

*This newsletter includes news briefs and abstracts of the current literature related to hospice and palliative care. Since abstracts are not always accurate reflections of the content of the article, please refer to the complete journal article before making changes to practice or patient care based on the information contained in this update. Editor: Bridget McCrate Protus, PharmD, CGP, [druginformation@hospiscript.com](mailto:druginformation@hospiscript.com)*

## **Hospital Use in the Last Year of Life for Children With Life-Threatening Complex Chronic Conditions**

Ananth P, Melvin P, Feudtner C, Wolfe J, Berry J

Although many adults experience resource-intensive and costly health care in the last year of life, less is known about these health care experiences in children with life-threatening complex chronic conditions (LT-CCCs). We assessed hospital resource use in children by type and number of LT-CCCs. **METHODS:** A retrospective analysis of 1252 children with LT-CCCs, ages 1 to 18 years, who died in 2012 within 40 US children's hospitals of the Pediatric Health Information System database. LT-CCCs were identified with International Classification of Diseases, 9th Revision, Clinical Modification codes. Using generalized linear models, we assessed hospital admissions, days, costs, and interventions (mechanical ventilation and surgeries) in the last year of life by type and number of LT-CCCs. **RESULTS:** In the last year of life, children with LT-CCCs experienced a median of 2 admissions (interquartile range [IQR] 1-5), 27 hospital days (IQR 7-84), and \$142 562 (IQR \$45 270-\$410 087) in hospital costs. During the terminal admission, 76% (n = 946) were mechanically ventilated; 36% (n = 453) underwent surgery. Hospital use was greatest (P < .001) among children with hematologic/immunologic conditions (99 hospital days [IQR 51-146]; cost = \$504 145 [IQR \$250 147-\$879 331]) and children with ≥3 LT-CCCs (75 hospital days [IQR 28-132]; cost = \$341 222 [IQR \$146 698-\$686 585]). **CONCLUSIONS:** Hospital use for children with LT-CCCs in the last year of life varies significantly across the type and number of conditions. Children with hematologic/immunologic or multiple conditions have the greatest hospital use. This information may be useful for clinicians striving to improve care for children with LT-CCCs nearing the end of life. *Pediatrics* 2015;136(5):938-945

## **Pediatrician Ambiguity in Understanding Palliative Sedation at the End of Life**

Henderson C, FitzGerald M, Hoehn K, Weidner N

Palliative sedation is a means of relieving intractable symptoms at the end of life, however, guidelines about its use lack consistency. In addition, ethical concerns persist around the practice. There are reports of palliative sedation in the pediatric literature, which highlight various institutional perspectives. **OBJECTIVES:** This survey of 4786 pediatric providers sought to describe their knowledge of and current practices around pediatric palliative sedation. **METHODS:** Our survey was administered to pediatricians who care for children at the end of life. The survey assessed agreement with a definition of palliative sedation, as well as thoughts about its alignment with aggressive symptom management. Bivariate analyses using  $\chi^2$  and analysis of variance were calculated to determine the relationship between responses to closed-ended questions. Open-ended responses were thematically coded by the investigators and reviewed for agreement. **RESULTS:** Nearly half (48.6%) of the respondents indicated that the stated definition of palliative sedation "completely" reflected their own views. Respondents were split when asked if they viewed any difference between palliative sedation and aggressive symptom management: Yes (46%) versus No (54%). Open-ended responses revealed specifics about the nature of variation in interpretation. **CONCLUSIONS:** Responses point to ambiguity surrounding the concept of palliative sedation. Pediatricians were concerned with a decreased level of consciousness as the goal of palliative sedation. Respondents were split on whether they view palliative sedation as a distinct entity or as one broad continuum of care, equivalent to aggressive symptom management. Institutional-based policies are essential to clarify acceptable practice, enable open communication, and promote further research. *Am J Hosp Palliat Med* 2015; epub ahead of print



