

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

“Good information is the best medicine...”

Donald A.B. Lindberg



The Fourth

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N° 4

1. J Pediatr Nurs. 2014 Sep 28. pii: S0882-5963(14)00258-9.

[Exploring the Perceived Met and Unmet Need of Life-Limited Children, Young People and Families.](#)

Coad J1, Kaur J2, Ashley N2, Owens C2, Hunt A3, Chambers L4, Brown E2.

ABSTRACT This article presents an original study commissioned by the UK charity, Together for Short Lives which explored children and young people up to 25years of age with life-threatening/limiting conditions and their families. Using Appreciative Inquiry and framework analysis, qualitative work sought to explore perceived met and unmet needs of services and care. Fifty-one families were interviewed from one UK area, 18 of which were children/young people up to 25years old. Findings indicated that children and their families felt medical/nursing needs were well met but provision was needed for broader financial, social and emotional support alongside more responsive specialist therapies. **KEYWORDS:** Children/young people/families; Complex/palliative care; Life limiting/life threatening condition; Met/unmet needs

[PMID:25301028](#)

2. J Palliat Med. 2014 Oct 9. [Epub ahead of print]

[Pediatric Palliative Care Consultation Services in California Hospitals.](#)

Reid T1, O'Riordan DL, Mazzini A, Bruno KA, Pantilat SZ.

ABSTRACT: The American Academy of Pediatrics recommends that palliative care be available to seriously ill hospitalized children, yet little is known about how these services are structured. **OBJECTIVE:** The study's aim is to report the prevalence of pediatric palliative care services (PCS) and compare the structure of pediatric PCS to adult PCS within California hospitals. **METHODS:** We surveyed 377 hospitals to assess the prevalence, structure, and characteristics of pediatric and adult PCS. Hospitals were categorized as children's hospitals with a pediatric-only PCS, mixed hospitals with pediatric and adult PCS, and hospitals with adult-only PCS. **RESULTS:** All 8 children's hospitals in the state reported having a pediatric PCS, and 36 pediatric PCSs were in mixed hospitals. Mixed hospitals saw fewer ($p=0.0001$) children per year (mean=5.6, standard deviation [SD]=3.6) than pediatric-only PCSs (mean=168, SD=73). Pediatric-only PCSs treated more patients for noncancer-related illness (82.5%) than pediatric PCSs in mixed hospitals (34.5%, $p=0.03$) or adult-only PCSs (52.4%, $p=0.001$). All PCSs were universally available (100%) during weekday business hours and half were available during weekend business hours. Pediatric-only PCSs had a mean total full-time equivalent (FTE) of 1.9, which was not significantly different ($p=0.3$) from the total FTE for pediatric PCSs in mixed hospitals (mean=1.1, SD=1.4) or for adult-only PCSs (mean=2.7, SD=2.0). However, in mixed hospitals the adult PCS had a significantly higher ($p=0.005$) total FTE (mean=2.4, SD=1.3) than the pediatric PCS (mean=1.1, SD=1.4). **CONCLUSION:** All children's hospital and a few mixed hospitals offer pediatric PCS. Better understanding of the palliative care needs of seriously ill children in mixed hospitals and assessment of the quality of care provided will help ensure that children seen in these hospitals receive necessary care.

[PMID:25299845](#)

3. Pediatr Crit Care Med. 2014 Oct;15(8):784-6.

[Palliative Care in the ICU: Together We Can Make a Greater Difference*.](#)

Custer JR.

[Link abstract n°3:](#)

http://journals.lww.com/pccmjournal/Citation/2014/10000Palliative_Care_in_the_ICU_Together_We_Can_Make.21.aspx

[PMID:25280153](#)

4. *Pediatr Crit Care Med*. 2014 Oct;15(8):777-8.

[Neonatal single-ventricle palliative surgery: lost in \(dead\) space?*](#)

[Bhalla A1, Markovitz BP.](#)

[Link abstract n°4:](#)

[http://journals.lww.com/pccmjournal/Citation/2014/10000/Neonatal Single Ventricle Palliative Surgery .17.aspx](http://journals.lww.com/pccmjournal/Citation/2014/10000/Neonatal_Single_Ventricle_Palliative_Surgery_.17.aspx)

[PMID:25280149](#)

5. *Pediatrics*. 2014 Oct;134 Suppl 2:S87-96.

[Deception and the death of Ilyusha: truth and the best interest of a dying child in the Brothers Karamazov.](#)

[Martin C.](#)

ABSTRACT For centuries, many physicians and parents assumed that it was ethically justifiable to lie to a dying child. The reasoning was clear. Because the lie would likely eliminate or prevent a concrete harm (the child's fear), and the lie is about a harm that is unavoidable anyway, a lie appeared to be the morally desirable thing to do. Today, the ethical consensus has shifted. Many doctors and other health professionals now argue that we have an obligation to tell children the cold, hard truth. In this article, I argue that "the cold, hard truth" (assuming we can know it with certainty) might not always be in the best interest of the patient. To illustrate the point, I analyze an episode in Dostoevsky's novel, *The Brothers Karamazov*, in which a child is dying, his father lies to him about it, and 2 doctors take very different approaches to the truth. Each of these individuals has a particular interest when it comes to the question of "the truth" about the death of Ilyusha. I use this story to ask whether it is ethically permissible to lie to a dying child and, if so, who has the moral authority to tell that lie.

