specific expertise with children. (When the child is brain damaged, or severely intellectually handicapped, or not mentally competent in the terminal phase, psychological /spiritual intervention may not appropriate). The healthy siblings must also be included in this care. As children, they participate in their sibling's dying and will live into bereavement and beyond throughout their lives marked by this premature loss. Children's words and images will highlight the themes of this discussion.

Guest Speaker



Disability

Ferrari A.

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The core of Rehabilitation Medicine, especially in the paediatric field, generally deals with pathologies without any feasible possibility of effective cure (i.e. cerebral palsy, neuromuscular diseases, spinal cord injury, neurodegenerative disorders, genetic syndromes, congenital malformation, etc.). By treating children with their pathologies (intended as care) and not the pathologies of children (explicitly cure), Rehabilitation can therefore be considered appropriately a type of palliative care. In fact rehabilitation:

- is a form of education that addresses damage produced by pathologies and (sometimes) also by received clinical therapies,
- most of the time is unable to correct the primary lesion, but all the same can bring about important adaptive changes in the child,
- cannot cancel defects or deficits, or even hide them, but works in order to produce adequate compensations and suitable substitutions,
- does not restore normality, but is able to reciprocally adapt individuals, community and environment (physical and cultural) to each other in order to make interaction, integration and independence in some way yet possible.

While in clinical medicine, for diagnosis, the stated goal is to identify what is missing or has been lost or damaged, in order to repair or substitute it, in rehabilitation, for prognosis, the challenge is undoubtedly to identify what is left and find out what can be done with it, in spite of the persistent pathology. The key word for rehabilitation is therefore “nonetheless”. This is the most difficult concept to transfer and accept both for clinicians and for children and families. Our instruments are the modifiability of the compromised function (versus natural history), the learning ability and motivation of the child, i.e. willingness, initiative, determination, resilience, etc. In fact, the principal actor of the rehabilitation process is, first of all, the child, their needs, their desires, their resources, including family and social facilities. Behaviour models, practical experience and positive emotions are the main components of the recovery process. Treatment in rehabilitation is a two-way street where the therapist must adapt to the child so that the child can draw advantage from the therapy. Physiotherapy is in fact an action carried out through interaction.

In order to facilitate the transferability of acquired competences and abilities, therapeutic proposals have to be “flavoured” with intrinsic pleasure. This represents the most difficult aspect in child rehabilitation. In fact, spasticity or loss of muscle strength, limited range of motion or bone deformity and restrained or compromised movement are often insuperable negative constraints. Therapeutic activities, on the other hand, are often tiring, exercises difficult to perform, some interventions aggressive, such as the adoption of orthoses and devices, and some painful such as surgical correction of congenital or acquired deformities. The environment of Rehabilitation itself could be psychologically isolating and stigmatising. In fact, the comparison with other patients can be encouraging (positive model in therapeutic group) but can also be detrimental (the more severely compromised patient in progressive pathologies).

The therapeutic effort directed at disabled children would be in any case insufficient in guaranteeing their full participation in society, if rehabilitation limits itself only to the education of the disabled individual. Indeed, it is necessary to educate general population to the presence of the disabled person, beginning with same aged children, in order for a true and complete integration in society to take place. Immigration requires a continuous change in social integration on both parts (natives and immigrants) and in this process, native culture and religious beliefs are important constraints. For sick children these constraints are still binding. For this reason, the most important progress in child rehabilitation has been, in my opinion, the Italian law established 40 years ago, that allowed all children, Italian and foreign, also disabled children, all types of disabled children, to attend the regular school. It is still, today, the only example of its kind in the world.

Guest Speaker



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Cultural and Ethnic Diversity - Intercultural Attitude in Paediatric Palliative Care

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People from different cultures and with a different ethnical background vary in their beliefs, value system, language and religion. However, people with the same cultural or ethnical background are not all the same, but are additionally imprinted by individual aspects. This diversity within a group of a certain ethnicity also presents in migrants. They are not all the same due to their ethnical background but rather a copy of the diversity of the local population in the country of origin.