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

Theinprayoon R, Marks E, Funes M, Martinez-Puente L, et al

Many children who die are eligible for hospice enrollment but little is known about parental perceptions of the hospice experience, the benefits, and disappointments. The objective of this study was to explore parental perspectives of the hospice experience in children with cancer, and to explore how race/ethnicity impacts this experience. **STUDY DESIGN:** We held 20 semistructured interviews with 34 caregivers of children who died of cancer and used hospice. Interviews were conducted in the caregivers' primary language: 12 in English and 8 in Spanish. Interviews were recorded, transcribed, and analyzed using accepted qualitative methods. **RESULTS:** Both English and Spanish speakers described the importance of honest, direct communication by medical providers, and anxieties surrounding the expectation of the moment of death. Five English-speaking families returned to the hospital because of unsatisfactory symptom management and the need for additional supportive services. Alternatively, Spanish speakers commonly stressed the importance of being at home and did not focus on symptom management. Both groups invoked themes of caregiver appraisal, but English-speaking caregivers more commonly discussed themes of financial hardship and fear of insurance loss, while Spanish-speakers focused on difficulties of bedside caregiving and geographic separation from family. **CONCLUSIONS:** The intense grief associated with the loss of a child creates shared experiences, but Spanish- and English-speaking parents describe their hospice experiences in different ways. Additional studies in pediatric hospice care are warranted to improve the care we provide to children at the end of life. *J Palliat Med* 2016;19(1):30-41

## **Treating Disorders of the Neonatal Central Nervous System: Pharmacokinetic and Pharmacodynamic Considerations with a Focus on Antiepileptics**

Donovan M, Boylan G, Murray D et al

A major consideration in the treatment of neonatal disorders is that the selected drug, dose and dosage frequency is safe, effective and appropriate for the intended patient population. Thus, a thorough knowledge of the pharmacokinetics and pharmacodynamics of the chosen drug within the patient population is essential. In paediatric and neonatal populations two additional challenges can often complicate drug treatment – the inherently greater physiological variability, and a lack of robust clinical evidence of therapeutic range. There has traditionally been an overreliance in paediatric medicine on extrapolating doses from adult values by adjusting for bodyweight or body surface area, but many other sources of variability exist which complicate the choice of dose in neonates. The lack of reliable drug dosage data in neonates has been highlighted by regulatory authorities, as only ~50% of the most commonly used paediatric medicines have been examined in a paediatric population. Moreover, there is a paucity of information on the pharmacokinetic parameters which affect drug concentrations in different body tissues, and pharmacodynamic responses to drugs in the neonate. Thus, in the present review, we draw attention to the main pharmacokinetic factors that influence the unbound brain concentration of neuroactive drugs. Moreover, the pharmacodynamic differences between neonates and adults that affect the activity of centrally-acting therapeutic agents are briefly examined, with a particular emphasis on antiepileptic drugs. *Brit J Clin Pharmacol* 2016;81(1):62-77

**Full text of this article is freely available at <http://onlinelibrary.wiley.com/doi/10.1111/bcp.12753/epdf>**



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## **Hospice Care for Children With Cancer: Where Do These Children Die?**

Thienprayoon R, Lee S, Leonard D, Winick N

Hospice is an important provider of end of life care; many children who die of cancer enroll in hospice programs. How frequently such children remain in hospice to die at home, or disenroll from hospice and die in the hospital, has not been described. A child's location of death has important implications for quality of life and parental adaptation. This represents a subanalysis of a retrospective study of 202 consecutive oncology patients who died at a single center between January 1, 2006 and December 31, 2010. Of 95 children who enrolled in hospice, 82 had known location of death. Sixty (73%) died at home or an inpatient hospice unit, 15 (18%) died in the oncology unit, 5 (6%) died in the intensive care unit, and 2 (2%) died in the emergency department. The median length of hospice services was 41 days, twice the national median of 21 days reported in adults. One quarter of children disenrolled from hospice care, ultimately dying in an acute care setting. Further studies are warranted to explore the hospice experience in children, and to address modifiable factors that may impact a family's choice to withdraw from hospice care. *J Pediatr Hematol Oncol* 2015;37(5):373-377