KEYWORDS: best interest; child; deception; ethics; family; law; literature; palliative care

[PMID:25274880](#)

6. *Br J Nurs*. 2014 Sep 25;23(17):930-4.

[Assessment of pain in children with brain injury: moving to best practice.](#)

[Nissen S1, Dunford C.](#)

ABSTRACT Nurses are guided to use pain tools for assessing pain. Appropriate tools exist for all ages of children, as well as accounting for diverse communicative abilities and impairments such as brain injury. Use of pain tools, and good documentation of pain management, is part of providing best practice, high-quality care. Clinical audit, based on compliance with the Royal College of Nursing guideline for pain assessment, measured current and changing practice at a 70-bed national specialist centre for children with brain injury. Compliance was initially poor. Changes in practice were supported by evidence-based measures, including a written guideline, classroom teaching, visits to practice areas, sharing of audit results, reminders and a special interest group. Over 3 years, the audits showed an increase of child-specific pain tools available in children's care files from 9% to 83%; assessment of pain using a pain tool, when indicated, increased from 0 to 30%. Documentation of interventions to relieve pain increased from 51% to 80% and reassessment of pain following an intervention increased from 15% to 63%. This article will resonate with any organisation trying to embed systematic pain assessment into routine practice. **KEYWORDS:** Brain injuries; Child; Cognition difficulties; Nursing audit; Pain measurement

[PMID:25251174](#)

7. *Jpn J Clin Oncol*. 2014 Sep 23. [Epub ahead of print]

[A Comprehensive Study of the Distressing Experiences and Support Needs of Parents of Children with Intractable Cancer.](#)

[Yoshida S1, Amano K2, Ohta H3, Kusuki S4, Morita T5, Ogata A6, Hirai K7.](#)

OBJECTIVE: The primary endpoints of this study were: (1) to explore the distressing experiences of parents of patients with intractable pediatric cancer in Japan from disclosure of poor prognosis to the present and (2) to explore support they regarded as necessary. **METHODS:** A multi-center questionnaire survey was conducted that included 135 bereaved parents of patients with pediatric cancer in Japan. **RESULTS:** The top five distressing experiences shared by over half of the bereaved parents were: 'Realize that the child's disease was getting worse' (96.7%), 'Witness the child's suffering' (96.7%), 'Make many decisions on the basis that the child will die in the not-so-distant future' (83.6%), 'Feel anxious and nervous about the child's acute deterioration' (82.0%) and 'Realize that there was nothing that I could do for the child' (78.7%). The top five support regarded as necessary were: 'Visit the room and speak to the sick child every day' (90.2%), 'Provide up-to-date information' (80.3%), 'Sufficiently explain the disadvantages of each treatment option' (80.3%), 'Show a never-give-up attitude until the end' (78.7%) and 'Make arrangements to allow the sick child to spend time with his/her siblings' (73.8%).

CONCLUSIONS: This study identified the common distressing experiences of parents and the support regarded as necessary by them. To provide efficient support with limited manpower in pediatric setting, healthcare professionals should recognize these tasks as high priorities when engage parents of intractable pediatric cancer patients. **KEYWORDS:** Japan; intractable cancer; parents; support need

[PMID:25249378](#)

8. *Pediatrics*. 2014 Oct;134(4):e1163-8.

[Infants' Best Interests in End-of-life Care for Newborns.](#)

[Willems DL1, Verhagen AA2, van Wijlick E3; Committee End-of-Life Decisions in Severely Ill Newborns of the Royal Dutch Medical Association.](#)

BACKGROUND AND OBJECTIVES: Pediatric bioethics presumes that decisions should be taken in the child's best interest. If it's ambiguous whether a decision is in the child's interest, we defer to parents. Should parents be permitted to consider their own interests in making decisions for their child? In the Netherlands, where neonatal euthanasia is legal, such questions sometimes arise in deciding whether to hasten the death of a critically ill, suffering child. We describe the recommendations of a national Dutch committee. Our objectives were to analyze the role of competing child and family interests

and to provide guidance on end-of-life decisions for doctors caring for severely ill newborns. **METHODS:** We undertook literature review, 7 consensus meetings in a multidisciplinary expert commission, and invited comments on draft report by specialists' associations. **RESULTS:** Initial treatment is mandatory for most ill newborns, to clarify the prognosis. Continuation of treatment is conditional on further diagnostic and prognostic data. Muscle relaxants can sometimes be continued after withdrawal of artificial respiration without aiming to shorten the child's life. When gasping causes suffering, or protracted dying is unbearable for the parents, muscle relaxants may be used to end a newborn's life. Whenever muscle relaxants are used, cases should be reported to the national review committee. **CONCLUSIONS:** New national recommendations in the Netherlands for end-of-life decisions in newborns suggest that treatment should generally be seen as conditional. If treatment fails, it should be abandoned. In those cases, palliative care should be directed at both infant and parental suffering. Sometimes, this may permit interventions that hasten death. **KEYWORDS:** clinical bioethics; end-of-life decisions; neonatal intensive care; palliative care

PMID:25246628

9. Am J Hosp Palliat Care. 2014 Sep 16. pii: 1049909114551014. [Epub ahead of print]

Palliative Care in Neonatal Intensive Care, Effects on Parent Stress and Satisfaction: A Feasibility Study.