Providing appropriate care for families with migration background can be a challenge for health care providers. Not only cultural differences need to be considered, but also individual needs. There is not the one recipe, which prescribes how to accompany families with migration background and how they have to be cared for. The basic idea of an intercultural understanding is very similar to the attitude promoted in palliative care: the specific needs of families and individuals need to be focused. Individual needs can best be explored in conversations imbedded in a close relationship; empathy is needed to find out which information the family is willing to reveal and which information they are not (yet) ready to share. Talking with families about their beliefs and their life philosophy will help health care providers to understand their particular needs and desires. To understand that migrants are not just characterised by their cultural background but much more by individual experiences will help health care providers to avoid stereotyping and to focus on the individual.

However, understanding the individual also includes an understanding of his/her cultural background. If the health care provider has a general idea of the underlying cultural aspects, it will be easier to capture the whole person.

Paediatric palliative care is a family-centred approach. Therefore, knowledge on culture-specific family roles and familial values is important. For many cultures, "family" does not only incorporate immediate relatives (e.g., parents and children) but also distant relatives (e.g., cousins). Sometimes "family" is even extended to community members. Many of these may be involved in the care of a dying child. While this may seem strange to western health care providers, it needs to be accepted that the definition of family and the extend of family support differs. For each family it needs to be explored, who has a relevant role in the family system, how the individuals interact with each other and who is included in decision processes.

Also, the conception of disease and death is shaped by the cultural background. This concept highly influences how people cope with illness and death. In case of severe disease and exposure to death and dying, cultural and religious aspects may even gain relevance. Nevertheless, in paediatric palliative care we also need to look beyond these obvious factors. A sole focus on the specific culture and religion bears the risk of neglecting factors arising due to the current living situation. Migrants may be confronted with daily hassles arising from a low socioeconomic status, a low level of education, language barriers or discrimination. Each individual may further have individual resources within the social environment. These factors need individual exploration so that they can be integrated in the care process.

In the care of patients with a migration background, difficulties in communication may arise due to language barriers. Communication is an important tool in paediatric palliative care; it is essential for the trust and relationship between the family and health providers. A lack of communication can lead to emotional detachment at a time when closeness is most needed. Language barriers may even cause misunderstanding.

This talk aims to convey, based on clinical cases, that cultural competence is more than the accumulated knowledge of a specific culture. In the paediatric palliative care of a child with migration background, intercultural understanding is needed. This means to be aware of interactions between cultural and religious values, disease-related and psychosocial stress as well as individual characteristics. Intercultural competence requires: (i) reflection of own values and cultural norms, (ii) empathy, (iii) acquisition of cultural knowledge and (iv) avoiding stereotyping.

Guest Speaker



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Assessing Local Needs

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Globally the need for paediatric palliative care services is increasingly being recognised. These advances have resulted in the recognition of gaps in services, development of new services and increased dialogue with stakeholders in order to formulate solutions to address this concern. The result of such has been recognising the need to integrate services using local resources. Education remains an integral part in disseminating the need for palliative care in children. However barriers almost universal include lack of funding, skilled staff and prioritising the need for paediatric palliative care.

Paediatric palliative care service provision challenges vary depend in different parts of the world. Assessment processes are more or less the same primarily concerned with access to palliative care for those in need. A systematic review of paediatric palliative care provision across the world was undertaken in 2011. The review found that 65.6% of countries had no known paediatric hospice-palliative care activity, 18.8% had recognised capacity building activity, 9.9% countries provided localised services, and 5.7% had integrated paediatric palliative care with mainstream service providers.

A recent report was also undertaken in three sub-Saharan countries, Zimbabwe, South Africa, and Kenya to estimate the palliative care need in children and to explore the countries' capacities to deliver children's palliative care (CPC). This project was conducted in collaboration with the United Nations Children's Fund and the International Children's Palliative Care Network. The report findings indicated very limited CPC service coverage for children in the public sector. Services were mainly localised yet only minimal children were covered. Barriers identified in the delivery of CPC included the fear of opioid use, lack of education on the need of CPC, lack of integration into the primary care system, lack of policies on CPC, and lack of community and health professional awareness of CPC needs and services. The report recommended the provision of paediatric palliative care integration into the public health system, increasing training of health workers in paediatric palliative care, services to increase capacity to expand on the education of the availability of paediatric palliative care services and to prioritise development of paediatric palliative care with relevant donors.

