Primo numero

Symptoms and management of pediatric patients with incurable brain tumors in palliative home care.
Kuhlen M1, Hoell F1, Balzer S2, Borkhardt A1, 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 (78.7%) 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.

[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 B4, Duguet A4, de Suremain N5, Petit A6.

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-blows fractions were recorded. RESULTS: Forty-two first-year residents were evaluated. Their median performance score was 4 out of 13. No-flow 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.

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PMID: 26774839
We identified nine studies that met all inclusion criteria. Reportedly, parental involvement in end-of-life care is suboptimal care. In order to address these gaps, we will implement and evaluate a national roll-out of education for health care professionals in pediatric palliative care and in the perceptions of bereaved parents who describe their experiences with the medical team.

**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.

**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.

**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.

**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.

**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.

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**REFERENCES:**

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.

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


**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 I/Norwood operation.

**INTERVENTIONS**: None.

**MEASUREMENTS AND MAIN RESULTS**: Baseline demographic and clinical information including first recorded postoperative hematocrit and subsequent mean, median, and nadir hematomits 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 hemococoncentration and used as an early marker of capillary leak syndrome.

PMID: 26825044

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**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 JM\(^1\), Rijmakers NJ, Van der Horst NS, Van Der Horst Jd, Francke A\(^1\).

**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 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.

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

Porkholm M\(^1\), Toivainen-Salo S\(^2\), Seurin R\(^3\), Lönngvist T\(^4\), Vepsäläinen K\(^3\), Saarinen-Pihlala UM\(^1\), Pentikäinen V\(^1\), Kivivuori SM\(^2\).

**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 38% 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.

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PMID: 26801815

**Moral distress within neonatal and paediatric intensive care units: a systematic review.**
Prentice T1, Janvier A2, Gillam LJ1, 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 neonate*, 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.

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**It is Time to Let in Pediatric Palliative Care.**
Hilden J1.

**An Order Protocol for Respiratory Distress/Acute Pain Crisis in Pediatric Palliative Care Patients: Medical and Nursing Staff Perceptions.**
Bidet C1, Daoust L2, Duval M3, Ducruet T4, Toledano B5, Humbert N1, Gauvin P1.

**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: 26798836

**Physician Perspectives on Palliative Care for Children With Neuroblastoma: An International Context.**
Balkin EM1, Thompson D2, Colson K3, Lam CG4, 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...
Continuous Lidocaine Infusions to Manage Opioid-Refractory Pain in a Pediatric Hospital.

Gibbons K1, DeMonbrun A2, Beckman EF1, Keefer PF1, Wagner D3, Stewart M4, Saul D1, Hakey S1, Liu M5, Niedner M2.

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.

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Continuous Lidocaine Infusions to Manage Opioid-Refractory Pain in a Pediatric Hospital.

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PMID: 26784868
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 lifestyle, need to eliminate as much cardiovascular risk factors as possible and sustain a regular blood pressure monitoring.

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The relationship between parental attitudes and behaviours in the context of paediatric chronic pain.
Jaaniste T1,2, Jia N1,2, Lang T1,2, Goodison-Farnsworth EM1,2, McCormick M1,2, 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 effectiveness and high levels of monitoring. METHODS: Participants were 138 child-parent dyads recruited from a tertiary chronic pain clinic. Patients were aged 8-17 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


The psychological impact of genetic information on children: a systematic review.
Wakefield CE1,2, Hanlon LV1, Tucker KM2,4, Patenaude AF1,2, Signorelli C1,2, McLoone IK1,2, Cohn RJ1,2.

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, 61.8%); 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 the 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


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: 26739855


Children’s palliative care in low- and middle-income countries.
Downing I1, Powell RA1, Marston J1, Huwa C4, Chandra L1, Garchakova A4, Harding R2.

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/
PMD: 26369876

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 PC2.

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 13 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, demographic 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); 38% 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=46, 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/
PMD: 26271752

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

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 (α = 0.78) 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 variance associated with scale and subscale scores. Significantly different mean subscale scores (P < .001) indicated more frequent thought frequency. Psychometrics were explored. Multivariable models identified personal and clinical characteristics associated with scale and subscale scores. 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Referring and transplantation clinicians should create opportunities to explore with parents their perspectives and concerns before and during the course of HSCT.
PMD: PMCID: PMC4706486 Free PMC Article
PMD: 26348891

Children: a protected species in palliative care.
Nyatanga B1. PMID: 26692138

PMD: 26632667

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 T1, 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: 26847276

Against euthanasia for children: a response to Bovens.
Kacor 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.

