

# Newsletter con aggiornamenti bibliografici sulla **Terapia del dolore** e sulle **Cure Palliative Pediatriche**

*“La Buona informazione è la miglior medicina...”*

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## Quinto numero

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1. J Gynecol Obstet Biol Reprod (Paris). 2015 Sep 29.

**[Antenatal palliative plan following diagnosis of fetal lethal condition: Rennes Teaching Hospital experience].**

Abstract

**OBJECTIVES:** To study the pregnancies followed at Rennes University Hospital from 2006 to 2012, after prenatal diagnosis of lethal fetal condition and prenatal project of palliative care at birth consisting of comfort care emphasizing parent-child encounters and bonding.

**MATERIAL AND METHODS:** Retrospective study of 20 pregnancies with diagnosis of lethal fetal condition where parents accepted antenatally the proposal or sought for palliative care at birth.

**RESULTS:** Diagnosis was made at a median age of 20 weeks gestation (12-33). Birth occurred at 37.4 WG, 6 caesarean sections were performed for maternal conditions. Six cases of hypoplastic left heart syndrome (HLHS) share common characteristics: good Apgar score, prolonged survival (26hours to 159days) transfer to neonatology ward (6) or later at home (4). In four multiple pregnancies, the choice of SP mainly contributed to protect healthy twins during pregnancy. In birth room, there was no need for invasive procedure or drugs. Death: one occurred during labor, 8 in birth room before H2, others in neonatal ward before d4 (excluding HLHS).

**CONCLUSION:** These data will enable better antenatal preparation of both teams and parents. Lifetime, however short, allowed parents to meet with their child alive this permitting collection of memory traces and bonding.

PMID: 26431619

2. Am J Hosp Palliat Care. 2015 Sep 30.

**Pediatric Primary Care Involvement in End-of-Life Care for Children.**

Lindley LC1, Nageswaran S2.

Abstract

**OBJECTIVES:** To examine the relationship between pediatric primary care involvement and hospice and home health care use at end of life.

**METHODS:** California Medicaid data were used to estimate the relationship between pediatric primary care involvement and use of hospice and home health care using generalized estimating equations.

**RESULTS:** Of the 2037 children who died between 2007 and 2010, 11% used hospice and 23% used home health. Among all children, primary care was not related to hospice use and was associated with home health use, usual source of care (OR = 1.83, P < .05), comprehensive care (OR = 1.60, P < .05), and continuous care (low: OR = 1.49, P < .05; moderate: OR = 2.57, P < .05; high: OR = 2.12, P < .05). Primary care for children aged 15 to 20 years was related to hospice use, usual source of care (OR = 4.06, P < .05) and continuous care (low: OR = 4.92, P < .05; moderate OR = 4.09, P < .05; high OR = 3.92, P < .05). Primary care for children under 5 years was associated with home health use, usual source of care (OR = 2.59, P < .05), comprehensive care (OR = 2.49, P < .05), and continuous care (low: OR = 2.22, P < .05; moderate: OR = 3.64, P < .05; high: OR = 3.62, P < .05). For children aged 6 to 14 years, this association was seen with continuous care (moderate: OR = 2.38, P < .05; high: OR = 2.13, P < .05). Home health for children aged 15 to 20 years was related to continuous care (moderate: OR = 2.32, P < .05). **CONCLUSION:** Primary care involvement affected hospice use among older age-groups and home health use among younger age-groups. These findings underscore the need for clinical knowledge about end-of-life care for children of all ages among primary care providers.

PMID: 26430133

3. Arch Pediatr. 2015 Sep 28.

**[Organization of collaborative deliberation for limiting or withholding treatments in children].**

[Article in French]

Cremer R1, Lervat C2, Laffargue A3, Le Cunff J4, Joriot S4, Minnaert C5, Cuisset JM4, Mention K6, Thomas D7, Guimber D8, Mattheus A9, Fayoux P10, Storme L11, Vandoolaeghe S12; pour le groupe de travail de l'EEHU de Lille.

Abstract

In 2005, the French law on patients' rights at the end of life required that decisions to withdraw or withhold life-sustaining treatments be made and carried out by the physician in charge of the patient, after obtaining advice from an independent consulting colleague and the caregiving team. The purpose of this study was to identify theoretical and practical obstacles to this collaborative deliberation and to propose practical guidelines to organize it.

PMID: 26428736

4. J Pediatr. 2015 Sep 28.

**Talking about Death with Children with Incurable Cancer: Perspectives from Parents.**

van der Geest IM1, van den Heuvel-Eibrink MM2, van Vliet LM3, Pluijm SM4, Streng IC4, Michiels EM4, Pieters R2, Darlington AE5.

Abstract

**OBJECTIVE:** To investigate the rationale and consequences associated with a parent's decision to discuss death with a child with incurable cancer.

**STUDY DESIGN:** We present data from a larger retrospective study involving bereaved parents of a child who died of cancer. Parents were asked whether they had discussed the impending death with their child, whether they reflected on this discussion positively, their reasons for not discussing death with their child, and the manner in which the conversation regarding death occurred. The data were analyzed qualitatively using a framework approach.

**RESULTS:** Of the 86 parents of 56 children who answered the questions regarding discussing death with their child, 55 parents of 35 children did not discuss the impending death with their child. The following themes were identified: the parents' inability to discuss the impending death; the parents' desire to protect their child; views regarding talking with children; parents' views of child characteristics; the child's unwillingness to discuss the subject; lack of opportunity to talk; and the child's disability. The parents who did discuss death with their child generally used symbolic and/or religious narratives, or they had brief, direct conversations regarding death. The majority of parents felt positive regarding their decision about whether to talk with their child about his/her impending death.

**CONCLUSION:** Most parents in this study cited several reasons for not discussing death with their child. Our findings highlight the sensitive and complex issues surrounding these conversations, indicating that there may be a role for clinicians in supporting parents.

PMID: 26427964

5. Am J Hosp Palliat Care. 2015 Sep 29.

**Community Palliative Care Nurses' Challenges and Coping Strategies on Delivering Home-Based Pediatric Palliative Care: A Qualitative Study.**

Chong L1, Abdullah A2.

Abstract

**OBJECTIVE:** The aim of this study was to explore the experience of community palliative care nurses providing home care to children.

**METHOD:** A qualitative study was conducted at the 3 community palliative care provider organizations in greater Kuala Lumpur from August to October 2014. Data were collected with semistructured interviews with 16 nurses who have provided care to children and was analyzed using thematic analysis. Two categories were identified: (1) challenges nurses faced and (2) coping strategies. The themes identified from the categories are (1) communication challenges, (2) inadequate training and knowledge, (3) personal suffering, (4) challenges of the system, (5) intrapersonal coping skills, (6) interpersonal coping strategies, and (7) systemic supports.

**CONCLUSIONS:** These results reinforces the need for integration of pediatric palliative care teaching and communication skills training into all undergraduate health care programs. Provider organizational support to meet the specific needs of the nurses in the community can help retain them in their role. It will also be important to develop standards for current and new palliative care services to ensure delivery of quality pediatric palliative care.

PMID: 26424764

6. J Palliat Med. 2015 Sep 29.

**Caring Decisions: The Development of a Written Resource for Parents Facing End-of-Life Decisions.**

Xafis V1,2, Gillam L3,4, Hynson J5, Sullivan J3,4, Cossich M6, Wilkinson D1,7,8.

Abstract

**BACKGROUND:** Written resources in adult intensive care have been shown to benefit families facing end of life (EoL) decisions. There are few resources for parents making EoL decisions for their child and no existing resources addressing ethical issues. The Caring Decisions handbook and website were developed to fill these gaps.

**AIM:** We discuss the development of the resources, modification after reviewer feedback and findings from initial pilot implementation.

**DESIGN:** A targeted literature review-to identify resources and factors that impact on parental EoL decision-making; development phase-guided by the literature and the researchers' expertise; consultation process-comprised a multi-disciplinary panel of experts and parents; pilot evaluation study-hard-copy handbook was distributed as part of routine care at an Australian Children's Hospital.

**SETTING/PARTICIPANTS:** Twelve experts and parents formed the consultation panel. Eight parents of children with life-limiting conditions and clinicians were interviewed in the pilot study.

**RESULTS:** Numerous factors supporting/impeding EoL decisions were identified. Caring Decisions addressed issues identified in the literature and by the multidisciplinary research team. The consultation panel provided overwhelmingly positive feedback. Pilot study parents found the resources helpful and comforting. Most clinicians viewed the resources as very beneficial to parents and identified them as ideal for training purposes.

**CONCLUSIONS:** The development of the resources addressed many of the gaps in existing resources. The consultation process and the pilot study suggest these resources could be of significant benefit to parents and clinicians.

PMID: 26418215

7. Int J Palliat Nurs. 2015 Sep 2;21(9):453-9.

**Experiences of hospice inpatient nurses in supporting children before the death of a parent.**

Clipsham L1, Islam Z2, Faull C3.

Abstract

**BACKGROUND:** The need for pre-bereavement support for children facing the death of a parent is well recognised but how this is done by hospice ward nurses in practice is not well known.

**METHOD:** To explore the experiences of hospice ward nurses' identification of the support needs of children under 18 years old facing the death of a parent, and the impact on hospice nurses when involved in providing this support.

**DESIGN:** Semi-structured individual interviews with hospice nurses working on a single UK inpatient unit were audio-taped and analysed using thematic analysis to produce themes and subthemes.

**RESULTS:** Nurses were highly reflective, discussing their personal experiences, and identified potential enablers and barriers to providing support. Child and family factors were identified as influencing identification of support needs.

**CONCLUSION:** Multiple factors influencing provision of support emerged. Formal training and readily available resources would support hospice nurses working with children.

PMID: 26412276

8. Eur J Pediatr. 2015 Sep 28.

**Experiences in palliative home care of infants with life-limiting conditions.**

Kuhlen M1, Höll J12, Sabir H3, Borkhardt A4, Janßen G5.

Abstract

The aim of this study was to determine the distinct issues neonates/infants with life-limiting conditions and their families face during palliative home care and to enable physicians/caregivers to carefully address their needs. Data on home-based palliative care of all neonates and infants, who were being taken care of by our paediatric palliative care team between 2007 and 2014, was analysed. A total of 31 patients (pts) were analysed. The majority of patients (n = 17) were diagnosed with congenital malformations or chromosomal abnormalities. Twenty pts died, five of them in hospital. A high percentage of pts presented with swallowing incoordination (83.9 %) and was fed either by nasogastric tube or percutaneous endoscopic gastrostomy. Of the pts, 71.0 % were treated with analgesics, 45.2 % were oxygen dependent, and 9.7 % required mechanical ventilation. Highest mortality was seen in pts with perinatal complications (75 %). In four (12.9 %) pts, palliative home care could come to an end as their conditions substantially improved.

**CONCLUSIONS:** Palliative treatment of neonates/very young infants with terminal conditions at home seems to be similar to that of older children and feasible in children even with unstable conditions. The spectrum of diagnoses, signs and symptoms varies from older children with swallowing incoordination and artificial nutrition being of particular importance.

PMID: 26411975

9. J Palliat Med. 2015 Sep 22.

**Psychological Well-Being and Family Environment of Siblings of Children with Life Threatening Illness.**

Humphrey LM1, Hill DL2, Carroll KW2, Rourke M3, Kang TI2, Feudtner C2.

Abstract

**BACKGROUND:** The psychological well-being of siblings of children with life threatening illness remains largely uncharted. Pediatric cancer research suggests that a supportive family environment may protect the psychological well-being of siblings.

**OBJECTIVE:** We hypothesized that (1) siblings of pediatric palliative care patients would show clinical/behavioral scores that were elevated but that rates of serious psychopathology would be comparable to the general population of children their age; and (2) higher family functioning scores would be associated with lower clinical scores and higher adaptive scores for these siblings.

**METHODS:** We conducted an observational study with families in which a patient receiving palliative care had one or more siblings between the ages of 6 and 11. Parents completed the Behavioral Assessment System for Children, Second Edition (BASC-2) to assess the siblings' psychological well-being and the Family Assessment Device (FAD) to assess the family environment.