In Australia we have been fortunate in New South Wales State (NSW) for government's commitment to improve the access and care of patients needing palliative care. New models of care are being developed and implemented by specialist palliative care providers working with all health workers. These innovations are expanding community-based services mostly in areas of need such as rural and regional areas. Primary health care will be integrated with specialist palliative care services across the state to maximise the use of resources and promote best practice. In order to ensure the success of this families and carers of people receiving palliative care will have expanded support with access to advice and after hours telephone support and volunteer support.

About two-thirds of children who are dying of a life limiting illness in NSW are supported by specialist paediatric palliative care services. The three children's hospitals specialist paediatric palliative care (PPC) services work collaboratively as the NSW Paediatric Palliative Care Programme to improve access for children requiring palliative care state-wide. These services provide hospital-based consultancy services to community palliative care services and primary care service providers. The support of local, rural and regional areas is also provided through new models of care such as "Pop Up" "interventions. Pop Up allows teams to be quickly mobilised around the child and family to provide support for the duration of the child's illness and for the family in bereavement. The teams provide training and education to local health care providers involved in the patient's and family care.

The Pop Up intervention aims to build confidence of the local health services to care for patients at home. This intervention includes the family/carer, local health services supported by the PPC service. If the care needs of the child and family change, additional support for local health services may be necessary and the PPC service will "POP UP" to re-coordinate a new management plan. This intervention may involve education and in time training in order keep the child and family at home or locally and not transferred to a tertiary centre.

In conclusion, assessing local palliative care needs is essential for the advancement and improvement of paediatric palliative care. A lot can be achieved by working collaboratively and using new models of care as discussed in this paper.

Guest Speaker



Integrative Therapies in Pediatric Palliative Care: Hypnosis

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"There were heaps of little computers, and each one was operate by, like, little people, and each one was operated by a different person. You can actually tell them if you want the pain to go down or the nausea to go down, or whatever..."

11-year old girl dying of acute myeloblastic leukemia when asked what it was like traveling to her own brain in hypnotic trance.

Pediatric Palliative Care-An Introduction

While comprehensive palliative care is the expected standard of care at the end-of-life (Council on Scientific Affairs, 1996; National Quality Forum, 2006), services for the majority of children with life-limiting or terminal conditions fall significantly below those for adults. In the United States and most countries in resource rich countries, the vast majority of infants, children, and teenagers at end-of-life do not have access to multidisciplinary pediatric palliative care (PPC) services in their community or at their children's hospital.

PPC is for children and teenagers suffering from a life-threatening or life-limiting condition that threatens their survival into adulthood if curative treatments fail. As a result, PPC may last over many years. According to the World Health Organization (WHO) [<http://www.who.int/cancer/palliative/definition/en>], Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

Provides relief from pain and other distressing symptoms;

Affirms life and regards dying as a normal process;

Intends neither to hasten or postpone death;

Integrates the psychological and spiritual aspects of patient care;

Offers a support system to help patients live as actively as possible until death;

Offers a support system to help the family cope during the patients illness and in their own bereavement;

Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;

Will enhance quality of life, and may also positively influence the course of illness;

Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Wolfe, Hinds and Sourkes in 2011 adapted the WHO definition for children (Wolfe 2011) and defined it as follows:

Active total care of the child's body, mind and spirit, and also involves giving support to the family



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Begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease

Demands that health providers evaluate and alleviate a child's physical, psychological, and social distress

Requires broad interdisciplinary approach

Includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited

Can be provided in tertiary care facilities, in community health and hospice centers, and in children's homes

Should be developmentally appropriate and in accordance with family values

Integrative approaches that address symptom management, emotional, spiritual and behavioral issues, and include parents, siblings and school concerns provided by a multi-disciplinary team are now becoming accepted practice. This review will examine mind-body integrative therapeutic interventions for children and teens during the provision of palliative care. The emphasis will be on hypnosis and related modalities such as imagery, biofeedback and distraction.