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

CONTEXT: Approximately 1 in 10 infants require neonatal intensive care unit (NICU) hospitalization, which causes parental stress. Palliative care (PC) provides an opportunity to alleviate suffering and stress. **OBJECTIVES:** This study examines the effects of PC on NICU parent stress and satisfaction. **METHODS:** A prospective cohort design compares stress and satisfaction among families receiving or not receiving PC. **RESULTS:** No significant differences in stress scores were found ($P = .27 - 1.00$). Palliative care parents (100%) were more likely to report being "extremely satisfied" with care than usual-care parents (50%). **CONCLUSION:** This study supports the feasibility of evaluating NICU PC services. Infants referred for PC typically have higher morbidity/mortality; therefore, higher parental stress scores may be expected. Stress levels were similar in both cohorts, thus PC did not increase stress and may decrease PC parent stress. **KEYWORDS:** infant; neonatal intensive care unit; palliative care; parent; premature; satisfaction; stress

PMID:25228642

10. J Palliat Med. 2014 Sep 16. [Epub ahead of print]

Reported Availability and Gaps of Pediatric Palliative Care in Low- and Middle-Income Countries: A Systematic Review of Published Data.

Caruso Brown AE1, Howard SC, Baker JN, Ribeiro RC, Lam CG.

ABSTRACT: The majority of young people in need of palliative care live in low- and middle-income countries, where curative treatment is less available. **OBJECTIVE:** We systematically reviewed published data describing palliative care services available to young people with life-limiting conditions in low- and middle-income countries and assessed core elements with respect to availability, gaps, and under-reported aspects. **METHODS:** PubMed, CINAHL, EMBASE (1980-2013), and secondary bibliographies were searched for publications that included patients younger than 25 years with life-limiting conditions and described palliative care programs in low- and middle-income countries. A data extraction checklist considered 15 items across seven domains: access, education/capacity building, health system support, pain management, symptom management, end-of-life care, and bereavement. Data were aggregated by program and country. Results: Of 1572 records, 238 met criteria for full-text review; 34 qualified for inclusion, representing 30 programs in 21 countries. The median checklist score was 7 (range, 1-14) of 10 reported (range, 3-14). The most pervasive gaps were in national health system support (unavailable in 7 of 17 countries with programs reporting), specialized education (unavailable in 7 of 19 countries with programs reporting), and comprehensive opioid access (unavailable in 14 of 21 countries with programs reporting). Underreported elements included specified practices for pain management and end-of-life support. **CONCLUSION:** Comprehensive pediatric palliative care provision is possible even in markedly impoverished settings. Improved national health system support, specialized training and opioid access are key targets for research and advocacy. Application of a checklist methodology can promote awareness of gaps to guide program evaluation, reporting, and strengthening.

PMID: 25225748

11. Death Stud. 2014 Sep 10. [Epub ahead of print]

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. We conclude that dyadic coping plays an important role in grief work and adjustment to bereavement.

PMID: 25204680

12. J Clin Oncol. 2014 Oct 10;32(29):3229-35.

Hope and persuasion by physicians during informed consent.

Miller VA1, Cousino M1, Leek AC1, Kodish ED2.

PURPOSE: To describe hopeful and persuasive messages communicated by physicians during informed consent for phase I trials and examine whether such communication is associated with physician and parent ratings of the likelihood of benefit, physician and parent ratings of the strength of the physician's recommendation to enroll, parent ratings of control, and parent ratings of perceived pressure. **PATIENTS AND METHODS:** Participants were children with cancer ($n = 85$) who were offered a phase I trial along with their parents and physicians. Informed consent conferences (ICCs) were audiotaped and

coded for physician communication of hope and persuasion. Parents completed an interview (n = 60), and physicians completed a case-specific questionnaire. **RESULTS:** The most frequent hopeful statements related to expectations of positive outcomes and provision of options. Physicians failed to mention no treatment and/or palliative care as options in 68% of ICCs and that the disease was incurable in 85% of ICCs. When physicians mentioned no treatment and/or palliative care as options, both physicians and parents rated the physician's strength of recommendation to enroll in the trial lower. **CONCLUSION:** Hopes and goals other than cure or longer life were infrequently mentioned, and a minority of physicians communicated that the disease was incurable and that no treatment and/or palliative care were options. These findings are of concern, given the low likelihood of medical benefit from phase I trials. Physicians have an important role to play in helping families develop alternative goals when no curative options remain.

PMID:25199753

13. *Pediatr Rev.* 2014 Sep;35(9):390-5.

Primary pediatric palliative care: psychological and social support for children and families.

