

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

"Good information is the best medicine..."
Donald A.B. Lindberg



The Second

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1. Arch Pediatr. 2015 Mar 31. [Epub ahead of print]

[\[Development, implementation, and analysis of a "collaborative decision-making for reasonable care" document in paediatric palliative care\]. \[Article in French\]](#)

Paoletti M¹, Litnhouvongs MN², Tandonnet J².

INTRODUCTION: In France, a legal framework and guidelines state that decisions to limit treatments (DLT) require a collaborative decision meeting and a transcription of decisions in the patient's file. The do-not-attempt-resuscitation order involves the same decision-making process for children in palliative care. To fulfill the law's requirements and encourage communication within the teams, the Resource Team in Pediatric Palliative Care in Aquitaine created a document shared by all children's hospital units, tracing the decision-making process. This study analyzed the decision-making process, quality of information transmission, and most particularly the relevance of this new "collaborative decision-making for reasonable care" card. **MATERIAL AND METHODS:** Retrospective study evaluating the implementation of a traceable document relating the DLT process. All the data sheets collected between January and December 2013 were analyzed. **RESULTS:** A total of 58 data sheets were completed between January and December 2013. We chose to collect the most relevant data to evaluate the relevance of the items to be completed and the transmission of the document, to draw up the patients' profile, and the contents of discussions with families. Of the 58 children for whom DLT was discussed, 41 data sheets were drawn up in the pediatric intensive care unit, seven in the oncology and hematology unit, five in the neonatology unit, four in the neurology unit, and one in the pneumology unit. For 30 children, one sheet was created, for 11 children, two sheets and for two children, three sheets were filled out. Thirty-nine decisions were made for withholding lifesaving treatment, 11 withdrawing treatment, and for five children, no limitation was set. Nine children survived after DLT. Of the 58 data sheets, only 31 discussions with families were related to the content of the data sheet. Of the 14 children transferred out of the unit with a completed data sheet, it was transmitted to the new unit for 11 children (79 %). **DISCUSSION:** The number of data sheets collected in 1 year shows the value of this document. The participation of several pediatric specialities' referents in its creation, then its progressive presentation in the children's hospital units, were essential steps in introducing and establishing its use. Items describing the situation, management proposals, and adaptation of the children's supportive care were completed in the majority of cases. They correspond to a clinical description, the object of the discussion, and the daily caregiver's practices, respectively. On the other hand, discussions with families were related to the card's contents in only 53 % of the cases. This can be explained by the time required to complete the DLT process. It is difficult for referring doctors to systematically, faithfully, and objectively transcribe discussions with parents. Although this process has been used for a long time in intensive care units, this document made possible an indispensable formalisation in the decision-making process. In other pediatric specialities, the sheet allowed introducing the palliative approach and was a starter and a tool for reflection on the do-not-attempt-resuscitation order, thus suggesting the need for anticipation in these situations. **CONCLUSION:** With the implementation of this new document, the DLT, data transmission, and continuity of care conditions were improved in the children's hospital units. Sharing this sheet with all professionals in charge of these children would support homogeneity and quality of management and care for children and their parents. Copyright © 2015 Elsevier Masson SAS. All rights reserved. PMID: 25840464 [PubMed - as supplied by publisher]

2. Cochrane Database Syst Rev. 2015 Mar 31;3:CD009596.

Buprenorphine for treating cancer pain.

Schmidt-Hansen M¹, Bromham N, Taubert M, Arnold S, Hilgart JS.

BACKGROUND: Many patients with cancer experience moderate to severe pain that requires treatment with strong analgesics. Buprenorphine, fentanyl and morphine are examples of strong opioids used for cancer pain relief. However, strong opioids are ineffective as pain treatment in all patients and are not well-tolerated by all patients. The aim of this Cochrane review is to assess whether buprenorphine is associated with superior, inferior or equal pain relief and tolerability compared to other analgesic options for patients with cancer pain. **OBJECTIVES:** To assess the effectiveness and tolerability of buprenorphine for pain in adults and children with cancer. **SEARCH METHODS:** We searched CENTRAL (the Cochrane Library) issue 12 or 12 2014, MEDLINE (via OVID) 1948 to 20 January 2015, EMBASE (via OVID) 1980 to 20 January 2015, ISI Web of Science (SCI-EXPANDED & CPCI-S) to 20 January 2015, ISI BIOSIS 1969 to 20 January 2015. We also searched ClinicalTrials.gov (<http://clinicaltrials.gov/>; metaRegister of Controlled Trials (mRCT) (<http://www.controlled-trials.com/mrct/>), the World Health Organization (WHO) International Clinical Trials Registry Platform (ICTRP) search portal (<http://apps.who.int/trialsearch/>) and the Proceedings of the Congress of the European Federation of International Association for the Study of Pain (IASP; via European Journal of Pain Supplements) on 16 February 2015. We checked the bibliographic references of identified studies as well as relevant studies and systematic reviews to find additional trials not identified by the electronic searches. We contacted authors of included studies for other relevant studies. **SELECTION CRITERIA:** We included randomised controlled trials, with parallel-group or crossover design, comparing buprenorphine (any formulation and any route of administration) with placebo or an active drug (including buprenorphine) for cancer background pain in adults and children. **DATA COLLECTION AND ANALYSIS:** Two review authors independently extracted data pertaining to study design, participant details (including age, cancer characteristics, previous analgesic medication and setting), interventions (including details about titration) and outcomes, and independently assessed the quality of the included studies according to standard Cochrane methodology. As it was not feasible to meta-analyse the data, we summarised the results narratively. We assessed the overall quality of the evidence for each outcome using the GRADE approach. **MAIN RESULTS:** In this Cochrane review we identified 19 relevant studies including a total of 1421 patients that examined 16 different intervention comparisons. Of the studies that compared buprenorphine to another drug, 11 studies performed comparative analyses between the randomised groups, and five studies found that buprenorphine was superior to the comparison treatment. Three studies found no differences between buprenorphine and the comparison drug, while another three studies found treatment with buprenorphine to be inferior to the alternative treatment in terms of the side effects profile or patients preference/acceptability. Of the studies that compared different doses or formulations/routes of administration of buprenorphine, pain intensity ratings did not differ significantly between intramuscular buprenorphine and buprenorphine suppository. However, the average severity of dizziness, nausea, vomiting and adverse events as a total were all significantly higher in the intramuscular group relatively to the suppository group (one study). Sublingual buprenorphine was associated with faster onset of pain relief compared to subdermal buprenorphine, with similar duration analgesia and no significant differences in adverse event rates reported between the treatments (one study). In terms of transdermal buprenorphine, two studies found it superior to placebo, whereas a third study found no difference between placebo and different doses of transdermal buprenorphine. The studies that examined different doses of transdermal buprenorphine did not report a clear dose-response relationship. The quality of this evidence base was limited by under-reporting of most bias assessment items (e.g., the patient selection items), by small sample sizes in several included studies, by attrition (with data missing from 8.2% of the enrolled/randomised patients for efficacy and from 14.6% for safety) and by limited or no reporting of the expected outcomes in a number of cases. The evidence for all the outcomes was very low quality. **AUTHORS' CONCLUSIONS:** Based on the available evidence, it is difficult to say where buprenorphine fits in the treatment of cancer pain with strong opioids. However, it might be considered to rank as a fourth-line option compared to the more standard therapies of morphine, oxycodone and fentanyl, and even there it would only be suitable for some patients. However, palliative care patients are often heterogeneous and complex, so having a number of analgesics available that can be given differently increases patient and prescriber choice. In particular, the sublingual and injectable routes seemed to have a more definable analgesic effect, whereas the transdermal route studies left more questions.

PMID: 25826743 [PubMed - in process]

3. BMJ Open. 2015 Mar 30;5(3):e006428.

Practice guidelines for sedation and analgesia management of critically ill children: a pilot study evaluating guideline impact and feasibility in the PICU.

Keogh SJ¹, Long DA², Horn DV³.

AIMS: The aim of this study was to develop and implement guidelines for sedation and analgesia management in the paediatric intensive care unit (PICU) and evaluate the impact, feasibility and acceptability of these as part of a programme of research in this area and as a prelude to future trial work. **METHOD:** This pilot study used a pre-post design using a historical control. **SETTING:** Two PICUs at different hospitals in an Australian metropolitan city. **PARTICIPANTS:** Patients admitted to the PICU and ventilated for ≥ 24 h, aged more than 1 month and not admitted for seizure management or terminal care. **INTERVENTION:** Guidelines for sedation and analgesia management for critically ill children including algorithm and assessment tools. **OUTCOME VARIABLES:** In addition to key outcome variables (ventilation time, medication dose and duration, length of stay), feasibility outcomes data (recruitment, data collection, safety) were evaluated. Guideline adherence was assessed through chart audit and staff were surveyed about merit and the use of guidelines. **RESULTS:** The guidelines were trialled for a total of 12 months on 63 patients and variables compared with the historical control group (n=75). Analysis revealed differences in median Morphine infusion duration between groups (pretest 3.63 days (87 h) vs post-test 2.83 days (68 h), p=0.05) and maximum doses (pretest 120 $\mu\text{g}/\text{kg}/\text{h}$ vs post-test 97.5 $\mu\text{g}/\text{kg}/\text{h}$) with no apparent change to ventilation duration. Chart audit revealed varied use of tools, but staff were positive about the guidelines and their use in practice. **CONCLUSIONS:** The sedation guidelines impacted on the duration and dosage of agents without any apparent impact on ventilation duration or length of stay. Furthermore, the guidelines appeared to be feasible and acceptable in clinical practice. The

results of the study have laid the foundation for follow-up studies in withdrawal from sedation, point prevalence and longitudinal studies of sedation practices as well as drug trial work. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>.

PMCID: PMC4386214 **Free PMC Article**

PMID: 25823444 [PubMed - in process]

4. *Pediatr Blood Cancer*. 2015 Mar 27. [Epub ahead of print]

Patient-controlled analgesia at the end of life at a pediatric oncology institution.

Anghelescu DL¹, Snaman JM, Trujillo L, Sykes AD, Yuan Y, Baker JN.

BACKGROUND: Patient controlled anesthesia (PCA) is increasingly used to manage pain in pediatric cancer patients and is important in the treatment of escalating pain at the end of life. The description of the use of opioid PCA in this population has been limited. **PROCEDURE:** This retrospective chart review of the last 2 weeks of life addressed the following objectives: (1) to describe the patient population treated with opioid PCA; (2) to describe the morphine-equivalent doses (MED) (mg/kg/day); and (3) to describe the pain scores (PS). **RESULTS:** Twenty-eight percent of inpatients used opioid PCA for pain control during the last 2 weeks of life. The mean MED (mg/kg/day) (SD) at 2 weeks prior and the day of death were 10.7 (17.9) and 19 (25.8). The mean MED increased over the last 2 weeks of life for all patients and across age groups and cancer diagnoses (all $P < 0.05$). The mean MED was significantly higher in the younger age group (age < 13 vs. age ≥ 13) on the day of death ($P < 0.04$). There was a significant change in mean PS over the last 2 weeks of life ($P < 0.001$), with the highest PS on the day before death. The most frequently used concurrent medications were benzodiazepines (91%). **CONCLUSIONS:** Children and young adults with cancer experience high opioid requirements and significant dose increases during the last 2 weeks of life. Additionally, PS increase toward the end of life. Opioid rotation and addition of adjuvant medications merit consideration in the context of escalating opioid requirements. *Pediatr Blood Cancer* © 2015 Wiley Periodicals, Inc. © 2015 Wiley Periodicals, Inc.

PMID: 25820345 [PubMed - as supplied by publisher]

5. *J Cyst Fibros*. 2015 Mar 24. [Epub ahead of print]

Development and evaluation of a palliative care curriculum for cystic fibrosis healthcare providers.

Linnemann RW¹, O'Malley PJ¹, Friedman D², Georgiopoulos AM², Buxton D², Altstein LL³, Sicilian L⁴, Lapey A¹, Sawicki GS⁵, Moskowitz SM⁶.

BACKGROUND: Primary palliative care refers to basic skills that all healthcare providers can employ to improve quality of life for patients at any stage of disease. Training in these core skills is not commonly provided to clinicians caring for cystic fibrosis (CF) patients. The objective of this study was to assess change in comfort with core skills among care team members after participation in CF-specific palliative care training focused on management of burdensome symptoms and difficult conversations. **METHODS:** A qualitative needs assessment was performed to inform the development of an 18-hour curriculum tailored to the chronicity and complexity of CF care. A 32-question pre- and post-course survey assessed CF provider comfort with the targeted palliative care skills in 5 domains using a 5-point Likert scale (1=very uncomfortable, 3=neutral, 5=very comfortable). **RESULTS:** Among course participants ($n=16$), mean overall comfort score increased by 0.9, from 3 (neutral) to 3.9 (comfortable) ($p < 0.001$). Mean comfort level increased significantly (range 0.8 to 1.4) in each skill domain: use of supportive care resources, pain management, non-pain symptom management, communication, and psychosocial skills. **CONCLUSIONS:** CF-specific palliative care training was well received by participants and significantly improved self-assessed comfort with core skills. Copyright © 2015 European Cystic Fibrosis Society. Published by Elsevier B.V. All rights reserved.

PMID: 25817162 [PubMed - as supplied by publisher]

6. *Int J Palliat Nurs*. 2015 Mar;21(3):152-3.

Research roundup.

Downing J¹.

Abstract Synopses of a selection of recently published research articles of relevance to palliative care.

PMID: 25815764 [PubMed - in process]

7. *Klin Padiatr*. 2015 Mar 26. [Epub ahead of print]

Critical Situations in Children, Adolescents and Young Adults with Terminal Cancer within the Home Setting.

Kuhlen M¹, Balzer S¹, Friedland C¹, Borkhardt A¹, Janßen G¹.

Background: Over the course of terminal cancer towards the end-of-life, children may experience symptoms that lead to distressing critical situations (CS) for the child and caregivers. **Methods:** We analysed the records of 133 children cared for by our paediatric palliative care team (PPCT) from 01/98-12/09. A CS was defined as deterioration of a condition caused by a symptom, which was life-threatening or acutely scaring the patient (pt) or caregivers. **Results:** The majority of pts who died sustained no CS. In 38 (28.6%) pts 45 CS occurred. These accumulated towards the end-of-life (62.2% within the last week). About two-thirds were anticipated. There was no clustering of CS during the night/weekend. Leading symptoms were neurological. In 4 CS a pre-hospital emergency physician was alerted. 5 pts were readmitted to hospital. Most CS (88.9%) could be controlled in the home setting. **Discussion:** Despite anticipation, a relevant number of pts developed CS, which needed either additional medical intervention or other support by the PPCT. Considering the distressing and suffering character of status epilepticus and dyspnoea, it is important to thoroughly address these conditions in palliative care. **Conclusion:** Advanced planning, close contact, good communication, detailed parental information, and a 24-h on-call service can reduce CS in children with terminal cancer. CS are mainly manageable within the home setting. Treatment of CS should focus on the child's symptoms and wishes, and the needs of the whole family. © Georg Thieme Verlag KG Stuttgart · New York.

PMID: 25811741 [PubMed - as supplied by publisher]

8. Indian J Crit Care Med. 2015 Mar;19(3):147-50.

Mortality patterns among critically ill children in a Pediatric Intensive Care Unit of a developing country.

Siddiqui NU¹, Ashraf Z², Jurair H¹, Haque A¹.