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PMID: 268474602

Use of guidelines when planning home care of a girl with severe congenital myopathy.
Gray K1, Isaacs D2,3, Kilham H3, Tobin B4, Watera K2,3.
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

Unexpected Death on an Acute Palliative Care Unit.
Mercadante S1, Ferrera P2, Casuccio A3.
PMID: 26476392

The Indirect Effect of Positive Parenting on the Relationship Between Parent and Sibling Bereavement Outcomes After the Death of a Child.
Morris AT1, Gabert-Quillen C2, Friebert S4, 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
ABSTRACT:


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 R1,2, Marks E3, Funes M3, Martinez-Puente LM3, Winick N4,5, Lee SC5,6. 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):35-01. What are Palliative Care Physicians for Adults Taught on Palliative Care for Children? Paediatric Aspects in Palliative Care Curricula for Adults. Schiessl C1, Gotschelings S2, Crowwald 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 interprofessional or medical palliative care curricula (PCC) and to evaluate the breadth and quality of PaedPC issues covered in these curricula. DESIGN: Interprofessional 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 the 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 EF2, Starkweather AR3, Guite FW4, 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
To study the feasibility of implementing a comfort care protocol using OTM medications in dying neonates, a protocol was developed and evaluated. The protocol was designed to be used in the last 30 days of life, with regular assessments performed before medication administration. The protocol included the following steps:

1. Assessment of pain, agitation, and sedation using the Neonatal Pain, Agitation, and Sedation Scale (N-PASS).
2. Medication administration by the OTM route.
3. Evaluation of the effectiveness of the protocol through the use of a questionnaire.

The protocol was evaluated in a single site, prospective cohort study involving 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 86%); (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 (<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


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 IW2, 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 MG1. 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 was 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


**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 ID, Lipschutz 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


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

**Park EM, Deal AM, Yopp JM, Edwards TP, Wilson DJ, Hanson LC, Rosenstein DL.**

**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 their own prognosis 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:** 26688117

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,2,4, 3 Bonadonna R,2 Wharton CM1, Bradford M2, Shaffer ML2,4, Wolfe JP2,7,8, Baker KS2,4,9.**

**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., 83% 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 HH, Steele R, Cadel S.**
Adolescents' preferences for treatment decisional involvement during their cancer.

Weaver MS\textsuperscript{1,2}, Baker JN\textsuperscript{3}, Côté D\textsuperscript{4}, Black BP\textsuperscript{5}, Gibson DV\textsuperscript{6}, Sykes AD\textsuperscript{6}, Hinds PS\textsuperscript{5,7}.

**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

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The Effect of Palliative Care Team Design on Referrals to Pediatric Palliative Care.

Keefe L\textsuperscript{1}, Keenan HT\textsuperscript{2}, Bratton SL\textsuperscript{3}.

**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 0.00-2.13. 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: 26670935

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Provision of Services in Perinatal Palliative Care: A Multicenter Survey in the United States.

Wool C\textsuperscript{1}, Cótede-Arsenault D\textsuperscript{2}, Black BP\textsuperscript{3}, Denney-Koeshc E\textsuperscript{4}, Kim S\textsuperscript{5}, Kavanaugh K\textsuperscript{6}.

**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 36% 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

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Bereaved Siblings’ Advice to Health Care Professionals Working With Children With Cancer and Their Families.

Lövgren M\textsuperscript{7}, Bylund-Grenklo T\textsuperscript{1}, Jalmassl L\textsuperscript{1}, Wallin AE\textsuperscript{1}, Kreierbergs U\textsuperscript{1}.

**INTRODUCTION:** Siblings of children with cancer experience psychosocial distress during the illness and after bereave-
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 own 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

‘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 MJ, Endacott R, Connell B, O’Connor M

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 during 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

Palliative care in neonatal neurology: robust support for infants, families and clinicians.
Lemmon ME, Bidegain M, Boss RD

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.

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PMID: 26688120

Healthcare users’ experiences of communicating with healthcare professionals about children who have life-limiting conditions: a qualitative systematic review protocol.
Ekberg S, Bradford N, Herbert A, Danby S, Yates P

PMID: 2663462

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

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 registries, obtained using Cox proportional hazards regression. RESULTS: A total of 99,832 children were included in the study, with 99,221 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 6,611 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, 1.08-1.41). 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.
ABSTRACT: Children with advanced cancer, including those with hematologic malignancies, can benefit from interdiscipli- 

nary 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.

METHODS: A prospective cohort design compares stress and satisfaction of PC on NICU parent stress and satisfaction. 

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RESULTS: 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.

OBJECTIVES: This study examines the effects of PC on NICU parent stress and satisfaction. METHODS: A prospective cohort design compares stress and satisfac-

CONCLUSION: 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.

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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 86 patients taking strong opioids, 89% required less than 0.5mg/kg/hr. Constipation was the most frequently observed secondary effect.