**RESULTS:** Twenty-four parents reported data for 30 siblings. Only three siblings scored in the clinical range on a BASC-2 composite clinical scale, and 11 siblings scored in the at-risk range on one or more composite scales. Higher FAD scores predicted significantly higher externalization composite clinical scores (7.54, 95% CI: 1.12, 13.97, p < 0.05) and significantly higher behavioral composite scores (7.88, 95% CI: 1.55, 14.21, p < 0.05).

**DISCUSSION:** Siblings of pediatric palliative care patients are not experiencing lower psychological well-being than the general population. The prediction that a positive family environment would be associated with higher levels of psychological health was supported.

PMID: 26393493

10. Aust Crit Care. 2015 Sep 18.

**End-of-life decisions in the Intensive Care Unit (ICU) - Exploring the experiences of ICU nurses and doctors - A critical literature review.**

Flannery L1, Ramjan LM2, Peters K3.

**Abstract**

**BACKGROUND:** End-of-life decision making in the Intensive Care Unit (ICU), can be emotionally challenging and multifaceted. Doctors and nurses are sometimes placed in a precarious position where they are required to make decisions for patients who may be unable to participate in the decision-making process. There is an increasing frequency of the need for such decisions to be made in ICU, with studies reporting that most ICU deaths are heralded by a decision to withdraw or withhold life-sustaining treatment.

**OBJECTIVES:** The purpose of this paper is to critically review the literature related to end-of-life decision making among ICU doctors and nurses and focuses on three areas: (1) Who is involved in end-of-life decisions in the ICU?; (2) What challenges are encountered by ICU doctors and nurses when making decisions?; and (3) Are these decisions a source of moral distress for ICU doctors and nurses?

**REVIEW METHOD:** This review considered both qualitative and quantitative research conducted from January 2006 to March 2014 that report on the experiences of ICU doctors and nurses in end-of-life decision making. Studies with a focus on paediatrics, family/relatives perspectives, advance care directives and euthanasia were excluded. A total of 12 papers were identified for review.

**RESULTS:** There were differences reported in the decision making process and collaboration between doctors and nurses (which depended on physician preference or seniority of nurses), with overall accountability assigned to the physician. Role ambiguity, communication issues, indecision on futility of treatment, and the initiation of end-of-life discussions were some of the greatest challenges. The impact of these decisions included decreased job satisfaction, emotional and psychological 'burnout'.

**CONCLUSIONS:** Further research is warranted to address the need for a more comprehensive, standardised approach to support clinicians (medical and nursing) in end-of-life decision making in the ICU.

PMID: 26388551

11. J Pain Symptom Manage. 2015 Sep 17.

**The Indirect Effect of Positive Parenting on the Relationship Between Parent and Sibling Bereavement Outcomes Following the Death of a Child.**

Morris AT1, Gabert-Quillen C2, Friebert S3, Carst N3, Delahanty DL4.

**Abstract**

**CONTEXT:** Families are referred to pediatric palliative care (PPC) programs when a child is diagnosed with a medical condition associated with less than a full life expectancy. When a child dies, PPC programs typically offer a range of bereavement interventions to these families, often focusing on parents. Currently, it is unclear which factors increase the likelihood that bereaved siblings will experience negative outcomes, limiting the development of empirically supported interventions that can be delivered in PPC programs.

**OBJECTIVES:** The current study explored the relationship between parents' and surviving sibling's mental health symptoms (i.e. posttraumatic stress disorder (PTSD), prolonged grief disorder (PGD), and depression symptoms) following a child's death. Additionally, the extent to which parent functioning indirectly impacted sibling functioning through parenting behaviors (i.e. positive parenting and parent involvement) was also examined, with a specific focus on differences based on parent gender.

**METHODS:** Sixty bereaved parents and siblings (aged 8-18) enrolled in a PPC program from 2008-2013 completed measures of PTSD, PGD and depression related to the loss of a child/sibling. Siblings also completed a measure of general parenting behaviors.

**RESULTS:** Maternal, but not paternal, symptoms of PTSD and PGD were directly associated with sibling outcomes. Paternal symptoms were associated with sibling symptoms indirectly, through parenting behaviors (i.e., via decreasing positive parenting).

**CONCLUSION:** These results underscore the importance of examining both maternal and paternal influences following the death of a child, demonstrate differential impact of maternal versus paternal symptoms on siblings, and stress the importance of addressing post-loss symptoms from a family systems perspective.

PMID: 2638782

12. BMC Med Educ. 2015 Sep 17;15(1):151.

**Undergraduate education in palliative medicine in Germany: a longitudinal perspective on curricular and infra-structural development.**

Ilse B1, Alt-Epping B2, Kiesewetter I3,4, Elsner F5, Hildebrandt J6, Laske A7,8, Scherg A9, Schiessl C10,11; Working Group on Medical Education of the German Society of Palliative Medicine (AG Bildung der DGP).

**Abstract**

**BACKGROUND:** In 2009, palliative medicine became an integrated and compulsory part of undergraduate training in Germany by legislation. After a transitional period, all medical faculties were required to provide adequate teaching with an according examination and certification procedure. In parallel, we conducted bi-annual surveys on all medical faculties in Germany to examine for potential discrepancies between the implementation process and their intended consequences on teaching time and content.

**METHODS:** Four consecutive bi-annual surveys (2006, 2008, 2010, 2012) of all 36 medical faculties in Germany were performed, using purposively for this study developed questionnaires. Likert scales and closed questions were analyzed descriptively.

**RESULTS:** Medical Faculty response rate increased from 50 % in 2006 to 88.9 % in 2012. Teaching coordinators in palliative

medicine primarily had an anesthesiology or internal medicine background. There was a noted increase over time of the involvement of specialized palliative care units (PCUs) as providing the setting for education. The number of faculties that were able to offer a complete 16 weeks of training in palliative medicine during the "final year" rose steadily. In addition, increased patient-centered teaching formats have been implemented over time. The faculties which offered innovative teaching formats with actors as patients (standardized patient interaction) increased, as did the total number of mandatory examinations. The number of faculties that provided compulsory teaching in a condensed manner within a single academic year increased sharply from 3 of 31 responding faculties in 2010 to 19 of 32 responding faculties in 2012.

CONCLUSIONS: Until now, teaching conditions and structures in palliative medicine in Germany have proven to be extraordinarily heterogeneous. Although professorships ("Chairs") in palliative medicine proved to be particularly beneficial and supportive in curricular and structural development, only a minority of faculties provide leading academic positions in palliative medicine. Free PMC Article  
PMID: 26383546

13. Nurs Crit Care. 2015 Sep 18.

**Appropriateness of care and moral distress among neonatal intensive care unit staff: repeated measurements.**

de Boer JC1, van Rosmalen J2, Bakker AB3, van Dijk M1.

Abstract

BACKGROUND: Perceived constraints to providing patient care in their own morally justified way may cause moral distress (MD) in neonatal nurses and physicians. Negative long-term effects of MD include substandard patient care, burnout and leaving the profession.

AIM: To assess the immediate impact of perceived inappropriate patient care on nurses' and physicians' MD intensity, and explore a possible moderating effect of ethical climate.

DESIGN: In a repeated measures design, after baseline assessment, each participant completed self-report questionnaires after five randomly selected shifts. Data were analysed with logistic and Tobit regression.

PARTICIPANTS: Data were collected among 117 of 147 eligible nurses and physicians (80%) in a level-III neonatal intensive care unit in the Netherlands.

RESULTS: At baseline, overall MD was relatively low; in nurses, it was significantly higher than in physicians. Few morally distressing situations were reported in the repeated measurements, but distress could be intense in these cases; nurses' and physicians' scores were comparable. Physicians were significantly more likely than nurses to disagree with their patients' level of care ( $p = 0.02$ ). Still, perceived overtreatment, but not undertreatment, was significantly related to distress intensity in both professional groups; ethical climate did not moderate this effect. Substandard patient care due to lack of continuity, poor communication and unsafe levels of staffing were rated as more important causes of MD than perceived inappropriate care.

CONCLUSIONS: Although infrequently perceived, overtreatment of patients caused considerable distress in nurses and physicians. Our unit introduced multidisciplinary medical ethical decision making 5 years ago, which may partly explain the low MD at baseline.

RELEVANCE TO CLINICAL PRACTICE: MD might be prevented by improved continuity of care, safe levels of staffing and better team communication, along with other targeted interventions with demonstrated effectiveness, such as palliative care programs and facilitated ethics conversations.

PMID: 26380963

14. Arch Dis Child. 2015 Sep 14.

**Children's palliative care in low- and middle-income countries.**

Downing J1, Powell RA2, Marston J3, Huwa C4, Chandra L5, Garchakova A6, Harding R7.

Abstract

One-third of the global population is aged under 20 years. For children with life-limiting conditions, palliative care services are required. However, despite 80% of global need occurring in low- and middle-income countries (LMICs), the majority of children's palliative care (CPC) is provided in high-income countries. This paper reviews the status of CPC services in LMICs-highlighting examples of best practice among service models in Malawi, Indonesia and Belarus-before reviewing the status of the extant research in this field. It concludes that while much has been achieved in palliative care for adults, less attention has been devoted to the education, clinical practice, funding and research needed to ensure children and young people receive the palliative care they need.

PMID: 26369576

15. J Pain Palliat Care Pharmacother. 2015 Sep 14:1-3.

**Systematic Reviews Published in the April 2015 Issue of the Cochrane Library.**

Wiffen PJ.

Abstract

The Cochrane Library of Systematic Reviews is published quarterly as a DVD and monthly online (<http://www.thecochranelibrary.com>). The April 2015 issue (first DVD for 2015) contains 6390 complete reviews, 2410 protocols for reviews in production, and 36,600 short summaries of systematic reviews published in the general medical literature. In addition, there are citations of 848,000 randomized controlled trials, and 15,700 cited papers in the Cochrane Methodology Register. The Health Technology Assessment database contains some 15,000 citations. One hundred new reviews have been published in the previous 3 months, of which five have potential relevance for practitioners in pain and palliative medicine. The impact factor of the Cochrane Library stands at 5.939. Readers are encouraged to access the full report for any articles of interest, as only a brief commentary is provided.

PMID: 26368545

16. BMJ Case Rep. 2015 Sep 10;2015.

**Palliative care conundrums in an Ebola treatment centre.**

Dhillon P1, McCarthy S2, Gibbs M3, Sue K4.

Abstract

We describe the treatment course and last days of a 33-year-old man from Western Africa who died from Ebola-related complications. Specifically, the issues around declaring a patient palliative in a low resource environment while dealing with a largely unknown entity, Ebola viral disease, make this an important discussion-stimulating case. The patient presented as a confirmed Ebola-positive case from a peripheral holding centre and then proceeded to deteriorate under our care. Significant neurological decline was noted and the prognosis was felt to be grim by certain providers. Other providers disagreed and a number of treatment algorithms were started and stopped during the patient's last days. He succumbed to Ebola complications after 17 days under our care.

PMID: 26359461

17. Semin Pediatr Neurol. 2015 Sep;22(3):166-71.

**Identifying the Unique Aspects of Adolescent and Young Adult Palliative Care: A Case Study to Propel Programmatic Changes in Pediatric Hospitals.**

Humphrey L1, Lynn Dell M2.

Abstract

Using a case study, in this article we seek to highlight how the distinct developmental needs of adolescent and young adult patients facing a life-threatening condition require a different approach to patient care by pediatric health care workers. The case underscores pitfalls in using a pediatric construct of care in areas of pain management, social stressors, and advanced care planning, and suggests programs to implement for improvement, including partnership with psychiatry, substance abuse, and palliative care specialists.

PMID: 26358426

18. Semin Pediatr Neurol. 2015 Sep;22(3):159-65.

**A Parent's Journey: Incorporating Principles of Palliative Care into Practice for Children with Chronic Neurologic Diseases.**

Brown A1, Clark JD2.

