

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

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

Donald A.B. Lindberg



Primo numero

Febbraio 2016

Volume III - N° 1

1. Eur J Paediatr Neurol. 2016 Mar;20(2):261-9. 2015 Dec 22.

[Symptoms and management of pediatric patients with incurable brain tumors in palliative home care.](#)

[Kuhlen M¹, Hoell J², Balzer S², Borkhardt A², Janssen G².](#)

INTRODUCTION: Brain tumors have the highest disease-related mortality rate of all pediatric cancers. The goal of this study was to determine whether all children with incurable brain tumors cared for by a pediatric palliative care team in a home setting suffer from the same symptoms towards the end of their lives or whether there are differences between the tumor localizations with implications for palliative care. **PATIENTS AND METHODS:** This study was conducted as a retrospective, single center chart review including all patients treated between January 1st 2000 and December 31st 2013. **RESULTS:** 70 children, adolescents and young adults were included in the analysis. Symptom burden was high with a mean number of symptoms of 7.2 per patient. 74% of the symptoms already existed one week before death. Within the last week of life, impaired consciousness (75.7%) most often occurred. Furthermore, symptoms considerably depended on tumor localization. Patients with supratentorial tumors presented more frequently with seizures ($p < 0.05$), coma ($p < 0.01$), nausea and emesis ($p < 0.01$). Ataxia ($p < 0.001$) occurred most frequently in infratentorial tumors and speech disturbances ($p < 0.05$), cranial nerve paralysis ($p < 0.001$), and tetraparesis ($p < 0.001$) in brain stem tumors. 84.3% of the patients needed analgesics, only 64.4% WHO class III analgesics. Anticonvulsants were given more often in supratentorial tumors ($p < 0.01$). **CONCLUSIONS:** Caring for a dying child suffering from a brain tumor needs increased awareness of the neurological deterioration. The symptom pattern strongly depends on the tumor localization and significantly differs between supratentorial, infratentorial and brain stem tumors.

Copyright © 2015 European Paediatric Neurology Society. Published by Elsevier Ltd. All rights reserved.

PMID: 26753538

2. Arch Pediatr. 2016 Feb;23(2):150-8.

[\[Newly formed French residents in pediatrics are not well prepared for conducting pediatric resuscitation after medical school\].](#)

[Article in French]

[Drummond D¹, Arnaud C², Thouvenin G³, Guedj R², Duguet A⁴, de Suremain N², Petit A⁵.](#)

BACKGROUND: Medical schools aim to prepare medical students for their residency responsibilities. However, in France, there is no assessment of medical students' skills when they start their residency. **GOAL:** The objective of this study was to assess the quality of basic life support delivered by first-year residents in pediatrics during a simulated pediatric cardiopulmonary arrest. **MATERIALS AND METHODS:** First-year residents in pediatrics were assessed during a simulated pediatric cardiopulmonary arrest. Their performance score (based on adherence to international guidelines) and no-flow and no-blow fractions were recorded. **RESULTS:** Forty-two first-year residents were evaluated. Their median performance score was 4 out of 13. No-blow and no-flow fractions were 55 and 81 %, respectively. There was no correlation between their skills and their knowledge assessed during the national ranking exam at the end of the 6th year of medical school. **CONCLUSION:** At the beginning of their residency, pediatric residents are not able to properly provide basic life support. The introduction of simulation in French medical schools may be an effective way to improve their skills.

Copyright © 2015 Elsevier Masson SAS. All rights reserved.

PMID: 26774839

3. J Med Ethics. 2016 Feb;42(2):116-8. Epub 2015 Dec 18.

Harm isn't all you need: parental discretion and medical decisions for a child.

Wilkinson D¹, Nair T².

PMID: 26685150

4. Res Dev Disabil. 2016 Feb-Mar;49-50:235-46.

End-of-life decision-making for children with severe developmental disabilities: The parental perspective.

Zaal-Schuller IH¹, de Vos MA², Ewals FV³, van Goudoever JB⁴, Willems DL⁵.

BACKGROUND AND AIMS: The objectives of this integrative review were to understand how parents of children with severe developmental disorders experience their involvement in end-of-life decision-making, how they prefer to be involved and what factors influence their decisions. **METHODS AND PROCEDURES:** We searched MEDLINE, EMBASE, CINAHL and PsycINFO. The search was limited to articles in English or Dutch published between January 2004 and August 2014. We included qualitative and quantitative original studies that directly investigated the experiences of parents of children aged 0-18 years with severe developmental disorders for whom an end-of-life decision had been considered or made. **OUTCOMES AND RESULTS:** We identified nine studies that met all inclusion criteria. Reportedly, parental involvement in end-of-life decision-making varied widely, ranging from having no involvement to being the sole decision-maker. Most parents preferred to actively share in the decision-making process regardless of their child's specific diagnosis or comorbidity. The main factors that influenced parents in their decision-making were: their strong urge to advocate for their child's best interests and to make the best (possible) decision. In addition, parents felt influenced by their child's visible suffering, remaining quality of life and the will they perceived in their child to survive. **CONCLUSIONS AND IMPLICATIONS:** Most parents of children with severe developmental disorders wish to actively share in the end-of-life decision-making process. An important emerging factor in this process is the parents' feeling that they have to stand up for their child's interests in conversations with the medical team.

PMID: 26741261

5. Pediatr Blood Cancer. 2016 Jan 29. [Epub ahead of print]

Communication Skills Training in Pediatric Oncology: Moving Beyond Role Modeling.

Feraco AM^{1,2,3}, Brand SR⁴, Mack JW^{1,2,5}, Kesselheim JC^{1,2,5}, Block SD^{3,4,6,7}, Wolfe J^{2,4}.

ABSTRACT Communication is central to pediatric oncology care. Pediatric oncologists disclose life-threatening diagnoses, explain complicated treatment options, and endeavor to give honest prognoses, to maintain hope, to describe treatment complications, and to support families in difficult circumstances ranging from loss of function and fertility to treatment-related or disease-related death. However, parents, patients, and providers report substantial communication deficits. Poor communication outcomes may stem, in part, from insufficient communication skills training, overreliance on role modeling, and failure to utilize best practices. This review summarizes evidence for existing methods to enhance communication skills and calls for revitalizing communication skills training within pediatric oncology.

PMID: 26822066

6. J Pain Symptom Manage. 2016 Jan 28. [Epub ahead of print]

Clinical Implications of C-Reactive Protein as a Prognostic Marker in Advanced Cancer Patients in Palliative Care Settings.

Amano K¹, Maeda I², Morita T³, Miura T⁴, Inoue S⁵, Ikenaga M⁶, Matsumoto Y⁴, Baba M⁷, Sekine R⁸, Yamaguchi T⁹, Hirohashi T¹⁰, Tajima T¹¹, Tatara R¹², Watanabe H¹³, Otani H¹⁴, Takigawa C¹⁵, Matsuda Y¹⁶, Nagaoka H¹⁷, Mori M¹⁸, Kinoshita H⁴.

CONTEXT: Plasma C-reactive protein (CRP) levels are elevated in patients with advanced cancer. **OBJECTIVES:** To investigate CRP as a prognostic marker in palliative settings. **METHODS:** This multicenter prospective cohort study comprised 2426 patients. Laboratory data were obtained at baseline, and all patients were followed until death or six months after their enrollment. A total of 1511 patients were eligible for the analyses. They were divided into four groups: low-CRP (CRP < 1 mg/dL), moderate-CRP (1 ≤ CRP < 5 mg/dL), high-CRP (5 ≤ CRP < 10 mg/dL), and very high-CRP (10 mg/dL ≤ CRP) groups. Survival was investigated by the Kaplan-Meier method with the log-rank test. The 30-, 60-, and 90-day mortality rates were tested by Chi-squared tests. Univariate- and multivariate-adjusted hazard ratios (HRs) and 95% CIs in each group were calculated using Cox proportional hazard models. **RESULTS:** Survival rate decreased and mortality rate increased with increasing CRP level. The differences in survival and 30-, 60-, and 90-day mortality rates among the groups were statistically significant (P < 0.001). Baseline CRP level was significantly associated with a higher risk of mortality after adjustment for age, gender, primary tumor site, metastasis, chemotherapy, Eastern Cooperative Oncology Group Performance Status, and setting of care (moderate-CRP: HR 1.47 [95% CI 1.24-1.73], high-CRP: HR 2.09 [95% CI 1.74-2.50], and very high-CRP: HR 2.55 [95% CI 2.13-3.05] vs. low-CRP). **CONCLUSION:** Clear dose-effect relationships between elevated CRP levels and prognoses indicate that CRP could be useful in predicting prognoses in patients with advanced cancer. Copyright © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

PMID: 26826676

7. BMC Palliat Care. 2016 Jan 27;15(1):12.

Protocol: Evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer.

Widger K^{1,2}, Friedrichsdorf S³, Wolfe J⁴, Liben S⁵, Pole JD⁶, Bouffet E⁷, Greenberg M⁸, Husain A⁹, Siden H¹⁰, Whitlock JA¹¹, Rapoport A¹².

BACKGROUND: There are identified gaps in the care provided to children with cancer based on the self-identified lack of education for health care professionals in pediatric palliative care and in the perceptions of bereaved parents who describe suboptimal care. In order to address these gaps, we will implement and evaluate a national roll-out of Education in Palliative

and End-of-Life Care for Pediatrics (EPEC®-Pediatrics), using a 'Train-the-Trainer' model. **METHODS/DESIGN:** In this study we are using a pre- post-test design and an integrated knowledge translation approach to assess the impact of the educational roll-out in four areas: 1) self-assessed knowledge of health professionals; 2) knowledge dissemination outcomes; 3) practice change outcomes; and 4) quality of palliative care. The quality of palliative care will be assessed using data from three sources: a) parent and child surveys about symptoms, quality of life and care provided; b) health record reviews of deceased patients; and c) bereaved parent surveys about end-of-life and bereavement care. After being trained in EPEC®-Pediatrics, 'Master Facilitators' will train 'Regional Teams' affiliated with 16 pediatric oncology programs in Canada. Each team will consist of three to five health professionals representing oncology, palliative care, and the community. Each team member will complete online modules and attend one of two face-to-face conferences, where they will receive training and materials to teach the EPEC®-Pediatrics curriculum to 'End-Users' in their region. Regional Teams will also choose a Tailored Implementation of Practice Standards (TIPS) Kit to guide implementation of a quality improvement project in their region; support will be provided via quarterly meetings with Co-Leads and via a listserv and webinars with other teams. **DISCUSSION:** Through this study we aim to raise the level of pediatric palliative care education amongst health care professionals in Canada. Our study will be a significant step forward in evaluation of the impact of EPEC®-Pediatrics both on dissemination outcomes and on care quality at a national level. Based on the anticipated success of our project we hope to expand the EPEC®-Pediatrics roll-out to health professionals who care for children with non-oncological life-threatening conditions.

PMCID: PMC4729125 **Free PMC Article**

PMID: 26818836

8. *Pediatr Crit Care Med.* 2016 Jan 27. [Epub ahead of print]

Exploring the Role of Polycythemia in Patients With Cyanosis After Palliative Congenital Heart Surgery.

Siehr SL¹, Shi S, Hao S, Hu Z, Jin B, Hanley F, Reddy VM, McElhinney DB, Ling XB, Shin AY.

OBJECTIVES: To understand the relationship between polycythemia and clinical outcome in patients with hypoplastic left heart syndrome following the Norwood operation. **DESIGN:** A retrospective, single-center cohort study. **SETTING:** Pediatric cardiovascular ICU, university-affiliated children's hospital. **PATIENTS:** Infants with hypoplastic left heart syndrome admitted to our medical center from September 2009 to December 2012 undergoing stage 1/Norwood operation. **INTERVENTIONS:** None. **MEASUREMENTS AND MAIN RESULTS:** Baseline demographic and clinical information including first recorded postoperative hematocrit and subsequent mean, median, and nadir hematocrits during the first 72 hours postoperatively were recorded. The primary outcomes were in-hospital mortality and length of hospitalization. Thirty-two patients were included in the analysis. Patients did not differ by operative factors (cardiopulmonary bypass time and cross-clamp time) or traditional markers of severity of illness (vasoactive inotrope score, lactate, saturation, and PaO₂/FIO₂ ratio). Early polycythemia (hematocrit value > 49%) was associated with longer cardiovascular ICU stay (51.0 [± 38.6] vs 21.4 [± 16.2] d; p < 0.01) and total hospital length of stay (65.0 [± 46.5] vs 36.1 [± 20.0] d; p = 0.03). In a multivariable analysis, polycythemia remained independently associated with the length of hospitalization after controlling for the amount of RBC transfusion (weight, 4.36 [95% CI, 1.35-7.37]; p < 0.01). No difference in in-hospital mortality rates was detected between the two groups (17.6% vs 20%). **CONCLUSIONS:** Early polycythemia following the Norwood operation is associated with longer length of hospitalization even after controlling for blood cell transfusion practices. We hypothesize that polycythemia may be caused by hemoconcentration and used as an early marker of capillary leak syndrome.