BACKGROUND AND AIM: Advances in biomedical technology have made medical treatment to be continued beyond a point, at which it does not confer an advantage but may increase the suffering of patients. In such cases, continuation of care may not always be useful, and this has given rise to the concept of limitation of life-sustaining treatment. Our aim was to study mortality patterns over a 6-year period in a Pediatric Intensive Care Unit (PICU) in a developing country and to compare the results with published data from other countries. **MATERIALS AND METHODS:** Retrospective cohort study was conducted in a PICU of a tertiary care hospital in Pakistan. Data were drawn from the medical records of children aged 1-month - 16 years of age who died in PICU, from January 2007 to December 2012. **RESULTS:** A total of 248 (from an admitted number of 1919) patients died over a period of 6 years with a mortality rate 12.9%. The median age of children who died was 2.8 years, of which 60.5% (n = 150) were males. The most common source of admission was from the emergency room (57.5%, n = 143). The most common cause of death was limitation of life-sustaining treatment (63.7%, n = 158) followed by failed cardio-pulmonary resuscitation (28.2%, n = 70) and brain death (8.1%, n = 20). We also found an increasing trend of limitation of life-sustaining treatment do-not-resuscitate (DNR) over the 6-year reporting period. **CONCLUSION:** We found limitation of life support treatment (DNR + Withdrawal of Life support Treatment) to be the most common cause of death, and parents were always involved in the end-of-life care decision-making.

PMCID: PMC4366912 **Free PMC Article**

PMID: 25810609 [PubMed]

9. Indian J Crit Care Med. 2015 Mar;19(3):133-5.

End-of-life care in the Pediatric Intensive Care Units: Challenges and ethical principles.

Morrow BM¹.

Abstract In this issue, Siddiqui, *et al.* present a report on the mortality patterns in Pediatric Intensive Care Units (PICU) in Pakistan, a developing country. It is difficult to interpret the apparently high mortality rate of almost 13% without the context of average predicted mortality on admission (i.e. standardized mortality rates [SMR]). Future studies would benefit from the use of SMR, to track performance of the PICU over time and to compare outcomes with other units nationally and internationally.

PMCID: PMC4366908 **Free PMC Article**

PMID: 25810605 [PubMed]

10. Pediatrics. 2015 Apr;135(4):694-700. Epub 2015 Mar 23.

Pediatric palliative care and inpatient hospital costs: a longitudinal cohort study.

Smith AG¹, Andrews S², Bratton SL³, Sheetz J³, Feudtner C⁴, Zhong W⁵, Maloney CG³.

BACKGROUND: Pediatric palliative care (PPC) improves the quality of life for children with life-limiting conditions, but the cost of care associated with PPC has not been quantified. This study examined the association between inpatient cost and receipt of PPC among high-cost inpatients. **METHODS:** The 10% most costly inpatients treated at a children's hospital in 2010 were studied, and factors associated with receipt of PPC were determined. Among patients dying during 2010, we compared 2010 inpatient costs between PPC recipients and nonrecipients. Inpatient costs during the 2-year follow up period between PPC recipients and nonrecipients were also compared. Patients were analyzed in 2 groups: those who died and those who survived the 2-year follow-up. **RESULTS:** Of 902 patients, 86 (10%) received PPC. Technology dependence, older age, multiple chronic conditions, PICU admission, and death in 2010 were independently associated with receipt of PPC. PPC recipients had increased inpatient costs compared with nonrecipients during 2010. Among patients who died during the 2-year follow-up, PPC recipients had significantly lower inpatient costs. Among survivors, PPC recipients had greater inpatient costs. When controlling for patient complexity, differences in inpatient costs were not significant. **CONCLUSIONS:** The relationship of PPC to inpatient costs is complex. PPC seems to lower costs among patients approaching death. Patients selectively referred to PPC who survive most often do so with chronic serious illnesses that predispose them to remain lifelong high-resource utilizers. Copyright © 2015 by the American Academy of Pediatrics.

PMID: 25802343 [PubMed - in process]

11. J Pediatr Nurs. 2015 Mar 20. [Epub ahead of print]

Compassion Fatigue in Pediatric Nurses.

Berger J¹, Polivka B², Smoot EA³, Owens H².

Abstract Compassion fatigue in nursing has been shown to impact the quality of patient care and employee satisfaction and engagement. The aims of this study were to determine the prevalence and severity of compassion fatigue among pediatric nurses and variations in prevalence based on respondent demographics using a cross-sectional survey design. Nurses under 40 years of age, with 6-10 years of experience and/or working in a medical-surgical unit had significantly lower compassion satisfaction and higher levels of burnout. Secondary traumatic stress from caring for children with severe illness or injury or end of life was a key contributor to compassion fatigue. Copyright © 2015 Elsevier Inc. All rights reserved.

PMID: 25800590 [PubMed - as supplied by publisher]

12. J Pediatr. 2015 Mar 19. [Epub ahead of print]

Pediatric Palliative Care: Current Evidence and Evidence Gaps.

Miller EG¹, Levy C², Linebarger JS³, Klick JC⁴, Carter BS³.

Abstract Hospice and palliative medicine (HPM) is an emerging medical subspecialty initially recognized by the American Board of Medical Specialties in 2006. As the Institute of Medicine reported in 2014, health care delivery and the challenges of care at the end of children's lives have evolved significantly over the past 15 years.¹ The last decade has seen the growth of pediatric palliative care (PPC) programs at children's hospitals and a transformation of the field.² Fifty percent of children's

hospitals nationwide have a PPC program, with a peak in new program development occurring in 2008.
PMID: 25799195 [PubMed - as supplied by publisher]

13. *Pediatr Blood Cancer*. 2015 Mar 18. [Epub ahead of print]

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

Cawkwell PB¹, Gardner SL, Weitzman M.

BACKGROUND: Approximately one in 285 children will be diagnosed with cancer before reaching their 20th birthday. While both oncologists and parents report a preference that these children die at home rather than in a hospital, there are limited data exploring this issue in depth. **PROCEDURE:** We performed a retrospective analysis of national-level data from 1999 to 2011 from the National Center for Health Statistics "Underlying Cause of Death" database. Characteristics investigated included sex, race, age, ethnicity, cancer type, geographic location, and population density where the child lived. **RESULTS:** Of the 2,130 children with a death attributable to neoplasm in 2011, 37.6% (95% CI, 35.5-39.6%) died at home compared to 36.9% (95% CI, 35.0-38.8%) in 1999. In 2011, there were statistically significant racial differences between white, black, and Hispanic children across nearly every age group, with white children consistently most likely to die at home. Children of non-Hispanic origin were significantly more likely to die at home than Hispanic children (40.3% vs. 29.3%, $P < 0.001$). Children with CNS tumors are more likely to die at home than children with neoplasms as a whole, while children with leukemia are less likely. Statistically significant differences by race and ethnicity persist regardless of cancer type. **CONCLUSIONS:** There has been no significant change in the rate of children with cancer who die at home over the past decade. Racial and ethnic differences have persisted in end of life care for children with cancer with white non-Hispanic children being most likely to die at home. *Pediatr Blood Cancer* © 2015 Wiley Periodicals, Inc. © 2015 Wiley Periodicals, Inc. PMID: 25787675 [PubMed - as supplied by publisher]

14. *J Oncol Pract*. 2015 Mar;11(2):e182-9.

Challenges faced by pediatric oncology fellows when patients die during their training.

Granek L¹, Bartels U², Barrera M², Scheinemann K².

PURPOSE: Given the paucity of research on the experience of pediatric oncology fellows regarding patient death, the purpose of this study was to explore the specific challenges that pediatric oncology fellows face when patients die during their training. **METHODS:** Six pediatric oncology fellows at two academic cancer centers in Ontario, Canada, were interviewed about their experiences with patient death during their fellowship training. The grounded theory method of data collection and data analysis was used. Line-by-line coding was used to establish themes, and constant comparison was used to establish relationships among emerging codes and themes. **RESULTS:** Fellows reported structural challenges that included ward duty and lack of follow-up opportunities with bereaved families. Personal challenges included feelings of vulnerability as a result of being a trainee, inexperience with patient death, and feeling alone with one's reactions to patient death. Relational challenges included duration of relationships with families and with supervising staff and perceived lack of modeling on how to cope with patient deaths. **CONCLUSION:** Structural changes to the fellowship model can be made in order to enhance support with patient death, including informing fellows of all patient deaths and incorporating fellows into follow-up practices with bereaved families. Moreover, integrating fellows' debriefing (facilitated by grief counselors) after a patient death into fellow training, as well as greater involvement with palliative care physicians, can lessen feelings of isolation and help fellows learn effective strategies for dealing with patient deaths from experienced palliative care physicians. Copyright © 2015 by American Society of Clinical Oncology. PMID: 25784578 [PubMed - in process]

15. *Nurse Educ Today*. 2015 Mar 5. [Epub ahead of print]

Effectiveness of a perinatal and pediatric End-of-Life Nursing Education Consortium (ELNEC) curricula integration.

O'Shea ER¹, Campbell SH², Engler AJ³, Beauregard R⁴, Chamberlin EC⁵, Currie LM⁶.

BACKGROUND: Educational practices and national guidelines for best practices of providing palliative care to children and their families have been developed and are gaining support; however, the dissemination of those practices lags behind expectations. Incorporating education for pediatric palliative care into nursing pre-licensure programs will provide guidelines for best practices with opportunities to enact them prior to graduation. **OBJECTIVE:** To evaluate the effect of an integrated curriculum for palliative care on nursing students' knowledge. **DESIGN:** Matched pretest-posttest. **SETTING:** One private and one public university in the northeastern United States. **PARTICIPANTS:** Two groups of baccalaureate nursing students, one exposed to an integrated curriculum for palliative care and one without the same exposure. **METHODS:** Pre-testing of the students with a 50-item multiple choice instrument prior to curriculum integration and post-testing with the same instrument at the end of the term. **RESULTS:** This analysis demonstrated changes in knowledge scores among the experimental (n=40) and control (n=19) groups that were statistically significant by time (Wilks' Lambda=.90, $F(1, 57)=6.70$, $p=.012$) and study group (Wilks' Lambda=.83, $F(1, 57)=11.79$, $p=.001$). **CONCLUSIONS:** An integrated curriculum for pediatric and perinatal palliative and end-of-life care can demonstrate an increased knowledge in a small convenience sample of pre-licensure baccalaureate nursing students when compared to a control group not exposed to the same curriculum. Future research can examine the effect on graduates' satisfaction with program preparation for this specialty area; the role of the use of the curriculum with practice-partners to strengthen transfer of knowledge to the clinical environment; and the use of this curriculum interprofessionally. Copyright © 2015 Elsevier Ltd. All rights reserved. PMID: 25771263 [PubMed - as supplied by publisher]

16. *Cochrane Database Syst Rev*. 2015 Mar 13;3:CD010750.

Pharmacological interventions for pain in children and adolescents with life-limiting conditions.

Beecham E¹, Candy B, Howard R, McCulloch R, Laddie J, Rees H, Vickerstaff V, Bluebond-Langner M, Jones L.

BACKGROUND: Pain is one of the most common symptoms in children and young people (CYP) with life-limiting conditions (LLCs) which include a wide range of diagnoses including cancer. The current literature indicates that pain is not well man-

aged, however the evidence base to guide clinicians is limited. There is a clear need for evidence from a systematic review to inform prescribing. **OBJECTIVES:** To evaluate the evidence on the effectiveness of different pharmacological interventions used for pain in CYP with LLCs. **SEARCH METHODS:** The following electronic databases were searched up to December 2014: CENTRAL (in the Cochrane Library), MEDLINE, EMBASE, PsycINFO and CINAHL. In addition, we searched conference proceedings and reference lists of included studies. For completeness, we also contacted experts in the field. No language restrictions were applied. **SELECTION CRITERIA:** Randomised controlled trials (RCTs), quasi-randomised studies and other studies that included a clearly defined comparator group were included. The studies investigated pharmacological treatments for pain associated with LLCs in CYP. The treatment included those specifically developed to treat pain and those that acted as an adjuvant, where the treatment was not primarily developed to treat pain but has pain relieving properties. The LLC was identified by its inclusion in the Richard Hain Directory of LLCs. **DATA COLLECTION AND ANALYSIS:** Citations were screened by five review authors. Data were extracted by one review author and checked by a second. Two review authors assessed the risk of bias of included studies. A sufficient number of studies using homogeneous outcomes was not identified so a meta-analysis was not possible. **MAIN RESULTS:** We identified 24,704 citations from our database search. Nine trials with 379 participants fulfilled our inclusion criteria. Participants had cerebral palsy (CP) in five of the studies and osteogenesis imperfecta (OI) in the other four. Participants across the trials ranged in age from 2 to 19 years. All studies, apart from one cross-over trial, were parallel designed RCTs. Three of the trials on CP evaluated intrathecal baclofen (ITB) and two botulinum toxin A (BoNT-A). All of the OI trials evaluated the use of bisphosphonates (two alendronate and one pamidronate). No trials were identified that evaluated a commonly used analgesic in this patient group. Pain was a secondary outcome in five of the eight identified studies. Overall the quality of the trials was mixed. Only one study involved over 100 participants. For the two ITB studies for pain in CP, in the same study population but assessed at different time points in their disease, both found an effect on pain favouring the intervention compared to the control group (standard care or placebo) (mean difference (MD) 4.20, 95% confidence interval (CI) 2.15 to 6.25; MD 26.60, 95% CI 2.61 to 50.59, respectively). In these studies most of the adverse events related to the procedure or device for administration rather than the drug, such as swelling at the pump site. In one trial there were also eight serious adverse effects; these included difficulty swallowing and an epileptic seizure. The trial did not state if these occurred in the intervention group. At follow-up in both BoNT-A trials there was no evidence of a difference in pain between the trial arms among CP participants. The adverse events in the BoNT-A trials mostly involved those who received the intervention drug and involved seizures. Gastrointestinal problems were the most frequent adverse event in those who received alendronate. The trial investigating pamidronate found no evidence of a difference in pain compared to the control group. No adverse events were reported in this trial. **AUTHORS' CONCLUSIONS:** Published, controlled evidence on the pharmacological interventions for pain in CYP with LLCs is limited. The evidence that is currently available evaluated pain largely as a secondary outcome and the drugs used were all adjuvants and not always commonly used in general paediatric palliative care for pain. Based on current data this systematic review is unable to determine the effects of pharmacological interventions for pain for CYP with LLCs. Future trials with larger populations should examine the effects of the drugs commonly used as analgesics; with the rising prevalence of many LLCs this becomes more necessary.

PMID: 25768935 [PubMed - in process]

17. J Med Ethics. 2015 Mar 10. [Epub ahead of print]

Child euthanasia: should we just not talk about it?

Bovens L.

Abstract Belgium has recently extended its euthanasia legislation to minors, making it the first legislation in the world that does not specify any age limit. I consider two strands in the opposition to this legislation. First, I identify five arguments in the public debate to the effect that euthanasia for minors is somehow worse than euthanasia for adults-viz, arguments from weightiness, capability of discernment, pressure, sensitivity and sufficient palliative care-and show that these arguments are wanting. Second, there is another position in the public debate that wishes to keep the current age restriction on the books and have ethics boards exercise discretion in euthanasia decisions for minors. I interpret this position on the background of Velleman's 'Against the Right to Die' and show that, although costs remain substantial, it actually can provide some qualified support against extending euthanasia legislation to minors. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>.

PMID: 25757464 [PubMed - as supplied by publisher]

18. J Adv Nurs. 2015 Mar 5. [Epub ahead of print]

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

Bergstraesser E¹, Zimmermann K, Eskola K, Luck P, Ramelet AS, Cignacco E.