Hirsh CD, Friebert S.

Families of children with complex, chronic, and/or life-limiting conditions experience unmet psychological, emotional, practical, and spiritual needs. Primary care pediatricians may lack sufficient knowledge, training, and/or resources to address these needs; pediatric palliative care teams can offer additional support services to families.

OBJECTIVES After completing this article, readers should be able to: 1) Recognize when a pediatric palliative care consultation would be appropriate to help the patient and family deal with psychosocial stressors related to diagnosis or illness. 2) Describe the roles of the various members of the palliative care interdisciplinary team in providing psychosocial and social support to a patient or family with a child who has a complex, chronic, or potentially life-limiting condition. 3) Understand the role overlap among various clinicians on a palliative care interdisciplinary team

PMID: 25183774

14. *Eur J Oncol Nurs.* 2014 Sep;18 Suppl 2:S97-S122. doi: 10.1016/j.ejon.2014.07.008. Epub 2014 Aug 27.

New models for elevating the practice and status of community-based nursing across the spectrum of cancer care in Central and Eastern Europe.

Grimes C1, Wanless RS2, Damonti J3.

PURPOSE: This supplement comprises an evaluation of Bridging Cancer Care, an initiative of the Bristol-Myers Squibb Foundation first conceived in 2007, addressing disparities in cancer care between Central and Eastern Europe and Western Europe. The strategic focus was refined in 2010 to put particular emphasis on capacity building of nurses in terms of education, training and empowerment. **METHODS:** The evaluation was based on review of data and information from the program's monitoring and evaluation framework and from biannual reports submitted by grantees to the Bristol-Myers Squibb Foundation. Eleven of the grantees were selected to develop case studies, which illustrate a) the role of nurses in tobacco cessation, b) expansion of the scope of practice for general practice nurses in health promotion, prevention and early detection of cancer, c) capacity building for nurses in contemporary models of cancer care, care navigation and psychosocial support and d) establishment of nurse training programs in palliative care in Central and Eastern Europe. **RESULTS:** Between 2010 and 2013, 22 grants were awarded in Russia, Poland, Czech Republic, Hungary and Romania. The evaluation characterized the program's impact in terms of improved health equity, health outcomes, capacity building of nurses and public awareness about cancer. With regard to health equity, all projects targeted disproportionately affected populations (children, poor, rural, ethnic) among whom 35,493 individuals were reached either through cancer screening or community and clinical care. In relation to capacity building, overall 5724 healthcare workers, primarily nurses, received training in various aspects of cancer care, while more than 50,000 patients and more than 470,000 members of the general public were reached through educational initiatives. Most of the programs have been sustained beyond Bristol-Myers Squibb Foundation funding. **CONCLUSION:** The positive results were achieved predominantly through greater nurse empowerment, supported by the development of 17 different, customized and nurse-focused curricula. Such training can increase nurses' knowledge and skills as demonstrated by examination testing and evaluation of nurses in the workplace. Several projects also resulted in enhanced nurse leadership attributes and eleven lead to positive changes in models of clinical or community care involving nurses. In eight cases, these changes were subsequently embodied in new health policies. **KEYWORDS:** Community involvement; Health equity; Nurse empowerment

PMID:25174879

15. *Pediatrics.* 2014 Sep;134(3):e765-72.

Characteristics of a pediatric hospice palliative care program over 15 years.

Siden H1, Chavoshi N2, Harvey B3, Parker A4, Miller T3.

OBJECTIVES: Pediatric palliative care has seen the adoption of several service provision models, yet there is minimal literature describing them. Canuck Place Children's Hospice (CPCH) is North America's first freestanding pediatric hospice. This study describes the characteristics of and services delivered to all children on the CPCH program from 1996 to 2010. **METHODS:** A retrospective review of all patient medical records CPCH was conducted. Analyses examined trends and correlations between 40 selected data points: linear regression modeling was used to assess trends over time; t tests were used to examine significant associations between independent means; and the Kaplan-Meier method was used to measure survival probabilities. **RESULTS:** The study cohort included 649 children. The majority of diagnoses belonged to cancers (30%), and diseases of the neuromuscular (20%), and central nervous systems (18%). The majority of deaths occurred among the cancer (45%), central nervous system (15%), and metabolic disease groups (14%). By study end date, 24% of children were still alive, 61% died, and 15% transitioned to adult services (more than half of whom were cognitively competent). On average, 1024 days were spent on the CPCH program (median = 301). The majority of inpatient hospice discharges were for respite (82%); only 7% were for end-of-life care. Location of death was shared between CPCH (61%), hos-

pital (22%), and home (16%). **CONCLUSIONS:** Diagnostic groups largely determine the nature and magnitude of services used, and our involvement with pediatric life-threatening conditions is increasing. Reviews of pediatric palliative programs can help evaluate the services needed by the population served. **KEYWORDS:** demographics; hospice care; life threatening; palliative care

PMID:25157003

16. Death Stud. 2014 Aug 25. [Epub ahead of print]

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

Jalmsell L1, Kontio T, Stein M, Henter JI, Kricbergs 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 paper 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

17. Semin Fetal Neonatal Med. 2014 Oct;19(5):296-299.

Neonatal euthanasia: Lessons from the Groningen Protocol.