PMID: 26825044

9. *Palliat Med.* 2016 Jan 26. [Epub ahead of print]

Differences in palliative care quality between patients with cancer, patients with organ failure and frail patients: A study based on measurements with the Consumer Quality Index Palliative Care for bereaved relatives.

Hofstede JM¹, Raijmakers NJ², van der Hoek LS³, Francke AL⁴.

BACKGROUND: Palliative care is rooted in the care for incurably ill cancer patients. Yet today there is a recognised need for palliative care for patients with non-cancer conditions. However, the often unpredictable illness trajectories and the difficulty in predicting the imminence of death in people with non-cancer conditions may hamper the provision of high-quality palliative care. **AIM:** To compare the quality of palliative care provided to patients with cancer, patients with organ failure and frail patients and their relatives. **DESIGN:** An existing dataset was analysed, consisting of data collected through the Consumer Quality Index Palliative Care questionnaire for bereaved relatives. **SETTING/PARTICIPANTS:** Data were analysed of 456 relatives of deceased patients with cancer, patients with organ failure and frail patients from various care settings in the Netherlands. **RESULTS:** Relatives (e.g. partners or children) of deceased patients with organ failure (n = 61) were more likely to have negative experiences regarding the expertise of healthcare professionals compared with relatives of patients with cancer (n = 215). Relatives of frail patients (n = 180) gave a relatively low rating of the general quality of the care in the last week of the patient's life, both as regards the care provided to patients (p = 0.015) and as regards the support to relatives (p = 0.009). **CONCLUSION:** Compared with the bereaved relatives of patients with cancer, bereaved relatives of patients with organ failure or frailty were more likely to negatively assess the palliative care provided to both the patient and themselves. Improving professionals' expertise in palliative care for people with non-cancer conditions is recommended. © The Author(s) 2016.

PMID: 26814214

10. *Acta Paediatr.* 2016 Jan 23. [Epub ahead of print]

Metronomic therapy can increase quality of life during paediatric palliative cancer care, but careful patient selection is essential.

Porkholm M¹, Toiviainen-Salo S², Seuri R², Lönnqvist T³, Vepsäläinen K⁴, Saarinen-Pihkala UM¹, Pentikäinen V¹, Kivivuori SM¹.

AIM: Children with refractory or high-risk malignancies frequently suffer from poor quality of life during palliative care. This study explored the effect of metronomic drug administration on survival and quality of life in paediatric patients with various refractory or high-risk tumours. **METHODS:** We treated 17 patients with a maintenance therapy that consisted of

metronomic thalidomide, etoposide and celecoxib. The endpoints of the study were overall and progression-free survival, changes in the Karnofsky-Lansky scores from baseline to the end of the study therapy and radiological responses. **RESULTS:** The median overall survival after the start of the study therapy was 6.2 months (range 2.0-57.7) and the six, 12 and 24-month survival rates were 59%, 18% and 18%, respectively. The median progression-free survival was 3.2 months (range 0.3-17.8). The Karnofsky-Lansky scores increased significantly during the study therapy ($p=0.02$), with 35% of the patients having a transient improvement in their clinical status. Radiologically, one partial response and two disease stabilisations were encountered. Grade III-IV adverse events occurred in 76% of the patients. **CONCLUSION:** Metronomic therapy may increase the quality of life during palliative care for childhood cancer, but requires careful patient selection to minimise the risk of serious adverse events. This article is protected by copyright. All rights reserved.

This article is protected by copyright. All rights reserved.

PMID: 26801815

11. Arch Dis Child. 2016 Jan 22. [Epub ahead of print]

Moral distress within neonatal and paediatric intensive care units: a systematic review.

Prentice T¹, Janvier A², Gillam L³, Davis PG⁴.

OBJECTIVE: To review the literature on moral distress experienced by nursing and medical professionals within neonatal intensive care units (NICUs) and paediatric intensive care units (PICUs). **DESIGN:** Pubmed, EBSCO (Academic Search Complete, CINAHL and Medline) and Scopus were searched using the terms neonat*, infant*, pediatric*, prematur* or preterm AND (moral distress OR moral responsibility OR moral dilemma OR conscience OR ethical confrontation) AND intensive care. **RESULTS:** 13 studies on moral distress published between January 1985 and March 2015 met our inclusion criteria. Fewer than half of those studies (6) were multidisciplinary, with a predominance of nursing staff responses across all studies. The most common themes identified were overly 'burdensome' and disproportionate use of technology perceived not to be in a patient's best interest, and powerlessness to act. Concepts of moral distress are expressed differently within nursing and medical literature. In nursing literature, nurses are often portrayed as victims, with physicians seen as the perpetrators instigating 'aggressive care'. Within medical literature moral distress is described in terms of dilemmas or ethical confrontations. **CONCLUSIONS:** Moral distress affects the care of patients in the NICU and PICU. Empirical data on multidisciplinary populations remain sparse, with inconsistent definitions and predominantly small sample sizes limiting generalisability of studies. Longitudinal data reflecting the views of all stakeholders, including parents, are required.

Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://www.bmj.com/company/products-services/rights-and-licensing/>

PMID: 26801075

12. Pediatr Blood Cancer. 2016 Jan 21. [Epub ahead of print]

It is Time to Let in Pediatric Palliative Care.

Hilden J¹.

PMID: 26797913

13. J Palliat Med. 2016 Jan 20. [Epub ahead of print]

An Order Protocol for Respiratory Distress/Acute Pain Crisis in Pediatric Palliative Care Patients: Medical and Nursing Staff Perceptions.

Bidet G¹, Daoust L¹, Duval M², Ducruet T³, Toledano B⁴, Humbert N¹, Gauvin F¹.

BACKGROUND: An order protocol for distress (OPD), including respiratory distress and acute pain crisis, has been established for pediatric palliative care patients at Sainte-Justine Hospital (SJH). After discussion with the patient/his or her family, the OPD is prescribed by the attending physician whenever judged appropriate. The OPD can then be initiated by the bedside nurse when necessary; the physician is notified after the first dose is administered. **OBJECTIVES:** The study objectives were to evaluate the perceptions and experience of the medical/nursing staff towards the use of the OPD. **METHODS:** A survey was distributed to all physicians/nurses working on wards with pediatric palliative care patients. Answers to the survey were anonymous, done on a voluntary basis, and after consent of the participant. **RESULTS:** Surveys (258/548) were answered corresponding to a response rate of 47%. According to the respondents, the most important motivations in using the OPD were the desire to relieve patient's distress and the speed of relief of distress by the OPD; the most important obstacles were going against the patient's/his or her family's wishes and fear of hastening death. The respondents reported that the OPD was frequently (56%) or always (36%) effective in relieving the patient's distress. The respondents felt sometimes (16%), frequently (34%), or always (41%) comfortable in giving the OPD. They thought the OPD could never (12%), rarely (32%), sometimes (46%), frequently (8%), or always (1%) hasten death. Physicians were less favorable than nurses with the autonomy of bedside nurses to initiate the OPD before notifying the physician ($p = 0.04$). Overall, 95% of respondents considered that they would use the OPD in the future. **CONCLUSIONS:** Data from this survey shows that respondents are in favor of using the OPD at SJH and find it effective. Further training as well as support for health care professionals are mandatory in such palliative care settings.

PMID: 26788836

14. Pediatr Blood Cancer. 2016 Jan 19. [Epub ahead of print]

Physician Perspectives on Palliative Care for Children With Neuroblastoma: An International Context.

Balkin EM¹, Thompson D¹, Colson KE², Lam CG³, Matthay KK⁴.

BACKGROUND: Studies have shown that children with cancer globally lack access to palliative care. Little is known regarding physicians' perceptions of palliative care, treatment access, and self-reported competence in providing palliative care. **PROCEDURE:** Members of the Global Neuroblastoma Network (online tumor board) were surveyed. Eighty-three respondents met inclusion criteria; 53 (64%) completed the survey. **RESULTS:** Most respondents trained in high-income countries (HIC) but practice in low- and middle-income countries (LMIC), and care for more than five patients with neuroblastoma

annually. WHO Essential Medicines in palliative care varied in availability, with incomplete access across LMIC centers. Nonpharmacologic therapies were inconsistently available. Contrary to international definitions, 17% of respondents inappropriately considered palliative care as that initiated only after curative therapy is stopped. Mean physician competence composite score (Likert scale 1-5, 5 = very competent) in providing symptomatic relief and palliative care across phases of care was 2.93 (95% CI 2.71-3.22). Physicians reported significantly greater competence in symptom management during cure-directed therapy than during end-of-life ($P = 0.02$) or when patients are actively dying ($P = 0.007$). Practicing in HIC, prior palliative care training, having access to radiotherapy, and not having to turn patients away due to bed shortages were significantly predictive of perceived competence in providing palliative care at end of life. **CONCLUSIONS:** An international sample identified gaps in treatment and palliative care service availability, in understanding the definition of palliative care, and in self-reported competence in providing palliative care. Increased perceived competence was associated with training, which supports the need for increased palliative care education and advocacy, especially in LMIC. © 2016 Wiley Periodicals, Inc.

PMID: 26784890

15. *Pediatr Blood Cancer*. 2016 Jan 19. [Epub ahead of print]

Continuous Lidocaine Infusions to Manage Opioid-Refractory Pain in a Series of Cancer Patients in a Pediatric Hospital.

Gibbons K¹, DeMonbrun A², Beckman EJ³, Keefer P⁴, Wagner D⁵, Stewart M¹, Saul D⁴, Hakel S¹, Liu M⁶, Niedner M⁷.

BACKGROUND: Research on the safety and efficacy of continuous lidocaine infusions (CLIs) for the treatment of pain in the pediatric setting is limited. This article describes a series of pediatric oncology patients who received lidocaine infusions for refractory, longstanding, cancer-related pain. **PROCEDURE:** This is a retrospective review of patients who underwent lidocaine infusions to manage severe, opioid-refractory, cancer-related pain. Four patients ranging in age from 8 to 18 years were admitted to a pediatric hospital for their medical conditions and/or pain management. Structured chart review established demographic and diagnosis information, infusion rates, side effects, and efficacy of infusions in providing pain relief. Lidocaine bolus doses, infusion rates, serum concentrations, and subjective pain scores were analyzed. **RESULTS:** Median pain scores prior to lidocaine infusions were 8/10, falling to 2/10 at the infusion termination ($P < 0.003$), and rising to 3/10 in the first 24 hr after lidocaine ($P < 0.029$ compared to preinfusion pain). The infusions were generally well tolerated, with few side effects noted. In most cases, the improvement in pain scores persisted beyond termination of the infusion. **CONCLUSIONS:** CLIs were a helpful adjuvant in the four cases presented and may be an effective therapy for a more diverse array of refractory cancer pain. The majority of patients experienced pain relief well beyond the metabolic elimination of the lidocaine, corroborating a modulation effect on pain windup. Additional research regarding infusion rates, serum concentrations, side effects, and outpatient follow-up in a larger group of patients will provide additional insight into the role and safety of this therapy in children. © 2016 Wiley Periodicals, Inc.

PMID: 26784686

16. *Int J Cancer*. 2016 Jan 15;138(2):332-9. Epub 2015 Sep 3.

Prospective, longitudinal assessment of quality of life in children from diagnosis to 3 months off treatment for standard risk acute lymphoblastic leukemia: Results of Children's Oncology Group study AALL0331.

Mitchell HR¹, Lu X², Myers RM³, Sung L⁴, Balsamo LM¹, Carroll WL⁵, Raetz E⁶, Loh ML⁷, Mattano LA Jr⁸, Winick NJ⁹, Devidas M², Hunger SP¹⁰, Maloney K¹¹, Kadan-Lottick NS¹.

ABSTRACT Standard risk acute lymphoblastic leukemia (SR-ALL) has high cure rates, but requires 2-3 years of therapy. We aimed to (i) prospectively evaluate health-related quality of life (HRQOL) during and after SR-ALL therapy, and (ii) identify associated predictors. Parents of 160 SR-ALL patients enrolled on Children's Oncology Group (COG) therapeutic trial AALL0331 at 31 sites completed the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales (physical, emotional and social functioning) and Family Assessment Device-General Functioning (FAD-GF) at 1, 6 and 12 months after diagnosis, and 3 months post-therapy. Mean PedsQL scores in physical, emotional and social functioning were impaired 1 month after diagnosis but steadily improved. Three months post-therapy, impaired physical and social functioning was observed in 27.8 and 25.8% of patients, respectively. In repeated-measures analysis, problematic family functioning predicted emotional (OR = 1.85, 95% CI 1.03-3.34) and social (OR = 1.99, 95% CI 1.21-3.27) impairment. Larger household size was associated with social impairment (OR = 1.21, 95% CI 1.02-1.45). Adverse neurological event(s) during therapy predicted post-therapy physical (OR = 5.17, 95% CI 1.61-16.63) and social (OR = 8.17, 95% CI 1.19-56.16) impairment. HRQOL 1 month after diagnosis was not predictive of HRQOL 3 months after therapy completion. In conclusion, children with SR-ALL experience considerable impairment in HRQOL at the end of induction, but rapidly improve. However, many still experience physical and social impairment 3 months post-therapy, suggesting a role for continued family and physical functioning support. Longer follow-up is needed to determine if post-therapy deficits change over time.