Distressing Symptoms at the End-of-Life

Studies looking at prevalence of symptoms in 473 children with malignant and non-malignant diseases reveal that the majority of dying children experience pain, vomiting and dyspnea (Table 1). Wolfe et al. (2000a) show in their retrospective study among bereaved parents of 103 cancer patients, that the majority of distressing symptoms were not treated, and when treated, the therapy was commonly ineffective. A dying child is often highly symptomatic, and providing symptom relief is one of the most compelling domains of PPC. Wolfe et al. (2000b) demonstrated that an earlier recognition by both physicians and parents of no realistic chance of cure led to a stronger emphasis on treatment to lessen suffering and integrate palliative care. Consequently, proponents in the field urge that these options be provided early—at best, at diagnosis or early in treatment. As medicine advances, many children are living longer with complex conditions, and the need for ongoing care, support, pain, and symptom management increases over longer periods of time.

Myths

Persisting myths and misconceptions have led to inadequate symptom control in children with terminal disease. One of the most enduring is the wrongly held belief that in the management of pain and dyspnea, opioids would hasten death and should only be administered as a last resort. It is a common experience of PPC teams that administering opioids and/or benzodiazepines, together with comfort care to relieve dyspnea and pain, improves the child's quality of life. Education about the use of opioids and an understanding that tolerance plus physical dependence does not equal addiction is an important principle in PPC. Furthermore PPC advocates the provision of comfort care, pain and symptom management concurrently with curative treatments. Families no longer have to opt for one or the other. They can pursue both options, and include integrative approaches to maximize the child's QoL.

Management of Pain and Distressing Symptoms

If a child is suffering from pain during the end-of-life, the team providing PPC needs to provide prompt and effective pharmacological pain management. Commonly this requires using strong opioids (e.g., morphine, fentanyl, hydromorphone, oxycodone, or methadone) by different routes of application (e.g., oral, sublingual, buccal, intranasal, transdermal, intravenous, subcutaneous, rectal, but not intramuscular, as it causes unnecessary pain). The use of adjuvant analgesia may be appropriate (e.g., gabapentinoids/anticonvulsants, tricyclic antidepressants, alpha-agonists, N-methyl-D-aspartate receptor [NMDA] antagonists, bisphosphonates, antispasmodics, low-dose general anesthetics) and anesthetic or neurosurgical options may be required (Friedrichsdorf & Kang, 2007).

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Today the state-of-the-art in managing pain and other distressing symptoms at the end of life requires integrating pharmacological with integrative treatment modalities. In our experience a pharmacological approach alone will not provide optimal symptom management. Drawing on a combination of rehabilitative (including physical, occupational, and/or speech therapy), physical methods (e.g., massage, physical therapy, cuddles/rocking from family/friends, transcutaneous electrical nerve stimulation [TENS], or hot water bottle or cold pack) with cognitive-behavioral methods (e.g., guided imagery, hypnosis, biofeedback, or abdominal breathing) or modalities such as acupuncture/acupressure, music, expressive art, provides the best possible symptom management.

Integrative Therapeutic Interventions in Palliative Care

Integrative therapies aim to restore balance and harmony by working simultaneously on physical, mental, emotional, and spiritual needs (McDonald et al., 2006). It is recognized that interventions that develop internal coping skills empower children and teens and enhance their quality of life. (Sourkes BM, 2000).

Mind-Body Medicine

Mind-body medicine focuses on intervention strategies that integrate mind processes with body function and experience in order to promote health. For children and teens, these include relaxation, hypnosis, imagery, meditation, yoga, biofeedback, tai chi, qi gong, cognitive-behavioral therapies, group support, autogenic training, and spiritual practices. Mind-body interventions constitute a major portion of the overall use of Integrative (or complementary alternative medicine, CAM) by the public (NCCAM, 2007). In 2002, mind-body techniques, including relaxation techniques, meditation, guided imagery, biofeedback, and hypnosis, were used for health reasons by about 17% and prayer was used by 45% of the adult US population (Barnes et al, 2002).