Abstract

Rather than in conflict or in competition with the curative model of care, pediatric palliative care is a complementary and transdisciplinary approach used to optimize medical care for children with complex medical conditions. It provides care to the whole child, including physical, mental, and spiritual dimensions, in addition to support for the family. Through the voice of a parent, the following case-based discussion demonstrates how the fundamentals of palliative care medicine, when instituted early in the course of disease, can assist parents and families with shared medical decision making, ultimately improving the quality of life for children with life-limiting illnesses. Pediatric neurologists, as subspecialists who provide medical care for children with chronic and complex conditions, should consider invoking the principles of palliative care early in the course of a disease process, either through applying general facets or, if available, through consultation with a specialty palliative care service.

PMID: 26358425

19. J Pediatr (Rio J). 2015 Sep 6.

**The pediatrician's role in the first thousand days of the child: the pursuit of healthy nutrition and development.**

da Cunha AJ1, Leite AJ2, de Almeida IS3.

Abstract

**OBJECTIVES:**To describe the concept of the first 1000 days, its importance for health, and actions to be implemented, particularly by pediatricians, in order to attain healthy nutrition and development.

**SOURCES:** A nonsystematic review was carried out in the SciELO, LILACS, MEDLINE, Scopus, and Web of Science databases, encompassing the last decade, using the terms 1000 days, child nutrition, child development, childhood, and child. A non-systematic search was performed online for organizations that use the 1000-day concept and give recommendations on children's health.

**SUMMARY OF THE FINDINGS:** The first 1000 days range from conception to the end of the second year of life. It represents an important period to implement interventions to ensure healthy nutrition and development, which will bring benefits throughout life. Children should receive adequate nutrition, through proper prenatal diet, exclusive breastfeeding for the first 6 months, addition of adequate complementary foods, and continued breastfeeding up to 2 years of life. Given the condition of absolute dependence on an adult's care, it is crucial to establish an enabling and friendly environment, necessary for the development of strong bonds with caregivers, laying the groundwork for a full and healthy development.

**CONCLUSIONS:** The pediatrician, together with other professionals, can act by promoting actions emphasizing the concept of the first 1000 days to ensure healthy nutrition and development. Focusing on actions in this period may increase the child's chance of having a healthy and productive life in the future, strengthening family and community ties, helping to break the intergenerational cycle of poverty.

Free Article

PMID: 26351769

20. Cancer. 2015 Sep 8.

**Adolescents' preferences for treatment decisional involvement during their cancer.**

Weaver MS1,2, Baker JN3, Gattuso JS4, Gibson DV3, Sykes AD5, Hinds PS6,7.

Abstract

**BACKGROUND:** This qualitative study investigated the medical decision-making preferences of adolescent oncology patients and the parental and clinician behaviors that adolescents report to be supportive of their preferred level of decision-making involvement.

**METHODS:** Interviews were conducted with 40 adolescents between the ages of 12 and 18 years who were undergoing cancer treatment in Memphis, Tenn or Washington, DC. Role preferences were converted into a predetermined Likert scale decisional preference score. A semantic content analysis was used to analyze patient reports of parental behaviors, attitudes, knowledge levels, and relational interactions that facilitated their preferred level of involvement in decision making. Clinician behaviors described as supportive of decisional processes were also categorized thematically. A teen advisory council validated study findings. Data reporting followed strict adherence to Consolidated Criteria for Reporting Qualitative Research guidelines.

**RESULTS:** Adolescents indicated a spectrum of preferred decisional roles, with the most common being an actively involved role (26 of 40 or 65%), although a shared decision-making approach was still valued. There was no statistically significant difference in the preferred decisional role with respect to demographic or medical characteristics, including the relapse status, although adolescents who preferred autonomous interview settings were more likely to prefer active decisional roles ( $P < .001$ ). Adolescents recognized that situational and social contexts might shift their preferred level of involvement in medical decisions. Although adolescents wanted to be involved in decisions, they also expressed an appreciation of family insight, parental presence, and clinician guidance.

**CONCLUSIONS:** Adolescents with cancer are able to retrospectively identify their preferences for inclusion in medical decision making, and even when preferring involvement, they value the input of trusted others.

PMID: 26348790

21. BMJ Support Palliat Care. 2015 Sep 3.

**Paediatric palliative care in the Asia Pacific region: where are we now?**

Chong PH1, Hamsah E2, Goh C3.

Abstract

Paediatric palliative care services have increased both in numbers and capacity around the world in response to the needs of children living with life-limiting conditions. Members of the Asia Pacific Hospice Network, who render care to children, have increasingly realised the need to map existing services for enhanced collaborative, educational and advocacy efforts. An online survey was conducted over 2 months among professionals in the region to document current service provision, and at the same time to explore individual training needs and practice challenges. A questionnaire crafted through consensus by members of a new special interest group within the network was used to collect data. 59 distinct responses from 16 countries were obtained to build a directory, which has already been circulated. Content analyses of narrative responses yield further findings. Half of these services catered to adults as well as to children. Staffing and service provision varied across the region but most members worked in teams consisting of multidisciplinary professionals. Numerous service and funding models were found, reflecting wide differences in local conditions and responses to diverse patient populations unique to paediatric palliative care. The highest training needs centred around bereavement and spiritual care. Capacity and funding issues were expected, but significant lack of support by paediatricians was found to be alarming and warrants further study. Amid the heterogeneity, these services share common struggles and face similar needs. Identifying individual profiles of different services potentially helps to draw everyone together, towards a common vision, and towards creating opportunities for sharing of expertise and experience.

PMID: 26338851

22. Pediatr Crit Care Med. 2015 Sep;16(7):e231-8.

**End-of-Life Practices Among Tertiary Care PICUs in the United States: A Multicenter Study.**

Meert KL1, Keele L, Morrison W, Berg RA, Dalton H, Newth CJ, Harrison R, Wessel DL, Shanley T, Carcillo J, Clark A, Holubkov R, Jenkins TL, Doctor A, Dean JM, Pollack M; Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network.

Abstract

**OBJECTIVE:**To describe variability in end-of-life practices among tertiary care PICUs in the United States.

**DESIGN:** Secondary analysis of data prospectively collected from a random sample of patients ( $n = 10,078$ ) admitted to PICUs affiliated with the Collaborative Pediatric Critical Care Research Network between December 4, 2011, and April 7, 2013.

**SETTING:** Seven clinical centers affiliated with the Collaborative Pediatric Critical Care Research Network.

**PATIENTS:** Patients included in the primary study were less than 18 years old, admitted to a PICU, and not moribund on PICU admission. Patients included in the secondary analysis were those who died during their hospital stay.

**INTERVENTIONS:** None.

**MEASUREMENTS AND MAIN RESULTS:** Two hundred and seventy-five (2.7%; range across sites, 1.3-5.0%) patients died during their hospital stay; of these, 252 (92%; 76-100%) died in a PICU. Discussions with families about limitation or withdrawal of support occurred during the initial PICU stay for 173 patients (63%; 47-76%;  $p = 0.27$ ) who died. Of these, palliative care was consulted for 67 (39%; 12-46%); pain service for 11 (6%; 10 of which were at a single site); and ethics committee for six (3%, from three sites). Mode of death was withdrawal of support for 141 (51%; 42-59%), failed cardiopulmonary resuscitation for 53 (19%; 12-28%), limitation of support for 46 (17%; 7-24%), and brain death for 35 (13%; 8-20%); mode of death did not differ across sites ( $p = 0.58$ ). Organ donation was requested from 101 families (37%; 17-88%;  $p < 0.001$ ). Of these, 20 donated (20%; 0-64%). Sixty-two deaths (23%; 10-53%;  $p < 0.001$ ) were medical examiner cases. Of nonmedical examiner cases ( $n = 213$ ), autopsy was requested for 79 (37%; 17-75%;  $p < 0.001$ ). Of autopsies requested, 53 (67%; 50-100%) were performed.

**CONCLUSIONS:** Most deaths in Collaborative Pediatric Critical Care Research Network-affiliated PICUs occur after life sup-

port has been limited or withdrawn. Wide practice variation exists in requests for organ donation and autopsy.  
 PMID: 26335128

23. Crit Care Nurs Clin North Am. 2015 Sep;27(3):341-54.

**Pediatric Palliative Care in the Intensive Care Unit.**

Madden K1, Wolfe J2, Collura C3.

Abstract

The chronicity of illness that afflicts children in Pediatric Palliative Care and the medical technology that has improved their lifespan and quality of life make prognostication extremely difficult. The uncertainty of prognostication and the available medical technologies make both the neonatal intensive care unit and the pediatric intensive care unit locations where many children will receive Pediatric Palliative Care. Health care providers in the neonatal intensive care unit and pediatric intensive care unit should integrate fundamental Pediatric Palliative Care principles into their everyday practice.

PMID: 26333755

24. Cancer. 2015 Aug 26.

**Preferences of advanced cancer patients for communication on anticancer treatment cessation and the transition to palliative care.**

Umezawa S1,2, Fujimori M2,3, Matsushima E1, Kinoshita H2,4, Uchitomi Y2,5,6.

Abstract

**BACKGROUND:**The objective of this study was to clarify the communication preferences of patients with advanced cancer regarding discussions about ending anticancer treatment and transitioning to palliative care and to explore the variables associated with those preferences.

**METHODS:**Participants were 106 Japanese patients with cancer who had been informed at least 1 week earlier about the cessation of their anticancer treatment. They completed a survey measuring their preferences for communication about ending anticancer treatment and transitioning to palliative care as well as their demographic characteristics. Medical records were also examined to investigate medical characteristics.

**RESULTS:** Results of the descriptive analysis indicated that patients strongly preferred their physicians to listen to their distress and concerns (96%), to assure them that their painful symptoms would be controlled (97.1%), and to explain the status of their illness and the physical symptoms that would likely occur in the future (95.1%). Multiple regression analyses identified the factors associated with these preferences: telling patients to prepare mentally and informing them of their expected life expectancy were associated with cancer site; sustaining hope was associated with cancer site and children; and empathic paternalism was associated with duration since cancer diagnosis.

**CONCLUSIONS:** The majority of patients preferred their physicians to be realistic about their likely future and wanted to be reassured that their painful symptoms would be controlled. For patients with cancer at certain sites, those with children, and those more recently diagnosed, physicians should communicate carefully and actively by providing information on life expectancy and mental preparation, sustaining hope, and behaving with empathic paternalism.

PMID: 26308376

25. Pediatr Int. 2015 Aug 19.

**Full circle: Resolving an adolescent's end-of-life issues.**

Abd Rahman FN1, Lee VY1, Shamsuddin AF1, Yaakup H2.

Abstract

We report the challenges in managing a troubled, medically ill adolescent with end-of-life issues. Our role as multi-professional service providers complemented the family's efforts to help him reconcile with himself before death. The present experience enhances understanding of the biopsychosocial aspects of care. Every child has the right to optimal care.

PMID: 26286660

26. Med Ethics. 2015 Oct;41(10):795-8.

**End-of-life decisions for children under 1 year of age in the Netherlands: decreased frequency of administration of drugs to deliberately hasten death.**

Ten Cate K1, van de Vathorst S2, Onwuteaka-Philipsen BD3, van der Heide A4.

Abstract

**OBJECTIVE:** To assess whether the frequency of end-of-life decisions for children under 1 year of age in the Netherlands has changed since ultrasound examination around 20 weeks of gestation became routine in 2007 and after a legal provision for deliberately ending the life of a newborn was set up that same year.

**METHODOLOGY:** This was a recurrent nationwide cross-sectional study in the Netherlands. In 2010, a sample of death certificates from children under 1 year of age was derived from the central death registry. All 223 deaths that occurred in a 4-month study period were included. Physicians who had reported a non-sudden death (n=206) were sent a questionnaire on the end-of-life decisions made. 160 questionnaires were returned (response 78%).

**FINDINGS:** In 2010, 63% of all deaths of children under 1 year of age were preceded by an end-of-life decision-a percentage comparable to other times when this study was conducted (1995, 2001, 2005). These end-of-life decisions were mainly decisions to withdraw or withhold potentially life-sustaining treatment. In 2010, the percentage of cases in which drugs were administered with the explicit intention to hasten death was 1%, while in 1995 and 2001, this was 9% and in 2005, this was 8%.