PMID: 26235006

17. *Ital J Pediatr*. 2016 Jan 15;42(1):4.

White coat hypertension in pediatrics.

Jurko A Jr¹, Minarik M², Jurko T³, Tonhajzerova I⁴.

ABSTRACT The article summarizes current information on blood pressure changes in children during clinic visit. White coat as a general dressing of physicians and health care personnel has been widely accepted at the end of the 19th century. Two problems can be associated with the use of white coat: white coat phenomenon and white coat hypertension. Children often attribute pain and other unpleasant experience to the white coat and refuse afterwards cooperation with examinations. Definition of white coat hypertension in the literature is not uniform. It has been defined as elevated blood pressure in the hospital or clinic with normal blood pressure at home measured during the day by ambulatory blood pressure monitoring system. White coat effect is defined as temporary increase in blood pressure before and during visit in the clinic, regardless what the average daily ambulatory blood pressure values are. Clinical importance of white coat hypertension is mainly because

of higher risk for cardiovascular accidents that are dependent on end organ damage (heart, vessels, kidney). Current data do not allow any clear recommendations for the treatment. Pharmacological therapy is usually started in the presence of hypertrophic left ventricle, changes in intimal/medial wall thickness of carotic arteries, microalbuminuria and other cardiovascular risk factors. Nonpharmacological therapy is less controversial and certainly more appropriate. Patients have to change their life style, need to eliminate as much cardiovascular risk factors as possible and sustain a regular blood pressure monitoring.

PMCID: PMC4717664 Free PMC Article

PMID: 26786497

18. Child Care Health Dev. 2016 Jan 14. [Epub ahead of print]

The relationship between parental attitudes and behaviours in the context of paediatric chronic pain.

Jaaniste T^{1,2}, Jia N^{1,2}, Lang T^{1,2}, Goodison-Farnsworth EM^{1,2}, McCormick M^{1,2}, Anderson D¹.

BACKGROUND: Within the context of paediatric chronic pain, parental attitudes are of particular importance given that they have the potential to impact on how parents respond to their child. The current study was designed to assess whether parental attitudes, such as parental confidence and beliefs in their child's ability to function in spite of pain, and parental catastrophising about their child's pain, are associated with parental pain-related behaviours known to be associated with poor child outcomes, such as protectiveness and high levels of monitoring. **METHODS:** Participants were 138 child-parent dyads recruited from a tertiary chronic pain clinic. Patients were aged 8- to 17-years. Prior to the initial clinic appointment, parents completed validated measures of parental pain catastrophising and parental responses to their child's pain. Patients completed measures of functional disability and pain intensity. **RESULTS:** Parents who reported lower confidence in their child's ability to cope with the pain engaged in significantly more protective, monitoring and distracting behaviours, even when controlling for the child's recent level of functioning. They also took more days off work due to their child's pain. Parents who catastrophised more about their child's pain engaged in significantly more protective and monitoring behaviours, even when controlling for the child's recent level of functioning. **CONCLUSIONS:** Parental behaviours in response to their child's pain are significantly related to parental confidence in their child's coping and parental pain-related catastrophising. Clinical interventions may benefit from addressing parental attitudes, especially their confidence in their child's ability to function.

PMID: 26767347

19. Genet Med. 2016 Jan 7. [Epub ahead of print]

The psychological impact of genetic information on children: a systematic review.

Wakefield CE^{1,2}, Hanlon LV¹, Tucker KM^{3,4}, Patenaude AF^{5,6}, Signorelli C^{1,2}, McLoone JK^{1,2}, Cohn RJ^{1,7}.

PURPOSE: This review assessed the psychological impact that acquiring personal and familial genetic information has on children. We also examined the concordance between the available empirical data and clinical guidance/perspectives articles. **METHODS:** We screened 591 ABSTRACTs and identified 13 studies, representing 966 children. Ten studies assessed 386 children tested for familial adenomatous polyposis (n = 171), hereditary cardiac disease (n = 134), and other conditions (n = 81). Three studies addressed the impact of BRCA1/2 testing of a family member on 580 children. **RESULTS:** Serious adverse psychological outcomes were uncommon. Most studies reported no significant increase in mean anxiety, depression, and distress scores (n = 8, 61.5%); however, some children experienced intrafamilial distress, discrimination, and guilt/regret. Some children were more concerned about their own health or their family members' health. There was limited consistency between anticipated adverse impact and empirical data. **CONCLUSIONS:** The review identified little conclusive evidence of deleterious psychological consequences for children acquiring genetic information. However, there is a lack of data regarding genetic testing for conditions that may not be treatable/modifiable, as well as a dearth of longitudinal studies. Therefore, clinical caution remains essential for the ethical integration of genetic testing into pediatrics. Further research assessing the potential positive and negative effects of genetic testing in childhood is warranted. Genet Med advance online publication 07 January 2016 Genetics in Medicine (2015); doi:10.1038/gim.2015.181.

PMID: 26741411

20. Pediatrics. 2016 Jan 5. [Epub ahead of print]

Tough Decisions for Premature Triplets.

Hurst A¹; Scott and Emily (parents), Vergales BD¹, Paget-Brown A¹, Mercurio M², Lantos JD³.

ABSTRACT When infants are born at the borderline of viability, doctors and parents have to make tough decisions about whether to institute intensive care or provide only palliative care. Often, these decisions are made in moments of profound emotional turmoil, and parents receive different information from different health professionals. Communication can become garbled. It may be difficult to tell when and whether the patient's clinical condition has changed enough so that certain choices that had once been permissible become impermissible. In this "Ethics Rounds," we present a case of triplets born at the borderline of viability. We sought comments from the triplets' parents, the doctors and ethicist who were caring for the infants, and a bioethicist/neonatologist from another hospital.

PMID: 26738882

21. Arch Dis Child. 2016 Jan;101(1):85-90. Epub 2015 Sep 14.

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

Downing J¹, Powell RA², Marston J³, Huwa C⁴, Chandra I⁵, 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.

Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://www.bmj.com/company/products-services/rights-and-licensing/>
PMID: 26369576

22. Arch Dis Child Fetal Neonatal Ed. 2016 Jan;101(1):37-42. Epub 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.

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.

Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://www.bmj.com/company/products-services/rights-and-licensing/>
PMID: 26271752

23. Biol Blood Marrow Transplant. 2016 Jan;22(1):104-111. Epub 2015 Sep 5.

Parent Outlook: How Parents View the Road Ahead as They Embark on Hematopoietic Stem Cell Transplantation for Their Child.

Ullrich CK¹, Rodday AM², Bingen K³, Kupst MJ³, Patel SK⁴, Syrjala KL⁵, Harris LL⁶, Recklitis CJ⁷, Schwartz L⁸, Davies S⁹, Guinan EC⁷, Chang C¹⁰, Wolfe J¹¹, Parsons SK¹².

ABSTRACT Pediatric hematopoietic stem cell transplantation (HSCT) offers cure for high-risk malignancies and other conditions, but carries a risk of complications. Parental outlook regarding their child's transplantation course and future health has been largely unexplored. This report presents the Parent Outlook Scale, describes its properties, and examines the outlook of parents embarking on their child's transplantation course and the associated variables. Parents of children scheduled to undergo HSCT (n = 363) at 8 US transplantation centers completed the Parent Outlook Scale, comprising 4 items assessing frequency of the parent's thoughts about the potential difficulty of the child's transplantation (Transplant Difficult subscale) and worsened health (Health Worse subscale). Item responses were rated on a 5-point Likert scale (ranging from "none" to "all of the time") and, along with scale/subscale scores, transformed to 100-point scales, with higher scores connoting greater thought frequency. Psychometrics were explored. Multivariable models identified personal and clinical characteristics associated with scale and subscale scores. The Parent Outlook Scale ($\alpha = 0.75$) and subscales were found to have sound psychometric properties. Factor loading supported the single scale with 2 subscales representing distinct aspects of overall outlook. Mean scores (Parent Outlook, 52.5 ± 21.7 ; Transplant Difficult, 64.4 ± 25.6 ; Health Worse, 40.7 ± 25.7) revealed variability within and across scale/subscales. Significantly different mean subscale scores ($P < .001$) indicated more frequent Transplant Difficult thoughts than Health Worse thoughts. Clinical factors (solid tumor diagnosis and unrelated donor transplant) and a parent factor (worse emotional functioning) were associated with higher scale and subscale scores. Our findings show that the outlook of parents embarking on their child's HSCT course is varied and not solely a product of clinical factors readily apparent to clinicians. Referring and transplantation clinicians should create opportunities to explore with parents their perspectives and concerns before and during the course of HSCT.

PMCID: PMC4706486 **Free PMC Article**

PMID: 26348891

24. Br J Community Nurs. 2016 Jan;21(1):55.

Children: a protected species in palliative care.

Nyatanga B¹. PMID: 26692138

25. Cancer Nurs. 2016 Jan-Feb;39(1):1-2.

The Global Champion for End-of-Life Care: Who Are You? What Is Keeping You?

Hinds PS¹, Lafond DA.

PMID: 26632667

26. Child Care Health Dev. 2016 Jan;42(1):51-9. Epub 2015 Nov 7.

Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model.

Ling J¹, Payne S², Connaire K³, McCarron M⁴.

BACKGROUND: Respite in children's palliative care aims to provide a break for family's from the routine of caring. Parental

decision-making regarding the utilisation of out-of-home respite is dependent on many interlinking factors including the child's age, diagnosis, geographical location and the family's capacity to meet their child's care needs. A proposed model for out-of-home respite has been developed based on the findings of qualitative case study research. **METHODS:** Utilising multiple, longitudinal, qualitative case study design, the respite needs and experiences of parents caring for a child with a life-limiting condition were explored. Multiple, in-depth interviews were undertaken with the parents identified by a hospital-based children's palliative care team. Data were analysed using thematic analysis. Each individual case consists of a whole study. Cross-case comparison was also conducted. **RESULTS:** Nine families were recruited and followed for two years. A total of 19 in-depth interviews were conducted with mothers and fathers (one or both) caring for a child with a life-limiting condition in Ireland. Each family reported vastly different needs and experiences of respite from their own unique perspective. Cross-case comparison showed that for all parents utilising respite care, regardless of their child's age and condition, home was the location of choice. Many interlinking factors influencing these decisions included: past experience of in-patient care, and trust and confidence in care providers. Issues were raised regarding the impact of care provision in the home on family life, siblings and the concept of home. **CONCLUSION:** Respite is an essential element of children's palliative care. Utilisation of out-of-home respite is heavily dependent on a number of interlinked and intertwined factors. The proposed model of care offers an opportunity to identify how these decisions are made and may ultimately assist in identifying the elements of responsive and family-focused respite that are important to families of children with life-limiting conditions.

PMID: 26547275

27. J Med Ethics. 2016 Jan;42(1):57-8. Epub 2015 Oct 16.

Against euthanasia for children: a response to Bovens.

Kaczor C.

ABSTRACT: If we accept euthanasia for adults, should we also accept voluntary euthanasia for children? In 'Child Euthanasia: Should We Just Not Talk about It?', Luc Bovens answers this question affirmatively. Bovens examines five arguments against extending euthanasia to minors, the arguments being weightiness, capability of discernment, pressure, sensitivity and sufficient palliative care. He rejects each of these arguments. In this paper, I provide a rejoinder for each of his responses. I also critique his view that opponents of euthanasia have extra responsibility to promote palliative care. On the contrary, if euthanasia is legalised, advocates of euthanasia have a special obligation to promote improvements in palliative care.

Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://www.bmj.com/company/products-services/rights-and-licensing/>

PMID: 26474602

28. J Paediatr Child Health. 2016 Jan;52(1):7-10

Use of guidelines when planning home care of a girl with severe congenital myopathy.

Gray K¹, Isaacs D^{2,3}, Kilham H^{2,3}, Tobin B⁴, Waters K^{5,3}.

ABSTRACT: We use issues that arose in the management of a 4-year old girl with a congenital myopathy to consider the tension between respecting the choices and decisions of the child's parents and applying clinical practice guidelines that emphasise minimising risk to the child. This case raises the issue of when it is reasonable to override parents' choice of management options.

PMID: 26776543

29. J Pain Symptom Manage. 2016 Jan;51(1):e1-2. Epub 2015 Oct 23.

Unexpected Death on an Acute Palliative Care Unit.

Mercadante S¹, Ferrera P², Casuccio A³.

PMID: 26476392

30. J Pain Symptom Manage. 2016 Jan;51(1):60-70. Epub 2015 Sep 18.

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

Morris AT¹, Gabert-Ouillen 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 present study explored the relationship between parents' and surviving sibling's mental health symptoms (i.e., post-traumatic stress disorder [PTSD], prolonged grief disorder (PGD), and depression symptoms) after 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) who enrolled in a PPC program from 2008 to 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 after the death of a child, demonstrate differential impact of maternal vs. paternal symptoms on siblings, and stress the importance of addressing postloss symptoms from a family systems perspective.

PMID: 26387829

31. J Palliat Med. 2016 Jan;19(1):7.

Response to Letter "End-of-Life Preferences in Advanced Cancer Patients".