Imagery

Imagery is a non-intrusive, child-centered, gentle therapeutic modality, which can provide a meaningful alternate experience when the present reality is fraught with pain, fear, fatigue, or physical tension. Imagery can be used in many ways. Two often-used techniques include, focusing directly on the distressing symptom, engaging with it so that it begins to change, or creating a favorite or familiar image that is a more pleasant alternative to the distressing symptom. Imagery is a precursor to hypnosis, and often used as an induction to hypnotic trance in which change can more rapidly occur.

When used for pain control, imagery works synergistically with analgesics to reduce pain and discomfort (Kuttner & Stutzer, 1995). This modality enables a child to focus attention on a personally meaningful imagery experience and as the imagery becomes more absorbing, the child or teen may dissociate from pain, increase comfort, reduce anxiety, or alter the pain sensations and perceptions (Kuttner 1997; LeBaron & Zeltzer 1984; Zeltzer & LeBaron 1982). For general principles, the book, *Mortally Wounded* details the clinical use of imagery to ease a patient's anguish at the end of life (Kearney, 1996).

Case Example 1

Ian was an 8-year-old boy with end-stage cancer (rhabdomyosarcoma). He experienced dyspnea during his last week of life. His parents were taught to assist him with guided imagery, which allowed Ian to review and enjoy important events in his life. Together, using a poster board they created a time line, starting with Ian's birth. Ian and his family spent hours each day on this activity. Ian visibly calmed during the sessions, his breathing becoming deeper and more regular. Focusing on his important life events, recreating images and soliciting information from his parents to round out the stories, he created a full and meaningful sense of his own life. Ian died peacefully the day after he completed his full imaginative reminiscing, bringing his own closure and giving his family the comfort of vivid memories of their life together.

Hypnosis

The use of hypnosis is well described in pediatric palliative care (Kuttner 2013, Friedrichsdorf 2010). Hypnosis

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involves the cultivation of an altered state of awareness, leading to heightened suggestibility that allows for changes in a child's perception and experience, bypassing conscious effort. In hypnosis the clinician enters the child's world, engaging the child's imagination as the agent of change and creating alternate experiences to promote therapeutic change. In trance, the child addresses distressing symptoms utilizing suggestions by the clinician for altering sensations, perceptions, and increasing comfort (Olness & Kohen, 1996).

Hypnosis is a natural fit for seriously ill children in palliative care (Gardner, 1976; Kuttner 1995; Kuttner 2006; Sourkes, 2006) As a therapeutic technique it is gentle, non-intrusive and child-centered. The hypnotic experience works well with mystery, paradox and uncertainty. When a seriously ill child learns hypnosis early during treatment it becomes part of the supportive therapeutic scaffold that the child leans on to deal with life and death concerns (Gardner, 1976; Kuttner, 1995; Kuttner 2006), either as self-hypnosis or during psychotherapy. Regular hypnosis or self-hypnosis has the capability to sustain the child's inner strength, or to conserve energy as the child's life force diminishes. In the imaginative engagement it provides a child with the experience of loved activities that can no longer be accessed but can still imbue meaning, sustain hope, ease despair, lessen pain and help to transport the child to places and experiences that diminish the threat of death, and ease their present experience. It is also an adjunctive method that combines well with pharmacological options to address distressing end of life symptoms, such as nausea, discomfort, anxiety, pain, and existential distress (Kuttner 1995; Kuttner 2006).

Hypnosis has been used over the last two decades in a number of RCT treatment studies to control pain during invasive medical procedures (e.g., Kuttner, 1988; Liossi, 2002; Zeltzer & LeBaron, 1982). Zeltzer et al. (2002) in a feasibility study successfully combined acupuncture and hypnosis for 33 children to improve chronic pain. Acupuncture, according to traditional Chinese medicine (TCM), and hypnosis comprised of muscle relaxation, the suggestion of going to a safe or favorite place, followed by imagery designed to strengthen the child's sense of mastery in which the child's brain became the cockpit of her airplane.

Self-Hypnosis is an altered state of consciousness and the increased attention leads to an openness to suggestion. The therapist guides the child's stream of consciousness and the modality in an adjunct to pain and symptom management. The goal is to provide the child with a sense of mastery and control of symptoms.