Eduard Verhagen AA.

ABSTRACT Decisions about neonatal end-of-life care have been studied intensely over the last 20 years in The Netherlands. Nationwide surveys were done to quantify these decisions, provide details and monitor the effect of guidelines, new regulations and other interventions. One of those interventions was the Groningen Protocol for newborn euthanasia in severely ill newborns, published in 2005. Before publication, an estimated 20 cases of euthanasia per year were performed. After publication, only two cases in five years were reported. Studies suggested that this might be partly caused by the lack of consensus about the dividing line between euthanasia and palliative care. New recommendations about paralytic medication use in dying newborns were issued to increase transparency and to improve reporting of euthanasia. New surveys will be needed to measure the effects of these interventions. This cycle of interventions and measurements seems useful for continuous improvement of end-of-life care in newborns. **KEYWORDS:** Ethics; Medical law; Neonatal euthanasia; Neonatal intensive care; Palliative care

PMID: 25150794

18. J Palliat Med. 2014 Aug 19. [Epub ahead of print]

A Statewide Survey of Adult and Pediatric Outpatient Palliative Care Services.

Rabow MW1, O'Riordan DL, Pantilat SZ.

ABSTRACT: Outpatient palliative care services can improve patient outcomes, yet little is known about their structure and characteristics. **OBJECTIVE:** To describe the structure and characteristics of outpatient palliative care services associated with California hospitals. **DESIGN:** Electronic survey. **SETTING/SUBJECTS:** All 377 acute care hospitals in California. **MEASUREMENTS:** Outpatient palliative care services structure and operational characteristics, including staffing, clinical availability, and funding. **RESULTS:** Overall 96% (361/377) of hospitals responded. Of the 136 hospitals with an adult palliative care service, 18% (n=24) reported an outpatient palliative care service with a mean age of 3.7 years. Of the 42 hospitals offering pediatric palliative care services, 19% (n=8) reported an outpatient palliative care service with a mean age of 3.4 years. On average, adult outpatient palliative care services see 159 new patients per year with 722 follow-up visits. Pediatric outpatient palliative care services see 10 new patients per year with 28 follow-up visits. The average staffing of adult outpatient palliative care services is 2.1 full-time equivalent (FTE; range, 0.2-12) and for pediatric outpatient palliative care services 0.7 FTE (range, 0.1-2.0). Adult outpatient palliative care services operate a mean of 3.9 days per week compared to 1.1 days per week for pediatric outpatient palliative care services. Few services provided 24/7 coverage (25% adult, 38% pediatric). Wait times for newly referred patients were 11 days for adults and 9 days for pediatrics. Most referrals are received from oncology (adult=47%, pediatric=43%). Funding for outpatient palliative care services is largely through institutional support (adult=80%, pediatric=62%), followed by foundations (adult=10.3%, pediatric=23%), billing (adult=8.8%, pediatric=0%), and philanthropy (adult=0.9%, pediatric=15%). Compared to similar data from 2007, the prevalence of outpatient palliative care services affiliated with hospitals in California has not changed significantly. **CONCLUSIONS:** Few California hospitals offer outpatient palliative care services. This finding has remained consistent over time. Adult and pediatric outpatient palliative care services care primarily for patients with cancer, operate part-time with modest staffing, and are funded primarily by their institution. Making the case for value to engender more institutional support, increasing billing revenue, system initiatives, and partnering with insurers may lead to the establishment of more outpatient palliative care services.

PMID: 25137356

19. J Spec Pediatr Nurs. 2014 Aug 17.

Who are the children using hospice care?

Lindley LC1, Shaw SL.

PURPOSE: The purpose was to examine the characteristics of children who use hospice care. **DESIGN AND METHODS:** Using the Andersen Model of Health Services Use, California Medicaid administrative databases were analyzed to describe the characteristics of 76 children in hospice. **RESULTS:** The predisposing, enabling, and need characteristics of children were identified. Children who used hospice were a diverse group with community resources that enabled them to access care while presenting with serious health needs. Children enrolled in hospice were more likely older (15-20 years of age), resided nearer a pediatric hospice, and had a serious health condition such as neuromuscular disease with multiple comor-

bidities. **PRACTICE IMPLICATIONS:** With this knowledge, pediatric nurses can improve their clinical practice by targeting conversations with families and children most in need of hospice care. **KEYWORDS:** End-of-life; Medicaid; hospice care; palliative care; pediatrics

PMID: 25131751

20. *Pediatr Blood Cancer*. 2014 Nov;61(11):2004-11.

End-of-life care in pediatric neuro-oncology.

Vallero SC¹, Lijoi S, Bertin D, Pittana LS, Bellini S, Rossi F, Peretta P, Basso ME, Fagioli F.