Schubart JR^{1,2}, Green MJ³, Levi BH⁴.

PMID: 26629733

32. J Palliat Med. 2016 Jan;19(1):30-41. Epub 2015 Nov 30.

Perceptions of the Pediatric Hospice Experience among English- and Spanish-Speaking Families.

Thienprayoon R^{1,2}, Marks E³, Funes M³, Martinez-Puente LM³, Winick N^{4,5}, Lee SC^{3,6}.

OBJECTIVE: Many children who die are eligible for hospice enrollment but little is known about parental perceptions of the hospice experience, the benefits, and disappointments. The objective of this study was to explore parental perspectives of the hospice experience in children with cancer, and to explore how race/ethnicity impacts this experience. **STUDY DESIGN:** We held 20 semistructured interviews with 34 caregivers of children who died of cancer and used hospice. Interviews were conducted in the caregivers' primary language: 12 in English and 8 in Spanish. Interviews were recorded, transcribed, and analyzed using accepted qualitative methods. **RESULTS:** Both English and Spanish speakers described the importance of honest, direct communication by medical providers, and anxieties surrounding the expectation of the moment of death. Five English-speaking families returned to the hospital because of unsatisfactory symptom management and the need for additional supportive services. Alternatively, Spanish speakers commonly stressed the importance of being at home and did not focus on symptom management. Both groups invoked themes of caregiver appraisal, but English-speaking caregivers more commonly discussed themes of financial hardship and fear of insurance loss, while Spanish-speakers focused on difficulties of bedside caregiving and geographic separation from family. **CONCLUSIONS:** The intense grief associated with the loss of a child creates shared experiences, but Spanish- and English-speaking parents describe their hospice experiences in different ways. Additional studies in pediatric hospice care are warranted to improve the care we provide to children at the end of life.

PMCID: PMC4692131 [Available on 2017-01-01]

PMID: 26618809

33. J Pediatr Hematol Oncol. 2016 Jan;38(1):53-7.

Colostomy for Perianal Sepsis With Ecthyma Gangrenosum in Immunocompromised Children.

Vuille-Dit-Bille RN¹, Berger C, Meuli M, Grotzer MA.

BACKGROUND: Perianal sepsis with ecthyma gangrenosum is a severe and potentially mutilating complication in immunocompromised children. Therapies include antimicrobial treatment, incision and drainage, generous tissue debridement, and skin transplantation. **PROCEDURE:** We describe 3 children with acute lymphoblastic leukemia having sepsis with *Pseudomonas aeruginosa* in febrile neutropenia and severe perianal infections treated relatively early with a protective colostomy. Indications for colostomy were nonhealing wounds, and ceaseless pain. **RESULTS:** All patients showed a rapid reduction of pain. Complete wound healing was seen in 2 patients, and considerable pain reduction and increased quality of life were seen in a third patient during palliative care.

CONCLUSIONS: These results suggest that a protective colostomy should be considered early in the management of immunocompromised children with ecthyma gangrenosum.

PMID: 25757025

34. Klin Padiatr. 2016 Jan;228(1):35-41. Epub 2016 Jan 14.

What are Palliative Care Physicians for Adults Taught on Palliative Care for Children? Paediatric Aspects in Palliative Care Curricula for Adults.

Schiessl C¹, Gottschling S², Gronwald BM³.

BACKGROUND: Children suffering from life limiting diseases are frequently cared for by adult palliative care teams due to missing paediatric structures in that field. However it is questionable whether palliative care curricula for physicians comprehensively cover issues of paediatric palliative care (PaedPC). **AIM:** To identify all PaedPC issues included in inter-professional or medical palliative care curricula (PCC) and to evaluate the breadth and quality of PaedPC issues covered in these curricula. **DESIGN:** Inter-professional or medical palliative care curricula (PCC) were identified by an extensive literature review in German and English using the search-engines Google as well as Medline, MedPilot and Pubmed. **RESULTS:** Worldwide 30 PCC were identified, with only 15 curricula mentioning any PaedPC issues. Of those 15 curricula, up to 22 PaedPC topics were highlighted in each. In 10 or more PaedPC following topics were highlighted: grief and bereavement in family, parents and siblings; communication with children; paediatric malignancies; pain management in PPC and pharmacology. In the majority of PCC curricula where PaedPC issues were identified the following topics were mentioned: grief and bereavement in the family, parents and siblings, communication with children, paediatric malignancies, paediatric pain management and pharmacology. **CONCLUSIONS:** The variability of inclusion of PaedPC issues and the lack of depth and standardisation of knowledge, skills and attitudes in PaedPC issues included in PCC curricula is not sufficient to guide adult palliative care physicians in their clinical work with children suffering from life limiting diseases.

PMID: 26766670

35. Med Clin North Am. 2016 Jan;100(1):183-97.

Managing Chronic Pain in Special Populations with Emphasis on Pediatric, Geriatric, and Drug Abuser Populations.

Baumbauer KM¹, Young EE², Starkweather AR³, Guite JW⁴, Russell BS⁵, Manworren RC⁶.

ABSTRACT: In the adult population chronic pain can lead to loss of productivity and earning potential, and decreased quality of life. There are distinct groups with increased vulnerability for the emergence of chronic pain. These groups may be defined by developmental status and/or life circumstances. Within the pediatric, geriatric, and drug abuser populations, chronic pain represents a significant health issue. This article focuses on known anatomic, physiologic, and genetic mechanisms underlying chronic pain in these populations, and highlights the need for a multimodal approach from multiple health

care professionals for management of chronic pain in those with the most risk.

PMID: 26614727

36. *Pediatr Blood Cancer*. 2016 Jan;63(1):105-11. Epub 2015 Sep 23.

Trajectory of Material Hardship and Income Poverty in Families of Children Undergoing Chemotherapy: A Prospective Cohort Study.

Bona K^{1,2,3,4}, London WB^{1,2,3}, Guo D^{1,2}, Frank DA^{5,6}, Wolfe J^{1,2,3,4,7}.

BACKGROUND: Poverty is correlated with negative health outcomes in pediatric primary care, and is emerging as a negative prognostic indicator in pediatric oncology. However, measures of poverty amenable to targeted intervention, such as household material hardship (HMH)-including food, energy, and housing insecurity-have not been described in pediatric oncology. We describe the trajectory of family reported HMH and income poverty at a pediatric oncology referral center in New England with high psychosocial supports. **PROCEDURE:** Single site, prospective cohort study including 99 English-speaking families of children receiving chemotherapy for primary cancer. Families completed face-to-face surveys at two time-points: (1) Within 30 days of child's diagnosis (T1) (N = 99, response rate 88%); (2) 6-months following diagnosis (T2) (N = 93, response rate 94%). HMH was assessed in three domains: food, energy, and housing insecurity. **RESULTS:** Twenty percent of families reported low-income ($\leq 200\%$ Federal Poverty Level) and at least one HMH prior to their child's diagnosis. At T2, 25% of families lost $>40\%$ annual household income secondary to treatment-related work disruptions, and 29% of families reported HMH despite utilization of psychosocial supports. **CONCLUSIONS:** Low-income and HMH are prevalent in a significant proportion of newly diagnosed pediatric oncology families at a large referral center. Despite psychosocial supports, the proportion of families experiencing unmet basic needs increases during chemotherapy to nearly one in three families. HMH provides a quantifiable and remediable measure of poverty in pediatric oncology. Interventions to ameliorate this concrete component of poverty could benefit a significant proportion of pediatric oncology families. *Pediatr Blood Cancer* © 2015 Wiley Periodicals, Inc.

PMID: 26398865

37. *Pediatrics*. 2016 Jan;137(1):1-6. Epub 2015 Dec 7.

Please Do Whatever It Takes to End Our Daughter's Suffering!

Clément de Cléty S¹, Friedel M², Verhagen AA³, Lantos JD⁴, Carter BS⁵.

Author information:

ABSTRACT: What is the best way to care for a child with severe neurologic impairment who seems to be dying and is in intractable pain? Can we give sedation as we remove life support? Is it ethically permissible to hasten death? In the United States, 5 states have legalized assisted suicide (although only for competent adults). In Belgium and the Netherlands, euthanasia is legal for children under some circumstances. We present a case in which parents and doctors face difficult decisions about palliative care. Experts from Belgium, the Netherlands, and the United States then discuss how they would respond to such a case.

PMID: 26644491

38. *J Pain Symptom Manage*. 2015 Dec 30. [Epub ahead of print]

Clusters of Multiple Complex Chronic Conditions: A Latent Class Analysis of Children at End of Life.

Lindley LC¹, Mack JW², Bruce DJ³.

CONTEXT: Children at end of life often experience multiple complex chronic conditions with more than 50% of children reportedly having two or more conditions. These complex chronic conditions are unlikely to occur in an entirely uniform manner in children at end of life. Previous work has not fully accounted for patterns of multiple conditions when evaluating care among these children. **OBJECTIVES:** The objective of the study was to understand the clusters of complex chronic conditions present among children in the last year of life. **METHODS:** Participants were 1423 pediatric decedents from the 2007 to 2008 California Medicaid data. A latent class analysis was used to identify clusters of children with multiple complex chronic conditions (neurological, cardiovascular, respiratory, renal, gastrointestinal, hematologic, metabolic, congenital, cancer). Multinomial logistic regression analysis was used to examine the relationship between demographic characteristics and class membership. **RESULTS:** Four latent classes were yielded: medically fragile (31%); neurological (32%); cancer (25%); and cardiovascular (12%). Three classes were characterized by a 100% likelihood of having a complex chronic condition coupled with a low or moderate likelihood of having the other eight conditions. The four classes exhibited unique demographic profiles. **CONCLUSION:** This analysis presented a novel way of understanding patterns of multiple complex chronic conditions among children that may inform tailored and targeted end-of-life care for different clusters.

PMID: 26747723

39. *J Palliat Med*. 2015 Dec 30. [Epub ahead of print]

Feasibility of a Comfort Care Protocol Using Oral Transmucosal Medication Delivery in a Palliative Neonatal Population.

Drolet C¹, Roy H¹, Laflamme J¹, Marcotte ME¹.

BACKGROUND: The oral transmucosal (OTM) route for administration of comfort medication in infants at the end-of-life has long been favored by our pediatric palliative care team but has rarely been described in the literature. **OBJECTIVE:** To determine the feasibility of implementing a standardized comfort care protocol using OTM medications in dying neonates. **METHOD:** A comfort protocol prescribing medication by the OTM route and standardized assessment were established. Each infant included in the study was assessed with the Neonatal Pain, Agitation, and Sedation Scale (N-PASS). Caretakers' satisfaction was assessed using a questionnaire. The feasibility of implementing the protocol was determined by the proportion of assessments done when required, the rate of termination of the protocol, and the feedback from nurses using the protocol. **RESULTS:** Twelve patients were enrolled. Regular evaluations were performed 85% of the time. When the medication was given as needed, 71% of cases were evaluated before versus 63% when regular doses were given. The as-needed

doses were followed by an assessment 30 minutes later in 49% of cases and in 41%, 60 minutes later, for a total of 64% in the hour after medication administration. The protocol was discontinued only for two patients who were discharged to continue end-of-life care at home. There were no significant adverse events reported. Finally, 17 of 18 nurses said they would recommend this protocol to other institutions. **CONCLUSION:** In the context of neonatal palliative care, the implementation of a standardized protocol for administration of drugs by the OTM route is feasible and safe. However, in the context of this study, adherence was limited because of too-frequent evaluations and misunderstanding of the protocol.

PMID: 26717305

40. J Pediatr. 2015 Dec 22. [Epub ahead of print]

Health-Related Quality of Life and Functional Status Are Associated with Cardiac Status and Clinical Outcome in Children with Cardiomyopathy.

Sleeper LA, Towbin JA, Colan SD, Hsu D, Orav EJ, Lemler MS, Clunie S, Messere J, Fountain D, Miller TL, Wilkinson JD, Lipshultz SE; **OBJECTIVES:** To measure the health-related quality of life (HRQOL) and functional status of children with cardiomyopathy and to determine whether they are correlated with sociodemographics, cardiac status, and clinical outcomes. **STUDY DESIGN:** Parents of children in the Pediatric Cardiomyopathy Registry completed the Child Health Questionnaire (CHQ; age ≥ 5 years) and Functional Status II (Revised) (age ≤ 18 years) instruments. Linear and Cox regressions were used to examine hypothesized associations with HRQOL. **RESULTS:** The 355 children evaluated at ≥ 5 years (median 8.6 years) had lower functioning (CHQ Physical and Psychosocial Summary Scores 41.7 ± 14.4 and 47.8 ± 10.7) than that of healthy historical controls. The most extreme CHQ domain score, Parental Impact-Emotional, was one SD below normal. Younger age at diagnosis and smaller left ventricular end-diastolic dimension z score were associated independently with better physical functioning in children with dilated cardiomyopathy. Greater income/education correlated with better psychosocial functioning in children with hypertrophic and mixed/other types of cardiomyopathy. In the age ≥ 5 year cohort, lower scores on both instruments predicted earlier death/transplant and listing for transplant in children with dilated and mixed/other types of cardiomyopathy ($P < .001$). Across all ages ($n = 565$), the Functional Status II (Revised) total score was 87.1 ± 16.4 , and a lower score was associated with earlier death/transplant for all cardiomyopathies. **CONCLUSIONS:** HRQOL and functional status in children with cardiomyopathy is on average impaired relative to healthy children. These impairments are associated with older age at diagnosis, lower socioeconomic status, left ventricular size, and increased risk for death and transplant. Identification of families at risk for functional impairment allows for provision of specialized services early in the course of disease. **TRIAL REGISTRATION:** ClinicalTrials.gov: NCT00005391.