**DISCUSSION AND CONCLUSION:** There has been a reduction of infant deaths that followed administration of drugs with the

explicit intention to hasten death. One explanation for this reduction relates to the introduction of routine ultrasound examination around 20 weeks of gestation. In addition, the introduction of legal criteria and a review process for deliberately ending the life of a newborn may have left Dutch physicians with less room to hasten death.  
PMID: 26272986

27. Arch Dis Child Fetal Neonatal Ed. 2015 Aug 13.

**End-of-life decision-making for newborns: a 12-year experience in Hong Kong.**

Chan LC1, Cheung HM1, Poon TC1, Ma TP1, Lam HS1, Ng PC1.

**Abstract**

**SETTING:** Neonatal end-of-life decisions could be influenced by cultural and ethnic backgrounds. These practices have been well described in the West but have not been systematically studied in an Asian population.

**OBJECTIVES:** To determine: (1) different modes of neonatal death and changes over the past 12 years and (2) factors influencing end-of-life decision-making in Hong Kong.

**DESIGN:** A retrospective study was conducted to review all death cases from 2002 to 2013 in the busiest neonatal unit in Hong Kong. Modes of death, demographical data, diagnoses, counselling and circumstances around the time of death, were collected and compared between groups.

**RESULTS:** Of the 166 deaths, 46% occurred despite active resuscitation (group 1); 35% resulted from treatment withdrawal (group 2) and 19% occurred from withholding treatment (group 3). A rising trend towards treatment withdrawal was observed, from 20% to 47% over the 12-year period. Similar number of parents chose extubation (n=44, 27%) compared with other modalities of treatment limitation (n=45, 27%). Significantly more parents chose to withdraw rather than to withhold treatment if clinical conditions were 'stable' (p=0.03), whereas more parents chose withholding therapy if treatment was considered futile (p=0.03).

**CONCLUSION:** In Hong Kong, a larger proportion of neonatal deaths occurred despite active resuscitation compared with Western data. Treatment withdrawal is, however, becoming increasingly more common. Unlike Western practice, similar percentages of parents chose other modalities of treatment limitation compared with direct extubation. Cultural variance could be a reason for the different end-of-life practice adopted in Hong Kong.

PMID: 26271752

28. J Adv Nurs. 2015 Aug 12.

**Development and initial validation of the Parental PELICAN Questionnaire (PaPEQu) - an instrument to assess parental experiences and needs during their child's end-of-life care.**

Zimmermann K1,2, Cignacco E1,3, Eskola K1, Engberg S4, Ramelet AS5, Von der Weid N6, Bergstraesser E7.

**Abstract**

**AIM:** To develop and test the Parental PELICAN Questionnaire, an instrument to retrospectively assess parental experiences and needs during their child's end-of-life care.

**BACKGROUND:** To offer appropriate care for dying children, healthcare professionals need to understand the illness experience from the family perspective. A questionnaire specific to the end-of-life experiences and needs of parents losing a child is needed to evaluate the perceived quality of paediatric end-of-life care.

**DESIGN:** This is an instrument development study applying mixed methods based on recommendations for questionnaire design and validation.

**METHOD:** The Parental PELICAN Questionnaire was developed in four phases between August 2012-March 2014: phase 1: item generation; phase 2: validity testing; phase 3: translation; phase 4: pilot testing. Psychometric properties were assessed after applying the Parental PELICAN Questionnaire in a sample of 224 bereaved parents in April 2014. Validity testing covered the evidence based on tests of content, internal structure and relations to other variables.

**RESULTS:** The Parental PELICAN Questionnaire consists of approximately 90 items in four slightly different versions accounting for particularities of the four diagnostic groups. The questionnaire's items were structured according to six quality domains described in the literature. Evidence of initial validity and reliability could be demonstrated with the involvement of healthcare professionals and bereaved parents.

**CONCLUSION:** The Parental PELICAN Questionnaire holds promise as a measure to assess parental experiences and needs and is applicable to a broad range of paediatric specialties and settings. Future validation is needed to evaluate its suitability in different cultures.

PMID: 26265326

29. J Palliat Med. 2015 Aug 11.

**Advanced Cancer and End-of-Life Preferences: Curative Intent Surgery Versus Noncurative Intent Treatment.**

Schubert JR1, Green MJ2, Van Scoy LJ3, Lehman E4, Farace E4, Gusani NJ5, Levi BH6.

**Abstract**

**BACKGROUND:** People with cancer face complex medical decisions, including whether to receive life-sustaining treatments at the end of life. It is not unusual for clinicians to make assumptions about patients' wishes based on whether they had previously chosen to pursue curative treatment.

**OBJECTIVE:** We hypothesized that cancer patients who initially underwent curative intent surgery (CIS) would prefer more aggressive end-of-life treatments compared to patients whose treatment was noncurative intent (non-CIT).

**METHODS:** This study was a retrospective review of data from a large, randomized controlled trial examining the use of an online decision aid for advance care planning, "Making Your Wishes Known" (MYWK), with patients who had advanced cancer. We reviewed patients' medical records to determine which patients underwent CIS versus non-CIT. In the parent trial, conducted at an academic medical center (2007-2012), 200 patients were enrolled with stage IV malignancy or other poor prognosis cancer. Patients' preferences for aggressive treatment were measured in two ways: using patient-selected Gen-

eral Wishes statements generated by the decision aid and patient-selected wishes for specific treatments under various hypothetical clinical scenarios (Specific Wishes).

**RESULTS:** We evaluated 79 patients. Of these, 48 had undergone initial CIS and 31 had non-CIT. Cancer patients who initially underwent CIS did not prefer more aggressive end-of-life treatments compared to patients whose treatment was non-CIT.

**CONCLUSIONS:** Clinicians should avoid assumptions about patients' preferences for life-sustaining treatment based on their prior choices for aggressive treatment.

PMID: 26262942

30. Curr Opin Support Palliat Care. 2015 Sep;9(3):217-26.

**Management of respiratory symptoms in paediatric palliative care.**

Craig F1, Henderson EM, Bluebond-Langner M.

Abstract

**PURPOSE OF REVIEW:** Respiratory symptoms in children with life-limiting and life-threatening conditions are common, distressing and have a lasting impact, yet there is a paucity of evidence to guide clinicians in their management. This article makes a series of recommendations for the management of the most frequent and distressing respiratory symptoms encountered in paediatrics (dyspnoea, cough, haemoptysis and retained secretions) with attention to the evidence from research.

**RECENT FINDINGS:** There are very few paediatric studies exploring any aspect of respiratory symptoms in paediatric palliative care, so much of the evidence base has been drawn from adult studies, few of which have been published in the past 12-18 months.

**SUMMARY:** In the absence of well designed paediatric studies we need to judiciously apply what we can extrapolate from adult studies to each child we are treating; selecting interventions and approaches carefully, adjusting them when there is no evidence of individual benefit.

PMID: 26258463

31. Pain Manag Nurs. 2015 Aug;16(4):552-60.

**Satisfaction with and Perception of Pain Management among Palliative Patients with Breakthrough Pain: A Qualitative Study.**

Pathmawathi S1, Beng TS2, Li LM2, Rosli R3, Sharwend S4, Kavitha RR3, Christopher BC5.

Abstract

Breakthrough pain is a significant contributor to much suffering by patients. The experience of intense pain may interfere with, and affect, daily life functioning and has major consequences on patients' well-being if it is not well managed. The area of breakthrough pain has not been fully understood. This study thus aimed to explore the experiences of breakthrough pain among palliative patients. A qualitative study based on a series of open-ended interviews among 21 palliative patients suffering from pain at an urban tertiary hospital in Malaysia was conducted. Five themes were generated: (i) pain viewed as an unbearable experience causing misery in the lives of patients, (ii) deterioration of body function and no hope of recovery, (iii) receiving of inadequate pain management for pain, (iv) insensitivity of healthcare providers toward patients' pain experience, and (v) pain coping experiences of patients. The findings revealed that nonpharmacologic approaches such as psychosocial support should be introduced to the patients. Proper guidance and information should be given to healthcare providers to improve the quality of patient care. Healthcare providers should adopt a sensitive approach in caring for patients' needs. The aim is to meet the needs of the patients who want to be pain free or to attain adequate relief of their pain for breakthrough pain.

PMID: 26256219

32. Arch Dis Child Fetal Neonatal Ed. 2015 Aug 7.

**Neonatal deaths: prospective exploration of the causes and process of end-of-life decisions.**

Hellmann J1, Knighton R2, Lee SK3, Shah PS3; Canadian Neonatal Network End of Life Study Group.

Collaborators: (17)

Andrews W, Payot A, Bullied B, Chiu A, Dow K, Doctor S, Hellmann J, Shah P, Coughlin K, McMillan DD, Ojah C, Peliowski A, Piedboeuf B, Riley P, Dabowal T, Watts J, Osiovich H.

Abstract

**OBJECTIVE:** To determine the causes and process of death in neonates in Canada.

**DESIGN:** Prospective observational study.

**SETTING:** Nineteen tertiary level neonatal units in Canada.

**PARTICIPANTS:** 942 neonatal deaths (215 full-term and 727 preterm).

**EXPOSURE AND OUTCOME:** Explored the causes and process of death using data on: (1) the rates of withdrawal of life-sustaining treatment (WLST); (2) the reasons for raising the issue of WLST; (3) the extent of consensus with parents; (4) the consensual decision-making process both with parents and the multidisciplinary team; (5) the elements of WLST; and (6) the age at death and time between WLST and actual death.

**RESULTS:** The main reasons for deaths in preterm infants were extreme immaturity, intraventricular haemorrhage and pulmonary causes; in full-term infants asphyxia, chromosomal anomalies and syndromic malformations. In 84% of deaths there was discussion regarding WLST. WLST was agreed to by parents with relative ease in the majority of cases. Physicians mainly offered WLST for the purpose of avoiding pain and suffering in imminent death or survival with a predicted poor quality of life. Consensus with multidisciplinary team members was relatively easily obtained. There was marked variation between centres in offering WLST for severe neurological injury in preterm (10%-86%) and severe hypoxic-ischaemic encephalopathy in full-term infants (5%-100%).

**CONCLUSIONS AND RELEVANCE:** In Canada, the majority of physicians offered WLST to avoid pain and suffering or survival with a poor quality of life. Variation between units in offering WLST for similar diagnoses requires further exploration.

PMID: 26253166

33. J Nurs Adm. 2015 Sep;45(9):423-8.

**The Benefits of a Nurse-Driven, Patient- and Family-Centered Pediatric Palliative Care Program.**

Mastro KA1, Johnson JE, McElvery N, Preuster C.

Abstract

This article describes the program and outcomes of a nurse driven, patient- and family-centered pediatric advanced comprehensive care team (PACCT) palliative program. This care delivery model improved patient outcomes by providing care across the healthcare continuum for pediatric patients. Since the inception of PACCT, no child has died on a ventilator in the pediatric ICU associated with end-of-life-related issues.

PMID: 26252724

34. BMC Palliat Care. 2015 Aug 4;14:36.

**Priorities for global research into children's palliative care: results of an International Delphi Study.**

Abstract

**BACKGROUND:** There is an urgent need to develop an evidence base for children's palliative care (CPC) globally, and in particular in resource-limited settings. Whilst the volume of CPC research has increased in the last decade, it has not been focused on countries where the burden of disease is highest. For example, a review of CPC literature in sub-Saharan Africa (SSA) found only five peer-reviewed papers on CPC. This lack of evidence is not confined to SSA, but can be seen globally in specific areas, such as an insufficient research and evidence base on the treatment of pain and other symptoms in children. This need for an evidence base for CPC has been recognised for some time, however without understanding the priorities for research in CPC organisations, many struggle with how to allocate scarce resources to research.