Misconception about hypnosis include that a child is being asleep or unconscious, that there is any loss of control and that the modality is "magic" or being "put under a spell". Hypnosis is indicated, if the child is responsive to hypnotic induction and the underlying problem is treatable using hypnosis. The therapist must be trained in pediatric hypnosis and has to be competent (i.e. must be trained in managing the underlying pain and distressing symptoms without the use of hypnosis). In addition a good rapport between child and therapist is required, the child must be motivated to solve the problem, the parents/caregivers are agreeable to treatment, and no harm is anticipated using hypnosis.

The medical diagnosis and effective treatment takes precedence to hypnosis. This modality is contraindicated in a child who is actively psychotic, if used solely for "fun" or entertainment or if using hypnotherapy is risking aggravation of emotional problems. Additional contraindication include if the referral to hypnosis is based on misdiagnosis or another form of treatment is indicated.

Case Example 2

Ann was a 17-year-old with a terminal prognosis of lung and abdominal metastases following a malignant bone tumor (osteosarcoma). She had three sessions to teach her self-hypnosis to reduce her anxiety and chronic pain before a radical pelvicectomy for palliation for unremitting bone pain. The hospice chaplain conducted a ceremony with Ann and her family before the amputation to acknowledge the impending loss of her leg.

After surgery she experienced phantom limb pain and found self-hypnosis insufficient. The therapist asked Ann for permission to talk to the part of her brain that perceives pain from her leg, and gave the suggestion that she did not need to listen to this part of the session if she did not want to. This was a confusing concept for Ann and helped to facilitate her trance. Using a hand levitation induction with the creation of a safe place image, the therapist said:

"I'm addressing the part of your brain that sends and receives messages about discomfort and pain from your

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right leg. You do not need to worry about not getting messages from the right leg anymore. The right leg is in a safe place where there is not any discomfort or pain. You can shift your attention to the rest of your body and know that the right leg is safe. It's not part of your job anymore to monitor the right leg."

This message was repeated several times interspersed with messages about how she could now allow herself to relax and be pain free. She experienced a marked decrease of phantom limb pain after this session. Four weeks later she was readmitted to remove lung metastases, and after surgery had a severe pain crisis with a return of phantom limb pain. Another hypnosis session was held. Ann was informed that her brain and neural pathways had been hyper-activated by the pain crisis, and we just needed to remind the part of the brain that had monitored the right leg that it could once again rest and not send messages to the right leg. Her phantom limb pain again subsided to mild and infrequent.

Case example 3

Katie was a 12-year-old girl with a rare progressive neurological disease, with its onset a year earlier. Previously diagnosed with Autism Spectrum disorder, she was cognitively intact but was losing muscle control requiring assistance with her personal care. She started experiencing dyspnea and used an opioid and a benzodiazepine medication to ease this symptom. The social worker had met Katie at her home and spent time with her parents discussing their coping of Katie's terminal diagnosis and their focus on providing comfort care for her. On the next visit she found Katie terrified, lying on the couch in the den experiencing breathlessness. Her mother had given Katie morphine for the dyspnea and was on her knees talking to Katie trying to reassure her. The therapist decided to coach the mother in calming Katie, who was whispering, "I can't breathe!" The therapist knelt beside the mother and talking to both mother and child in a calm voice said:

"Katie, I want to help you and your mother breathe. Katie, look into your mother's eyes, she is going to help you breath. Joan (mother), Breathe nice and easy and keep looking into Katie's eyes. Katie, you can now breathe with your mother. She can help you while your medicine starts to work. Your mother has you."

The mother had a hand on each of Katie's arms. Katie quickly slowed her respirations and started to breath with her mother. Her panic quickly subsided. There was no need for an induction, as Katie terrified, was already in a trance. The therapist became directive, and drawing upon their healthy attachment, restructured the experience for both mother and child. The mother naturally joined with her child to help her to regulate her anxiety and her breathing. With this coaching, Katie's mother was able to calm and prevent panic as Katie became weaker and approached death.

Biofeedback

Biofeedback is a self-regulatory skill that uses electronic or electromechanical equipment to measure and then return information about physiologic functions, which the child uses to gain control over these responses in a desired direction. The functions include, heartbeat, blood pressure, and muscle tension. The feedback is provided in auditory, visual and multimedia game formats that appeal to children. There are no published adult RCT or pediatric case reports using biofeedback in palliative care.