PMID: 26725459

41. BMJ Support Palliat Care. 2015 Dec 18. [Epub ahead of print]

End-of-life experiences of mothers with advanced cancer: perspectives of widowed fathers.

Park EM¹, Deal AM², Yopp JM¹, Edwards TP³, Wilson DJ², Hanson LC⁴, Rosenstein DL⁵.

OBJECTIVE: Despite the importance of parenting-related responsibilities for adult patients with terminal illnesses who have dependent children, little is known about the psychological concerns of dying parents and their families at the end of life (EOL). The aim of this study was to elicit widowed fathers' perspectives on how parental status may have influenced the EOL experiences of mothers with advanced cancer. **SUBJECTS:** 344 men identified themselves through an open-access educational website as widowed fathers who had lost a spouse to cancer and were raising dependent children. **METHODS:** Participants completed a web-based survey about their wife's EOL experience and cancer history, and their own depression (Center for Epidemiologic Studies Depression Scale, CES-D) and bereavement (Texas Revised Inventory of Grief, TRIG) symptoms. Descriptive statistics, Fisher's exact tests, and linear regression modelling were used to evaluate relationships between variables. **RESULTS:** According to fathers, 38% of mothers had not said goodbye to their children before death and 26% were not at all 'at peace with dying.' Ninety per cent of widowed fathers reported that their spouse was worried about the strain on their children at the EOL. Fathers who reported clearer prognostic communication between wife and physician had lower CES-D and TRIG scores. **CONCLUSIONS:** To improve EOL care for seriously ill patients and their families, we must understand the concerns of parents with dependent children. These data underscore the importance of parenting-related worries in this population and the need for additional clinical and research programmes devoted to addressing these issues. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://www.bmj.com/company/products-services-rights-and-licensing/>

PMID: 26685117

42. Pediatr Blood Cancer. 2015 Dec 18. [Epub ahead of print]

Adolescent and Young Adult Patient Engagement and Participation in Survey-Based Research: A Report From the "Resilience in Adolescents and Young Adults With Cancer" Study.

Rosenberg AR^{1,2,3,4}, Bona K^{5,6,7}, Wharton CM^{1,2}, Bradford M², Shaffer ML^{2,4}, Wolfe J^{5,7,8}, Baker KS^{1,2,4,9}.

ABSTRACT: Conducting patient-reported outcomes research with adolescents and young adults (AYAs) is difficult due to low participation rates and high attrition. Forty-seven AYAs with newly diagnosed cancer at two large hospitals were prospectively surveyed at the time of diagnosis and 3-6 and 12-18 months later. A subset participated in 1:1 semistructured interviews. Attrition prompted early study closure at one site. The majority of patients preferred paper-pencil to online surveys. Interview participants were more likely to complete surveys (e.g., 93% vs. 58% completion of 3-6 month surveys, $P = 0.02$). Engaging patients through qualitative methodologies and using patient-preferred instruments may optimize future research success.

PMID: 26681427

43. Palliat Med. 2015 Dec 18. [Epub ahead of print]

Crocker, et al.: Reducing barriers to parent participation in pediatric palliative care research.

Siden HH¹, Steele R², Cadell S³.

PMID: 26684794

44. Cancer. 2015 Dec 15;121(24):4416-24. Epub 2015 Sep 8.

Adolescents' preferences for treatment decisional involvement during their cancer.Weaver MS^{1,2}, Baker JN³, Cattuso JS⁴, Gibson DV³, Sykes AD⁵, Hinds PS^{6,7}.

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

45. J Palliat Med. 2015 Dec 15. [Epub ahead of print]

The Effect of Palliative Care Team Design on Referrals to Pediatric Palliative Care.Keele L¹, Keenan HT², Bratton SL².

BACKGROUND: The American Academy of Pediatrics (AAP) and the American Academy of Hospice and Palliative Medicine (AAHPM) have recommended minimal standards for palliative care (PC) team composition and availability. It is unknown whether team composition affects utilization of PC. **OBJECTIVE:** The study objective was to describe pediatric PC team composition, evaluate whether composition and availability are associated with utilization, and examine PC referral patterns. **METHODS:** The study was a descriptive survey. Subjects were pediatric PC team directors or hospital administrators at Pediatric Health Information System (PHIS) hospitals ($N = 44$). **RESULTS:** The overall response rate was 86%. Teams varied in size from <1 to 9 full-time members. Average referrals per hospital bed were 0.46, range 0.05-2.13. Among individual PC team roles, referral rates were 34% greater in teams with an advanced nurse practitioner (ANP) ($p = 0.07$). Likewise, teams with acute pain, chronic pain, or hospice palliative medicine specialists tended to have greater referral rates (39%, 36%, and 25%), though reported differences were not statistically significant. Teams adherent to the original AAP recommendations had a 31% greater referral rate ($p = 0.22$). Teams available 24 hours daily had similar referral rates to those with less availability (0.47 versus 0.46 [$p = 0.94$]). **CONCLUSIONS:** Team composition and availability are not crucial to PC utilization. Hospitals with some personnel but not all recommended team members should create formal teams and modify them over time. The addition of team members that tend to increase referrals, namely ANPs and acute pain, chronic pain, or hospice palliative medicine specialists, should be considered.

PMID: 26670933

46. J Palliat Med. 2015 Dec 14. [Epub ahead of print]

Provision of Services in Perinatal Palliative Care: A Multicenter Survey in the United States.Wool C¹, Côté-Arsenault D², Black BP³, Denney-Koelsch E⁴, Kim S⁵, Kavanaugh K⁶.

BACKGROUND: Congenital anomalies account for 20% of neonatal and infant deaths in the United States. Perinatal palliative care is a recent addition to palliative care and is meant to meet the needs of families who choose to continue a pregnancy affected by a life-limiting diagnosis. **OBJECTIVE:** To examine characteristics of programs and services provided, assess alignment with the National Consensus Project domains of care, and identify providers and disciplines involved in programs. **DESIGN:** A cross-sectional survey design included 48 items addressing funding and domains of quality care. **SUBJECTS:** Program representatives from 30 states ($n = 75$). **PRINCIPAL RESULTS:** Perinatal palliative care programs are housed in academic medical centers, regional or community hospitals, local hospices, or community-based organizations. Significant differences by program setting were observed for type of fetal diagnoses seen, formal training in communicating bad news to parents, mechanisms to ensure continuity of care, and reimbursement mechanisms. One hundred percent of programs provided attention to spiritual needs and bereavement services; 70% of programs are less than 10 years old. Follow-up with parents to assess whether goals were met occurs at 43% of the perinatal palliative care programs. Formal measures of quality assessment were articulated in 38% of programs. **CONCLUSION:** This study dramatically adds to the literature available on perinatal palliative care program settings, types, and domains of care. It is clear that there are a variety of types of programs and that the field is still developing. More work is needed to determine which quality measures are needed to address perinatal care needs in this population.

PMID: 26652200

47. J Pediatr Oncol Nurs. 2015 Dec 14. [Epub ahead of print]

Bereaved Siblings' Advice to Health Care Professionals Working With Children With Cancer and Their Families.Lövgren M¹, Bylund-Grenklo T², Jalmzell L³, Wallin AE⁴, Kreicbergs U⁵.**INTRODUCTION:** Siblings of children with cancer experience psychosocial distress during the illness and after bereave-

ment, but often stand outside the spotlight of attention and care. This study explored bereaved siblings' advice to health care professionals (HCPs) working with children with cancer and their families. **MATERIALS AND METHODS:** In a nationwide Swedish survey of bereaved siblings, 174/240 (73%) participated. Of these, 108 answered an open-ended question about what advice they would give to HCPs working with children with cancer and their families. In this study, responses to this single question were analyzed using content analysis. **RESULTS:**

The most common advice, suggested by 56% of siblings, related to their own support. One third suggested giving better medical information to siblings. Some siblings wanted to be more practically involved in their brother's/sister's care and suggested that HCPs should give parents guidance on how to involve siblings. Other common advice related to psychosocial aspects, such as the siblings' wish for HCPs to mediate hope, yet also realism, and the importance of asking the ill child about what care they wanted. **CONCLUSION:** Information, communication, and involvement should be emphasized by HCPs to support siblings' psychosocial needs in both the health care setting and within the family.

PMID: 26669875

48. Intensive Crit Care Nurs. 2015 Dec 10. [Epub ahead of print]

'Something normal in a very, very abnormal environment' - Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia.

Bloomer MJ¹, Endacott R², Copnell B³, O'Connor M⁴.

ABSTRACT: The majority of deaths of children and infants occur in paediatric and neonatal intensive care settings. For nurses, managing an infant/child's deterioration and death can be very challenging. Nurses play a vital role in how the death occurs, how families are supported leading up to and after the infant/child's death. This paper describes the nurses' endeavours to create normality amidst the sadness and grief of the death of a child in paediatric and neonatal ICU. Focus groups and individual interviews with registered nurses from NICU and PICU settings gathered data on how neonatal and paediatric intensive care nurses care for families when a child dies and how they perceived their ability and preparedness to provide family care. Four themes emerged from thematic analysis: (1) respecting the child as a person; (2) creating opportunities for family involvement/connection; (3) collecting mementos; and (4) planning for death. Many of the activities described in this study empowered parents to participate in the care of their child as death approached. Further work is required to ensure these principles are translated into practice.

PMID: 26687773

49. J Perinatol. 2015 Dec 10.. [Epub ahead of print]

Palliative care in neonatal neurology: robust support for infants, families and clinicians.

Lemmon ME^{1,2}, Bidegain M³, Boss RD^{4,5}.

ABSTRACT: Infants with neurological injury and their families face unique challenges in the neonatal intensive care unit. As specialty palliative care support becomes increasingly available, we must consider how to intentionally incorporate palliative care principles into the care of infants with neurological injury. Here, we review data regarding neonatal symptom management, prognostic uncertainty, decision making, communication and parental support for neonatal neurology patients and their families. Journal of Perinatology advance online publication, 10 December 2015;

PMID: 26658120

50. JBI Database System Rev Implement Rep. 2015 Dec 10;13(11):33-42.

Healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions: a qualitative systematic review protocol.

Ekberg S^{1,2}, Bradford N^{3,2}, Herbert A⁴, Danby S⁵, Yates P.

PMID: 26657462

51. JAMA Pediatr. 2015 Dec 7;169(12):e153759.

Infant Growth and Risk of Childhood-Onset Type 1 Diabetes in Children From 2 Scandinavian Birth Cohorts.

Magnus MC¹, Olsen SF², Granström C², Joner G³, Skrivarhaug T⁴, Svensson J⁵, Johannesen J⁵, Njølstad P⁶, Magnus P⁷, Stordal K⁸, Stene LC¹.

IMPORTANCE: Type 1 diabetes mellitus is one of the most common chronic diseases with onset in childhood, but environmental risk factors have not been convincingly established. **OBJECTIVE:** To test whether increased growth during the first year of life is associated with higher risk of childhood-onset type 1 diabetes. **DESIGN, SETTING, AND PARTICIPANTS:** This is a cohort study using information from 2 population-based cohort studies in Norway and Denmark, the Norwegian Mother and Child Cohort Study (MoBa) and the Danish National Birth Cohort (DNBC), of children born between February 1998 and July 2009. The current study was conducted between November 2014 and June 2015. **EXPOSURES:** Change in weight and length from birth to age 12 months. **MAIN OUTCOMES AND MEASURES:** Unadjusted and adjusted hazard ratios (HRs) of type 1 diabetes, classified based on nationwide childhood diabetes registers, obtained using Cox proportional hazards regression. **RESULTS:** A total of 99 832 children were included in the study, with 59 221 in MoBa (51.2% boys and 48.8% girls; mean age at end of follow-up, 8.6 years [range, 4.6-14.2 years]) and 40 611 in DNBC (50.6% boys and 49.4% girls; mean age at end of follow-up, 13.0 years [range, 10.4-15.7 years]). The incidence rate of type 1 diabetes from age 12 months to the end of follow-up was 25 cases per 100 000 person-years in DNBC and 31 cases per 100 000 person-years in MoBa. The change in weight from birth to 12 months was positively associated with type 1 diabetes (pooled unadjusted HR = 1.24 per 1-SD increase; 95% CI, 1.11-1.39; pooled adjusted HR = 1.24 per 1-SD increase; 95% CI, 1.09-1.41). There was no significant association between length increase from birth to 12 months and type 1 diabetes (pooled unadjusted HR = 1.06 per 1-SD increase; 95% CI, 0.93-1.22; pooled adjusted HR = 1.06 per 1-SD increase; 95% CI, 0.86-1.32). The associations were similar in both sexes. **CONCLUSIONS AND RELEVANCE:** This is the first prospective population-based study, to our knowledge, providing evidence that weight increase during the first year of life is positively associated with type 1 diabetes. This supports the early environmental origins of type 1 diabetes.