**METHOD:** The International Children's Palliative Care Network (ICPCN) undertook a Delphi study between October 2012 and February 2013 in order to identify the global research priorities for CPC. Members of the ICPCN Scientific Committee formed a project working group and were asked to suggest areas of research that they considered to be important. The list of 70 areas for research was put through two rounds of the Delphi process via a web-based questionnaire. ICPCN members and affiliated stakeholders (n = 153 from round 1 and n = 95 from round 2) completed the survey. Participants from SSA were the second largest group of respondents (28.1 % round 1, 24.2 % round 2) followed by Europe.

**RESULTS:** A list of 26 research areas reached consensus. The top five priorities were: Children's understanding of death and dying; Managing pain in children where there is no morphine; Funding; Training; and Assessment of the WHO two-step analgesic ladder for pain management in children.

**CONCLUSIONS:** Information from this study is important for policy makers, educators, advocates, funding agencies, and governments. Priorities for research pertinent to CPC throughout the world have been identified. This provides a much needed starting place for the allocation of funds and building research infrastructure. Researchers working in CPC are in a unique position to collaborate and produce the evidence that is needed.

PMID: 26238244 Free PMC Article

35. Adv Neonatal Care. 2015 Aug;15(4):239-40.

**Palliative and End-of-Life Care for Newborns and Infants: From the National Association of Neonatal Nurses.**

Catlin A1, Brandon D, Wool C, Mendes J.

PMID: 26225591

36. J Palliat Med. 2015 Aug;18(8):697-702.

**End-of-Life Decisions in Pediatric Cancer Patients.**

van Loenhout RB1,2,3, van der Geest IM2,4, Vrakking AM3, van der Heide A3, Pieters R4, van den Heuvel-Eibrink MM4.

Abstract

**BACKGROUND:** End-of-life decisions (ELDs) have been investigated in several care settings, but rarely in pediatric oncology.

**OBJECTIVE:** The aims of this study were to characterize the practice of end-of-life decision making in a Dutch academic medical center and to explore pediatric oncologists' perspectives on decision making.

**METHODS:** Between 2001 and 2010, in a specified period of 2 years, 57 children died of cancer. The attending pediatric oncologists of 48 deceased children were eligible for this study. They were requested to complete a retrospective questionnaire on characteristics of ELDs that may have preceded a child's death. ELDs were defined as decisions concerning administering or forgoing treatment that may unintentionally or intentionally hasten death.

**RESULTS:** In 31 of 48 cases (65%) one or more ELDs were made. In 20 of 31 cases potentially life-prolonging treatments were discontinued or withheld, and in 22 of 31 cases drugs were administered to alleviate pain or other symptoms in potentially life-shortening dosages. Frequently mentioned considerations for making ELDs were no prospects of improvement (n=21;68%) and unbearable suffering without a curative perspective (n=13;42%). ELDs were discussed with parents in all cases, and with the child in 9 of 31 cases. After the child's death, the pediatric oncologist met the parents in all ELD cases and in 11 of 17 non-ELD cases. Pediatric oncologists were satisfied with care around the child's death in 90% of the ELD cases versus 59% of the non-ELD cases.

**CONCLUSIONS:** In two-thirds of cases, ELDs preceded the death of a child with cancer. This is the first study providing insights into the characteristics of ELDs from a pediatric oncologist's point of view.

PMID: 26218579

37. J Palliat Med. 2015 Sep;18(9):740-6.

**The Language of End-of-Life Decision Making: A Simulation Study.**

Lu A1, Mohan D2, Alexander SC3, Mescher C4, Barnato AE5,6.

Abstract

**BACKGROUND:** Framing is known to influence decision making.

**OBJECTIVE:** The study objective was to describe language used by physicians when discussing treatment options with a critically and terminally ill elder.

**METHODS:** High-fidelity simulation was used, involving an elder with end-stage cancer and life-threatening hypoxia, followed by a debriefing interview. Subjects were hospitalist, emergency medicine, and critical care physicians from three academic medical centers. Measures were observation of encounters in real time followed by content analysis of simulation and debriefing interview transcripts. During the simulation we identified the first mention ("broaching") of principal treatment options-intubation and mechanical ventilation (life-sustaining treatment [LST]) and palliation in anticipation of death (palliation)-and used constant comparative methods to identify language used. We identified physician opinions about the use of LST in this clinical context during the debriefing interviews, and compared language used with opinions.

**RESULTS:** Among 114 physician subjects, 106 discussed LST, 86 discussed palliation, and 84 discussed both. We identified five frames: will (decided), must (necessary), should (convention), could (option), and ask (elicitation of preferences). Physicians broached LST differently than palliation ( $p < 0.01$ ), most commonly framing LST as necessary (53%), while framing palliation as optional (49%). Among physicians who framed LST as imperative (will or must), 16 (30%) felt intubation would be inappropriate in this clinical situation.

**CONCLUSIONS:** In this high-fidelity simulation experiment involving a critically and terminally ill elder, the majority of physicians framed the available options in ways implying LST was the expected or preferred choice. Framing of treatment options could influence ultimate treatment decisions.

PMID: 26186668

38. JAMA Oncol. 2015 Aug 1;1(5):592-600.

**End-of-Life Care Intensity Among Adolescent and Young Adult Patients With Cancer in Kaiser Permanente Southern California.**

Mack JW1, Chen LH2, Cannavale K3, Sattayapiwat O3, Cooper RM4, Chao CR2.

Abstract

**IMPORTANCE:** Cancer is the leading disease-related cause of death among adolescents and young adults (AYAs), but little is known about the care that AYA patients with cancer receive at the end of life (EOL).

**OBJECTIVE:** To evaluate the intensity of EOL care among AYA patients with cancer.

**DESIGN, SETTING, AND PARTICIPANTS:** Cross-sectional study of Kaiser Permanente Southern California (KSPC) cancer registry data and electronic health records for 663 AYA patients with either stage I to III cancer and evidence of cancer recurrence or stage IV cancer at diagnosis. All patients were treated within KSPC, an integrated health care delivery system, and died between 2001 and 2010 before age 40 years (age range at time of death, 15-39 years).

**MAIN OUTCOMES AND MEASURES:** (1) Chemotherapy use in the last 14 days of life; (2) intensive care unit (ICU) care in the last 30 days of life; (3) more than 1 emergency department (ED) visit in the last 30 days of life; (4) hospitalization in the last 30 days of life; and (5) a composite measure of medically intensive EOL care including any of the aforementioned measures.

**RESULTS:** Eleven percent of patients (72 of 663) received chemotherapy within 14 days of death. In the last 30 days of life, 22% of patients (144 of 663) were admitted to the ICU; 22% (147 of 663) had more than 1 ED visit; and 62% (413 of 663) were hospitalized. Overall, 68% of patients (449 of 663) received at least 1 medically intensive EOL care measure.

**CONCLUSIONS AND RELEVANCE:**

Most AYA patients received at least 1 form of medically intensive EOL care. These findings suggest the need to better understand EOL care preferences and decision making in this young population.

PMID: 26181778

39. JAMA Oncol. 2015 Aug 1;1(5):579-80.

**The Death Burden and End-of-Life Care Intensity Among Adolescent and Young Adult Patients With Cancer.**

Bleyer A1.

PMID: 26181237

40. J Pain Symptom Manage. 2015 Sep;50(3):424-7.

**The Spirit of "Ubuntu" in Children's Palliative Care.**

Marston JM1.

Abstract

The concept of "ubuntu," a Nguni word, is found in many southern African cultures and means that we are part of all humanity and we are who we are through our interconnectedness with others. Children with life-limiting conditions often become isolated and take on a new identity in the eyes of others, linked to their illness and treatment. Terms that are used can dehumanize the child. The concept of ubuntu can help the child, the family, and the community to ensure the child remains connected to society. Programs providing palliative care for children often say they feel isolated; ubuntu principles are relevant to effective network development.

PMID: 26166185

41. Crit Care Med. 2015 Sep;43(9):1964-77.

**Integrating Palliative Care Into the Care of Neurocritically Ill Patients: A Report From the Improving Palliative Care in the ICU Project Advisory Board and the Center to Advance Palliative Care.**

Frontera JA1, Curtis JR, Nelson JE, Campbell M, Gabriel M, Mosenthal AC, Mulkerin C, Puntillo KA, Ray DE, Bassett R, Boss RD, Lustbader DR, Brasel KJ, Weiss SP, Weissman DE; Improving Palliative Care in the ICU Project Advisory Board.

Abstract

**OBJECTIVES:** To describe unique features of neurocritical illness that are relevant to provision of high-quality palliative care; to discuss key prognostic aids and their limitations for neurocritical illnesses; to review challenges and strategies for establishing realistic goals of care for patients in the neuro-ICU; and to describe elements of best practice concerning symptom

management, limitation of life support, and organ donation for the neurocritically ill.

**DATA SOURCES:** A search of PubMed and MEDLINE was conducted from inception through January 2015 for all English-language articles using the term "palliative care," "supportive care," "end-of-life care," "withdrawal of life-sustaining therapy," "limitation of life support," "prognosis," or "goals of care" together with "neurocritical care," "neurointensive care," "neurological," "stroke," "subarachnoid hemorrhage," "intracerebral hemorrhage," or "brain injury."

**DATA EXTRACTION AND SYNTHESIS:** We reviewed the existing literature on delivery of palliative care in the neurointensive care unit setting, focusing on challenges and strategies for establishing realistic and appropriate goals of care, symptom management, organ donation, and other considerations related to use and limitation of life-sustaining therapies for neurocritically ill patients. Based on review of these articles and the experiences of our interdisciplinary/interprofessional expert advisory board, this report was prepared to guide critical care staff, palliative care specialists, and others who practice in this setting.

**CONCLUSIONS:** Most neurocritically ill patients and their families face the sudden onset of devastating cognitive and functional changes that challenge clinicians to provide patient-centered palliative care within a complex and often uncertain prognostic environment. Application of palliative care principles concerning symptom relief, goal setting, and family emotional support will provide clinicians a framework to address decision making at a time of crisis that enhances patient/family autonomy and clinician professionalism.

PMID: 26154929

42. Dev Med Child Neurol. 2015 Aug;57(8):688.

**End-of-life management in children.**

Dan B.

PMID: 26153089

43. Eur J Cancer. 2015 Aug;51(12):1618-29.

**Survival prediction for advanced cancer patients in the real world: A comparison of the Palliative Prognostic Score, Delirium-Palliative Prognostic Score, Palliative Prognostic Index and modified Prognosis in Palliative Care Study predictor model.**

Baba M1, Maeda I2, Morita T3, Inoue S4, Ikenaga M5, Matsumoto Y6, Sekine R7, Yamaguchi T8, Hirohashi T9, Tajima T10, Tatara R11, Watanabe H12, Otani H13, Takigawa C14, Matsuda Y15, Nagaoka H16, Mori M17, Tei Y18, Hiramoto S19, Suga A20, Kinoshita H21.

Abstract

**PURPOSE:**The aim of this study was to investigate the feasibility and accuracy of the Palliative Prognostic Score (PaP score), Delirium-Palliative Prognostic Score (D-PaP score), Palliative Prognostic Index (PPI) and modified Prognosis in Palliative Care Study predictor model (PiPS model).

**PATIENTS AND METHODS:** This multicentre prospective cohort study involved 58 palliative care services, including 19 hospital palliative care teams, 16 palliative care units and 23 home palliative care services, in Japan from September 2012 to April 2014. Analyses were performed involving four patient groups: those treated by palliative care teams, those in palliative care units, those at home and those receiving chemotherapy.

**RESULTS:** We recruited 2426 participants, and 2361 patients were finally analysed. Risk groups based on these instruments successfully identified patients with different survival profiles in all groups. The feasibility of PPI and modified PiPS-A was more than 90% in all groups, followed by PaP and D-PaP scores; modified PiPS-B had the lowest feasibility. The accuracy of prognostic scores was  $\geq 69\%$  in all groups and the difference was within 13%, while c-statistics were significantly lower with the PPI than PaP and D-PaP scores.