AIM: To present a protocol for a multi-phase study about the current practice of end-of-life care in paediatric settings in Switzerland. **BACKGROUND:** In Switzerland, paediatric palliative care is usually provided by teams, who may not necessarily have specific training. There is a lack of systematic data about specific aspects of care at the end of a child's life, such as symptom management, involvement of parents in decision-making and family-centred care and experiences and needs of parents, and perspectives of healthcare professionals. **DESIGN:** This retrospective nationwide multicentre study, Paediatric End-of-Life CAre Needs in Switzerland (PELICAN), combines quantitative and qualitative methods of enquiry. **METHODS:** The PELICAN study consists of three observational parts, PELICAN I describes practices of end-of-life care (defined as the last 4 weeks of life) in the hospital and home care setting of children (0-18 years) who died in the years 2011-2012 due to a cardiac, neurological or oncological disease, or who died in the neonatal period. PELICAN II assesses the experiences and needs of parents during the end-of-life phase of their child. PELICAN III focuses on healthcare professionals and explores their perspectives concerning the provision of end-of-life care. **CONCLUSION:** This first study across Switzerland will provide comprehensive insight into the current end-of-life care in children with distinct diagnoses and the perspectives of affected parents and health professionals. The results may facilitate the development and implementation of programmes for

end-of-life care in children across Switzerland, building on real experiences and needs. Trial registration: ClinicalTrials.gov Identifier: NCT01983852. © 2015 John Wiley & Sons Ltd.
PMID: 25740472 [PubMed - as supplied by publisher]

19. Support Care Cancer. 2015 Mar 5. [Epub ahead of print]

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

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

PURPOSE: We aimed to explore the perceived timeliness of referral to hospice palliative care unit (HPCU) among bereaved family members in Korea and factors associated therewith. **METHODS:** Cross-sectional questionnaire survey was performed for bereaved family members of patients who utilized 40 designated HPCUs across Korea. The questionnaire assessed whether admission to the HPCU was "too late" or "appropriate" and the Good Death Inventory (GDI). **RESULTS:** A total of 383 questionnaires were analyzed. Of participants, 25.8 % replied that admission to HPCU was too late. Patients with hepatobiliary cancer, poor performance status, abnormal consciousness level, and unawareness of terminal status were significantly related with the too late perception. Family members with younger age and being a child of the patient were more frequently noted in the too late group. Ten out of 18 GDI scores were significantly lower in the too late group. Multiple logistic regression analysis revealed patients' unawareness of terminal status, shorter stay in the HPCU, younger age of bereaved family, and lower scores for two GDI items (staying in a favored place, living without concerning death or disease) were significantly associated with the too late group. **CONCLUSIONS:** To promote timely HPCU utilization and better quality of end of life care, patients need to be informed of the terminal status and their preference should be respected.

PMID: 25739751 [PubMed - as supplied by publisher]

20. Am Psychol. 2015 Feb-Mar;70(2):146-58.

The integration of psychology in pediatric oncology research and practice: Collaboration to improve care and outcomes for children and families.

Kazak AE¹, Noll RB².

Abstract Childhood cancers are life-threatening diseases that are universally distressing and potentially traumatic for children and their families at diagnosis, during treatment, and beyond. Dramatic improvements in survival have occurred as a result of increasingly aggressive multimodal therapies delivered in the context of clinical research trials. Nonetheless, cancers remain a leading cause of death in children, and their treatments have short- and long-term impacts on health and well-being. For over 35 years, pediatric psychologists have partnered with pediatric oncology teams to make many contributions to our understanding of the impact of cancer and its treatment on children and families and have played prominent roles in providing an understanding of treatment-related late effects and in improving quality of life. After discussing the incidence of cancer in children, its causes, and the treatment approaches to it in pediatric oncology, we present seven key contributions of psychologists to collaborative and integrated care in pediatric cancer: managing procedural pain, nausea, and other symptoms; understanding and reducing neuropsychological effects; treating children in the context of their families and other systems (social ecology); applying a developmental perspective; identifying competence and vulnerability; integrating psychological knowledge into decision making and other clinical care issues; and facilitating the transition to palliative care and bereavement. We conclude with a discussion of the current status of integrating knowledge from psychological research into practice in pediatric cancer. (PsycINFO Database Record (c) 2015 APA, all rights reserved).

PMID: 25730721 [PubMed - in process]

21. Palliat Med. 2015 Apr;29(4):371-9. Epub 2015 Feb 26.

Advance Care Planning in palliative care: A qualitative investigation into the perspective of Paediatric Intensive Care Unit staff.

Mitchell S¹, Dale J².

BACKGROUND: The majority of children and young people who die in the United Kingdom have pre-existing life-limiting illness. Currently, most such deaths occur in hospital, most frequently within the intensive care environment. **AIM:** To explore the experiences of senior medical and nursing staff regarding the challenges associated with Advance Care Planning in relation to children and young people with life-limiting illnesses in the Paediatric Intensive Care Unit environment and opportunities for improvement. **DESIGN:** Qualitative one-to-one, semi-structured interviews were conducted with Paediatric Intensive Care Unit consultants and senior nurses, to gain rich, contextual data. Thematic content analysis was carried out. **SETTING/PARTICIPANTS:** UK tertiary referral centre Paediatric Intensive Care Unit. Eight Paediatric Intensive Care Unit consultants and six senior nurses participated. **FINDINGS:** Four main themes emerged: recognition of an illness as 'life-limiting'; Advance Care Planning as a multi-disciplinary, structured process; the value of Advance Care Planning and adverse consequences of inadequate Advance Care Planning. Potential benefits of Advance Care Planning include providing the opportunity to make decisions regarding end-of-life care in a timely fashion and in partnership with patients, where possible, and their families. Barriers to the process include the recognition of the life-limiting nature of an illness and gaining consensus of medical opinion. Organisational improvements towards earlier recognition of life-limiting illness and subsequent Advance Care Planning were recommended, including education and training, as well as the need for wider societal debate. **CONCLUSIONS:** Advance Care Planning for children and young people with life-limiting conditions has the potential to improve care for patients and their families, providing the opportunity to make decisions based on clear information at an appropriate time, and avoid potentially harmful intensive clinical interventions at the end of life. © The Author(s) 2015.

PMID: 25721360 [PubMed - in process]

22. BMJ Support Palliat Care. 2015 Mar;5(1):102.

Research priority setting in palliative and end of life care: the james lind alliance approach consulting patients, carers and clinicians.

Best S¹, Tate T¹, Noble B¹, Smith R¹, Tuft J¹, Tracey N¹, McCullough A¹, Eley J², Black J³, Stockton M⁴, Cheesley A⁵, Berry I⁵, Burton C⁶, Dechamps A⁷, Stevens E⁸, Penny A⁹, McEnhill L¹⁰, McNair A¹¹, Cupid B¹², Maeso B¹³, Chapman D¹⁴, McIlpatrick S¹⁵, Nelson A¹⁶, Sivell S¹⁶, Baillie J¹⁶, VanGodwin J¹⁶, Candy B¹⁷, Beaumont N¹⁸, Cowan K¹⁹.

INTRODUCTION: There can be a mismatch between what the public see as important unanswered questions and those which are actually researched. The Palliative and end of life care Priority Setting Partnership, facilitated by the James Lind Alliance (JLA), identified and prioritised questions about palliative and end of life care that people in the last years of life, current/bereaved carers and professionals feel are important for research to address. **AIMS AND METHODS:** A UK public survey (December 2013-April 2014) identified questions about support, care and treatment of people in the last years of life. Some 83 questions were formulated and prioritised via a second public survey. The resulting top 28 were prioritised in a workshop comprising patients, carers and clinicians to determine the top 10 research questions. **RESULTS:** 1403 surveys were returned. Most respondents identified as bereaved family/friends and health or social care professionals. Respondents submitted a range of questions on services, communication, symptoms and perceptions of palliative care. 1331 respondents completed the second survey. In November 2014, 24 people participated in a workshop to prioritise the 'top 10' questions (using the Nominal Group Technique) which will be reported in January 2015. Responses that are 'out of scope' of the JLA protocol will be analysed and reported separately. **CONCLUSIONS:** The 'top 10' uncertainties will guide project partners' and other organisations' funding strategies, ensuring that future research is relevant to palliative care populations. We will discuss how the results of this project will guide the palliative and end of life care research agenda in future.

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PMID: 25713227 [PubMed - in process]

23. Cancer. 2015 Feb 11. [Epub ahead of print]

Patient beliefs that chemotherapy may be curative and care received at the end of life among patients with metastatic lung and colorectal cancer.

Mack JW¹, Walling A, Dy S, Antonio AL, Adams J, Keating NL, Tisnado D.

BACKGROUND: Many patients with incurable cancer inaccurately believe that chemotherapy may cure them. Little is known about how such beliefs affect choices for care at the end of life. This study assessed whether patients with advanced cancer who believed that chemotherapy might offer a cure were more likely to receive chemotherapy in the last month of life and less likely to enroll in hospice care before death. **METHODS:** This study examined patients diagnosed with stage IV lung or colorectal cancer in the Cancer Care Outcomes Research and Surveillance consortium, a population- and health system-based prospective cohort study. Among 722 patients who completed a baseline survey and died during the study period, logistic regression was used to assess the association of understanding goals of chemotherapy with chemotherapy use in the last month of life and hospice enrollment before death; adjustments were made for patient and tumor characteristics. **RESULTS:** One-third of the patients (33%) recognized that chemotherapy was "not at all" likely to cure their cancer. After adjustments, such patients were no less likely than other patients to receive end-of-life chemotherapy (odds ratio [OR], 1.32; 95% confidence interval [CI], 0.84-2.09), but they were more likely than other patients to enroll in hospice (OR, 1.97; 95% CI, 1.37-2.82). **CONCLUSIONS:** An understanding of the purpose of chemotherapy for incurable cancer is a critical aspect of informed consent. Still, advanced cancer patients who were well informed about chemotherapy's goals received late-life chemotherapy at rates similar to those for other patients. An understanding of the incurable nature of cancer, however, is associated with increased hospice enrollment before death, and this suggests important care outcomes beyond chemotherapy use. Cancer 2015. © 2015 American Cancer Society. © 2015 American Cancer Society.

PMID: 25677655 [PubMed - as supplied by publisher]

24. Nurs Child Young People. 2015 Feb;27(1):15.

Starting out - A place of happiness, joy and possibility.

Kirwan L¹.

Abstract I HAVE always wanted to volunteer and share the skills I have acquired during my training as a nurse. I also have a keen interest in the provision of end of life care and palliative care to children. And this is why I decided to volunteer in a hospice for children who have been abandoned in China. My trip is entirely self-funded and I will be here for seven weeks.

PMID: 25671748 [PubMed - in process]

25. Nurs Child Young People. 2015 Feb;27(1):13.

Nurses should be open with parents about range of resources available.

Smith J¹.

Abstract Research about parents' health-related decisions on behalf of their child has been undertaken in various domains, such as prenatal screening and diagnosis, infant feeding, immunisation, long-term conditions, life support and palliative care (Jackson et al 2008).

PMID: 25671746 [PubMed - in process]

26. N Engl J Med. 2015 Feb 12;372(7):595-8.

Should we practice what we profess? Care near the end of life.

Pizzo PA¹, Walker DM.

Abstract Vast majorities of U.S. physicians and other Americans say they'd like to avoid high-intensity care at the end of life, but these wishes are frequently overridden. An Institute of Medicine committee has concluded that major changes in the health care system are needed.

PMID: 25671250 [PubMed - indexed for MEDLINE]

27. Palliat Med. 2015 Apr;29(4):346-53. Epub 2015 Feb 10.

Novel legislation for pediatric advance directives: Surveys and focus groups capture parent and clinician perspectives.

Boss RD¹, Hutton N², Griffin PL², Wieczorek BH², Donohue PK³.

BACKGROUND: Legislative measures increasingly require consideration of pediatric inpatients for Medical Orders for Life-Sustaining Treatment. **AIM:** To explore pediatric clinicians' experiences with life-sustaining treatments prior to the Medical Orders for Life-Sustaining Treatment mandate and to describe clinician and family concerns and preferences regarding pediatric Medical Orders for Life-Sustaining Treatment. **DESIGN:** Clinician surveys and clinician and parent focus groups. **SETTING/PARTICIPANTS:** Pediatric clinicians and parents from one of Maryland's largest health systems. **RESULTS:** Of 96 survey respondents, 72% were physicians and 28% were nurse practitioners. A total of 73% of physicians and 34% of nurse practitioners felt able to lead discussions about limiting therapies "most" or "all" of the time. A total of 75% of physicians and 37% of nurse practitioners led such a discussion in the prior year. A total of 55% of physicians and 96% of nurse practitioners had written no order to limit therapies in the past year. Only for children predicted to die within 30 days did >80% of clinicians agree that limitation discussions were warranted. A total of 100% of parent focus group participants, but 17% of physicians and 33% of nurse practitioners, thought that all pediatric inpatients warranted Medical Orders for Life-Sustaining Treatment discussions. Parents felt that universal Medical Orders for Life-Sustaining Treatment would decrease the stigma of limitation discussions. Participants believed that Medical Orders for Life-Sustaining Treatment would clarify decision making and increase utilization of palliative care. Medical Orders for Life-Sustaining Treatment communication skills training was recommended by all. **CONCLUSION:** A minority of clinicians, but all parents, support universal pediatric Medical Orders for Life-Sustaining Treatment. Immediately prior to the Medical Orders for Life-Sustaining Treatment mandate, many clinicians felt unprepared to lead limitation discussions, and few had written relevant orders in the prior year. Communication training is perceived essential to successful Medical Orders for Life-Sustaining Treatment conversations. © The Author(s) 2015.

PMID: 25670471 [PubMed - in process]

28. Am J Hosp Palliat Care. 2015 Feb 8. [Epub ahead of print]

Pediatric Euthanasia and Palliative Care Can Work Together.

Hanson SS¹.

Abstract Since the Netherlands produced the Groningen protocol describing the methods to be used for pediatric euthanasia and Belgium passed laws authorizing euthanasia for children who consent to it, the issue of pediatric euthanasia has become a relevant topic to discuss. Most rejections of pediatric euthanasia fall into 1 or more of 3 categories, each of which has problems. This article shows how several recent arguments against pediatric euthanasia fail to prove that pediatric euthanasia is unacceptable. It does not follow from this that the practice is permissible but rather that if one is to reject such a practice, stronger arguments will need to be made, especially in countries where adult euthanasia or assisted suicide is already permitted. © The Author(s) 2015.

PMID: 25667147 [PubMed - as supplied by publisher]

29. Psychooncology. 2015 Feb 6. [Epub ahead of print]

An exploratory study of end-of-life prognostic communication needs as reported by widowed fathers due to cancer.

Park EM¹, Check DK, Yopp JM, Deal AM, Edwards TP, Rosenstein DL.