PMID: 26642117

52. Hematology Am Soc Hematol Educ Program. 2015 Dec 5;2015(1):490-5.

Palliative care in pediatric patients with hematologic malignancies.

Humphrey L¹, Kang T².

ABSTRACT: Children with advanced cancer, including those with hematologic malignancies, can benefit from interdisciplinary palliative care services. Palliative care includes management of distressing symptoms, attention to psychosocial and spiritual needs, and assistance with navigating complex medical decisions with the ultimate goal of maximizing the quality-of-life of the child and family. Palliative care is distinct from hospice care and can assist with the care of patients throughout the cancer continuum, irrespective of prognosis. While key healthcare organizations, including the Institute of Medicine, the American Academy of Pediatrics and the American Society of Clinical Oncology among many others endorse palliative care for children with advanced illness, barriers to integration of palliative care into cancer care still exist. Providing assistance with advance care planning, guiding patients and families through prognostic uncertainty, and managing transitions of care are also included in goals of palliative care involvement. For patients with advanced malignancy, legislation, included in the Patient Protection and Affordable Health Care Act allows patients and families more options as they make the difficult transition from disease directed therapy to care focused on comfort and quality-of-life.

PMID: 26637763

53. Hematology Am Soc Hematol Educ Program. 2015 Dec 5;2015(1):479-83.

Early integration of palliative care into the care of patients with cancer.

Thienprayoon R¹, LeBlanc T².

PMID: 26637761

54. Rev Chil Pediatr. 2015 Dec 4. [Epub ahead of print]

[Use of opioids in palliative care of children with advanced cancer].

[Article in Spanish]

Fernández Urtubia B¹, Trevigno Bravo A¹, Rodríguez Zamora N², Palma Torres C³, Cid Barria L¹.

INTRODUCTION: Despite advances in the treatment of cancer in paediatric patients, 15% of children die from the illness progression in Chile, and pain is the most significant symptom in advanced stages. Although the World Health Organization guidelines demonstrate that opioids are fundamental in pain management, there is still resistance to their use. The main objective of this article was to describe the experience in the use of opioids for pain management in paediatric patients with advanced cancer in palliative care (PC). **PATIENTS AND METHOD:** Retrospective study of patients admitted into the PC Program at the Hospital Roberto del Río between 2002 and 2013. Analysis was carried out on demographic data; oncological diagnosis; pain intensity on admission and discharge, according to validated scales; use of non-steroidal anti-inflammatory drugs; weak opioids; strong opioids; adjuvants drugs; the presence of secondary effects resulting from the use of morphine, and the need for palliative sedation. **RESULTS:** Of the 99 medical records analysed, the median age was 8 years, 64.6% were male, and there was a similar distribution in three oncological diagnosis groups. Upon admission, 43.4% presented intense to severe pain, and upon discharge there were four patients, but with a maximum VAS score of 7 in only one case. Of the 66 patients taking strong opioids, 89% required less than 0.5mg/kg/hr. Constipation was the most frequently observed secondary effect. **CONCLUSIONS:** Two thirds of the patients studied required strong opioids, with which adequate pain management was achieved, with no serious complications observed. The use of opioids in this group of patients, following a protocol, is considered effective and safe.

Free Article

PMID: 26655881

55. BMC Palliat Care. 2015 Dec 2;14(1):70.

Counseling for personal care options at neonatal end of life: a quantitative and qualitative parent survey.

Shelkowitz E^{1,2}, Vessella SL³, O'Reilly P⁴, Tucker R⁵, Lechner BE^{6,7}.

BACKGROUND: The death of a newborn is a traumatic life changing event in the lives of parents. We hypothesized that bereaved parents of newborn infants want to have choices in the personal care of their infant at the end of life. **METHODS:** Parents who had suffered a perinatal or neonatal loss between 1 and 6 years before the survey in a regional level IV neonatal intensive care unit (NICU) and associated labor and delivery room were invited to participate. Parents chose between an online survey, paper survey or telephone interview. The survey included multiple choice and open ended questions. **RESULTS:** Parents prefer multiple options for the personal care of their infant at the end of life. Emergent themes were need for guidance by the medical team, memory making, feeling cared for and respected by staff, and regrets related to missed opportunities. **CONCLUSION:** While parents differ in their preferences in utilizing specific personal care options for their infant's end of life, they share a common preference for being presented with multiple options to choose from and in being guided and supported by healthcare providers, while being afforded the opportunity to make memories with their infant by bonding with and parenting them.

PMCID: PMC4667527 **Free PMC Article**

PMID: 26626572

56. Am J Hosp Palliat Care. 2015 Dec;32(8):869-75. Epub 2014 Sep 16.

Palliative care in neonatal intensive care, effects on parent stress and satisfaction: a feasibility study.

Petteys AR¹, Goebel JR², Wallace JD³, Singh-Carlson S².

CONTEXT: Approximately 1 in 10 infants require neonatal intensive care unit (NICU) hospitalization, which causes parental stress. Palliative care (PC) provides an opportunity to alleviate suffering and stress. **OBJECTIVES:** This study examines the effects of PC on NICU parent stress and satisfaction. **METHODS:** A prospective cohort design compares stress and satisfac-

tion among families receiving or not receiving PC. **RESULTS:** No significant differences in stress scores were found ($P = .27-1.00$). Palliative care parents (100%) were more likely to report being "extremely satisfied" with care than usual-care parents (50%). **CONCLUSION:** This study supports the feasibility of evaluating NICU PC services. Infants referred for PC typically have higher morbidity/mortality; therefore, higher parental stress scores may be expected. Stress levels were similar in both cohorts, thus PC did not increase stress and may decrease PC parent stress.

PMID: 25228642

57. Am J Hosp Palliat Care. 2015 Dec;32(8):841-8. Epub 2014 Jul 15.

Ketamine PCA for treatment of end-of-life neuropathic pain in pediatrics.

Taylor M¹, Jakacki R², May C³, Howrie D⁴, Maurer S⁵.

ABSTRACT: Control of neuropathic pain (NP) for children at end of life is challenging. Ketamine improves control of NP, but its use in children is not well described. We describe a retrospective case review of 14 children with terminal prognoses treated with ketamine patient-controlled analgesia (PCA) for management of opioid-refractory NP at the end of life. Median ketamine dose was 0.06 mg/kg/h (range 0.014-0.308 mg/kg/h) with a 0.05 mg/kg (range 0.03-0.5mg/kg) demand dose available every 15 minutes (range 10-60 minutes). All patients noted subjective pain relief with ketamine, and 79% had no adverse effects. Benzodiazepines limited neuropsychiatric side effects. Ketamine treatment arrested dose escalation of opioids in 64% of patients, and 79% were discharged to home hospice. Ketamine PCA is an effective, well-tolerated therapy for opioid-refractory NP in pediatric end-of-life care.

PMID: 25028743

58. Am J Hosp Palliat Care. 2015 Dec;32(8):849-54. Epub 2014 Jul 15.

Geographic access to hospice care for children with cancer in Tennessee, 2009 to 2011.

Lindley LC¹, Edwards SL².

ABSTRACT: The geographic interface between the need for and the supply of pediatric hospice may be critical in whether children with cancer access care. This study sought to describe the geographic distribution of pediatric hospice need and supply and identify areas lacking pediatric hospice care in Tennessee over a 3-year time period. Using ArcGIS, a series of maps were created. There was a consistent need for care among children with cancer across the state. Most urban areas were supplied by pediatric hospices, except the Knoxville area. Areas within the state were identified where the supply of pediatric hospice care declined, while the need for hospice care was unchanging. This study has important regulatory implications for clinicians practicing in certificate of need states such as Tennessee.

PMCID: PMC4294986

PMID: 25028742

59. Cancer. 2015 Dec 1;121(23):4240-9. Epub 2015 Aug 26.

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

Umezawa S^{1,2}, Fujimori M^{2,3}, Matsushima E¹, Kinoshita H^{2,4}, Uchitomi Y^{2,5,6}.

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. Cancer 2015;121:4240-4249.

PMID: 26308376

60. Cancer Epidemiol. 2015 Dec;39(6):838-41. Epub 2015 Oct 24.

A national profile of the impact of parental cancer on their children in Japan.

Inoue I¹, Higashi T², Iwamoto M², Heiney SP³, Tamaki T⁴, Osawa K⁵, Inoue M⁶, Shiraishi K⁷, Kojima R⁸, Matoba M⁹.

OBJECTIVE: Dependent children under the age of 18 are particularly vulnerable to the stress of parental death from cancer or of having a parent diagnosed and treated for the disease. More and more Japanese couples are postponing parenthood, which increases their chances of developing cancer while they still have a dependent child. However, the problem has not received enough attention from healthcare professionals and policy-makers because the extent and breadth of the problem has never been examined in the Japanese population. Therefore, we aimed to estimate the nationwide incidence of cancer patients who have children under the age of 18 years, as well as the incidence of children who have a parent diagnosed with cancer in Japan. **STUDY DESIGN:** We calculated the proportion of patients who have children stratified by age, gender and cancer type using electronic medical records of cancer patients (20-59 years old) admitted to the National Cancer Center Hospital (NCCH) for the first time between January 2009 and December 2013. We projected these estimates onto the Japanese population using 2010 population-based cancer registry data, and repeated the projection using 2011 hospital-based

cancer registry data so that estimates of patients receiving care at Designated Cancer Care (DCC) hospitals could be obtained. **RESULTS:** We found that an estimated 56,143 cancer patients who have 87,017 dependent children are diagnosed with cancer every year in Japan. The proportion of children in Japan who had a parent newly diagnosed with cancer in 2010 was approximately 0.38%. We estimated that in 2011 there were on average about 82 cancer patients with minor children and 128 minor children who have at least one parent diagnosed with cancer in every DCC hospital in Japan. **CONCLUSION:** Parental cancer is common. We have identified that many adults diagnosed with cancer have the double burden of coping with the diagnosis and treatment as well as supporting their children through this experience. Additional data on socioeconomic characteristics and needs assessment of these patients are required to understand and how best to help children and families cope with cancer.

PMID: 26651443

61. Crit Care Nurse. 2015 Dec;35(6):46-56.

Caring for Pediatric Patients' Families at the Child's End of Life.

Mullen JE¹, Reynolds MR², Larson JS².

ABSTRACT: Nurses play an important role in supporting families who are faced with the critical illness and death of their child. Grieving families desire compassionate, sensitive care that respects their wishes and meets their needs. Families often wish to continue relationships and maintain lasting connections with hospital staff following their child's death. A structured bereavement program that supports families both at the end of their child's life and throughout their grief journey can meet this need.

PMID: 26628545

62. Curr Opin Support Palliat Care. 2015 Dec;9(4):357-60.

Evaluation tools for spiritual support in end of life care: increasing evidence for their clinical application.

Oliver A¹, Galiana L, Benito E.

PURPOSE OF REVIEW: To summarize current evidence on evaluation tools for spiritual care, paying special attention to recent validations and new instruments, systematic reviews, recent consensus on spiritual care and its measurement, plus other emergent topics. **RECENT FINDINGS:** The systematic review resulted in 45 identified studies, 14 of which were considered: five works addressed the need for development and validation of spiritual tools; three studies reviewed tools for spirituality assessment, interventions, or related concepts; three more covered the efforts to define guidelines and priorities for spiritual care and its measurement. Other topics such as pediatric spiritual care, the use of new technologies, or nationwide surveys, also arose. **SUMMARY:** Recent contributions outline usability traits such as to shorten scales and measurement protocols for maximum respect of patients' quality of life. Other works addressed complicated grief or satisfaction with attention to spiritual care, transcending the patients, family and professionals' focus in on a sort of combined perspective. Further attention to culturally based specific models supporting questionnaires, a deeper understanding of quality of the spiritual care, both for patients and families, or further research on the relation between spiritual care and life span should be welcomed.

PMID: 26509861

63. Eur J Hum Genet. 2015 Dec;23(12):1744-8. Epub 2015 Aug 12.

Biallelic RFX6 mutations can cause childhood as well as neonatal onset diabetes mellitus.

Sansbury FH¹, Kirel B², Caswell R¹, Lango Allen H¹, Flanagan SE¹, Hattersley AT¹, Ellard S¹, Shaw-Smith CJ¹.

ABSTRACT: Neonatal diabetes is a highly genetically heterogeneous disorder. There are over 20 distinct syndromic and non-syndromic forms, including dominant, recessive and X-linked subtypes. Biallelic truncating or mis-sense mutations in the DNA-binding domain of the RFX6 transcription factor cause an autosomal recessive, syndromic form of neonatal diabetes previously described as Mitchell-Riley syndrome. In all, eight cases have been reported, with the age at onset of diabetes in the first 2 weeks of life. Here we report two individuals born to double first cousins in whom intestinal atresias consistent with a diagnosis of Mitchell-Riley syndrome were diagnosed at birth, but in whom diabetes did not present until the ages of 3 and 6 years. Novel compound heterozygous RFX6 nonsense mutations (p.Arg726X/p.Arg866X) were identified at the 3' end of the gene. The later onset of diabetes in these patients may be due to incomplete inactivation of RFX6. Genetic testing for RFX6 mutations should be considered in patients presenting with intestinal atresias in the absence of neonatal diabetes.