**CONCLUSION:** The PaP score, D-PaP score, PPI and modified PiPS model provided distinct survival groups for patients in the three palliative care settings and those receiving chemotherapy. The PPI seems to be suitable for routine clinical use for situations where rough estimates of prognosis are sufficient and/or patients do not want invasive procedure. If clinicians can address more items, the modified PiPS-A would be a non-invasive alternative. In cases where blood samples are available or those requiring more accurate prediction, the PaP and D-PaP scores and modified PiPS-B would be more appropriate.

PMID: 26074396

44. J Pediatr. 2015 Aug;167(2):467-70.e3.

**Research Priorities in Pediatric Palliative Care.**

Baker JN1, Levine DR2, Hinds PS3, Weaver MS2, Cunningham MJ4, Johnson L2, Anghelescu D2, Mandrell B5, Gibson DV2, Jones B6, Wolfe J7, Feudtner C8, Friebert S9, Carter B10, Kane JR11.

Abstract

**OBJECTIVE:** To synthesize the perspectives of a broad range of pediatric palliative care (PPC) clinicians and parents, to formulate a consensus on prioritization of the PPC research agenda.

**STUDY DESIGN:** A 4-round modified Delphi online survey was administered to PPC experts and to parents of children who had received PPC. In round 1, research priorities were generated spontaneously. Rounds 2 and 3 then served as convergence rounds to synthesize priorities. In round 4, participants were asked to rank the research priorities that had reached at least 80% consensus.

**RESULTS:** A total of 3093 concepts were spontaneously generated by 170 experts and 72 parents in round 1 (65.8% response rate [RR]). These concepts were thematically organized into 78 priorities and recirculated for round 2 ratings (n = 130; 53.7% RR). Round 3 achieved response stability, with 31 consensus priorities oscillating within 10% of the mode (n = 98; 75.4% RR). Round 4 resulted in consensus recognition of 20 research priorities, which were thematically grouped as decision making, care coordination, symptom management, quality improvement, and education.

**CONCLUSIONS:** This modified Delphi survey used professional and parental consensus to identify preeminent PPC research priorities. Attentiveness to these priorities may help direct resources and efforts toward building a formative evidence base.

Investigating PPC implementation approaches and outcomes can help improve the quality of care services for children and families.

PMID: 26028284

45. J Pediatr. 2015 Aug;167(2):299-304.e3.

**Sedatives and Analgesics Given to Infants in Neonatal Intensive Care Units at the End of Life.**

Zimmerman KO1, Hornik CP1, Ku L1, Watt K1, Laughon MM2, Bidegain M3, Clark RH4, Smith PB5.

Abstract

**OBJECTIVE:** To describe the administration of sedatives and analgesics at the end of life in a large cohort of infants in North American neonatal intensive care units.

**STUDY DESIGN:** Data on mortality and sedative and analgesic administration were from infants who died from 1997-2012 in 348 neonatal intensive care units managed by the Pediatrix Medical Group. Sedatives and analgesics of interest included opioids (fentanyl, methadone, morphine), benzodiazepines (clonazepam, diazepam, lorazepam, midazolam), central alpha-2 agonists (clonidine, dexmedetomidine), ketamine, and pentobarbital. We used multivariable logistic regression to evaluate the association between administration of these drugs on the day of death and infant demographics and illness severity.

**RESULTS:** We identified 19 726 infants who died. Of these, 6188 (31%) received a sedative or analgesic on the day of death; opioids were most frequently administered, 5366/19 726 (27%). Administration of opioids and benzodiazepines increased during the study period, from 16/283 (6%) for both in 1997 to 523/1465 (36%) and 295/1465 (20%) in 2012, respectively. Increasing gestational age, increasing postnatal age, invasive procedure within 2 days of death, more recent year of death, mechanical ventilation, inotropic support, and antibiotics on the day of death were associated with exposure to sedatives or analgesics.

**CONCLUSIONS:** Administration of sedatives and analgesics increased over time. Infants of older gestational age and those more critically ill were more likely to receive these drugs on the day of death. These findings suggest that drug administration may be driven by severity of illness.

PMID: 26012893

46. J Palliat Med. 2015 Aug;18(8):667-76.

**Place of Death among Hospitalized Patients with Cancer at the End of Life.**

Wallace SK1, Waller DK2, Tilley BC3, Piller LB2,3, Price KJ4, Rathi N4, Haque S4, Nates JL4.

Abstract

**BACKGROUND:** The majority of hospital deaths in the United States occur after ICU admission. The characteristics associated with the place of death within the hospital are not known for patients with cancer.

**OBJECTIVE:** The study objective was to identify patient characteristics associated with place of death among hospitalized patients with cancer who were at the end of life.

**METHODS:** A retrospective cohort study design was implemented. Subjects were consecutive patients hospitalized between 2003 and 2007 at a large comprehensive cancer center in the United States. Multinomial logistic regression analysis was used to identify patient characteristics associated with place of death (ICU, hospital following ICU, hospital without ICU) among hospital decedents.

**RESULTS:** Among 105,157 hospital discharges, 3860 (3.7%) died in the hospital: 42% in the ICU, 14% in the hospital following an ICU stay, and 44% in the hospital without ICU services. Individuals with the following characteristics had an increased risk of dying in the ICU: nonlocal residence, newly diagnosed hematologic or nonmetastatic solid tumor malignancies, elective admission, surgical or pediatric services. A palliative care consultation on admission was associated with dying in the hospital without ICU services.

**CONCLUSIONS:** Understanding existing patterns of care at the end of life will help guide decisions about resource allocation and palliative care programs. Patients who seek care at dedicated cancer centers may elect more aggressive care; thus the generalizability of this study is limited. Although dying in a hospital may be unavoidable for patients who have uncontrolled symptoms that cannot be managed at home, palliative care consultations with patients and their families in advance regarding end-of-life preferences may prevent unwanted admission to the ICU.

PMID: 25927588

47. Lancet. 2015 Aug 8;386(9993):527.

**Surgical palliative care in resource-limited settings.**

Riesel JN1, Mandigo M2, Gillies R3, Damuse R4, Farmer PE5, Cusack JC6, Krakauer EL7, Shulman LN8.

PMID: 25924837

48. J Pain Symptom Manage. 2015 Sep;50(3):375-80.

**Parents' Experiences of Pediatric Palliative Transports: A Qualitative Case Series.**

Nelson H1, Mott S2, Kleinman ME3, Goldstein RD4.

Abstract

**CONTEXT:** Pediatric palliative transports, the practice of transporting critically ill children home for end-of-life care including extubation, are an option for children requiring high levels of medical support at end of life. Little is known about the experience from the perspective of the children and families.

**OBJECTIVES:** To understand parents' perspectives on the experience of pediatric palliative transports.

**METHODS:** Open-ended interviews were conducted using a qualitative descriptive design. Each parent was asked to reflect on the process of bringing their child home to die. Conventional content analysis was used for data analysis.

**RESULTS:** Nine parents participated. The decision to transport the child home was a process motivated by promises to the child or a conviction that it was the right thing to do. The parents were gratified by the attention to safety and detail involved, but the actual transport home was stressful to them. The arrival home was typically recounted as a celebration. Being home

provided time with the child in the context of their family and contributed to their lives. Memories of the experience brought comfort and a sense of fulfillment.

**CONCLUSION:** Each parent found the experience positive and meaningful. The child's experiences when alive, not events at the time of death, were remembered. All parents recommended palliative transports, emphasizing the importance of home and family, when desired. These interviews strongly suggest that palliative transports make a positive, important contribution to the care of at least some children facing end of life, and their families.

PMID: 25891665

49. J Pain Symptom Manage. 2015 Sep;50(3):305-12.

**Patterns of End-of-Life Care in Children With Advanced Solid Tumor Malignancies Enrolled on a Palliative Care Service.**

Vern-Gross TZ1, Lam CG2, Graff Z3, Singhal S3, Levine DR3, Gibson D3, Sykes A4, Anghelescu DL5, Yuan Y4, Baker JN6.

Abstract

**CONTEXT:** Pediatric patients with solid tumors can have a significant symptom burden that impacts quality of life (QoL) and end-of-life care needs.

**OBJECTIVES:** We evaluated outcomes and symptoms in children with solid tumors and compared patterns of end-of-life care after implementation of a dedicated institutional pediatric palliative care (PC) service.

**METHODS:** We performed a retrospective cohort study of children with solid tumors treated at St. Jude Children's Research Hospital, before and after implementation of the institutional QoL/PC service in January 2007. Patients who died between July 2001 and February 2005 (historical cohort; n = 134) were compared with those who died between January 2007 and January 2012 (QoL/PC cohort; n = 57).

**RESULTS:** Median time to first QoL/PC consultation was 17.2 months (range 9-33). At consultation, 60% of children were not receiving or discontinued cancer-directed therapy. Within the QoL/PC cohort, 54 patients had documented symptoms, 94% required intervention for  $\geq 3$  symptoms, and 76% received intervention for  $\geq 5$  symptoms. Eighty-three percent achieved their preferred place of death. Compared with the historical cohort, the QoL/PC cohort had more end-of-life discussions per patient (median 12 vs. 3;  $P < 0.001$ ), earlier end-of-life discussions, with longer times before do-not-resuscitate orders (median 195 vs. 2 days;  $P < 0.001$ ), and greater hospice enrollment (71% vs. 46%,  $P = 0.002$ ).

**CONCLUSION:** Although children with solid tumor malignancies may have significant symptom burden toward the end of life, positive changes were documented in communication and in places of care and death after implementation of a pediatric PC service.

PMID: 25891664

50. J Pain Symptom Manage. 2015 Aug;50(2):155-62. doi: 10.1016/j.jpainsymman.2015.02.026. Epub 2015 Apr 16.

**Correlates and Predictors of Conflict at the End of Life Among Families Enrolled in Hospice.**

Kramer BJ1, Boelk AZ2.

Abstract

**CONTEXT:** Despite the palliative care mandate to view family as the unit of care, and the high prevalence and detrimental consequences of conflict at the end of life, little research has been conducted with hospice families to understand what contributes to family conflict.

**OBJECTIVES:** Using a recently generated explanatory matrix of family conflict at the end of life, this study sought to identify the correlates and predictors of family conflict.

**METHODS:** As part of a larger mixed methods cross-sectional study, a 100-item survey was administered to 161 hospice family caregivers enrolled in a Medicare/Medicaid certified non-profit hospice organization located in the Midwest U.S.

**RESULTS:** Although overall levels of conflict were relatively low, 57% of hospice caregivers reported experiencing some family conflict at the end of life. Contextual variables associated with family conflict included a history of family conflict, female gender, younger caregiver age, presence of children in the home, and less advance care planning discussions. Significant main effects in the prediction of family conflict in the final hierarchical multiple regression model included prior family conflict, caregiver age, caregiver gender, advance care planning discussions, family "coming out of the woodwork," communication constraints, and family members asserting control. The model explained 59% of the variance in family conflict.

**CONCLUSION:** Results support the multidimensional theoretical model of family conflict specifying the importance of the family context, key conditions that set the stage for conflict, and essential contributing factors. Implications for routine assessment and screening to identify families at risk and recommendations for future research are highlighted.

PMID: 25891662

51. Pediatr Blood Cancer. 2015 Aug;62(8):1409-13.

**Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team.**

Kassam A1, Skiadaresis J2, Alexander S1, Wolfe J3,4,5,6.

Abstract

**BACKGROUND:** There is a general consensus that involving a specialized palliative care team in the care of children with advanced cancer can help optimize end-of-life communication; however, how this compares to standard oncology care is still unknown. We aimed to determine whether there was an association between specialist palliative care involvement and improved end-of-life communication for children with advanced cancer and their families.

**PROCEDURE:** We administered questionnaires to 75 bereaved parents (response rate 54%). Outcome measures were presence or absence of 11 elements related to end-of-life communication.

**RESULTS:** Parents were significantly more likely to receive five communication elements if their child was referred to a palliative care team. These elements are: discussion of death and dying with parents by the healthcare team ( $P < 0.01$ ); discussion of death and dying with child by the healthcare team when appropriate ( $P < 0.01$ ); providing parents with guidance on

how to talk to their child about death and dying when appropriate ( $P < 0.01$ ); preparing parents for medical aspects surrounding death ( $P = 0.02$ ) and sibling support ( $P = 0.02$ ). Children were less likely to be referred to a palliative care team if they had a hematologic malignancy.