OBJECTIVE: Effective physician communication about prognosis is a critical aspect of quality care for families affected by terminal illness. This is particularly important for spousal caregivers of terminally ill parents of dependent children, who may have unique needs for communication about anticipated death. The objective of this study was to explore end-of-life prognostic communication experiences reported by bereaved fathers whose wives died from cancer. **METHODS:** From October 2012 to November 2013 we surveyed widowed fathers whose wives died from cancer through an open-access educational website. The survey included the following open-ended questions regarding prognostic communication: 'What is the most important thing you would like us to know about whether/how your wife's doctors communicated with you about her anticipated death? What do you wish had been different, if anything?' We performed traditional content analysis of responses. Two researchers coded and categorized the data. **RESULTS:** Two hundred forty-four men responded to the survey questions on prognostic communication. Major themes addressed by respondents were the importance of clear and honest communication and physician bedside manner. They also identified unmet information needs, including wanting to know prognosis sooner. Relevant sub-themes included death coming as a surprise, avoidance, and caregiver regret. **CONCLUSIONS:** Surviving spouses due to cancer can provide important insights for health care providers about optimum prognostic communication at the end of life. Increased physician attention to the communication preferences of both patients and their partners may improve bereavement outcomes for family members. Copyright © 2015 John Wiley & Sons, Ltd. Copyright © 2015 John Wiley & Sons, Ltd.

PMID: 25655038 [PubMed - as supplied by publisher]

30. Pediatrics. 2015 Mar;135(3):545-9. Epub 2015 Feb 2.

Are we allowed to discontinue medical treatment in this child?

Leeuwenburgh-Pronk WG¹, Miller-Smith L², Forman V³, Lantos JD², Tibboel D⁴, Buysse C⁴.

Abstract One of the most difficult ethical dilemmas in pediatrics today arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life. In the context of medical futility, it is harmful to prolong medical treatment. The question is: How can medical treatment be discontinued when the child is not dependent on mechanical ventilation or ICU treatment? What is the appropriate palliative care and does it justify the use of sedatives or analgesics if this also might shorten life? Copyright © 2015 by the American Academy of Pediatrics.

PMID: 25647670 [PubMed - in process]

31. Palliat Med. 2015 Mar;29(3):223-30. Epub 2015 Jan 29.

A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions.

Remedios C¹, Willenberg L², Zordan R², Murphy A³, Hessel G³, Philip J².

BACKGROUND: Respite services are recommended as an important support for caregivers of children with life-threatening conditions. However, the benefits of respite have not been convincingly demonstrated through quantitative research. **AIM:** To determine the impact of out-of-home respite care on levels of fatigue, psychological adjustment, quality of life and relationship satisfaction among caregivers of children with life-threatening conditions. **DESIGN:** A mixed-methods, pre-test and post-test study **SETTING/PARTICIPANTS:** A consecutive sample of 58 parental caregivers whose children were admitted to a children's hospice for out-of-home respite over an average of 4 days. **RESULTS:** Caregivers had below-standard levels of quality of life compared to normative populations. Paired t-tests demonstrated that caregivers' average psychological adjustment scores significantly improved from pre-respite (mean = 13.9, standard error = 0.71) to post-respite (mean = 10.7, standard error = 1); $p < 0.001$, 95% confidence interval: 1.25-5.11). Furthermore, caregivers' average fatigue scores significantly improved from pre-respite (mean = 14.3, standard error = 0.85) to post-respite (mean = 10.9, standard error = 1.01; $p < 0.001$, 95% confidence interval: 1.69-7.94), and caregivers' average mental health quality of life scores significantly improved from pre-respite (mean = 44.2, standard error = 1.8) to post-respite (mean = 49.1, standard error = 1.6; $p < 0.01$, 95% confidence interval: -9.56 to 0.36). Qualitative data showed caregivers sought respite for relief from intensive care provision and believed this was essential to their well-being. **CONCLUSION:** Findings indicate the effectiveness of out-of-home respite care in improving the fatigue and psychological adjustment of caregivers of children with life-threatening conditions. Study outcomes inform service provision and future research efforts in paediatric palliative care. © The Author(s) 2015. PMID: 25634634 [PubMed - in process]

32. Curr Opin Support Palliat Care. 2015 Mar;9(1):52-7.

Parenting challenges in the setting of terminal illness: a family-focused perspective.

Zaider TI¹, Salley CG, Terry R, Davidovits M.

PURPOSE OF REVIEW: In the advanced stages of illness, families with dependent children experience disruption across all dimensions of family life. The need for family support during palliative care is well recognized, yet little is understood about how parents and their children navigate these difficult circumstances. This review summarizes the current body of research on parenting challenges in advanced cancer. **RECENT FINDINGS:** To date, the study of parental cancer has focused predominantly on the early stages of disease and its impact on children and adolescents. Less is known about how families with minor children prepare for parental loss. Evidence suggests that having dependent children influences parents' treatment decisions at the end of life, and that a central concern for children and parents is optimizing time spent together. Parents may feel an urgency to engage in accelerated parenting, and maintaining normalcy remains a consistent theme for the ill and healthy parent alike. There is a growing evidence base affirming the importance of responsive communication prior to death. **SUMMARY:** Advancing knowledge about the parenting experience at the end of life is critical for ensuring effective support to the entire family, as it accommodates and prepares for the loss of a vital member.

PMID: 25588207 [PubMed - in process]

33. Curr Opin Support Palliat Care. 2015 Mar;9(1):40-5.

Understanding death with limited experience in life: dying children's and adolescents' understanding of their own terminal illness and death.

Bates AT¹, Kearney JA.

PURPOSE OF REVIEW: An up-to-date summary of the literature on children's and adolescents' understanding of their own terminal illness and death. **RECENT FINDINGS:** Clinicians still find it difficult to speak with pediatric patients about death even though guidelines for facilitating communication on the topic exist. As a result, pediatric patients are less likely to develop a clear understanding of their illness and there is a disconnect between clinicians and parents about prognosis, even when clinicians have concluded there is no longer possibility for cure. Insufficient communication and poor understanding may increase the risk of patients feeling isolated, mistrustful and anxious, and deprive them of a role model who can communicate about painful issues or share difficult feelings. Despite these complexities, young people often show remarkable resiliency in the face of death and want to get the most out of the remaining time they have. **SUMMARY:** In addition to these most recent findings, this review examines the challenges in researching this topic, obstacles to patients receiving information about prognosis, and how physical symptoms affect patients' ability to develop an understanding. It also reviews sources of insight into pediatric patients' understanding including the development of concepts of death, fears about their own death, legal interpretations of what patients understand, and how terminally ill young people continue to treasure life. It concludes by addressing ways clinicians can use the knowledge we have to communicate well with dying children and adolescents and their families.

PMID: 25581454 [PubMed - in process]

34. Curr Opin Support Palliat Care. 2015 Mar;9(1):58-63.

Supporting youth grieving the dying or death of a sibling or parent: considerations for parents, professionals, and communities.

Warnick AL¹.

PURPOSE OF REVIEW: The aim of this article is to highlight considerations for parents, professionals, and communities regarding supporting children and adolescents who are grieving the dying or death of a parent or sibling. **RECENT FINDINGS:** Current research is directly engaging the voices of youth who have experienced a parent or sibling's death. Although there continues to be much evidence about the distressing effect of such deaths on children and adolescents, there is a welcome emerging tendency to distinguish between adaptive and maladaptive grief. Although the literature strongly encourages parents to take an open and honest approach to supporting youth prior to a death, many barriers remain to them doing

so. The literature identifies healthcare providers as being ideally positioned to provide guidance to families around best practice in the area of preparing youth for the death of a parent or sibling. Following a death, there is now encouraging evidence regarding the efficacy of certain interventions for bereaved youth, both in the short and long term, which is an important development in the field. **SUMMARY:** Youth benefit from being involved in open and honest conversations about a family member's cancer diagnosis, treatment, prognosis, and end-of-life care. Although advances are being made with regard to understanding the grief experience of youth, there remains a wide gap between the current theoretical knowledge and the availability of practical well informed support for grieving youth.

PMID: 25581448 [PubMed - in process]

35. J Pain Palliat Care Pharmacother. 2015 Mar;29(1):72-4. Epub 2015 Jan 12.

Evidence-based Pain Management and Palliative Care.

Wiffen PJ.

Abstract The Cochrane library of systematic reviews is published quarterly as a DVD and monthly online (<http://www.thecochranelibrary.com>). The October 2014 issue (4th DVD for 2014) contains 6157 complete reviews, 2,353 protocols for reviews in production and 32,000 short summaries of systematic reviews published in the general medical literature. In addition, there are citations of 807,000 randomized controlled trials, and 15,700 cited papers in the Cochrane Methodology Register. The Health Technology Assessment database contains some 14,000 citations. Ninety-seven new reviews have been published in the previous 3 months of which five have potential relevance for practitioners in pain and palliative medicine. The impact factor of the Cochrane Library stands at 5.939. Readers are encouraged to access the full report for any articles of interest as only a brief commentary is provided.

PMID: 25580716 [PubMed - in process]

36. Clin Pediatr (Phila). 2015 Mar;54(3):222-7. Epub 2015 Jan 5.

Continuing education needs of pediatricians across diverse specialties caring for children with medical complexity.

Bogetz JF¹, Bogetz AL², Gabhart JM³, Bergman DA⁴, Blankenburg RL⁴, Rassbach CE⁴.

OBJECTIVE: Care for children with medical complexity (CMC) relies on pediatricians who often are ill equipped, but striving to provide high quality care. We performed a needs assessment of pediatricians across diverse subspecialties at a tertiary academic US children's hospital about their continuing education needs regarding the care of CMC. **METHODS:** Eighteen pediatricians from diverse subspecialties were asked to complete an online anonymous open-ended survey. Data were analyzed using modified grounded theory. **RESULTS:** The response rate was 89% (n = 16). Of participants, 31.2% (n = 5) were general pediatricians, 18.7% (n = 3) were hospitalists, and 50% (n = 8) were pediatric subspecialists. Pediatricians recognized the need for skills in care coordination, giving bad news, working in interprofessional teams, and setting goals of care with patients. **CONCLUSIONS:** Practicing pediatricians need skills to improve care for CMC. Strategically incorporating basic palliative care education may fill an important training need across diverse pediatric specialties. © The Author(s) 2015.

PMID: 25561699 [PubMed - in process]

37. Pediatrics. 2015 Feb;135(2):e465-76. Epub 2015 Jan 5.

Talking with parents about end-of-life decisions for their children.

de Vos MA¹, Bos AP², Plötz FB³, van Heerde M⁴, de Graaff BM⁵, Tates K⁶, Truog RD⁷, Willems DL⁸.

BACKGROUND AND OBJECTIVE: Retrospective studies show that most parents prefer to share in decisions to forgo life-sustaining treatment (LST) from their children. We do not yet know how physicians and parents communicate about these decisions and to what extent parents share in the decision-making process. **METHODS:** We conducted a prospective exploratory study in 2 Dutch University Medical Centers. **RESULTS:** Overall, 27 physicians participated, along with 37 parents of 19 children for whom a decision to withhold or withdraw LST was being considered. Forty-seven conversations were audio recorded, ranging from 1 to 8 meetings per patient. By means of a coding instrument we quantitatively and qualitatively analyzed physicians' and parents' communicative behaviors. On average, physicians spoke 67% of the time, parents 30%, and nurses 3%. All physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in 2 cases were parents asked to share in the decision-making. Despite their intense emotions, most parents made great effort to actively participate in the conversation. They did this by asking for clarifications, offering their preferences, and reacting to the decision being proposed (mostly by expressing their assent). In the few cases where parents strongly preferred LST to be continued, the physicians either gave parents more time or revised the decision. **CONCLUSIONS:** We conclude that parents are able to handle a more active role than they are currently being given. Parents' greatest concern is that their child might suffer. Copyright © 2015 by the American Academy of Pediatrics.

PMID: 25560442 [PubMed - indexed for MEDLINE]

38. Acad Med. 2015 Mar;90(3):314-6.

Recording medical students' encounters with standardized patients using Google Glass: providing end-of-life clinical education.

Tully J¹, Dameff C, Kaib S, Moffitt M.

PROBLEM: Medical education today frequently includes standardized patient (SP) encounters to teach history-taking, physical exam, and communication skills. However, traditional wall-mounted cameras, used to record video for faculty and student feedback and evaluation, provide a limited view of key nonverbal communication behaviors during clinical encounters. **APPROACH:** In 2013, 30 second-year medical students participated in an end-of-life module that included SP encounters in which the SPs used Google Glass to record their first-person perspective. Students reviewed the Google Glass video and traditional videos and then completed a postencounter, self-evaluation survey and a follow-up survey about the experience. **OUTCOMES:** Google Glass was used successfully to record 30 student/SP encounters. One temporary Google Glass

hardware failure was observed. Of the 30 students, 7 (23%) reported a "positive, nondistracting experience"; 11 (37%) a "positive, initially distracting experience"; 5 (17%) a "neutral experience"; and 3 (10%) a "negative experience." Four students (13%) opted to withhold judgment until they reviewed the videos but reported Google Glass as "distracting." According to follow-up survey responses, 16 students (of 23; 70%) found Google Glass "worth including in the [clinical skills program]," whereas 7 (30%) did not. **NEXT STEPS:** Google Glass can be used to video record students during SP encounters and provides a novel perspective for the analysis and evaluation of their interpersonal communication skills and nonverbal behaviors. Next steps include a larger, more rigorous comparison of Google Glass versus traditional videos and expanded use of this technology in other aspects of the clinical skills training program.

PMID: 25551855 [PubMed - in process]

39. Palliat Med. 2015 Mar;29(3):231-40. Epub 2014 Dec 17.

Inviting parents to take part in paediatric palliative care research: a mixed-methods examination of selection bias.

Crocker JC¹, Beecham E², Kelly P³, Dinsdale AP⁴, Hemsley J⁴, Jones L⁵, Bluebond-Langner M⁶.

BACKGROUND: Recruitment to paediatric palliative care research is challenging, with high rates of non-invitation of eligible families by clinicians. The impact on sample characteristics is unknown. **AIM:** To investigate, using mixed methods, non-invitation of eligible families and ensuing selection bias in an interview study about parents' experiences of advance care planning (ACP). **DESIGN:** We examined differences between eligible families invited and not invited to participate by clinicians using (1) field notes of discussions with clinicians during the invitation phase and (2) anonymised information from the service's clinical database. **SETTING:** Families were eligible for the ACP study if their child was receiving care from a UK-based tertiary palliative care service (Group A; N = 519) or had died 6-10 months previously having received care from the service (Group B; N = 73). **RESULTS:** Rates of non-invitation to the ACP study were high. A total of 28 (5.4%) Group A families and 21 (28.8%) Group B families (p < 0.0005) were invited. Family-clinician relationship appeared to be a key factor associated qualitatively with invitation in both groups. In Group A, out-of-hours contact with family was statistically associated with invitation (adjusted odds ratio 5.46 (95% confidence interval 2.13-14.00); p < 0.0005). Qualitative findings also indicated that clinicians' perceptions of families' wellbeing, circumstances, characteristics, engagement with clinicians and anticipated reaction to invitation influenced invitation. **CONCLUSION:** We found evidence of selective invitation practices that could bias research findings. Non-invitation and selection bias should be considered, assessed and reported in palliative care studies. © The Author(s) 2014.

PMCID: PMC4361415 **Free PMC Article**

PMID: 25519146 [PubMed - in process]

40. J Nurs Scholarsh. 2015 Mar;47(2):117-25. Epub 2014 Nov 29.

Moral distress among healthcare professionals: report of an institution-wide survey.

Whitehead PB¹, Herbertson RK, Hamric AB, Epstein EG, Fisher JM.