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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: 25288642


Ketamine PCA for treatment of end-of-life neuropathic pain in pediatrics.
Taylor M1, Jakacki R2, May C2, Howrie D1, Maurer S3.

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 0.08 mg/kg/h (range 0.014-0.308 mg/kg/h) with a 0.05 mg/kg (range 0.03-0.8mg/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 78% 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


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 unchanged. This study has important regulatory implications for clinicians practicing in certificate of need states such as Tennessee.

PMCID: PMC4294986
PMID: 25028742


Preferences of advanced cancer patients for communication on anticancer treatment cessation and the transition to palliative care.
Umezawa S1,2, Fujimori M1,2,3, Matsushima E1,2, Kinoshita H1,2,4, Uchitomi Y2,5,6.

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


A national profile of the impact of parental cancer on their children in Japan.
Inoue I1, Hirashiro T2, Iwamoto M1, Heiney SP3, Tamaki T1, Osawa K1, Inoue M2, Shirasaki K1, Kojima R5, Matoba M6.

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 how best to help children and families cope with cancer.

PMID: 26651443

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**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

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**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 46 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 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

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**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 missense mutations in the DNA-binding domain of the RFX6 transcription factor cause an autosomal recessive, syndromic form of neonatal diabetes presenting 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

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**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 (58.8%) 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

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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 CA2,3, Jansen R4, Servaes F5, 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

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 speciality of Irish children’s palliative care is to continue its evolution.

PMID: 26707488

Development and initial validation of the Parental PELICAN Questionnaire (PaPEQu) - an instrument to assess parental experiences and needs during their child’s end-of-life care.
Zimmermann K1,2, Cignacco E1,2,3, Eskola K1, Engberg S4, Ramelet AS5, Von der Weid N6, Bergstraesser F2.

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 324 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 during their child’s end-of-life care.

PMID: 26265326

Extraluminal EZ-blocker Placement for One-lung Ventilation in Pediatric Thoracic Surgery.
Piccioni F1, Vecchi I1, Spinelli E1, Previtali F2, Langer M4.

PMID: 26342270

Modern Marvels of Children’s Palliative Care.
Pravin RR1.

PMID: 26649779

Fentanyl-Induced Neurotoxicity in Children.
Ostwal S1, Salina N1, Deodhar J1, 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.

PMD: 26654412

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 B1, McMillan S1, Bakitas M2.

BACKGROUND: The prevalence 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 age 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.

PMD: 26940092

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

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, 45 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.

PMD: 26962842

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

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 86 children who answered the questions regarding discussing death with their child, 58 parents of 58 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.

PMD: 26427964
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.

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PMID: 26891980

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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
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.
PMD: 25800062

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 undoubt-
edly impacts their relatives. The aim of our study was to illuminate and interpret relatives’ lived experiences of health per-
sonnel’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 compre-
hensive 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 relat-
ing, 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 ad-
justed to the situation. Our study results led to reflections on the impact of how nurses behave when providing care to pa-
tients 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.
PMD: 24182691

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 refer-
ce to their clinical application as well as their reflection in current empirical literature. Social attachment theory is pro-
posed 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 pal-
liative 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 pro-
tection of the child, as well as executive activities such as decision making and other prominent parental operations, parent-
al psychological resolution of the child’s diagnosis and illness as well as coping and meaning making, and the core signifi-
cance of parental relationships with providers who provide secure-base and safe-haven functions. SIGNIFICANCE OF RE-
SULTS: 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 be-
haviors and processes within the context of a well-studied and contextually appropriate model will inform this task effi-
ciently. 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.
PMD: 24524227

Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology.
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 be-
reaved 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 con-
sist of at least one meaningful contact between the healthcare team and bereaved parents to identify those at risk for nega-
tive psychosocial sequelae and to provide resources for bereavement support. Pediatr Blood Cancer © 2015 Wiley Periodi-
cals, Inc.
PMCID: PMC4692196
PMD: 26700929

Palliative Care as a Standard of Care in Pediatric Oncology.
Weaver MS1,2, Heinez KE1, Kelly KP1, Wiener L3, Casey RF4, Bell CF2,8, Wolle F9, Garee AM10, Watson A11, Hinds PS4,12.
ABSTRACT: The study team conducted a systematic review of pediatric and adolescent palliative care cancer literature from
1995 to 2015 using four databases to inform development of a palliative care psychosocial standard. A total of 209 pa-
papers were reviewed with inclusion of 75 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


Standards of Psychosocial Care for Parents of Children With Cancer.

Kearney JA, Salley CG, Muriel AG.

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


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


Newborn Screening for Biliary Atresia.

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

Collaborators: (23)


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


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


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


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

Abrams EI1,2, Strasser S3.

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.