BACKGROUND: The management of children with cancer during the end-of-life (EOL) period is often difficult and requires skilled medical professionals. Patients with tumors of the central nervous system (CNS) with relapse or disease progression might have additional needs because of the presence of unique issues, such as neurological impairment and altered consciousness. Very few reports specifically concerning the EOL period in pediatric neuro-oncology are available. **PROCEDURE:** Among all patients followed at our center during the EOL, we retrospectively analyzed data from 39 children and adolescents with brain tumors, in order to point out on their peculiar needs. **RESULTS:** Patients were followed-up for a median time of 20.1 months. Eighty-two percent were receiving only palliative therapy before death. Almost half the patients (44%) died at home, while 56% died in a hospital. Palliative sedation with midazolam was performed in 58% of cases; morphine was administered in 51.6% of cases. No patient had uncontrolled pain. **CONCLUSIONS:** The EOL in children with advanced CNS cancer is a period of active medical care. Patients may develop complex neurological symptoms and often require long hospitalization. We organized a network-based collaboration among the reference pediatric oncology center, other pediatric hospitals and domiciliary care personnel, with the aim to ameliorate the quality of care during the EOL period. In our cohort, palliative sedation was widely used while no patients died with uncontrolled pain. A precise process of data collection and a better sharing of knowledge are necessary in order to improve the management of such patients. *Pediatr Blood Cancer* 2014;61:2004-2011. **KEYWORDS:** brain cancer; end-of-life; neuro-oncology; palliative care; pediatric oncology; supportive therapy

PMID: 25131215

21. *Am J Med Genet A*. 2014 Oct;164(10):2551-6.

Differences in perspective on prognosis and treatment of children with trisomy 18.

Hurley EH¹, Krishnan S, Parton LA, Dozor AJ.

ABSTRACT Differences in perspective between physicians caring for children with trisomy 18 may be confusing and stressful for parents. The hypothesis of this study was that neonatologists and pediatric pulmonologists differ in their opinions regarding long-term prognosis and recommended interventions. Neonatologists and pediatric pulmonologists in New York State were surveyed. Respondents were asked to report their personal experience caring for affected children, opinions on prognosis, major influences on their opinions, and their likelihood of recommending specific medical or surgical interventions for two clinical vignettes. A total of 393 surveys were mailed, 327 to neonatologists and 66 to pediatric pulmonologists. Sixty-six (20%) neonatologists and 21 (32%) pediatric pulmonologists completed the survey. Neonatologists had cared for more patients with trisomy 18. Twenty-nine percent of pediatric pulmonologists had never cared for a patient with trisomy 18 compared to 2% of neonatologists, $P < 0.001$. Pediatric pulmonologists were more likely to recommend almost all interventions including antibiotics for pneumonia, mechanical ventilation, cardiac and orthopedic surgery, and "full code resuscitation." Neonatologists were more likely to recommend comfort care only or palliative care. Fifty-four percent of neonatologists and 5% of pediatric pulmonologists thought patients with trisomy 18 without significant congenital heart disease would die before age one despite aggressive medical care, $P < 0.001$. The major influences impacting these recommendations also varied. Pediatric pulmonologists are more optimistic about the prognosis for children than neonatologists and more likely to recommend medical and surgical interventions. Experience with the condition and perception of survivability may contribute to these differences in approach. **KEYWORDS:** Trisomy 18; neonatology; pediatric pulmonology; prognosis

PMID:25098974

22. *Pediatr Crit Care Med*. 2014 Oct;15(8):762-7.

Integrating Palliative Care Into the PICU: A Report From the Improving Palliative Care in the ICU Advisory Board*.

Boss R¹, Nelson J, Weissman D, Campbell M, Curtis R, Frontera J, Gabriel M, Lustbader D, Mosenthal A, Mulkerin C, Puntillo K, Ray D, Bassett R, Brasel K, Hays R.

OBJECTIVE: This review highlights benefits that patients, families and clinicians can expect to realize when palliative care is intentionally incorporated into the PICU. **DATA SOURCES:** We searched the MEDLINE database from inception to January 2014 for English-language articles using the terms "palliative care" or "end of life care" or "supportive care" and "pediatric intensive care." We also hand-searched reference lists and author files and relevant tools on the Center to Advance Palliative Care website. **STUDY SELECTION:** Two authors (physicians with experience in pediatric intensive care and palliative care) made final selections. **DATA EXTRACTION:** We critically reviewed the existing data and tools to identify strategies for incorporating palliative care into the PICU. **DATA SYNTHESIS:** The Improving Palliative Care in the ICU Advisory Board used data and experience to address key questions relating to: pain and symptom management, enhancing quality of life, communication and decision-making, length of stay, sites of care, and grief and bereavement. **CONCLUSIONS:** Palliative care should begin at the time of a potentially life-limiting diagnosis and continue throughout the disease trajectory, regardless of the expected outcome. Although the PICU is often used for short term postoperative stabilization, PICU clinicians also care for many chronically ill children with complex underlying conditions and others receiving intensive care for prolonged periods. Integrating palliative care delivery into the PICU is rapidly becoming the standard for high quality care of critically ill children. Interdisciplinary ICU staff can take advantage of the growing resources for continuing education in pediatric palliative care principles and interventions.