PURPOSE: Moral distress is a phenomenon affecting many professionals across healthcare settings. Few studies have used a standard measure of moral distress to assess and compare differences among professions and settings. **DESIGN:** A descriptive, comparative design was used to study moral distress among all healthcare professionals and all settings at one large healthcare system in January 2011. **METHODS:** Data were gathered via a web-based survey of demographics, the Moral Distress Scale-Revised (MDS-R), and a shortened version of Olson's Hospital Ethical Climate Scale (HECS-S). **FINDINGS:** Five hundred ninety-two (592) clinicians completed usable surveys (22%). Moral distress was present in all professional groups. Nurses and other professionals involved in direct patient care had significantly higher moral distress than physicians (p = .001) and other indirect care professionals (p < .001). Moral distress was negatively correlated with ethical workplace climate (r = -0.516; p < .001). Watching patient care suffer due to lack of continuity and poor communication were the highest-ranked sources of moral distress for all professional groups, but the groups varied in other identified sources. Providers working in adult or intensive care unit (ICU) settings had higher levels of moral distress than did clinicians in pediatric or non-ICU settings (p < .001). Providers who left or considered leaving a position had significantly higher moral distress levels than those who never considered leaving (p < .001). Providers who had training in end-of-life care had higher average levels of moral distress than those without this training (p = .005). **CONCLUSIONS:** Although there may be differences in perspectives and experiences, moral distress is a common experience for clinicians, regardless of profession. **CLINICAL RELEVANCE:** Moral distress is associated with burnout and intention to leave a position. By understanding its root causes, interventions can be tailored to minimize moral distress with the ultimate goal of enhancing patient care, staff satisfaction, and retention. © 2014 Sigma Theta Tau International.

PMID: 25440758 [PubMed - in process]

41. Pediatr Transplant. 2015 Feb;19(1):11-7. Epub 2014 Nov 25.

Palliative and end-of-life care in pediatric solid organ transplantation.

Fowler A¹, Freiberger D, Moonan M.

Abstract End-of-life care is a component of palliative care and takes a holistic, individualized approach to patients, focusing on the assessment of quality of life and its maintenance until the end of life, and beyond, for the patient's family. Transplant teams do not always make timely referrals to palliative care teams due to various clinician and perceived family barriers, an important one being the simultaneous, active care plan each patient would have alongside an end-of-life plan. Application of findings and further research specific to the pediatric solid organ population would be of significant benefit to guide transplant teams as to the most effective time to introduce end-of-life care, who to involve in ongoing discussions, and important ethical and cultural considerations to include in care planning. Attention must also be paid to clinician training and support in this challenging area of health care.

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PMID: 25422076 [PubMed - in process]

42. J Palliat Med. 2015 Feb;18(2):120-6. Epub 2014 Nov 20.

Comparison of pediatric and adult hospice patients using electronic medical record data from nine hospices in the United States, 2008-2012.

Dingfield L¹, Bender L, Harris P, Newport K, Hoover-Regan M, Feudtner C, Clifford S, Casarett D.

BACKGROUND: Most pediatric hospice patients receive services from agencies typically oriented to adults. Information regarding how pediatric hospice patients differ from adult hospice patients is lacking. **OBJECTIVE:** We aim to assess differences between pediatric and adult hospice patients regarding patient characteristics and outcomes. **METHODS:** We compiled a retrospective inception cohort of patients enrolled at nine hospices in the CHOICE network (Coalition of Hospices Organized to Investigate Comparative Effectiveness) between August 1, 2008 and June 30, 2012. Measurements included patient characteristics and outcomes, including discharge from hospice and site of death. **RESULTS:** Among 126,620 hospice patients, 986 (0.8%) were 18 years of age or younger. Pediatric patients were less likely to have an admitting diagnosis of cancer (odds ratio [OR] 0.62; 95% confidence interval [CI]: 0.54-0.72). Although children were less likely to use oxygen at enrollment (OR 0.31; 95% CI: 0.26-0.37), they were more likely to have an enteral feeding tube (OR 4.04; 95% CI: 3.49-4.67). Pediatric patients were half as likely as adults to have a do-not-resuscitate order (DNR) order upon hospice enrollment (OR 0.52; 95% CI: 0.46-0.59). The average hospice length of stay for pediatric patients was longer than that of adults (103 days versus 66 days, $p < 0.001$). Children were more likely to leave hospice care (OR 2.59; 95% CI: 2.00-3.34), but among patients who died while enrolled in hospice, pediatric patients were more likely to die at home (OR 3.25; 95% CI: 2.27-3.88). **CONCLUSIONS:** Pediatric hospice patients differ from adult patients in their broader range of underlying diagnoses and their use of hospice services.

PMID: 25411904 [PubMed - in process]

43. J Palliat Med. 2015 Feb;18(2):143-50. Epub 2014 Nov 17.

Improved quality of life at end of life related to home-based palliative care in children with cancer.

Friedrichsdorf SJ¹, Postier A, Dreyfus J, Osenka K, Sencer S, Wolfe J.

BACKGROUND: Nearly 2000 children die due to a malignancy in the United States annually. Emerging data suggest that home is the desired location of care for children with cancer at end of life. However, one obstacle to enrollment in a pediatric palliative care (PPC) home care program may be fear that distressing symptoms at end of life cannot be adequately managed outside the hospital. **OBJECTIVE:** To compare the symptom distress and quality-of-life experience for children who received concurrent end-of-life care from a PPC home care program (PPC/Oncology) with that of those who died without exposure to the PPC program (Oncology). **METHODS:** We conducted a retrospective survey study of a cohort of bereaved parents of children who died of cancer between 2002 and 2008 at a U.S. tertiary pediatric institution. **RESULTS:** Sixty bereaved parents were surveyed (50% PPC/Oncology). Prevalence of constipation and high distress from fatigue were more common in the PPC/Oncology group; other distressing symptoms were similar between groups, showing room for improvement. Children who received PPC/Oncology were significantly more likely to have fun (70% versus 45%), to experience events that added meaning to life (89% versus 63%), and to die at home (93% versus 20%). **CONCLUSIONS:** This is the first North American study to assess outcomes among children with cancer who received concurrent oncology and palliative home care compared with those who received oncology care alone. Symptom distress experiences were similar in groups. However, children enrolled in a PPC home care program appear to have improved quality of life and are more likely to die at home.

PMID: 25401507 [PubMed - in process]

44. Palliat Med. 2015 Mar;29(3):212-22. Epub 2014 Nov 11.

Pediatric advance care planning from the perspective of health care professionals: a qualitative interview study.

Lotz JD¹, Jox RJ², Borasio GD³, Führer M⁴.

BACKGROUND: Pediatric advance care planning differs from the adult setting in several aspects, including patients' diagnoses, minor age, and questionable capacity to consent. So far, research has largely neglected the professionals' perspective. **AIM:** We aimed to investigate the attitudes and needs of health care professionals with regard to pediatric advance care planning. **DESIGN:** This is a qualitative interview study with experts in pediatric end-of-life care. A qualitative content analysis was performed. **SETTING/PARTICIPANTS:** We conducted 17 semi-structured interviews with health care professionals caring for severely ill children/adolescents, from different professions, care settings, and institutions. **RESULTS:** Perceived problems with pediatric advance care planning relate to professionals' discomfort and uncertainty regarding end-of-life decisions and advance directives. Conflicts may arise between physicians and non-medical care providers because both avoid taking responsibility for treatment limitations according to a minor's advance directive. Nevertheless, pediatric advance care planning is perceived as helpful by providing an action plan for everyone and ensuring that patient/parent wishes are respected. Important requirements for pediatric advance care planning were identified as follows: repeated discussions and shared decision-making with the family, a qualified facilitator who ensures continuity throughout the whole process, multi-professional conferences, as well as professional education on advance care planning. **CONCLUSION:** Despite a perceived need for pediatric advance care planning, several barriers to its implementation were identified. The results remain to be verified in a larger cohort of health care professionals. Future research should focus on developing and testing strategies for overcoming the existing barriers. © The Author(s) 2014.

PMID: 25389347 [PubMed - in process]

45. J Palliat Med. 2015 Feb;18(2):162-6. Epub 2014 Oct 29.

Assessing need for palliative care services for children in Mexico.

Cardenas-Turanzas M¹, Tovalin-Ahumada H, Romo CG, Okhuysen-Cawley R.

BACKGROUND: Pediatric palliative care increasingly became integrated into health care institutions worldwide over the last decade. However, in Mexico and other developing countries with large populations of children, little is known regarding

the need for palliative care services. We aimed to assess the need for palliative and end-of-life care for children dying in public hospitals affiliated with Secretaria de Salud in Mexico. **MEASUREMENT:** We conducted a retrospective review of deaths of children (1-17 years old) occurring during 2011 and determined deaths associated with underlying complex chronic conditions by reviewing the four causes of death listed in the death certificate. We collected sociodemographic and clinical data and utilized univariate and multivariate analyses to determine factors associated with complex chronic conditions. **RESULTS:** A total of 2715 pediatric deaths were studied. We found 41% were associated with a complex chronic condition. The most frequent types of conditions were malignancies (47%), neuromuscular (18%), cardiovascular (12%), and renal (10%). Children with renal and malignant conditions died at an older age than children with other types of complex chronic conditions. Multivariate analysis indicated the independent predictors of death with complex chronic condition were no indigenous ethnicity, lack of admission to the intensive care unit during the final hospital stay, and having affiliation with an institution for health care. **CONCLUSIONS:** A large proportion of pediatric deaths are associated with complex chronic conditions indicating the provision of adequate funding for professional education and palliative care initiatives for children in Mexico, should be a topic of the national health care agenda.

PMID: 25353338 [PubMed - in process]

46. J Perinatol. 2015 Mar;35(3):218-22. Epub 2014 Oct 23.

Impact of a palliative care program on end-of-life care in a neonatal intensive care unit.

Younge N¹, Smith PB¹, Goldberg RN¹, Brandon DH¹, Simmons C¹, Cotten CM¹, Bidegain M¹.

OBJECTIVE: Evaluate changes in end-of-life care following initiation of a palliative care program in a neonatal intensive care unit. **STUDY DESIGN:** Retrospective study comparing infant deaths before and after implementation of a Palliative Care Program comprised of medication guidelines, an individualized order set, a nursing care plan and staff education. **RESULT:** Eighty-two infants died before (Era 1) and 68 infants died after implementation of the program (Era 2). Morphine use was similar (88% vs 81%; P =0.17), whereas benzodiazepines use increased in Era 2 (26% vs 43%; P=0.03). Withdrawal of life support (73% vs 63%; P=0.17) and do-not-resuscitate orders (46% vs 53%; P=0.42) were similar. Do-not-resuscitate orders and family meetings were more frequent among Era 2 infants with activated palliative care orders (n=21) compared with infants without activated orders (n=47). **CONCLUSION:** End-of-life family meetings and benzodiazepine use increased following implementation of our program, likely reflecting adherence to guidelines and improved communication.

PMID: 25341195 [PubMed - in process]

47. Adv Neonatal Care. 2015 Feb;15(1):48-55.

Medical record documentation and symptom management at the end of life in the NICU.

Fortney CA¹, Steward DK.

PURPOSE: In neonates, the course of illness is often unpredictable and symptom assessment is difficult. This is even truer at the end of life (EOL). Time to death can take minutes to days, and ongoing management of the infant is needed during the time between discontinuation of life-sustaining treatment and death to ensure that the infant remains free of pain and suffering. The symptoms experienced by neonates as they die, as well as best ways to treat those symptoms, are understudied. The purpose of this study was to examine symptoms exhibited by neonates at the EOL and the treatments used to manage those symptoms as documented in the medical record during the last 24 hours of life. **SUBJECTS:** The sample included 20 neonates who died at a large children's hospital. **DESIGN:** This was an exploratory, descriptive study. **METHODS:** Descriptive data, such as diagnosis, ongoing therapy at time of treatment withdrawal or withholding, pharmacologic and nonpharmacologic interventions associated with treatment withdrawal, time of treatment withdrawal and death, age at time of death, signs and symptoms exhibited during EOL care, and pain scores, were abstracted from the infant's medical record. **MAIN OUTCOME MEASURES:** Inadequate documentation in the medical record resulted in missing data that made it not possible to fully explore aspects of symptom management during the last 24 hours of life; however, some important results were found. **RESULTS:** This study showed a difference in the way neonates approach the EOL period. Other findings were that most infants in the study received pain medication, even though pain scores were infrequently documented and drug dosages varied across infants. Finally, documentation of nonpharmacologic interventions utilized at the EOL was also lacking.

PMCID: PMC4310764 [Available on 2016-02-01]

PMID: 25313801 [PubMed - in process]

48. J Perinatol. 2015 Feb;35(2):151-4. Epub 2014 Sep 18.

Does diagnosis influence end-of-life decisions in the neonatal intensive care unit?

Weiner J¹, Sharma J¹, Lantos J², Kilbride H¹.

OBJECTIVE: To determine the influence of physiological status and diagnosis at the time of death on end-of-life care. **STUDY DESIGN:** Retrospective descriptive study in a regional referral level IV neonatal intensive care unit (NICU) of infants who died from 1 January 1999 to 31 December 2008. Infants were categorized based on diagnosis (very preterm, congenital anomalies or other) and level of stability. Primary outcome was level of clinical service provided at end of life (care withheld, care withdrawn or full resuscitation). **RESULT:** From 1999 to 2008, there were 414 deaths in the NICU. Congenital anomaly was the leading diagnosis at the time of death, representing 45% of all deaths. Comparing mode of death, very preterm newborns were more likely than infants with congenital anomalies to have received cardio-pulmonary resuscitation (CPR) at the time of death (26% vs 13%, P < 0.01) and were significantly more unstable (75% vs 52%, P < 0.01). Infants aged 22 to 24 weeks were mostly unstable and significantly more likely to receive CPR than infants with any other diagnosis. **CONCLUSION:** Over the 10-year period, very preterm infants were more likely to be physiologically unstable and to receive CPR at the time of death than infants with any other diagnosis. This finding was especially true for infants at the edge of viability (22 to 24 weeks). These differences in end-of-life care suggest that the quality of life and medical futility may be viewed differently for the least mature infants.

PMID: 25233192 [PubMed - in process]

49. J Palliat Med. 2015 Feb;18(2):167-9. Epub 2014 Sep 12.

Radiation therapy at end of life in children.

Panoff J¹, Simoneaux RV, Shah N, Scott M, Buchsbaum JC, Johnstone PA, McMullen KP.

OBJECTIVE: Few data exist on evaluating utilization patterns of radiotherapy (RT) at the end of life (EOL) in children. Metastatic disease in pediatric patients is not pathognomonic for palliative treatment intent; further complicating the issue are complexities surrounding the very select population of children receiving proton therapy (PrT). We compared data for RT and PrT in terms of death rate within 30 days. **METHODS:** We performed chart reviews for patients receiving radiation therapy at age ≤ 21 years treated at Indiana University Health Proton Therapy Center (IUHPTC) between June 2008 and June 2013 and University of Miami Radiation Oncology Department (UM) between June 2000 and June 2013. Included were patients not completing prescribed courses of RT, and those dying within 30 days of therapy. Comparison was made of differences between practice data for PrT and conventional RT. **RESULTS:** At IUHPTC, 2 children of 272 did not complete their courses and died within 30 days (0.7%). At UM, data are available for 425 children; 9 did not complete their courses and 7 died within 30 days (1.6%). Neither the number of patients who did not complete treatment nor the 30-day death rates ($P=.21$) for PrT and RT were significantly different. **CONCLUSIONS:** Delivery of RT for children at EOL is complex. Frequency of RT at EOL in children occurs in is $<2\%$ of cases, and is not significantly less frequent in the proton milieu. This appears to be about an order of magnitude less than in adults.