**CONCLUSIONS:** Children who receive standard oncology care are at higher risk of not receiving critical communication elements at end of life. Strategies to optimize end-of-life communication for children who are not referred to a palliative care team are needed.

PMID: 25882665

52. *Pediatr Blood Cancer*. 2015 Aug;62(8):1403-8.

**Persistent racial and ethnic differences in location of death for children with cancer.**

Cawkwell PB1, Gardner SL2, Weitzman M1,3,4.

Abstract

**BACKGROUND:** Approximately one in 285 children will be diagnosed with cancer before reaching their 20th birthday. While both oncologists and parents report a preference that these children die at home rather than in a hospital, there are limited data exploring this issue in depth.

**PROCEDURE:** We performed a retrospective analysis of national-level data from 1999 to 2011 from the National Center for Health Statistics "Underlying Cause of Death" database. Characteristics investigated included sex, race, age, ethnicity, cancer type, geographic location, and population density where the child lived.

**RESULTS:** Of the 2,130 children with a death attributable to neoplasm in 2011, 37.6% (95% CI, 35.5-39.6%) died at home compared to 36.9% (95% CI, 35.0-38.8%) in 1999. In 2011, there were statistically significant racial differences between white, black, and Hispanic children across nearly every age group, with white children consistently most likely to die at home. Children of non-Hispanic origin were significantly more likely to die at home than Hispanic children (40.3% vs. 29.3%,  $P < 0.001$ ). Children with CNS tumors are more likely to die at home than children with neoplasms as a whole, while children with leukemia are less likely. Statistically significant differences by race and ethnicity persist regardless of cancer type.

**CONCLUSIONS:** There has been no significant change in the rate of children with cancer who die at home over the past decade. Racial and ethnic differences have persisted in end of life care for children with cancer with white non-Hispanic children being most likely to die at home.

PMID: 25787675

53. *J Med Ethics*. 2015 Aug;41(8):630-4.

**Child euthanasia: should we just not talk about it?**

Bovens L.

Abstract

Belgium has recently extended its euthanasia legislation to minors, making it the first legislation in the world that does not specify any age limit. I consider two strands in the opposition to this legislation. First, I identify five arguments in the public debate to the effect that euthanasia for minors is somehow worse than euthanasia for adults--viz, arguments from weightiness, capability of discernment, pressure, sensitivity and sufficient palliative care--and show that these arguments are wanting. Second, there is another position in the public debate that wishes to keep the current age restriction on the books and have ethics boards exercise discretion in euthanasia decisions for minors. I interpret this position on the background of Velleman's 'Against the Right to Die' and show that, although costs remain substantial, it actually can provide some qualified support against extending euthanasia legislation to minors.

PMID: 25757464

54. *J Adv Nurs*. 2015 Aug;71(8):1940-7.

**Paediatric end-of-life care needs in Switzerland: current practices, and perspectives from parents and professionals.**

**A study protocol.**

Bergstraesser E1, Zimmermann K2,3, Eskola K2, Luck P2, Ramelet AS4, Cignacco E2,5.

Abstract

**AIM:** To present a protocol for a multi-phase study about the current practice of end-of-life care in paediatric settings in Switzerland.

**BACKGROUND:** In Switzerland, paediatric palliative care is usually provided by teams, who may not necessarily have specific training. There is a lack of systematic data about specific aspects of care at the end of a child's life, such as symptom management, involvement of parents in decision-making and family-centred care and experiences and needs of parents, and perspectives of healthcare professionals.

**DESIGN:** This retrospective nationwide multicentre study, Paediatric End-of-Life CAre Needs in Switzerland (PELICAN), combines quantitative and qualitative methods of enquiry.

**METHODS:** The PELICAN study consists of three observational parts, PELICAN I describes practices of end-of-life care (defined as the last 4 weeks of life) in the hospital and home care setting of children (0-18 years) who died in the years 2011-2012 due to a cardiac, neurological or oncological disease, or who died in the neonatal period. PELICAN II assesses the experiences and needs of parents during the end-of-life phase of their child. PELICAN III focuses on healthcare professionals and explores their perspectives concerning the provision of end-of-life care.

**CONCLUSION:** This first study across Switzerland will provide comprehensive insight into the current end-of-life care in children with distinct diagnoses and the perspectives of affected parents and health professionals. The results may facilitate the development and implementation of programmes for end-of-life care in children across Switzerland, building on real experiences and needs.

**TRIAL REGISTRATION:** ClinicalTrials.gov Identifier: NCT01983852.

PMID: 25740472

55. Support Care Cancer. 2015 Sep;23(9):2805-11.

**Perceived timeliness of referral to hospice palliative care among bereaved family members in Korea.**

Jho HJ1, Chang YJ, Song HY, Choi JY, Kim Y, Park EJ, Paek SJ, Choi HJ.

**Abstract**

**PURPOSE:** We aimed to explore the perceived timeliness of referral to hospice palliative care unit (HPCU) among bereaved family members in Korea and factors associated therewith.

**METHODS:** Cross-sectional questionnaire survey was performed for bereaved family members of patients who utilized 40 designated HPCUs across Korea. The questionnaire assessed whether admission to the HPCU was "too late" or "appropriate" and the Good Death Inventory (GDI).

**RESULTS:** A total of 383 questionnaires were analyzed. Of participants, 25.8 % replied that admission to HPCU was too late. Patients with hepatobiliary cancer, poor performance status, abnormal consciousness level, and unawareness of terminal status were significantly related with the too late perception. Family members with younger age and being a child of the patient were more frequently noted in the too late group. Ten out of 18 GDI scores were significantly lower in the too late group. Multiple logistic regression analysis revealed patients' unawareness of terminal status, shorter stay in the HPCU, younger age of bereaved family, and lower scores for two GDI items (staying in a favored place, living without concerning death or disease) were significantly associated with the too late group.

**CONCLUSIONS:** To promote timely HPCU utilization and better quality of end of life care, patients need to be informed of the terminal status and their preference should be respected.

PMID: 25739751

56. J Pediatr Oncol Nurs. 2015 Sep;32(5):337-47.

**Evaluation of Physician and Nurse Dyad Training Procedures to Deliver a Palliative and End-of-Life Communication Intervention to Parents of Children with a Brain Tumor.**

Hendricks-Ferguson VL1, Kane JR2, Pradhan KR3, Shih CS3, Gauvain KM4, Baker JN5, Haase JE6.

**Abstract**

When a child's prognosis is poor, physicians and nurses (MDs/RNs) often struggle with initiating discussions about palliative and end-of-life care (PC/EOL) early in the course of illness trajectory. We describe evaluation of training procedures used to prepare MD/RN dyads to deliver an intervention entitled: Communication Plan: Early Through End of Life (COMPLETE) intervention. Our training was delivered to 5 pediatric neuro-oncologists and 8 pediatric nurses by a team of expert consultants (i.e., in medical ethics, communication, and PC/EOL) and parent advisors. Although half of the group received training in a 1-day program and half in a 2-day program, content for all participants included 4 modules: family assessment, goal-directed treatment planning, anticipatory guidance, and staff communication and follow-up. Evaluations included dichotomous ratings and qualitative comments on content, reflection, and skills practice for each module. Positive aspects of our training included parent advisors' insights, emphasis on hope and non-abandonment messages, written materials to facilitate PC/EOL communication, and an MD/RN dyad approach. Lessons learned and challenges related to our training procedures will be described. Overall, the MDs and RNs reported that our PC/EOL communication-training procedures were helpful and useful. Future investigators should carefully plan training procedures for PC/EOL communication interventions.

PMID: 25623029

57. J Pediatr Oncol Nurs. 2015 Sep;32(5):265-77.

**Establishing Feasibility of Early Palliative Care Consultation in Pediatric Hematopoietic Stem Cell Transplantation.**

Lafond DA1, Kelly KP2, Hinds PS2, Sill A3, Michael M4.

**Abstract**

Children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) encounter a number of distressing physical symptoms and existential distress but may not be afforded timely access to palliative care services to help ameliorate the distress. This feasibility study investigated the acceptability and outcomes of early palliative care consultation to promote comfort in this population. A longitudinal, descriptive cohort design examined both provider willingness to refer and willingness of families to receive palliative care interventions as well as satisfaction. Feasibility was demonstrated by 100% referral of eligible patients and 100% of patient and family recruitment (N = 12). Each family received 1 to 3 visits per week (ranging from 15 to 120 minutes) from the palliative care team. Interventions included supportive care counseling and integrative therapies. Families and providers reported high satisfaction with the nurse-led palliative care consultation. Outcomes included improvement or no significant change in comfort across the trajectory of HSCT, from the child and parental perspective. Early integration of palliative care in HSCT is feasible and acceptable to families and clinicians.

PMID: 25616372

58. Pain Manag Nurs. 2015 Aug;16(4):526-33.

**Families' Views of Pediatric Palliative Aquatics: A Qualitative Study.**

Gaab E1, Steinhorn DM2.

**Abstract**

Although pediatric palliative care policies and services have been developed, research in this area continues to lag. An integrated model of palliative care has been suggested by the American Academy of Pediatrics and includes complementary and alternative services aimed at improving the well-being of children and their families. The first-known pediatric palliative aquatics program (PPAP) in California uses several techniques to decrease pain and promote well-being through relaxation and interaction between patients, specialists, and family members. This study investigates the perceptions of family members of their children's experiences with a PPAP. Researchers from an outside institution conducted focus groups and interviews. Themes were extracted from the focus group transcripts using Braun and Clarke's method of inductive thematic analysis. Data were collected at the host site, local libraries, and participant homes. Participants were primary caregivers and siblings (n = 23) of children in a PPAP, an independent children's respite, transitional, and end-of-life care facility in

California. The research described and drew implications from the diverse perceptions that family members expressed about the benefits of having a child in the PPAP, including sensory, physical, and social experiences. Although the PPAP aims to promote well-being through relaxation, several other benefits were expressed by family members of children going through the program, including pain relief.

PMID: 25547919

59. Am J Hosp Palliat Care. 2015 Sep;32(6):581-7.

**The Use of Emergency Medication Kits in Community Palliative Care: An Exploratory Survey of Views of Current Practice in Australian Home-Based Palliative Care Services.**

Bullen T1, Rosenberg JP2, Smith B3, Maher K3.

Abstract

Improving symptom management for palliative care patients has obvious benefits for patients and advantages for the clinicians, as workload demands and work-related stress can be reduced when the emergent symptoms of patients are managed in a timely manner. The use of emergency medication kits (EMKs) can provide such timely symptom relief. The purpose of this study was to conduct a survey of a local service to examine views on medication management before and after the implementation of an EMK and to conduct a nationwide prevalence survey examining the use of EMKs in Australia. Most respondents from community palliative care services indicated that EMKs were not being supplied to palliative care patients but believed such an intervention could improve patient care.

PMID: 24871345

60. Am J Hosp Palliat Care. 2015 Sep;32(6):660-71.

**Palliative Sedation: An Analysis of International Guidelines and Position Statements.**

Gurschick L1, Mayer DK2, Hanson LC2.

Abstract

**PURPOSE:** To describe the suggested clinical practice of palliative sedation as it is presented in the literature and discuss available guidelines for its use.

**METHODS:** CINAHL, PubMed, and Web of Science were searched for publications since 1997 for recommended guidelines and position statements on palliative sedation as well as data on its provision. Keywords included palliative sedation, terminal sedation, guidelines, United States, and end of life. Inclusion criteria were palliative sedation policies, frameworks, guidelines, or discussion of its practice, general or oncology patient population, performance of the intervention in an inpatient unit, for humans, and in English. Exclusion criteria were palliative sedation in children, acute illness, procedural, or burns, and predominantly ethical discussions.