PMID:25080152

23. Adv Neonatal Care. 2014 Oct;14(5):322-8.

The relationship between providing neonatal palliative care and nurses' moral distress: an integrative review.

Cavinder C.

ABSTRACT Moral distress has been identified in multiple clinical settings especially in critical care areas. The neonatal intensive care unit (NICU) has frequent situations in which moral distress may occur including providing palliative care. The purpose of this integrative review was to determine the relationship between the provision of palliative care in a NICU and nurses' moral distress. The evidence reviewed supports that moral distress does occur with the provision of neonatal palliative care. An interdisciplinary care team, an established protocol, and educational interventions may decrease moral distress in nurses providing end-of-life care to infants in the NICU.

PMID: 25022749

24. Arch Dis Child. 2014 Sep;99(9):798-9.

Euthanasia: 10 myths.

Hain RD.

Over the two decades that have elapsed since I first became interested in the ethics of euthanasia and physician-assisted suicide, I have changed my mind. Not about whether or not I think it should be made legally permissible, but about why I think it should not. My early objections were merely matters of morality. Actively killing patients (ie, euthanasia in the sense in which I am using it here) seemed self-evidently wrong in principle. But at the same time, it seemed quite a good idea in practice. As the years have passed, some of the myths presented by proselytes have made me less sure of both propositions. In a bid to dispel some of those myths, let's start by applauding the Belgian government for recognising that children can participate in decisions in respect of their own lives. Myth number one is that *euthanasia in children is wrong because children cannot have meaningful autonomy in medical care*. Let's also remind ourselves that those who favour euthanasia for children are not child-haters. They are not *recommending that children be killed because they consider children unimportant or because they value life insufficiently highly*. That is myth number two. Most are well-intentioned, caring people who support euthanasia because they genuinely believe it is the most compassionate way to treat suffering patients when there is no prospect of a cure. Supporters often appeal to the compassion of the owner who asks the vet to put his dog out of its misery. Myth number three, then, is that *euthanasia and physician-assisted suicide do not ameliorate suffering*. They certainly do. Loving families and compassionate professionals faced with the day-to-day agony of caring for a dying child will certainly feel the same sort of relief as the child dies that loving dog-owner experiences. **KEYWORDS:** Ethics; Palliative Care; Philosophy

PMID:25016612

25. Curr Opin Support Palliat Care. 2014 Sep;8(3):296-302..

Supportive and palliative care of children with metabolic and neurological diseases.

Hauer JM¹, Wolfe J.

PURPOSE OF REVIEW: To review the role of pediatric palliative care (PPC) for children with metabolic and neurological diseases. **RECENT FINDINGS:** There is a growing body of literature in PPC, though it remains limited for children with metabolic and neurological diseases. Evidence indicates the benefit of PPC. Utilization of PPC programmes can facilitate communication, ensure that families are better informed, improve certainty with decisions, enhance positive emotions, result in fewer invasive interventions at the end of life, and have an impact on location of death. Barriers to utilization of PPC include concern about taking away hope and uncertainty about prognosis. Challenging areas for children with metabolic and neurological diseases include the identification of distressing symptoms and prognostic uncertainty. This article aims to review literature relevant to this group of children, as well as provide a framework when considering specific palliative care needs. **SUMMARY:** PPC for children with metabolic and neurological diseases can lessen a child's physical discomfort and enhance parental certainty with decision-making. These areas along with other needs throughout the illness trajectory and bereavement are being increasingly met by the growing availability of PPC programmes.

PMID: 25004174

26. Crit Care Med. 2014 Sep;42(9):2101-8.

Epidemiology of death in the PICU at five U.S. teaching hospitals*.

Burns JP¹, Sellers DE, Meyer EC, Lewis-Newby M, Truog RD.

OBJECTIVE: To determine the epidemiology of death in PICUs at 5 geographically diverse teaching hospitals across the United States. **DESIGN:** Prospective case series. **SETTING:** Five U.S. teaching hospitals. **SUBJECTS:** We concurrently identified 192 consecutive patients who died prior to discharge from the PICU. Each site enrolled between 24 and 50 patients. Each PICU had similar organizational and staffing structures. **INTERVENTIONS:** None. **MEASUREMENTS AND MAIN RESULTS:** The overall mortality rate was 2.39% (range, 1.85-3.38%). One hundred thirty-three patients (70%) died following the withholding or withdrawal of life-sustaining treatments, 30 (16%) were diagnosed as brain dead, and 26 (14%) died following an unsuccessful resuscitation attempt. Fifty-seven percent of all deaths occurred within the first week of admission; these patients, who were more likely to have new onset illnesses or injuries, included the majority of those who died following unsuccessful cardiopulmonary resuscitation attempts or brain death diagnoses. Patients who died beyond 1-week length of stay in the PICU were more likely to have preexisting diagnoses, to be technology dependent prior to admission, and to have died following the withdrawal of life-sustaining treatment. Only 64% of the patients who died following the withholding or withdrawing of life support had a formal do-not-resuscitate order in place at the time of their death. **CONCLUSIONS:** The mode of death in the PICU is proportionally similar to that reported over the past two decades, while the mortality rate has nearly halved. Death is largely characterized by two fairly distinct profiles that are associated with whether death occurs within or beyond 1-week length of stay. Decisions not to resuscitate are often made in the absence of a formal do-not-resuscitate order. These data have implications for future quality improvement initiatives, especially around palliative care, end-of-life decision making, organ donation. **Comment:** Death in the ICU: when comfort is therapeutic*. [Crit Care Med. 2014] PMID:24979486

27. J Palliat Med. 2014 Sep;17(9):1049-53.

[Advance care planning: challenges and approaches for pediatricians.](#)

[Heckford E1](#), [Beringer AJ](#).