PMID: 25216446 [PubMed - in process]

50. Death Stud. 2015 Feb;39(2):111-7. Epub 2014 Nov 25.

On the Child's Own Initiative: Parents Communicate with Their Dying Child About Death.

Jalmsell L¹, Kontio T, Stein M, Henter JI, Kreicbergs U.

Abstract Open and honest communication has been identified as an important factor in providing good palliative care. However, there is no easy solution to if, when, and how parents and a dying child should communicate about death. This article reports how bereaved parents communicated about death with their child, dying from a malignancy. Communication was often initiated by the child and included communication through narratives such as fairy tales and movies and talking more directly about death itself. Parents also reported that their child prepared for death by giving instructions about his or her grave or funeral and giving away toys.

PMID: 25153166 [PubMed - in process]

51. J Pain Symptom Manage. 2015 Mar;49(3):521-529.e5. Epub 2014 Aug 15.

Hospital End-of-Life Treatment Intensity Among Cancer and Non-Cancer Cohorts.

Barnato AE¹, Cohen ED², Mistovich KA³, Chang CC⁴.

CONTEXT: Hospitals vary substantially in their end-of-life (EOL) treatment intensity. It is unknown if patterns of EOL treatment intensity are consistent across conditions. **OBJECTIVES:** To explore the relationship between hospitals' cancer- and non-cancer-specific EOL treatment intensity. **METHODS:** We conducted a retrospective cohort analysis of Pennsylvania acute care hospital admissions for either cancer or congestive heart failure (CHF) and/or chronic obstructive pulmonary disease (COPD) between 2001 and 2007, linked to vital statistics through 2008. We calculated Bayes's shrunken case-mix standardized (observed-to-expected) ratios of intensive care and life-sustaining treatment use among two EOL cohorts: those prospectively identified at high probability of dying on admission and those retrospectively identified as terminal admissions (decedents). We then summed these to create a hospital-specific prospective and retrospective overall EOL treatment intensity index for cancer vs. CHF/COPD. **RESULTS:** The sample included 207,523 admissions with 15% or greater predicted probability of dying on admission among 172,041 unique adults and 120,372 terminal admissions at 166 hospitals; these two cohorts overlapped by 52,986 admissions. There was substantial variation between hospitals in their standardized EOL treatment intensity ratios among cancer and CHF/COPD admissions. Within hospitals, cancer- and CHF/COPD-specific standardized EOL treatment intensity ratios were highly correlated for intensive care unit (ICU) admission (prospective $\rho = 0.81$; retrospective $\rho = 0.78$), ICU lengths of stay ($\rho = 0.76$; 0.64), mechanical ventilation ($\rho = 0.73$; 0.73), and hemodialysis ($\rho = 0.60$; 0.71) and less highly correlated for tracheostomy ($\rho = 0.43$; 0.53) and gastrostomy ($\rho = 0.29$; 0.30). Hospitals' overall EOL intensity index for cancer and CHF admissions were correlated (prospective $\rho = 0.75$; retrospective $\rho = 0.75$) and had equal group means (P -value = 0.631; 0.699). **CONCLUSION:** Despite substantial difference between hospitals in EOL treatment intensity, within-hospital homogeneity in EOL treatment intensity for cancer- and non-cancer populations suggests the existence of condition-insensitive institutional norms of EOL treatment. Copyright © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

PMCID: PMC4329285 [Available on 2016-03-01]

PMID: 25135656 [PubMed - in process]

52. J Med Ethics. 2015 Feb;41(2):201-2. Epub 2014 Jun 23.

Ethics of paediatric end-of-life decision making and consent for publication.

Isaacs D¹.

In their interesting paper in this issue, De Vos *et al* consider the ethical issues when parents want treatment for their child to be withdrawn against the recommendations of the medical team. They discuss whether or not such end-of-life decisions should be shared with parents and whether or not physicians should protect parents from guilt or doubt in decision-making. De Vos *et al* conclude that the parents should be involved in decision-making, that it is not appropriate to exclude them from decision-making in order to protect them and that it should be hard to overrule parents' decisions about terminating treatment. I should make it clear that they mean life-prolonging invasive treatment; they are not proposing euthanasia.

Comment on Parents who wish no further treatment for their child. [J Med Ethics. 2015]

PMID: 24958335 [PubMed - in process]

53. Cancer Nurs. 2015 Mar-Apr;38(2):155-61.

Facebook advertisements recruit parents of children with cancer for an online survey of web-based research preferences.

Akard TF¹, Wray S, Gilmer MJ.

BACKGROUND: Studies involving samples of children with life-threatening illnesses and their families face significant challenges, including inadequate sample sizes and limited diversity. Social media recruitment and Web-based research methods may help address such challenges yet have not been explored in pediatric cancer populations. **OBJECTIVE:** This study examined the feasibility of using Facebook advertisements to recruit parent caregivers of children and teenagers with cancer. We also explored the feasibility of Web-based video recording in pediatric palliative care populations by surveying parents of children with cancer regarding (a) their preferences for research methods and (b) technological capabilities of their computers and phones. **METHODS:** Facebook's paid advertising program was used to recruit parent caregivers of children currently living with cancer to complete an electronic survey about research preferences and technological capabilities. **RESULTS:** The advertising campaign generated 3 897 981 impressions, which resulted in 1050 clicks at a total cost of \$1129.88. Of 284 screened individuals, 106 were eligible. Forty-five caregivers of children with cancer completed the entire electronic survey. Parents preferred and had technological capabilities for Web-based and electronic research methods. Participant survey responses are reported. **CONCLUSION:** Facebook was a useful, cost-effective method to recruit a diverse sample of parent caregivers of children with cancer. Web-based video recording and data collection may be feasible and desirable in samples of children with cancer and their families. **IMPLICATIONS FOR PRACTICE:** Web-based methods (eg, Facebook, Skype) may enhance communication and access between nurses and pediatric oncology patients and their families.

PMCID: PMC4270949 [Available on 2016-03-01]

PMID: 24945264 [PubMed - in process]

54. J Med Ethics. 2015 Feb;41(2):195-200. Epub 2014 Jun 10.

Parents who wish no further treatment for their child.

de Vos MA¹, Seeber AA², Gevers SK³, Bos AP⁴, Gevers F⁵, Willems DL¹.

Comment in Ethics of paediatric end-of-life decision making and consent for publication. [J Med Ethics. 2015]

BACKGROUND: In the ethical and clinical literature, cases of parents who want treatment for their child to be withdrawn against the views of the medical team have not received much attention. Yet resolution of such conflicts demands much effort of both the medical team and parents. **OBJECTIVE:** To discuss who can best protect a child's interests, which often becomes a central issue, putting considerable pressure on mutual trust and partnership. **METHODS:** We describe the case of a 3-year-old boy with acquired brain damage due to autoimmune-mediated encephalitis whose parents wanted to stop treatment. By comparing this case with relevant literature, we systematically explored the pros and cons of sharing end-of-life decisions with parents in cases where treatment is considered futile by parents and not (yet) by physicians. **CONCLUSIONS:** Sharing end-of-life decisions with parents is a more important duty for physicians than protecting parents from guilt or doubt. Moreover, a request from parents on behalf of their child to discontinue treatment is, and should be, hard to over-rule in cases with significant prognostic uncertainty and/or in cases with divergent opinions within the medical team. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>.

PMID: 24917616 [PubMed - in process]

55. J Med Ethics. 2015 Mar;41(3):234-9. Epub 2014 Apr 24.

Balancing obligations: should written information about life-sustaining treatment be neutral?

Xafis V¹, Wilkinson D², Gillam L³, Sullivan J⁴.

Abstract Parents who are facing decisions about life-sustaining treatment for their seriously ill or dying child are supported by their child's doctors and nurses. They also frequently seek other information sources to help them deal with the medical and ethical questions that arise. This might include written or web-based information. As part of a project involving the development of such a resource to support parents facing difficult decisions, some ethical questions emerged. Should this information be presented in a strictly neutral fashion? Is it problematic if narratives, arguments or perspectives appear to favour stopping over continuing life-sustaining treatment? Similar questions might arise with written materials about decisions for adults, or for other ethically contentious decisions. This paper explores the meaning of 'balance' in information provision, focusing particularly on written information about life-sustaining treatment for children. We contrast the norm of non-directiveness in genetic counselling with the shared decision-making model often endorsed in end-of-life care. We review evidence that parents do not find neutrality from medical professionals helpful in discussions. We argue that balance in written information must be understood in the light of the aim of the document, the most common situation in which it will be used, and any existing biases. We conclude with four important strategies for ensuring that non-neutral information is nevertheless ethically appropriate. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>.

PMCID: PMC4345516 **Free PMC Article**

PMID: 24763219 [PubMed - in process]

56. Am J Hosp Palliat Care. 2015 Feb;32(1):101-11. Epub 2013 Nov 6.

Young adult palliative care: challenges and opportunities.

Clark JK¹, Fasciano K².

Abstract Young adulthood is a time of immense growth and possibilities. As a result, it is also a time when serious illness can have profound effects. This review examines the current data pertinent to young adult palliative care and discusses the chal-

lenges and opportunities where palliative medicine can enhance the care provided to this growing and vulnerable population. From the data, 2 primary themes emerged (1) ongoing young adult development not only generates unique biologic disease burdens and clinical treatment options but also requires frequent assessment and promotion and (2) binary health care systems often leave young adults without access to developmentally appropriate health care. Given its interdisciplinary approach, palliative care is uniquely poised to address the challenges known to caring for the seriously ill young adult. © The Author(s) 2013.

PMID: 24198063 [PubMed - in process]

57. Palliat Support Care. 2015 Mar 24;1-7. [Epub ahead of print]

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

Melcher U¹, Sandell R², Henriksson A¹.

OBJECTIVE: Teenagers are living through a turbulent period in their development, when they are breaking away from the family to form their own identities, and so they are particularly vulnerable to the stressful situation of having a parent affected by a progressive and incurable illness. The current study sought to gain more knowledge about the ways that teenagers themselves describe living in a family with a seriously ill and dying parent. More specifically, the aims were to describe how teenagers are emotionally affected by everyday life in a family with a dying parent and to determine how they attempt to adapt to this situation. **METHOD:** The study employed a descriptive and interpretive design using qualitative content analysis. A total of 10 teenagers (aged 14-19 years, 7 boys and 3 girls) participated through repeated, individual, informal interviews that were carried out as free-ranging conversations. **RESULTS:** While contending with their own vulnerable developmental period of life, the teenagers were greatly affected by their parent's illness and took on great responsibility for supporting their parents and siblings, and for maintaining family life. Lacking sufficient information and support left them rather unprepared, having to guess and to interpret the vague signs of failing health on their own, with feelings of uncertainty and loneliness as a consequence. **SIGNIFICANCE OF RESULTS:** Support from healthcare professionals should be designed to help and encourage parents to have open communications about their illness with their teenaged children. Our results add further support to the literature, reinforcing the need for an approach that uses a systemic perspective and considers the family to be the appropriate unit of care and offers a suitable support system.

PMID: 25800062 [PubMed - as supplied by publisher]

58. J Pain Symptom Manage. 2015 Mar 7. [Epub ahead of print]

Authors' Response to van der Geest et al. - comment

Rosenberg AR¹, Wolfe J².

PMID: 25757836 [PubMed - as supplied by publisher]

59. JAMA Pediatr. 2015 Mar 1;169(3):285-6.

Don'T forget palliative patients. - comment

Frader J¹, Derrington S¹, Morgan E¹.

PMID: 25730687 [PubMed - in process]

60. Cochrane Database Syst Rev. 2015 Feb 26;2:CD011404.

As required versus fixed schedule analgesic administration for postoperative pain in children.

Hobson A¹, Wiffen PJ, Conlon JA.

BACKGROUND: Acute postoperative pain occurs as a result of tissue damage following surgery. Administering the appropriate analgesia to children is a complex process and it is unclear whether children's postoperative pain is more successfully treated by using 'as required' (when pain occurs) (termed 'pro re nata' or PRN) or (irrespective of pain at the time of administration). **OBJECTIVES:** To assess the efficacy of as required versus fixed schedule analgesic administration for the management of postoperative pain in children under the age of 16 years. **SEARCH METHODS:** On 2 July 2014, we searched the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, EMBASE, and CINAHL databases. We reviewed the bibliographies of all included studies and of reviews, and searched two clinical trial databases, ClinicalTrials.gov and the World Health Organization (WHO) International Clinical Trials Registry Platform, to identify additional published or unpublished data. **SELECTION CRITERIA:** We included randomised controlled trials (RCTs) comparing PRN versus ATC analgesic administration for postoperative pain in children under the age of 16 years who had undergone any surgical procedure requiring postoperative pain relief, in any setting. **DATA COLLECTION AND ANALYSIS:** Two review authors (AH, PW) independently extracted efficacy and adverse event data, examined issues of study quality, and assessed risk of bias as recommended in the Cochrane Handbook for Systematic Reviews of Interventions. **MAIN RESULTS:** We included three RCTs (four reports) of 246 children aged under 16 years undergoing tonsillectomy. Children were given weight-appropriate doses of the study medication, either PRN or ATC, by a parent or carer at home for up to four days following surgery. We did not identify any studies assessing the management of postoperative pain in children in any other setting (i.e. as an inpatient). All studies included in this review were based on the use of paracetamol, and an opioid was added to paracetamol in two studies. Analgesics were administered either orally (tablet or elixir) or rectally (suppository). Reporting quality was poor and there were fewer than 50 children in each arm. Mean pain intensity scores decreased over time, as did medication use. However, children were still reporting pain at the final assessment, suggesting that no administration schedule provided adequate analgesia. There were no significant differences in pain intensity scores at any time point. The studies reported adverse events that may have been related to the study medication, such as nausea and vomiting, and constipation, but no statistically significant differences were noted between the groups. There were too few data from only three small studies and meta-analysis was not possible. One study reported that a higher amount of analgesics was consumed in the ATC group compared with the PRN group: it would have been helpful to show that the higher volume in the ATC group led to better an-

algnesia but we were not able to demonstrate this. **AUTHORS' CONCLUSIONS:** There was limited evidence available to draw any conclusions about the efficacy of PRN versus ATC analgesic administration for the management of postoperative pain in children.

PMID: 25719451 [PubMed - in process]

61. Eur J Oncol Nurs. 2015 Feb 14. [Epub ahead of print]

Adherence to treatment in patient with severe cancer pain: A qualitative enquiry through illness narratives.

Torresan MM¹, Garrino L², Borraccino A³, Macchi G¹, De Luca A¹, Dimonte V².

PURPOSE: Pain is a common symptom in cancer patients and often the most tangible sign of disease they and their families perceive. Despite currently available treatments, cancer pain frequently remains underrated and undertreated because of lack of adherence to the prescribed drug regimen. With this study we sought to identify elements that could facilitate pain management by exploring through narrative interviews the lived experiences of patients with severe chronic cancer pain in relation to their adherence to pain therapy. **METHOD:** A purposive sample of 18 cancer patients, treated at the Centre for Oncology and Haematology (COES), City Hospital for Health and Science, Turin, were interviewed. The interview contents were analysed using a qualitative phenomenological methodology as described by Giorgi. **RESULTS:** Three themes emerged from analysis of the interview transcripts: the significance of pain in subjective experience; the experience of being a patient pursuing a care pathway and the importance attributed to pain therapy. Factors facilitating adherence included the perception of the physical and psychological benefits of having and following a pain medications plan, subjective self-efficacy in pain control, and trust in the healthcare team. Barriers to adherence were negative attitudes toward opioid analgesic therapy, debilitating drug side effects, and denial of pain as a tangible sign of disease. **CONCLUSION:** Probing into the significance of the pain experience and its treatment through these narrative interviews revealed several core constituents of adherence. Healthcare providers can use this better understanding to build a trusting relationship with patients and foster adherence to treatment throughout the care pathway. Copyright © 2015 Elsevier Ltd. All rights reserved.