## **When a Child Dies: Pediatric Oncologists' Follow-up Practices with Families after the Death of Their Child**

Granek L, Barrera M, Scheinemann K, Bartels U

**Objectives:** Follow-up practices with bereaved families are considered a part of good medical care, yet little is known about pediatric oncologists' protocol with families when their patients die. The objective of this study was to examine follow-up practices employed by pediatric oncologists after patient death using an in-depth qualitative analysis. **Methods:** The Grounded Theory method of data collection and analysis was used. Twenty-one pediatric oncologists at two Canadian pediatric hospitals were interviewed about their follow-up practices with bereaved families after patients died. Line-by-line coding was used to establish codes and themes, and constant comparison was used to establish relationships among emerging codes and themes. **Results:** Pediatric oncologists actively engage in follow-up practices that include making phone calls, sending an email or condolence card, attending funerals or visitations, having long-term and short-term meetings with parents, and attending hospital or departmental memorials for the deceased child. Attending funerals or visitations was less frequent and varied widely across pediatric oncologists. Reasons for not participating in bereavement follow-up practices included logistical, emotional, and practical considerations. **Conclusions:** While the majority of pediatric oncologists at two Canadian centers engage in some follow-up practices with bereaved families, these practices are complex and challenging because of the emotional nature of these interactions. Medical institutions should provide both structured time for this follow-up work with families, as well as medical education and financial and emotional support to pediatric oncologists who continue caring for these families long after their child has died. *Psycho-Oncol* 2015;24(12):1626-1631

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## **Systematic Review on Intensive Interdisciplinary Pain Treatment of Children With Chronic Pain**

Hechler T, Kanstrup M, Holley A, et al

Pediatric debilitating chronic pain is a severe health problem, often requiring complex interventions such as intensive interdisciplinary pain treatment (IIPT). Research is lacking regarding the effectiveness of IIPT for children. The objective was to systematically review studies evaluating the effects of IIPT. **METHODS:** Cochrane, Medline/Ovid, PsycInfo/OVID, PubMed, PubPsych, and Web of Science were searched. Studies were included if (1) treatment was coordinated by  $\geq 3$  health professionals, (2) treatment occurred within an inpatient/day hospital setting, (3) patients were  $< 22$  years, (4) patients experienced debilitating chronic pain, (5) the study was published in English, and (6) the study had  $\geq 10$  participants at posttreatment. The child's pain condition, characteristics of the IIPT, and 5 outcome domains (pain intensity, disability, school functioning, anxiety, depressive symptoms) were extracted at baseline, posttreatment, and follow-up. **RESULTS:** One randomized controlled trial and 9 nonrandomized treatment studies were identified and a meta-analysis was conducted separately on pain intensity, disability, and depressive symptoms revealing positive treatment effects. At posttreatment, there were large improvements for disability, and small to moderate improvements for pain intensity and depressive symptoms. The positive effects were maintained at short-term follow-up. Findings demonstrated extreme heterogeneity. **CONCLUSIONS:** Effects in nonrandomized treatment studies cannot be attributed to IIPT alone. Because of substantial heterogeneity in measures for school functioning and anxiety, meta-analyses could not be computed. There is preliminary evidence for positive treatment effects of IIPT, but the small number of studies and their methodological weaknesses suggest a need for more research on IIPTs for children. *Pediatrics* 2015;136(1):115-127

## **Safety and Effectiveness of Patient-controlled Analgesia in Outpatient Children and Young Adults With Cancer: A Retrospective Study**

Anghelescu D, Zhang K, Faughnan L, Pei D

Patient-controlled analgesia (PCA) is safe and effective in hospitalized children; however, data regarding its use for outpatients are limited. The aims of the study are to determine the safety of outpatient PCA and to compare the standard and proxy PCA groups. **METHODS:** All patients receiving outpatient PCA over 54 months were included in this retrospective study. Data regarding age, sex, diagnosis, PCA initiation/discontinuation circumstances, patient versus proxy-authorized PCA type, opioid doses, pain scores, and complications were collected. Nonparametric tests (Wilcoxon-Mann-Whitney test for comparing 2 groups or Kruskal-Wallis rank-sum test for comparing  $> 2$  groups) were used to compare duration of PCA use, opioid doses, pain scores, and circumstances of initiation and discontinuation of outpatient PCA. **RESULTS:** Forty-five patients used 69 outpatient PCAs. The complication rate was 0.36%. The starting mean MED (mg/kg/d) was 1.67 when initiation was for an outpatient and 4.04 for those discharged from the hospital with PCA; this difference was not statistically significant ( $P=0.13$ ). The analysis of mean opioid doses in relationship to the circumstances for the discontinuation of the outpatient PCA revealed a significantly higher dose (mg/kg/d) in the group of patients who died (19.54) than in the group with a change of status to inpatient or transfer to another hospital or hospice (3.70) and in the group in which PCA was discontinued because pain management no longer required a PCA (1.19). The mean opioid daily doses and pain scores were significantly higher at the end of life ( $P<0.0001$ ). **CONCLUSIONS:** Outpatient PCA use for children and young adults with cancer is safe. *J Pediatr Hematol Oncol* 2015;37(5):378-382