Case Example 4

Ravi, a 16-year-old with terminal cancer (recurrent germ-cell tumor and myelodysplastic syndrome) with recurrent chest pain at the site of tumor, leg pain of unknown cause, and recurrent nausea associated with anxiety. He took morphine doses for chest pain, resulting in drowsiness and additional nausea. His coping pattern in the hospital consisted of withdrawal, isolation, little physical activity and keeping his room dark. Ravi denied emotional distress, and when not withdrawn, he frequently used humor. Although Ravi had met psychosocial and CAM providers in the hospital, he reported "those things do not work on me." At home, Ravi met the team psychologist, and agreed to meet again in the outpatient pain and palliative clinic.

Ravi had 13 visits over four months with the psychologist, focused on rapport, emotional support, processing



medical events, and address symptoms using relaxation strategies. Initially he reported little relief with guided imagery or diaphragmatic breathing. He tried the biofeedback game on a couple of occasions, then participated in self-hypnosis and relaxation, ultimately acknowledging their benefit and initiating use on his own. The biofeedback program was based on heart rate variability, and Ravi's ability to control heart rate with breathing. It was explained that the better he became at controlling his breathing, the more likely he could control his pain. This was illustrated concretely on the computer screen with changing color patterns as well as transforming images (e.g., the higher the hot air balloon, the better the performance). Ravi said that he saw the biofeedback as a challenge and wanted to get good at it. By coupling the physical challenge with suggestion of pleasant memories or feelings, Ravi enjoyed the activity and challenged himself to evoke the relaxation response. The biofeedback program, with its technology and entertainment provided him with a personally acceptable technique suiting his age, personality and avoidant coping style.

Endorphine-release at periaqueductal gray?

How can the effectiveness of mind-body techniques such as distraction, imagery, biofeedback or self-hypnosis explained? Distraction significantly increases the activation of the cingulo-frontal cortex including the orbitofrontal and perigenual anterior cingulate cortex, as well as the periaqueductal gray and the posterior thalamus. (Valet 2004) Active distraction techniques, such as imagery, appear to modulate endorphine release in the midbrain, including the periaqueductal grey and thereby increase activity of descending inhibiting pathways thereby decreasing nociception from the dorsal horn resulting in gate pain modulation during distraction. (Tracey 2002, Derbyshire 2007, Bingel 2011)

Summary

Pediatric palliative care is an emerging field of care for children and teens with life-limiting illness. It draws on all commonly used Western-based medical treatments as well as complementary and alternative treatments to attain the best patient comfort and ease at end of life. While there are no RCTs evaluating the use of these integrative therapeutic interventions—interestingly the same holds true for pharmacologic treatments in PPC. Both published case studies and our personal experience strongly endorse integrative treatment modalities, especially imagery, hypnosis, music, aromatherapy, massage, therapeutic/healing touch, and acupuncture as effective therapies to control distressing symptoms at a child's end-of-life, and improve quality of life for them. Parents and other caregivers can be trained in some of these methods empowering their capacity to provide care. Participation in a child's end-of-life care lessens bereavement complications in families, and promotes parents' ability to come to terms with the loss of their child.

Hypnosis Training

In the USA the National Pediatric Hypnosis Training Institute (NPHTI <http://www.nphti.net>) offers a forum in the US providing state-of-the-art education and skill development for health care professionals in the art and science of clinical hypnosis and hypnotherapy for children and adolescents.

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Table 1 Symptom prevalence of children with malignant and non-malignant life-limiting conditions during their end-of-life period.

	Dangel, 2001 (Poland) n = 160	Drake, 2003 (Australia) n = 30	Goldman, 2000 (United Kingdom) n = 152	Hongo, 2003 (Japan) n = 28	Wolfe, 2000a (United States) n = 103	Total n = 473	Prevalence in %
Pain	134	16	140	21	84	395	84
Fatigue	86	21	79	20	100	297	63
Vomiting	101	12	87	16	58	274	58
Dyspnea	80	12	62	23	84	261	55
Constipation	94	8	58	13	51	224	47