PMID: 25691299 [PubMed - as supplied by publisher]

62. J Pediatr Nurs. 2015 Feb 11. [Epub ahead of print]

Family Functioning as a Constituent Aspect of a Child's Chronic Illness.

Cipolletta S¹, Marchesin V², Benini F³.

Abstract This study explored how family functioning may contribute to trace a child's illness trajectory. We conducted semi-structured interviews with 33 parents of children in care at a hospice in northern Italy. We also examined the medical records of the children, and interviewed the physician who cared for them. Data analysis was based on the grounded theory approach. Different illness progressions corresponded to the different ways with which families experienced the illness: possibility, focus on illness, denial, and anger. Clinical interventions should involve the whole family and take into account their role in the construction of illness trajectories. Copyright © 2015 Elsevier Inc. All rights reserved.

PMID: 25682020 [PubMed - as supplied by publisher]

63. J Palliat Med. 2015 Mar;18(3):305. Epub 2015 Feb 11.

A big pot of colored sweets.

Bender HU¹.

Abstract Several years ago, when beginning my specialization in pediatric oncology and palliative care, I saw JS, a nine-year-old girl, at the pediatric oncology and palliative care clinic. She had a relapsed and progressing rhabdomyosarcoma of the orbita and had undergone chemotherapy, radiotherapy, and experimental therapy with no success. In the following months He saw her weekly and got to know her and her mother. The tumor mass grew substantially, displacing the left eye, bursting the temporomandibular joint, forcing the mouth open and ultimately growing out of the mouth.

PMID: 25671349 [PubMed - in process]

64. J Child Neurol. 2015 Feb 6. [Epub ahead of print]

How Can We Practice Ethical Medicine When the Evidence Is Always Changing?

Noritz G¹.

Abstract The practice of ethical medicine requires that the clinician offers interventions that are likely to help (beneficence), avoid interventions that are likely to harm (nonmaleficence), and allow for autonomous decision making. Our determination of what is in the best interest of the patient is dependent on the state of medical evidence at the time. However, as evidence evolves, the balance of beneficence and nonmaleficence may change, even to the extent of a complete reversal. In this article, I explore the issues of autonomy, particularly parental autonomy for a child, in a world in which the evidence is always changing. © The Author(s) 2015.

PMID: 25660134 [PubMed - as supplied by publisher]

65. Hosp Pediatr. 2015 Feb;5(2):85-91.

A premeditation fluid bolus does not decrease the incidence of propofol-induced hypotension in pediatric patients.

Jager MD¹, Aldag JC², Deshpande GC³.

BACKGROUND AND OBJECTIVE: Propofol is commonly used in pediatric sedation, which may cause hypotension during induction. Our goal was to determine the effect of a preinduction 20-mL/kg isotonic fluid bolus on propofol-induced hypotension, assess clinical signs of hypoperfusion during hypotension, and evaluate for age-related propofol dosing differences. **METHODS:** This prospective, randomized, controlled, nonblinded study was conducted at Children's Hospital of Illinois. Patients were children 6 to 60 months of age who needed sedation for MRI or auditory brainstem-evoked response testing. The treatment group received a preinduction 20-mL/kg isotonic saline bolus before procedure initiation. Patients were con-

tinuously monitored via cardiorespiratory monitor with pulse oximetry and end-tidal carbon dioxide measurements. Cardiovascular indices and clinical signs of hypoperfusion were compared between groups, and propofol dosing differences were compared between age groups. **RESULTS:** One hundred twenty-six patients were randomly assigned to treatment (n = 52) or control (n = 74) conditions. Twelve patients in the treatment group and 14 patients in the control group experienced post-induction hypotension, as defined by the Pediatric Advanced Life Support guidelines. One patient in each group was given volume resuscitation when blood pressure did not improve after a reduction in the propofol infusion rate. No hypotensive patients had physical signs of hypoperfusion, and patients ≤ 1 year of age needed significantly more propofol. **CONCLUSIONS:** A 20-mL/kg preinduction isotonic saline bolus does not prevent propofol-induced hypotension. No clinical signs of hypoperfusion were noted with induced hypotension, and infants ≤ 12 months old need significantly more propofol per kilogram for procedures. Copyright © 2015 by the American Academy of Pediatrics. PMID: 25646201 [PubMed - in process]

66. Pediatrics. 2015 Feb;135(2):e457-64.

Sustained lung inflation at birth for preterm infants: a randomized clinical trial.

Listà G¹, Boni L², Scopesi F³, Mosca F⁴, Trevisanuto D⁵, Messner H⁶, Vento G⁷, Magaldi R⁸, Del Vecchio A⁹, Agosti M¹⁰, Gizzi C¹¹, Sandri F¹², Biban P¹³, Bellettato M¹⁴, Gazzolo D¹⁵, Boldrini A¹⁶, Dani C¹⁷; SLI Trial Investigators.

Collaborators: (30)

Bruschettini M, Colnaghi MR, Vanzati M, Doglioni N, Roncati D, Pratesi S, Buzzi V, Castoldi F, Caviglioli F, Wanker P, Chiodin E, Lio A, Perelli S, Maffei G, Popolo G, Petrillo F, Brancale F, Francescato G, Di Marco A, Massenzi L, Palatta S, Alati S, Giura F, Spaggiari S, Vecchiato L, Vedovato S, Strozzi MC, Bellissima V, Cianfelli M, Scaramuzzo R.

BACKGROUND: Studies suggest that giving newly born preterm infants sustained lung inflation (SLI) may decrease their need for mechanical ventilation (MV) and improve their respiratory outcomes. **METHODS:** We randomly assigned infants born at 25 weeks 0 days to 28 weeks 6 days of gestation to receive SLI (25 cm H₂O for 15 seconds) followed by nasal continuous positive airway pressure (nCPAP) or nCPAP alone in the delivery room. SLI and nCPAP were delivered by using a neonatal mask and a T-piece ventilator. The primary end point was the need for MV in the first 72 hours of life. The secondary end points included the need for respiratory supports and survival without bronchopulmonary dysplasia (BPD). **RESULTS:** A total of 148 infants were enrolled in the SLI group and 143 in the control group. Significantly fewer infants were ventilated in the first 72 hours of life in the SLI group (79 of 148 [53%]) than in the control group (93 of 143 [65%]); unadjusted odds ratio: 0.62 [95% confidence interval: 0.38-0.99]; P = .04). The need for respiratory support and survival without BPD did not differ between the groups. Pneumothorax occurred in 1% (n = 2) of infants in the control group compared with 6% (n = 9) in the SLI group, with an unadjusted odds ratio of 4.57 (95% confidence interval: 0.97-21.50; P = .06). **CONCLUSIONS:** SLI followed by nCPAP in the delivery room decreased the need for MV in the first 72 hours of life in preterm infants at high risk of respiratory distress syndrome compared with nCPAP alone but did not decrease the need for respiratory support and the occurrence of BPD. Copyright © 2015 by the American Academy of Pediatrics.

PMID: 25624390 [PubMed - indexed for MEDLINE]

67. JAMA Intern Med. 2015 Mar 1;175(3):420-7.

Out-of-Hospital Mortality Among Patients Receiving Methadone for Noncancer Pain.

Ray WA¹, Chung CP², Murray KT³, Cooper WO⁴, Hall K¹, Stein CM⁵.

IMPORTANCE: Growing methadone use in pain management has raised concerns regarding its safety relative to other long-acting opioids. Methadone hydrochloride may increase the risk for lethal respiratory depression related to accidental overdose and life-threatening ventricular arrhythmias. **OBJECTIVE:** To compare the risk of out-of-hospital death in patients receiving methadone for noncancer pain with that in comparable patients receiving sustained-release (SR) morphine sulfate. **DESIGN, SETTING, AND PARTICIPANTS:** A retrospective cohort study was conducted using Tennessee Medicaid records from 1997 through 2009. The cohort included patients receiving morphine SR or methadone who were aged 30 to 74 years, did not have cancer or another life-threatening illness, and were not in a hospital or nursing home. At cohort entry, 32 742 and 6014 patients had filled a prescription for morphine SR or methadone, respectively. The patients' median age was 48 years, 57.9% were female, and comparable proportions had received cardiovascular, psychotropic, and other musculoskeletal medications. Nearly 90% of the patients received the opioid for back pain or other musculoskeletal pain. The median doses prescribed for morphine SR and methadone were 90 mg/d and 40 mg/d, respectively. **MAIN OUTCOMES AND MEASURES:** The primary study end point was out-of-hospital mortality, given that opioid-related deaths typically occur outside the hospital. **RESULTS:** There were 477 deaths during 28 699 person-years of follow-up (ie, 166 deaths per 10 000 person-years). After control for study covariates, patients receiving methadone had a 46% increased risk of death during the follow-up period, with an adjusted hazard ratio (HR) of 1.46 (95% CI, 1.17-1.83; P < .001), resulting in 72 (95% CI, 27-130) excess deaths per 10 000 person-years of follow-up. Methadone doses of 20 mg/d or less, the lowest dose quartile, were associated with an increased risk of death (HR, 1.59; 95% CI, 1.01-2.51, P = .046) relative to a comparable dose of morphine SR (<60 mg/d). **CONCLUSIONS AND RELEVANCE:** The increased risk of death observed for patients receiving methadone in this retrospective cohort study, even for low doses, supports recommendations that it should not be a drug of first choice for noncancer pain.

PMCID: PMC4346542 [Available on 2016-03-01]

PMID: 25599329 [PubMed - in process]

68. Orthop Traumatol Surg Res. 2015 Feb;101(1 Suppl):S129-37. Epub 2014 Dec 29.

Sequelae of pediatric osteoarticular infection.

Iharreborde B¹.

Abstract The epidemiology and diagnosis of osteoarticular infections (OAI) have changed considerably in recent years, partly due to the development of molecular biology. *Kingella kingae* is now recognized as the most frequent pathogen in

children under 4 years of age, while methicillin-resistant *Staphylococcus aureus* (SA) has been increasingly reported. Although the clinical course of OAI is mostly benign, with shorter antibiotic regimens and simplified treatments, serious functional impairments and life-threatening complications can still occur, especially in case of delayed diagnosis or infection caused by Panton-Valentine leukocidin-producing strains of SA. Newborns and patients with sickle cell disease have greater risk of orthopaedic sequelae, which need to be detected and managed early. The main sequelae of osteomyelitis are angular limb deformity, due to partial growth arrest, and lower limb discrepancy. Therapeutic options are guided by the patient's age and predictions at maturity. The main complications of septic arthritis are joint stiffness and osteonecrosis. The procedures to consider are arthrodesis, joint reconstruction in immature children, and arthroplasty at the end of growth. Copyright © 2014. Published by Elsevier Masson SAS.

PMID: 25553604 [PubMed - in process]

69. Anesthesiology. 2015 Mar;122(3):699-707.

Invasive treatments for complex regional pain syndrome in children and adolescents: a scoping review.

Zernikow B¹, Wager J, Brehmer H, Hirschfeld G, Maier C.

Abstract This review aimed to synthesize the current evidence on the effectiveness of invasive treatments for complex regional pain syndrome in children and adolescents. Studies on children and adolescents with complex regional pain syndrome that evaluated the effects of invasive treatment were identified in PubMed (search March 2013). Thirty-six studies met the inclusion criteria. Articles reported on a total of 173 children and adolescents with complex regional pain syndrome. Generally, many studies lack methodological quality. The invasive treatments applied most often were singular sympathetic blocks, followed by epidural catheters and continuous sympathetic blocks. Rarely, spinal cord stimulation and pain-directed surgeries were reported. An individual patient frequently received more than one invasive procedure. Concerning outcome, for approximately all patients, an improvement in pain and functional disability was reported. However, these outcomes were seldom assessed with validated tools. In conclusion, the evidence level for invasive therapies in the treatment of complex regional pain syndrome in children and adolescents is weak.

PMID: 25539076 [PubMed - in process]

70. Environ Res. 2015 Feb;137:108-19. Epub 2014 Dec 19.

Quantile regression in environmental health: Early life lead exposure and end-of-grade exams.

Magzamen S¹, Amato MS², Imm P³, Havlena JA⁴, Coons MJ³, Anderson HA³, Kanarek MS⁵, Moore CF⁶.

Abstract Conditional means regression, including ordinary least squares (OLS), provides an incomplete picture of exposure-response relationships particularly if the primary interest resides in the tail ends of the distribution of the outcome. Quantile regression (QR) offers an alternative methodological approach in which the influence of independent covariates on the outcome can be specified at any location along the distribution of the outcome. We implemented QR to examine heterogeneity in the influence of early childhood lead exposure on reading and math standardized fourth grade tests. In children from two urban school districts (n=1,076), lead exposure was associated with an 18.00 point decrease (95% CI: -48.72, -3.32) at the 10th quantile of reading scores, and a 7.50 point decrease (95% CI: -15.58, 2.07) at the 90th quantile. Wald tests indicated significant heterogeneity of the coefficients across the distribution of quantiles. Math scores did not show heterogeneity of coefficients, but there was a significant difference in the lead effect at the 10th (β =-17.00, 95% CI: -32.13, -3.27) versus 90th (β =-4.50, 95% CI: -10.55, 4.50) quantiles. Our results indicate that lead exposure has a greater effect for children in the lower tail of exam scores, a result that is masked by conditional means approaches. Copyright © 2014 Elsevier Inc. All rights reserved. PMID: 25531815 [PubMed - in process]

71. Arch Dis Child Fetal Neonatal 2015 Mar;100(2):F155-60. Epub 2014 Dec 4.

The outcome of treatment limitation discussions in newborns with brain injury.

Brecht M¹, Wilkinson DJ².

BACKGROUND: Most deaths in severely brain-injured newborns in neonatal intensive care units (NICUs) follow discussions and explicit decisions to limit life-sustaining treatment. There is little published information on such discussions. **OBJECTIVE:** To describe the prevalence, nature and outcome of treatment limitation discussions (TLDs) in critically ill newborns with severe brain injury. **DESIGN:** A retrospective statewide cohort study. **SETTING:** Two tertiary NICUs in South Australia. **PATIENTS:** Ventilated newborns with severe hypoxic ischaemic encephalopathy and periventricular / intraventricular haemorrhage (P/IVH) admitted over a 6-year period from 2001 to 2006. **MAIN OUTCOME MEASURES:** Short-term outcome (until hospital discharge) including presence and content of TLDs, early childhood mortality, school-age functional outcome. **RESULTS:** We identified 145 infants with severe brain injury; 78/145 (54%) infants had documented TLDs. Discussions were more common in infants with severe P/IVH or hypoxic-ischaemic encephalopathy ($p<0.01$). Fifty-six infants (39%) died prior to discharge, all following treatment limitation. The majority of deaths (41/56; 73%) occurred in physiologically stable infants. Of 78 infants with at least one documented TLD, 22 (28%) survived to discharge, most in the setting of explicit or inferred decisions to continue treatment. Half of long-term survivors after TLD (8/16, 50%) were severely impaired at follow-up. However, two-thirds of surviving infants with TLD in the setting of unilateral P/IVH had mild or no disability. **CONCLUSIONS:** Some critically ill newborn infants with brain injury survive following TLDs between their parents and physicians. Outcome in this group of infants provides valuable information about the integrity of prognostication in NICU, and should be incorporated into counselling. PMID: 25477313 [PubMed - in process]

72. Biol Blood Marrow Transplant. 2015 Feb;21(2):312-8. Epub 2014 Oct 23.

Prevalence and impact of financial hardship among New England pediatric stem cell transplantation families.