PMID: 26264437

64. Int J Immunopathol Pharmacol. 2015 Dec;28(4):590-4 Epub 2015 Apr 21.

Anaphylaxis in pediatric population: A 1-year survey on the Medical Emergency Service in Liguria, Italy.

Ruffoni S¹, Barberi S², Bernardo L², Ferrara F², Furgani A¹, Tosca MA³, Schiavetti I⁴, Ciprandi G⁵.

ABSTRACT: Anaphylaxis is a severe, life-threatening, generalized, or systemic hypersensitivity reaction. The diagnosis is mainly based on a clinical ground. This study aimed to evaluate the records of both phone calls and medical visits for anaphylaxis managed by the Liguria Medical Emergency Service (MES) in a pediatric population, occurred during 2013. The phone call is managed at each center and classified according to a level of care intensity and a presumed level of criticality, according to established criteria. Criticality is then re-evaluated (detected criticality) at the end of the medical visit following the same score adding the black code for patients who died. Most of the phone calls (86) to the MES were recorded in summer (40.7%), followed by spring (26.7%), autumn (16.3%), and winter (16.3%). Forty-eight patients (55.8%) were male. Anaphylaxis was confirmed in about half of patients. In addition, almost all subjects (97.7%) were referred to the Emergency Room. In conclusion, the present study shows that anaphylaxis represents a serious and relevant medical problem in the pediatric population and should be ever carefully managed.

PMID: 25899548

65. J Adolesc Young Adult Oncol. 2015 Dec 1. [Epub ahead of print]

Experiences of Parents and General Practitioners with End-of-Life Care in Adolescents and Young Adults with Cancer.

Kaal SE¹, Kuijken NM¹, Verhagen CA^{1,2}, Jansen R¹, Servaes P³, van der Graaf WT¹.

ABSTRACT: This study aims to analyze the experiences of Dutch bereaved parents and general practitioners (GPs) with palliative care of AYAs (18-35 years) in the terminal stage. Fifteen parents and nine GPs involved with nine deceased AYAs filled out questionnaires and were interviewed by telephone, respectively. In general, the parents were satisfied with the emotional care they themselves received and the medical care that their child received. The GPs were very satisfied with the cooperation with the palliative team. Gaps are present in the areas of symptom control, communication between hospital professionals and parents, aftercare, and transition between hospital and GP.

PMID: 26812457

66. Int J Palliat Nurs. 2015 Dec;21(12):596-601.

Findings from a Clinical Learning Needs Survey at Ireland's first children's hospice.

Quinn C¹, Hillis R².

PURPOSE: Caring for children with life-limiting conditions places exceptional demands on health professionals. Staff require the optimal skills and expertise necessary to provide the highest quality of care and to achieve this it is essential to understand their learning requirements. **AIM:** The aim is to share the main findings from a Clinical Learning Needs Survey conducted at LauraLynn, currently Ireland's only children's hospice. To date no other Irish service has conducted a formal identification of professional learning and development needs specific to the Irish context. The findings from the study assist workforce planning by providing a glimpse into the immediate study needs of staff working in a children's palliative care setting. The study had two main aims: a) Assist clinical staff within one organisation to identify their own professional learning priorities in children's palliative care and b) Inform the design and delivery of a responsive suite of workshops, programmes and study sessions for children's palliative care. **RESULTS:** The study identified the key learning needs as end-of-life care, palliative emergencies, communication skill development and bereavement support. **CONCLUSION:** These findings are similar to those found internationally and demonstrate the commitment of a new organisation to ensure that specific employee learning requirements are met if the organisation and wider specialty of Irish children's palliative care is to continue its evolution.

PMID: 26707488

67. J Adv Nurs. 2015 Dec;71(12):3006-17. Epub 2015 Aug 12.

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

Zimmermann K^{1,2}, Cignacco E^{1,3}, Eskola K¹, Engberg S⁴, Ramelet AS⁵, Von der Weid N⁶, Bergstraesser E⁷.

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

68. J Cardiothorac Vasc Anesth. 2015 Dec;29(6):e71-3. Epub 2015 May 27.

Extraluminal EZ-blocker Placement for One-lung Ventilation in Pediatric Thoracic Surgery.

Piccioni F¹, Vecchi I², Spinelli E³, Previtali P², Langer M⁴.

PMID: 26342270

69. J Palliat Med. 2015 Dec;18(12):1078-9.

Modern Marvels of Children's Palliative Care.

Pravin RR¹.

PMID: 26649779

70. J Pain Palliat Care Pharmacother. 2015 Dec;29(4):385-7.

Fentanyl-Induced Neurotoxicity in Children.

Ostwal S, Salins N, Deodhar J, Muckaden MA.

ABSTRACT: Fentanyl-induced neurotoxicity is an uncommon adverse effect of fentanyl and is seldom seen in pediatric palliative care practice. It presents as myriad of nonspecific symptoms such as severe pain, allodynia, insomnia, agitation, hallucinations, behavioral changes, and headache. In children, it is often missed and misdiagnosed. This is a case report of an

11-year-old girl; a case of locally advanced neuroblastoma, progressed on disease-modifying treatment, and referred to pediatric palliative care for best supportive care. She developed features of fentanyl-induced neurotoxicity during upward titration of transdermal fentanyl that was promptly identified and managed in a pediatric palliative care setting.

PMID: 26654412

71. J Palliat Med. 2015 Dec;18(12):1026-32. Epub 2015 Nov 5.

Exploring the Relationship of Patient and Informal Caregiver Characteristics with Heart Failure Self-Care Using the Actor-Partner Interdependence Model: Implications for Outpatient Palliative Care.

Buck HG¹, Mogle J¹, Riegel B², McMillan S³, Bakitas M⁴.

BACKGROUND: The convergence of prevalence, cost, symptom experience, community setting, and informal caregiving in heart failure (HF) has profound implications for outpatient palliative care. The majority of HF patients depend on informal caregiver's assistance. Dyadic (patients and caregiver) characteristics can complicate this assistance. Yet relatively little is known concerning dyadic characteristics' impact on self-care. HF self-care involves routine, daily treatment adherence and symptom monitoring (self-care maintenance), and symptom response (self-care management). **OBJECTIVE:** Describe the dyadic characteristics of mood and perception of the relationship in HF patients and caregivers, then explore the relationship of the characteristics with self-care. **DESIGN:** Prospective, cross sectional study of hospitalized HF patients in mixed dyads (spousal/adult child/relative) analyzed using Actor-Partner Interdependence Model (APIM) techniques. **MEASUREMENTS:** Mood was measured by the Brief Symptom Inventory and Patient Health Questionnaire, perception of the relationship by the Dyadic Adjustment Scale, and self-care by the Self-care in Heart Failure Index. **RESULTS:** In 40 dyads the average patient was a 71 year old male (n = 30); caregiver was a 59 years old female (n = 26). Overall self-care scores were consistently low. Patient depression scores were significantly greater than caregivers (p = .0055). Greater caregiver anxiety were associated with lower caregiver maintenance scores (p < .0001) but greater caregiver depression were associated with lower patient maintenance scores (p < .0001). While patient and caregiver's perception of the relationship was associated with their self-care, more importantly, caregiver's perception of the relationship was associated with their confidence to engage in the patient's self-care (p = .003). **DISCUSSION/CONCLUSION:** This study suggests that caregivers, often unacknowledged or unmeasured, impact patient's day to day HF self-care. Palliative care clinicians need to talk to dyads with a history of poor self-care about their relationship.

PMID: 26540092

72. J Palliat Med. 2015 Dec;18(12):1015-8. Epub 2015 Aug 11.

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

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

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 General 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

73. J Pediatr. 2015 Dec;167(6):1320-6. doi: 10.1016/j.jpeds.2015.08.066. Epub 2015 Oct 1.

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

van der Geest IM¹, van den Heuvel-Eibrink MM², van Vliet LM³, Pluijms SM⁴, Streng IC⁴, Michiels EM⁴, Pieters R², Darlington AS⁵.

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

74. J Perinatol. 2015 Dec;35 Suppl 1:S19-23.

Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach.

Kenner C^{1,2}, Press J³, Ryan D⁴.

ABSTRACT

Technological advances have increased our ability to detect a life-threatening, life-limiting or lethal problem early in pregnancy, leaving parents months to anticipate a death or a prematurely born infant. Babies can also be born with unanticipated problems that could lead to death. In either scenario, perinatal palliative care should be offered as a strategy for family support. Since the preponderance of professional training focuses on saving lives, many health professionals are uncomfortable with palliative care. This article's purpose is to define best practices for the provision of family-centered perinatal and neonatal palliative care and provision of support to bereaved families experiencing anticipated and unanticipated life-limiting conditions or death of their infant. An overview of core concepts and values is presented, followed by intervention strategies to promote an integrated family-centered approach to palliative and bereavement care. The concluding section presents evidence-based recommendations.

PMCID: PMC4660047 **Free PMC Article**

PMID: 26597801

75. J Perinatol. 2015 Dec;35(12):1000-5. Epub 2015 Oct 22.

Primary palliative care in the delivery room: patients' and medical personnel's perspectives.

Garten L¹, Glöckner S¹, Siedentopf JP², Bühner C¹.

OBJECTIVE: To investigate circumstances of primary palliative care (PPC) in the delivery room (DR), medical personnel's experience with neonates who died under PPC in the DR and perceived sources of care-related distress in DR staff. **STUDY DESIGN:** Retrospective chart review of all neonates who were cared for under PPC in the DR during the years 2000-2010 at Charité University Medical Center Berlin, and structured face-to-face interviews with DR nursing staff and physicians. **RESULT:** Neonates undergoing PPC could be grouped as preterm infants at the limits of viability with a gestational age between 22 (0)/7 and 23 (6)/7 weeks (n=86, 76%) and newborn infants with complex chronic conditions (n=27, 24%). The median age of neonates at death was 59 min (interquartile range [IQR] 28-105 min). Most of DR staff did not report relevant signs of distress in dying neonates, and providing palliative care was not named as a relevant care-related source of distress by medical personnel. However, half of the participants reported on high degrees of caregiver's emotional distress in PPC situations, identifying insecurity of how to communicate with parents and to provide emotional support as the most common source of distress. **CONCLUSION:** Caregiver's emotional distress primarily originates from providing support to parents and not from providing medical care to the dying newborn. Implications for future practice include the need for structured education to improve DR staff's communication and counselling skills related to parents in PPC situations.

PMID: 26491848

76. Med Care. 2015 Dec;53(12):1018-26.

High Intensity of End-of-Life Care Among Adolescent and Young Adult Cancer Patients in the New York State Medicaid Program.

Mack JW¹, Chen K, Boscoe FP, Gesten FC, Roohan PJ, Schymura MJ, Schrag D.

BACKGROUND: Little is known about the care that adolescent and young adult (AYA) cancer patients receive at the end of life (EOL). **OBJECTIVE:** To evaluate use of intensive measures and hospice and location of death of AYA cancer patients insured by Medicaid in New York State. **DESIGN:** Using linked patient-level data from the New York State Cancer Registry and state Medicaid program, we identified 705 Medicaid patients who were diagnosed with cancer between the ages of 15 and 29 in the years 2004-2011, who subsequently died, and who were continuously enrolled in Medicaid in the last 60 days of life. We evaluated use of intensive EOL measures (chemotherapy within 14 d of death; intensive care unit care, >1 emergency room visit, and hospitalizations in the last 30 d of life), hospice use, and location of death (inpatient hospice, long-term care facility, acute care facility, home with hospice, home without hospice). **RESULTS:** 75% of AYA Medicaid decedents used at least 1 aspect of intensive EOL care. 38% received chemotherapy in the last 2 weeks of life; 21% received intensive care unit care, 44% had >1 emergency room visit, and 64% were hospitalized in the last month of life. Only 23% used hospice. 65% of patients died in acute care settings, including the inpatient hospital or emergency room. **CONCLUSIONS:** Given the high rates of intensive measures and low utilization of hospice at the EOL among AYA Medicaid enrollees, opportunities to maximize the quality of EOL care in this high-risk group should be prioritized.

PMCID: PMC4648674

PMID: 26492211

77. Palliat Support Care. 2015 Dec;13(6):1595-601.

Maintaining everyday life in a family with a dying parent: Teenagers' experiences of adapting to responsibility.

Melcher U¹, Sandell R², Henriksson A¹.