**RESULTS:** Guidelines were published by American College of Physicians-American Society of Internal Medicine (2000), Hospice and Palliative Nurses Association (2003), American Academy of Hospice and Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice and Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). Variances throughout guidelines include definitions of the practice, indications for its use, continuation of life-prolonging therapies, medications used, and timing/prognosis.

**RECOMMENDATIONS:** The development and implementation of institutional-based guidelines with clear stance on the discussed variances is necessary for consistency in practice. Data on provision of palliative sedation after implementation of guidelines needs to be collected and disseminated for a better understanding of the current practice in the United States.

PMID: 24807825

61. Am J Hosp Palliat Care. 2015 Aug;32(5):484-9.

**Supporting Family Caregivers With Palliative Symptom Management: A Qualitative Analysis of the Provision of an Emergency Medication Kit in the Home Setting.**

Rosenberg JP1, Bullen T2, Maher K3.

Abstract

**PURPOSE:**

The purpose of this qualitative analysis was to examine the experiences of family caregivers supporting a dying person in the home setting. In particular, it explores caregivers' perceptions of receiving palliative care at home when supplied with an emergency medication kit (EMK).

**RESULTS:**

Most family caregivers described preexisting medication management strategies that were unable to provide timely intervention in symptoms. The EMK was largely viewed as an effective strategy in providing timely symptom control and preventing readmission to inpatient care. Caregivers reported varying levels of confidence in the administration of medication.

**CONCLUSION:**

The provision of an EMK is an effective strategy for improving symptom control and preventing inpatient admissions of home-dwelling palliative care patients.

PMID: 24803586

62. Am J Hosp Palliat Care. 2015 Sep;32(6):654-9.

**Chronic Pain and Risk Factors for Opioid Misuse in a Palliative Care Clinic.**

Childers JW1, King LA2, Arnold RM2.

Abstract

**OBJECTIVES:** To describe the prevalence of chronic pain and the risk of opioid misuse in a palliative care clinic.

**METHODS:** We reviewed patient records for 6 months for source of pain, treatment status, opioid misuse risk (Cut down, Annoyed, Guilty, and Eye-opener [CAGE] and Screener and Opioid Assessment for Patients with Pain version 1.0-Short

Form [SOAPP-SF] scores), and urine drug screens.

RESULTS: Of 323 patients, 91% had cancer, 56% undergoing cancer treatment, while 28% had no evidence of disease.

Eighty-six (27%) patients had noncancer pain. In all, 46% of new patients had positive scores on the SOAPP-SF and 15% had a positive CAGE. Of the less than 5% of visits that included a urine drug screen, 56% had aberrant results.

CONCLUSION: Chronic pain and indicators of opioid misuse risk were prevalent. Outpatient palliative care practices should develop policies to address these issues.

PMID: 24744398

63. BMJ Support Palliat Care. 2015 Sep;5(3):306-15.

**Identifying the key elements of an education package to up-skill multidisciplinary adult specialist palliative care teams caring for young adults with life-limiting conditions: an online Delphi study.**

Sivell S1, Lidstone V2, Taubert M3, Thompson C4, Nelson A1.

Abstract

OBJECTIVES: To collect the views of experts to inform the development of an education package for multidisciplinary adult specialist palliative care (SPC) teams caring for young people with life-limiting conditions.

METHODS: A modified online Delphi process collated expert opinion on format, delivery and content of an education package to up-skill adult SPC teams. Round 1 participants (n=44) answered free-text questions, generating items for Round 2. In Round 2, 68 participants rated the extent to which they agreed/disagreed with the items on 5-point Likert-type scales. Median and mean scores assessed the importance of each item. IQR scores assessed level of consensus for each item; items lacking consensus were rerated by 35 participants in Round 3.

RESULTS: In the Delphi, consensus was reached on a range of suggested formats, on who should deliver the training, and on several clinical, psychosocial and practical topics.

CONCLUSIONS:

Development of a continuous/rolling programme of education, tailored for content and mode of delivery and incorporated into working practice is recommended. As a direct outcome of the results of this study, a series of six linked study days has been established, focusing specifically on the issues around caring for young adults with life-limiting conditions and palliative care needs. Free PMC Article

PMID: 24670554

64. BMJ Support Palliat Care. 2015 Sep;5(3):240-8.

**Parents and end-of-life decision-making for their child: roles and responsibilities.**

Sullivan J1, Gillam L1, Monagle P2.

Abstract

BACKGROUND: Whether parents want to be and should be the decision-maker for their child in end-of-life matters are contested clinical and ethical questions. Previous research outcomes are equivocal.

METHOD: A qualitative interview method was used to examine the views and experiences of 25 bereaved parents in end-of-life decision-making for their child. Data were analysed thematically.

RESULTS: Three types of decision-making roles were identified: self-determined, guided (both involving active decision-making) and acquiescent (passive). The majority of parents had been active in the decision-making process for their child. They perceived themselves as the ultimate end-of-life decision-maker. This was perceived as part of their parental responsibility. A minority of parents did not consider that they had been an active, ultimate decision-maker. Generally, parents in the self-determined and guided groups reported no negative consequences from their decision-making involvement. Importantly, parents in the acquiescent group described their experience as difficult at the time and subsequently, although not all difficulties related directly to decision-making. Parents considered that in principle parents should be the end-of-life decision-maker for their child, but understood personal characteristics and preference could prevent some parents from taking this role.

CONCLUSIONS: This study unequivocally supports parents' desire to fulfil the end-of-life decision-making role. It provides a nuanced understanding of parents' roles and contributes evidence for the ethical position that parents should be the end-of-life decision-makers for their child, unless not in the child's best interests. On the whole, parents want this role and can manage its consequences. Indeed, not being the end-of-life decision-maker could be detrimental to parents' well-being.

PMID: 24644205

65. BMJ Support Palliat Care. 2015 Sep;5(3):249-58.

**The Spectrum of Children's Palliative Care Needs: a classification framework for children with life-limiting or life-threatening conditions.**

Shaw KL1, Brook L2, Mpundu-Kaambwa C3, Harris N4, Lapwood S5, Randall D6.

Abstract

OBJECTIVES: This paper examined the potential of a new classification framework, The Spectrum of Children's Palliative Care Needs, to facilitate identification of children with palliative care needs for the purposes of minimum data set collection and population needs assessment.

METHODS: Health and social care professionals (n=50) in a range of paediatric palliative care settings applied The Spectrum to (i) clinical vignettes and (ii) consecutive children on their caseloads. They also provided confidence ratings and written comments about their experiences. Inter-rater reliability, conceptual validity, acceptability, feasibility and sustainability were examined. A subset of professionals (n=9) also participated in semistructured telephone interviews to provide further insight.

RESULTS: Inter-rater reliability for the vignettes ( $\kappa=0.255$ ) was fair. However, professionals were more confident applying The Spectrum to their caseloads, which included children (n=74) with a range of life-limiting/life-threatening conditions. The Spectrum made conceptual sense in relation to these children and was considered to offer a meaningful way to define the

eligible population in service mapping. Benefits for clinical work (eg, facilitating patient review, workload management, clinical audit) and research were also identified. However, important threats to reliability were highlighted.

**CONCLUSIONS:** Preliminary assessment of The Spectrum confirms its potential to promote consistent data set collection in children's palliative care. The results have been used to produce a revised version and user guidelines to address issues raised by participants. However, further research is required to further validate the framework and establish its relevance to families' self-defined needs.

PMID: 24644200

66. BMJ Support Palliat Care. 2015 Sep;5(3):232-9.

**Experiences of healthcare professionals in the community dealing with the spiritual needs of children and young people with life-threatening and life-limiting conditions and their families: report of a workshop.**

Llewellyn H1, Jones L2, Kelly P3, Barnes J4, O'Gorman B4, Craig F5, Bluebond-Langner M6.

Abstract

**OBJECTIVE:** We sought to understand how healthcare professionals (HCP) conceptualise spirituality among seriously ill children and young people (CYP) and their families, and their experiences in dealing with spiritual issues that emerge in practice.

**METHOD:** We analysed thematically presentations and small group discussions with HCP that took place as part of a day-long workshop exploring the place of spirituality in paediatric healthcare.

**RESULTS:** (1) HCP conceptualised spirituality as highly individualised searches for meaning, hope and connectedness to self, others and the world. They saw spirituality within a developmental context. (2) HCP described spiritual concerns that were tied to their own conceptualisations of spirituality, centring on ideas of loss, including loss of hope or meaning. (3) HCP approached spiritual concerns of CYP and families by 'being there' and supporting spiritual enquiry. (4) Challenges to their work included managing hopes of CYP and families in the face of poor prognoses, discussions about miracles and issues with their own faith. Spiritual care was seen as different to other areas of care which HCP felt had a greater prescription in delivery.

**CONCLUSIONS:** The findings underscore the complexity of spirituality in times of illness and the challenges faced in its management. HCP should be alerted to the myriad ways spirituality emerges in serious illness and opportunities for developing confidence in attending to spiritual issues with CYP and families through training. Research should explore with patients, families and HCP how tensions among CYP, autonomy, the maintenance of hope and miracle beliefs are best approached within care.

PMID: 24644181

67. BMJ Support Palliat Care. 2015 Sep;5(3):287-93.

**Volunteer activity in specialist paediatric palliative care: a national survey.**

Burbeck R1, Low J1, Sampson EL1, Scott R1, Bravery R1, Candy B1.

Abstract

**OBJECTIVE:** To assess the involvement of volunteers with direct patient/family contact in UK palliative care services for children and young people.

**METHOD:** Cross-sectional survey using a web-based questionnaire.

**SETTING:** UK specialist paediatric palliative care services.

**PARTICIPANTS:** Volunteer managers/coordinators from all UK hospice providers (n=37) and one National Health Service palliative care service involving volunteers (covering 53 services in total).

**MAIN OUTCOMES:**

Service characteristics, number of volunteers, extent of volunteer involvement in care services, use of volunteers' professional skills and volunteer activities by setting.

**RESULTS:** A total of 21 providers covering 31 hospices/palliative care services responded (30 evaluable responses). Referral age limit was 16-19 years in 23 services and 23-35 years in seven services; three services were Hospice at Home or home care only. Per service, there was a median of 25 volunteers with direct patient/family contact. Services providing only home care involved fewer volunteers than hospices with beds. Volunteers entirely ran some services, notably complementary therapy and pastoral/faith-based care. Complementary therapists, school teachers and spiritual care workers most commonly volunteered their professional skills. Volunteers undertook a wide range of activities including emotional support and recreational activities with children and siblings.

**CONCLUSIONS:** This is the most detailed national survey of volunteer activity in palliative care services for children and young people to date. It highlights the range and depth of volunteers' contribution to specialist paediatric palliative care services and will help to provide a basis for future research, which could inform expansion of volunteers' roles.

PMID: 24644170 Free PMC Article

68. J Child Health Care. 2015 Sep;19(3):304-19.

**'Being a presence': The ways in which family support workers encompass, embrace, befriend, accompany and endure with families of life-limited children.**

Carter B1, Edwards M2, Hunt A3.

Abstract

Children with life-limiting and disabling conditions are surviving longer than previously, and many require palliative and supportive care, usually at home. Home-based care can put family life under considerable strain, as parents care for their child's complex, often unpredictable, continuing care needs. Rainbow Trust Children's Charity aims to bridge gaps in services for children with life-threatening or terminal conditions by providing family support workers (FSWs). The study used a range of methods (surveys, interviews and ethnographic observation) approach to explore key aspects of the work of the FSWs. The target population for the surveys was families with a child having complex, life-threatening or terminal conditions



receiving care from FSWs. The participants included 55 families (12 bereaved) and 39 children aged 2-18 years. Thematic analysis revealed how the FSWs became a presence in families' lives in three main ways: (1) encompassing and embracing families through supporting needs and promoting resilience; (2) befriending and bonding through developing knowledge, trusting relationships and a sense of closeness; and (3) accompanying and enduring by 'being with' families in different settings, situations and crises and by enduring alongside the families. The study demonstrated the fundamental importance of workers who are able to provide aspects of support that is usually not provided by other services.

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