Bona K¹, London WB², Guo D³, Abel G⁴, Lehmann L², Wolfe J⁵.

Abstract Poverty is correlated with negative health outcomes in pediatric primary care and subspecialties; its association with childhood hematopoietic stem cell transplantation (HSCT) patterns of care and clinical outcomes is not known. We describe family-reported financial hardship at a primary referral center in New England and explore the relationship between measures of poverty and patterns of care and clinical outcomes. Forty-five English-speaking parents of children after allogeneic HSCT in the prior 12 months completed a 1-time survey (response rate 88%). Low-income families, defined as $\leq 200\%$ federal poverty level (FPL), were compared with all others. Eighteen (40%) families reported pre-HSCT incomes $\leq 200\%$ FPL. Material hardship, including food, housing, or energy insecurity was reported by 17 (38%) families in the cohort. Low-income families reported disproportionate transplantation-related income losses, with 7 (39%) reporting annual income losses of $>40\%$ compared with 2 (18%) wealthier families ($P = .02$). In univariate analyses, 11 (61%) low-income children experienced graft-versus-host disease (GVHD) of any grade in the first 180 days after HSCT compared with 2 (7%) wealthier children ($P = .004$). We conclude that low income and, in particular, material hardship, are prevalent in a New England pediatric HSCT population and represent targets for improvement in quality of life. The role of poverty in mediating GVHD deserves further investigation in larger studies that can control for known risk factors and may provide a targetable source of transplantation-associated morbidity.

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PMID: 25445021 [PubMed - in process]

73. Pract Radiat Oncol. 2015 Mar-Apr;5(2):120-6. Epub 2014 Jul 24.

Canadian radiation oncologists' opinions regarding peer review: A national survey.

Hamilton SN¹, Hasan H², Parsons C³, Tyldesley S³, Howard AF⁴, Bobinski MA⁵, Goddard K³.

PURPOSE: To determine Canadian radiation oncologists' (ROs) views regarding the benefits, workload implications, and legal liability of the peer review quality assurance (QA) process. **METHODS AND MATERIALS:** A 26-item anonymous survey was electronically distributed to all current practicing ROs in Canada through the Canadian Association of Radiation Oncologists membership to obtain their opinions regarding peer review. **RESULTS:** The survey was completed by 145 (36%) of 404 ROs. Most (82%) reported their practice is moderately or very busy and more than two-thirds (69%) felt stressed by their workload. A peer review process is standard at 92% of respondents' institutions. The majority reported this consists of weekly meetings where ROs and other health care providers convene to review radiation treatment plans; some have tumor site-specific rounds while others have 1 meeting for all sites. Nearly all (97%) found this type of QA is beneficial for review of radical plans and 71% found it is beneficial for palliative plans. Incorporating peer review into their current work schedule for all sites was deemed by 37% of respondents to be not or slightly difficult, while 40% found it moderately difficult and 22% very or extremely difficult. The majority (91%) reported that creating a work code to document QA meetings would be helpful and 69% stated that extra resources such as scheduling protected time, designating other health care providers QA coordinators, and increasing overall RO manpower are needed to implement effective peer review. Over half (52%) felt documenting QA meeting minutes would increase legal liability. **CONCLUSIONS:** The majority of ROs who responded found that peer review is beneficial and participate in peer review for at least some of the tumor sites they treat. However, most stated that extra resources are required to effectively implement QA for all tumor sites in their current schedule.

PMID: 25413408 [PubMed - in process]

74. Palliat Med. 2015 Mar;29(3):193-210. Epub 2014 Nov 13.

Hospital-based bereavement services following the death of a child: a mixed study review.

Donovan LA¹, Wakefield CE², Russell V³, Cohn RJ².

BACKGROUND: There has been a breadth of research on the grief experience of parents following the death of a child. However, the role and impact of hospital-based bereaved services remain unclear. **AIM:** To identify services offered to bereaved families in perinatal, neonatal, and pediatric hospital settings and summarize the psychosocial impact of these services and published recommendations for best practice hospital-based bereavement care. **DESIGN:** Systematic review of qualitative, quantitative, and mixed method studies guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist and methodological quality appraised in accordance with the Mixed Method Appraisal Tool. **DATA SOURCES:** MEDLINE, EMBASE, Cumulative Index to Nursing and Allied Health, and PsychINFO were searched to find studies describing hospital-based bereavement services/interventions for parents, siblings, and grandparents. **RESULTS:** In all, 14 qualitative, 6 quantitative, and 10 mixed method studies were identified. Nine descriptive articles were also included. Qualitatively, family members described feeling cared for and supported by staff, a reduction in sense of isolation, and improved coping and personal growth. Quantitatively, bereavement services have most effect for parents experiencing more complex mourning. It is recommended that bereavement services be theoretically driven and evidence based, offer continuity of care prior to and following the death of a child, and provide a range of interventions for the "whole family" and flexibility in service delivery. **CONCLUSIONS:** There is a role for transitional hospital-based services/interventions for families in the lead up to and following the death of a child. Further mixed method research is required to inform best practice bereavement care guidelines in the perinatal, neonatal, and pediatric hospital settings. © The Author(s) 2014.

PMID: 25395578 [PubMed - in process]

75. J Perinatol. 2015 Mar;35(3):223-8. Epub 2014 Oct 23.

End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative.

Samsel C¹, Lechner BE².

OBJECTIVE: We hypothesized that the implementation of a neonatal palliative care initiative will result in improved markers of end-of-life care. **STUDY DESIGN:** A retrospective and prospective chart review of neonatal intensive care unit deaths was performed for 24 months before, 16 months during and 24 months after the implementation of palliative care provider education and practice guidelines (n=106). Ancillary care, redirection of care, palliative medication usage and outcome meetings in the last 48 h of life and basic demographic data were compared between epochs. Parametric and nonparametric

analysis was performed. **RESULT:** There was an increase in redirection of care and palliative medication usage and a decrease in variability of use of end-of-life interventions ($P=0.012$, 0.022 and <0.001). **CONCLUSION:** The implementation of a neonatal palliative care initiative was associated with increases in palliative interventions for neonates in their final 48 h of life, suggesting that such an initiative may enhance end-of-life care.
PMID: 25341197 [PubMed - in process]

76. Death Stud. 2015 Mar;39(3):128-38. Epub 2014 Dec 22.

Dyadic coping of parents after the death of a child.

Bergstraesser E¹, Inglin S, Hornung R, Landolt MA.

Abstract This article explores the grief process of parents following the death of a child due to a life-limiting illness, putting particular focus on dyadic coping. Participants included 46 married parents (23 couples). A mixed-methods design was used with in-depth interviews and standardized questionnaires. All parents were interviewed separately. Aspects of common dyadic coping (e.g., sharing emotions or maintaining bonds to the child) helped them work through their grief as a couple but also individually. The authors conclude that dyadic coping plays an important role in grief work and adjustment to bereavement. PMID: 25204680 [PubMed - in process]

77. J Pediatr Hematol Oncol. 2015 Mar;37(2):104-8.

Childhood cancer in Africa: an overview of resources.

Stefan DC¹.

BACKGROUND: Information about pediatric oncology in most of Africa is not widely available. The aim of this study was to provide an overview of childhood cancer and resources for patient care in a cross-section of African hospitals. **METHODS:** Between 2011 and 2013, 49 health professionals involved in the care of children with cancer, from 38 hospitals in 29 African countries, were asked to respond to a questionnaire about the types and number of childhood cancers seen in their facilities; types and numbers of health care professionals; diagnostic, therapeutic, and palliative capabilities; survival statistics and compliance with treatment; support from parent groups; opportunities for ongoing medical training; and perceived challenges to care delivery. **RESULTS:** New diagnoses annually ranged from 10 to 350, with neuroblastoma, leukemia, retinoblastoma, and Burkitt lymphoma being the most common in most centers. Care was provided often by nonpediatric oncologists. Radiotherapy was available in 21/38 hospitals, palliation in 27/38, and tumor registries in 21/38 centers. **CONCLUSIONS:** Capabilities for care of children with cancer varied widely. Recommendations for improving care are discussed. PMID: 24487917 [PubMed - in process]

78. Arch Pediatr. 2015 Apr;22(4):418-26. Epub 2015 Feb 28.

[Cognitive remediation therapy for children: Literature data and clinical application in a child and adolescent psychiatry department]. [Article in French]

Doyen C¹, Contejean Y², Risler V², Asch M³, Amado I⁴, Launay C⁵, Redon Pde B², Burnouf I², Kaye K².

Abstract The hypothesis of cerebral plasticity in psychiatric disorders has encouraged clinicians to develop cognitive remediation therapy (CRT), a new therapeutic approach based on attention, memory, planning, and mental flexibility tasks. The first cognitive remediation programs were developed and validated for adults with schizophrenia and were shown to have a positive impact on executive functions as well as on quality of life. In children and adolescents, researchers emphasized the existence of executive dysfunction in neurodevelopmental disorders such as autistic spectrum disorder, attention deficit disorder, and eating disorders. For these disorders, neuropsychological studies suggest that memory, planning, attention and mental flexibility are impaired. Despite the paucity of studies on cognitive remediation (CR) in children, preliminary results have suggested, as in adults with schizophrenia, good compliance and optimization of executive functioning. Consequently, programs dedicated to young subjects were developed in English-speaking countries, and the Department of Child and Adolescent Psychiatry of Sainte Anne Hospital (Paris) developed a new CR program for children with attention deficit disorder, academic problems, or eating disorders. These programs complete the field of CRT proposed by Sainte Anne Hospital's Remediation and Psychosocial Rehabilitation Reference Center, initially designed for adults with schizophrenia. Our team used and adapted validated tools such as Delahunty and Wykes's CRT program (translated and validated in French by Amado and Franck) and Lindvall and Lask's CRT Resource Pack. One program was developed for an adolescent with anorexia nervosa and applied to the subject and her family, but the purpose of this paper is to present a CR approach for children with attention deficit disorder or academic disorder, a 6-month program based on paper-pencil tasks and board and card games. The team was trained in different kinds of cognitive remediation, and the program was applied by a clinical nurse with the supervision of a child and adolescent psychiatrist and the department's neuropsychologists. Paper-pencil tasks were adapted from the CRT program for adults; the card and board games used were geometric figures, illusions, Rush Hour®, Set®, Jungle Speed®, Color Addict®, etc. These games are available in stores and the program can be applied at home, which helps families set aside their preoccupations with their child's academic performance. Diagnostic and neuropsychological evaluations were done before the beginning of the therapy and repeated at the end of the 6-month program. This program does not ignore the metapsychological impact of the therapy, and work on self-esteem is also done. The presence of the therapist is necessary, which seems better than a computer program, which cannot encourage the young subject in the same personalized and empathetic way. We therefore conducted the first clinical feasibility trial of cognitive remediation in young subjects and present a clinical case of a 6-year-old boy with attention deficit disorder and academic disorder. The results of neuropsychological evaluations before and after therapy suggest improvement in executive functions and better self-esteem. Satisfaction for the boy and his family was high. Even if these results need to be replicated, cognitive remediation appears to be a new therapeutic tool, complementary to classical approaches used in childhood psychiatric disorders. The Department of Child and Adolescent Psychiatry will submit this program to a research program conducted by the National Health Department to study the impact of this approach in a controlled study. Copyright © 2015 Elsevier Masson SAS. PMID: 25736104 [PubMed - in process]

79. BMJ Open. 2015 Feb 13;5(2):e005918.

Psychotherapy for depression in children and adolescents: study protocol for a systematic review and network meta-analysis.

Oin B¹, Zhou X¹, Michael KD², Liu Y¹, Whittington C³, Cohen D⁴, Zhang Y¹, Xie P¹.

INTRODUCTION: Depression is common among children and adolescents and is associated with significantly negative effects. A number of structured psychosocial treatments are administered for depression in children and adolescents; however, evidence of their effectiveness is not clear. We describe the protocol of a systematic review and network meta-analysis to evaluate the efficacy, quality of life, tolerability and acceptability of the use of psychological intervention for this young population. **METHODS AND ANALYSIS:** We will search PubMed, EMBASE, CENTRAL (the Cochrane Central Register of Controlled Trials), Web of Science, PsycINFO, CINAHL, LiLACS, Dissertation Abstracts, European Association for Grey Literature Exploitation (EAGLE) and the National Technical Information Service (NTIS) from inception to July 2014. There will be no restrictions on language, publication year or publication type. Only randomised clinical trials (RCTs) with psychosocial treatments for depression in children and adolescents will be considered. The primary outcome of efficacy will be the mean overall change of the total score in continuous depression severity scales from baseline to end point. Data will be independently extracted by two reviewers. Traditional pairwise meta-analyses will be performed for studies that directly compared different treatment arms. Then we will perform a Bayesian network meta-analyses to compare the relative efficacy, quality of life, tolerability and acceptability of different psychological intervention. Subgroup analyses will be performed by the age of participants and the duration of psychotherapy, and sensitivity analyses will be conducted to assess the robustness of the findings. **ETHICS AND DISSEMINATION:** No ethical issues are foreseen. The results will be published in a peer-reviewed journal and disseminated electronically and in print. The meta-analysis may be updated to inform and guide management of depression in children and adolescents. **TRIALS REGISTRATION NUMBER:** PROSPERO CRD42014010014.

PMCID: PMC4330321 **Free PMC Article**

PMID: 25681311 [PubMed - in process]

80. Aust Crit Care. 2015 Feb 3. [Epub ahead of print]

Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: Nurses' emotional talk and sources of discomfort. A mixed methods study.

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BACKGROUND: The majority of in-hospital deaths of children occur in paediatric and neonatal intensive care units. For nurses working in these settings, this can be a source of significant anxiety, discomfort and sense of failure. **OBJECTIVES:** The objectives of this study were to explore how NICU/PICU nurses care for families before and after death; to explore the nurses' perspectives on their preparedness/ability to provide family care; and to determine the emotional content of language used by nurse participants. **METHODS:** Focus group and individual interviews were conducted with 22 registered nurses from neonatal and paediatric intensive care units of two major metropolitan hospitals in Australia. All data were audio recorded and transcribed verbatim. Transcripts were then analysed thematically and using Linguistic Inquiry to examine emotional content. **RESULTS:** Four core themes were identified: preparing for death; communication challenges; the nurse-family relationship and resilience of nurses. Findings suggested that continuing to provide aggressive treatment to a dying child/infant whilst simultaneously caring for the family caused discomfort and frustration for nurses. Nurses sometimes delayed death to allow families to prepare, as evidenced in the Linguistic Inquiry analysis, which enabled differentiation between types of emotional talk such as anger talk, anxiety talk and sadness talk. PICU nurses had significantly more anxiety talk ($p=0.018$) than NICU nurses. **CONCLUSION:** This study provided rich insights into the experiences of nurses who are caring for dying children including the nurses' need to balance the often aggressive treatments with preparation of the family for the possibility of their child's death. There is some room for improvement in nurses' provision of anticipatory guidance, which encompasses effective and open communication, focussed on preparing families for the child's death.

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