OBJECTIVE: Teenagers are living through a turbulent period in their development, when they are breaking away from the family to form their own identities, and so they are particularly vulnerable to the stressful situation of having a parent affected by a progressive and incurable illness. The current study sought to gain more knowledge about the ways that teenagers themselves describe living in a family with a seriously ill and dying parent. More specifically, the aims were to describe how teenagers are emotionally affected by everyday life in a family with a dying parent and to determine how they attempt to adapt to this situation. **METHOD:** The study employed a descriptive and interpretive design using qualitative content analysis. A total of 10 teenagers (aged 14-19 years, 7 boys and 3 girls) participated through repeated, individual, informal interviews that were carried out as free-ranging conversations. **RESULTS:** While contending with their own vulnerable developmental period of life, the teenagers were greatly affected by their parent's illness and took on great responsibility for supporting their parents and siblings, and for maintaining family life. Lacking sufficient information and support left them rather unprepared, having to guess and to interpret the vague signs of failing health on their own, with feelings of uncer-

tainty and loneliness as a consequence. **SIGNIFICANCE OF RESULTS:** Support from healthcare professionals should be designed to help and encourage parents to have open communications about their illness with their teenaged children. Our results add further support to the literature, reinforcing the need for an approach that uses a systemic perspective and considers the family to be the appropriate unit of care and offers a suitable support system.
PMID: 25800062

78. Palliat Support Care. 2015 Dec;13(6):1547-58. Epub 2013 Nov 4.

Acting with dedication and expertise: Relatives' experience of nurses' provision of care in a palliative unit.

Grothe Å¹, Biong S², Grov EK³.

OBJECTIVES: Admission of a cancer patient to a palliative unit when near the final stage of their disease trajectory undoubtedly impacts their relatives. The aim of our study was to illuminate and interpret relatives' lived experiences of health personnel's provision of care in a palliative ward. **METHODS:** A phenomenological/hermeneutic approach was employed that was inspired by the philosophical tradition of Heidegger and Ricoeur and further developed by Lindseth and Nordberg. The perspectives of the narrator and the text were interpreted by highlighting relatives' views on a situation in which they have to face existential challenges. The analysis was undertaken in three steps: naïve reading, structural analysis, and comprehensive understanding, including the authors' professional experiences and theoretical background.

RESULTS: Six subthemes appeared: the dying person, the bubble, the sight, the cover, the provision for children's needs, and the availability of immediate help. These components were further constructed into three themes: the meaning of relating, the meaning of action, and the meaning of resources. Our comprehensive understanding of the results suggests that the most important theme is "acting with dedication and expertise." **SIGNIFICANCE OF RESULTS:** The following aspects are crucial for relatives of cancer patients hospitalized in a palliative ward: time and existence, family dynamics, and care adjusted to the situation. Our study results led to reflections on the impact of how nurses behave when providing care to patients during the palliative phase, and how they interact with relatives in this situation. We found that cancer patients in a palliative unit most appreciate nurses who act with dedication and expertise.

PMID: 24182691

79. Palliat Support Care. 2015 Dec;13(6):1559-68. Epub 2014 Feb 13.

Understanding parental behavior in pediatric palliative care: Attachment theory as a paradigm.

Kearney JA¹, Byrne MW¹.

OBJECTIVE: The objective of this conceptual paper was to present important constructs in attachment theory as they apply to parent and caregiver behavior in pediatric palliative care. Clarification of these constructs is provided with specific reference to their clinical application as well as their reflection in current empirical literature. Social attachment theory is proposed as a developmentally contextual model for the study of parenting in pediatric palliative and end-of-life care.

METHOD: A comprehensive search was conducted of pertinent literatures. These included classic as well as recent theory and research in attachment theory in addition to the empirical literatures on parent and family experience in pediatric palliative care, serious illness, and beyond to parental bereavement. Other relevant literature was examined with respect to the phenomena of concern. **RESULTS:** The empirical literature in pediatric palliative care supports the use of central concepts in attachment theory as foundational for further inquiry. This is evidenced in the emphasis on the importance of parental protection of the child, as well as executive activities such as decision making and other prominent parental operations, parental psychological resolution of the child's diagnosis and illness as well as coping and meaning making, and the core significance of parental relationships with providers who provide secure-base and safe-haven functions. **SIGNIFICANCE OF RESULTS:** The promise for developing integrated, conceptually based interventions from construction through implementation is of urgent importance to children and families receiving pediatric palliative care services. Focusing on key parental behaviors and processes within the context of a well-studied and contextually appropriate model will inform this task efficiently. The attachment paradigm meets these criteria and has promise in allowing us to move forward in developing well-defined, inclusive, and conceptually grounded protocols for child and family psychosocial research, practice, and education in this specialty.

PMID: 24524227

80. Pediatr Blood Cancer. 2015 Dec;62 Suppl 5:S834-69.

Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology.

Lichtenthal WC¹, Sweeney CR^{1,2}, Roberts KE¹, Corner GW^{1,3}, Donovan LA⁴, Prigerson HG⁵, Wiener L⁶.

Author information:

ABSTRACT: After a child's death to cancer, families commonly want continued connection with the healthcare team that cared for their child, yet bereavement follow-up is often sporadic. A comprehensive literature search found that many bereaved parents experience poor psychological outcomes during bereavement and that parents want follow-up and benefit from continued connection with their child's healthcare providers. Evidence suggests that the standard of care should consist of at least one meaningful contact between the healthcare team and bereaved parents to identify those at risk for negative psychosocial sequelae and to provide resources for bereavement support. Pediatr Blood Cancer © 2015 Wiley Periodicals, Inc.

PMCID: PMC4692196

PMID: 26700929

81. Pediatr Blood Cancer. 2015 Dec;62 Suppl 5:S829-33.

Palliative Care as a Standard of Care in Pediatric Oncology.

Weaver MS^{1,2}, Heinze KE³, Kelly KP⁴, Wiener L⁵, Casey RL⁶, Bell CJ^{7,8}, Wolfe J⁹, Garee AM¹⁰, Watson A¹¹, Hinds PS^{4,12}.

ABSTRACT: The study team conducted a systematic review of pediatric and adolescent palliative cancer care literature from 1995 to 2015 using four databases to inform development of a palliative care psychosocial standard. A total of 209 pa-

pers were reviewed with inclusion of 73 papers for final synthesis. Revealed topics of urgent consideration include the following: symptom assessment and intervention, direct patient report, effective communication, and shared decision-making. Standardization of palliative care assessments and interventions in pediatric oncology has the potential to foster improved quality of care across the cancer trajectory for children and adolescents with cancer and their family members.
PMID: 26700928

82. *Pediatr Blood Cancer*. 2015 Dec;62 Suppl 5:S632-83.

Standards of Psychosocial Care for Parents of Children With Cancer.

Kearney JA¹, Salley CG¹, Muriel AC².

ABSTRACT Parents and caregivers of children with cancer are both resilient and deeply affected by the child's cancer. A systematic review of published research since 1995 identified 138 studies of moderate quality indicating that parent distress increases around diagnosis, then returns to normal levels. Post-traumatic symptoms are common. Distress may be impairing for vulnerable parents and may impact a child's coping and adjustment. Moderate quality evidence and expert consensus informed a strong recommendation for parents and caregivers to receive early and ongoing assessment of their mental health needs with access to appropriate interventions facilitated to optimize parent, child, and family well being.

PMID: 26700921

83. *Pediatr Rev*. 2015 Dec;36(12):527-34.

Pain and Symptom Management in Pediatric Palliative Care.

Komatz K¹, Carter B².

ABSTRACT: Pain and symptom management is considered one of the cornerstones of palliative and hospice medicine. However, general clinicians and specialists are not usually comfortable addressing the most common forms of pain seen in the pediatric population. In addition, non-pain symptom management, especially when related to underlying chronic medical conditions, can be managed by the general clinician and specialists. The goal of this article is to educate clinicians about pain categories, taking a detailed pain history, and developing a plan for treatment, including nonpharmacologic methods. Finally, we discuss common symptoms in patients with chronic medical conditions, including first-line treatment options.

PMID: 26628733

84. *Pediatrics*. 2015 Dec;136(6):e1663-9.

Newborn Screening for Biliary Atresia.

Wang KS; SECTION ON SURGERY; COMMITTEE ON FETUS AND NEWBORN; CHILDHOOD LIVER DISEASE RESEARCH NETWORK.

Collaborators: (23)

Moss RL, Caty MG, Davidoff A, Fallat ME, Heiss KF, Holcomb G 3rd, Meyers RL, Watterberg KL, Aucott S, Benitz WE, Cummings JJ, Eichenwald EC, Goldsmith J, Poindexter BB, Puopolo K, Stewart DL, Wang KS, Kerkar N, Karpen SJ, Sokol RJ, Schwarz KB, Mogul DB, Harpavat S.

ABSTRACT: Biliary atresia is the most common cause of pediatric end-stage liver disease and the leading indication for pediatric liver transplantation. Affected infants exhibit evidence of biliary obstruction within the first few weeks after birth. Early diagnosis and successful surgical drainage of bile are associated with greater survival with the child's native liver. Unfortunately, because noncholestatic jaundice is extremely common in early infancy, it is difficult to identify the rare infant with cholestatic jaundice who has biliary atresia. Hence, the need for timely diagnosis of this disease warrants a discussion of the feasibility of screening for biliary atresia to improve outcomes. Herein, newborn screening for biliary atresia in the United States is assessed by using criteria established by the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children. Published analyses indicate that newborn screening for biliary atresia by using serum bilirubin concentrations or stool color cards is potentially life-saving and cost-effective. Further studies are necessary to evaluate the feasibility, effectiveness, and costs of potential screening strategies for early identification of biliary atresia in the United States.

PMID: 26620065

85. *Salud Publica Mex*. 2015 Dec;57(6):489-95.

End-of-life decisions in perinatal care: A view from health-care providers in Mexico.

Grether P¹, Lisker R², Loria A³, Álvarez-Del-Río A⁴.

OBJECTIVE: To examine the opinions of a perinatal health team regarding decisions related to late termination of pregnancy and severely ill newborns. **MATERIALS AND METHODS:** An anonymous questionnaire was administered to physicians, social workers, and nurses in perinatal care. Differences were evaluated using the chi square and Student's t tests.

RESULTS: When considering severely ill fetuses and newborns, 82% and 93% of participants, respectively, opted for providing palliative care, whereas 18% considered feticide as an alternative. Those who opted for palliative care aimed to diminish suffering and those who opted for intensive care intended to protect life or sanctity of life. There was poor knowledge about the laws that regulate these decisions. **CONCLUSIONS:** Although there is no consensus on what decisions should be taken with severely ill fetuses or neonates, most participants considered palliative care as the first option, but feticide or induced neonatal death was not ruled out.

Free Article

PMID: 26679311

86. *J Int AIDS Soc*. 2015 Dec 2;18(7 Suppl 6):20296.

90-90-90 - Charting a steady course to end the paediatric HIV epidemic.

Abrams EJ^{1,2}, Strasser S¹.

INTRODUCTION: The new "90-90-90" UNAIDS agenda proposes that 90% of all people living with HIV will know their HIV

status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have viral suppression by 2020. By focusing on children, the global community is in the unique position of realizing an end to the paediatric HIV epidemic. **DISCUSSION:** Despite vast scientific advances in the prevention and treatment of paediatric HIV infection over the last two decades, in 2014 there were an estimated 220,000 new paediatric infections attributed to mother-to-child HIV transmission (MTCT) and 150,000 HIV-related paediatric deaths. Furthermore, adolescents remain at particularly high risk for acquisition of new HIV infections, and HIV/AIDS remains the second leading cause of death in this age group. Among the estimated 2.6 million children less than 15 years of age living with HIV infection, only 32% were receiving life-saving antiretroviral treatment. After decades of languishing, good progress is now being made to prevent MTCT. Unfortunately, efforts to scale up HIV treatment services have been less robust for children and adolescents compared with adult populations. These discrepancies reflect substantial gaps in essential services and numerous missed opportunities to prevent HIV transmission and provide effective life-saving antiretroviral treatment to children, adolescents and families. The road to an AIDS-free generation will require bridging the gaps in HIV services and addressing the particular needs of children across the developmental spectrum from infancy through adolescence. To reach the ambitious new targets, innovations and service improvements will need to be rapidly escalated at each step along the prevention-treatment cascade. **CONCLUSIONS:** Charting a successful course to reach the 90-90-90 targets will require sustained political and financial commitment as well as the rapid implementation of a broad set of systematic improvements in service delivery. The prospect of a world where HIV no longer threatens the lives of infants, children and adolescents may finally be within reach.

PMCID: PMC4670839 **Free PMC Article**

PMID: 26639119

87. [Pediatric Supportive Care \(PDQ®\): Health Professional Version \[Internet\].](#)

PDQ Supportive and Palliative Care Editorial Board.

PDQ Cancer Information Summaries [Internet]. Bethesda (MD): National Cancer Institute (US); 2002-. 2015 Nov 13.

EXCERPT: This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about supportive care issues related to treatment in children and adolescents. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making health care decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive and Palliative Care Editorial Board, which is editorially independent of the National Cancer Institute (NCI). The summary reflects an independent review of the literature and does not represent a policy statement of NCI or the National Institutes of Health (NIH).

Free Books & Documents

PMID: 26389208

**Fondazione 3BI
Biblioteca Biomedica Biellese**

Sito: www.3bi.info

tel.: 015-15153132

Dott.sa Roberta Maoret

Responsabile Documentalista biomedico

biblioteca@3bi.info

**Maruzza Lefebvre d'Ovidio
Foundation**

Site: www.maruzza.org

tel.: 06-3290609

info@maruzza.org