ABSTRACT: There is increasing recognition of the value of advance care planning for children with life-limiting conditions. It is important that we acknowledge and reflect on the challenges that this work presents in order to optimize practice. **OBJECTIVE:** Our aim was to review advance care planning for children with life-threatening or life-limiting conditions (LTLICs) in our local area. **METHODS:** We conducted a retrospective case note review. Study subjects were from two National Health Service (NHS) Trusts in Bristol in the United Kingdom. Cases were identified from Child Death Overview Panel data. Forty-two sets of case notes were reviewed in relation to 20 children. Measurements included quantitative and qualitative review of advance care planning in relation to standards set by The Association for Children's Palliative Care (ACT). **RESULTS:** In 25% of cases there was no documented discussion with families about the approach to end of life (EOL). In 25% of cases there was no evidence of an advance care plan, and the content and accessibility of those that did exist was variable. Forty-five percent of families were not offered a choice with regard to location of care (LOC) in the last months of life and 50% were not offered a choice about location of death (LOD). **CONCLUSIONS:** We hope that acknowledgement of some of the challenges, alongside recognition of the clear benefits, of planning will help pediatricians to deliver this important area of care.

PMID: 24955940

28. Arch Dis Child. 2014 Sep;99(9):812-6.

[Withdrawal of ventilatory support outside the intensive care unit: guidance for practice.](#)

[Laddie J1](#), [Craig F2](#), [Brierley J3](#), [Kelly P4](#), [Bluebond-Langner M5](#).

OBJECTIVE: To review the work of one tertiary paediatric palliative care service in facilitating planned withdrawal of ventilatory support outside the intensive care setting, with the purpose of developing local guidance for practice. **METHODS:** Retrospective 10-year (2003-2012) case note review of intensive care patients whose parents elected to withdraw ventilation in another setting. Demographic and clinical data revealed common themes and specific incidents relevant to local guideline development. **RESULTS:** 18 children (aged 2 weeks to 16 years) were considered. Three died prior to transfer. Transfer locations included home (5), hospice (8) and other (2). Primary pathologies included malignant, neurological, renal and respiratory diseases. Collaborative working was evidenced in the review including multidisciplinary team meetings with the palliative care team prior to discharge. Planning included development of symptom management plans and emergency care plans in the event of longer than anticipated survival. Transfer of children and management of extubations demonstrated the benefits of planning and recognition that unexpected events occur despite detailed planning. We identified the need for local written guidance supporting healthcare professionals planning and undertaking extubation outside the intensive care setting, addressing the following phases: (i) introduction of withdrawal, (ii) preparation pretransfer, (iii) extubation, (iv) care postextubation and (v) care postdeath. **CONCLUSIONS:** Planned withdrawal of ventilatory support outside the intensive care setting is challenging and resource intensive. The development of local collaborations and guidance can enable parents of children dependent on intensive care to consider a preferred place of death for their child, which may be outside the intensive care unit. **KEYWORDS:** Guidelines; Paediatric Intensive Care (PICU); Palliative Care; Place of Death

Comment in: [Redirection in treatment goals: withdrawal of mechanical ventilation outside of the intensive care unit.](#) [Arch Dis Child. 2014]

PMID: 24951460

29. Pediatr Blood Cancer. 2014 Oct;61(10):1840-5.

[Development of a quality of life instrument for children with advanced cancer: the pediatric advanced care quality of life scale \(PAC-QoL\).](#)

[Cataudella D1](#), [Morley TE](#), [Nesin A](#), [Fernandez CV](#), [Johnston DL](#), [Sung L](#), [Zelcer S](#).

BACKGROUND: There is currently no published, validated measures available that comprehensively capture quality of life (QoL) symptoms for children with poor-prognosis malignancies. The pediatric advanced care-quality of life scale (PAC-QoL) has been developed to address this gap. The current paper describes the first two phases in the development of this measure. **PROCEDURES:** The first two phases included: (1) construct and item generation, and (2) preliminary content validation. Domains of QoL relevant to this population were identified from the literature and items generated to capture each; items were then adapted to create versions sensitive to age/developmental differences. Two types of experts reviewed the draft PAC-QoL and rated items for relevance, understandability, and sensitivity of wording: bereaved parents (n = 8) and health care professionals (HCP; n = 7). Content validity was calculated using the index of content validity (CVI [Lynn. Nurs Res 1986;35:382-385]). **RESULTS:** One hundred and forty-one candidate items congruent with the domains identified as relevant to children with advanced malignancies were generated, and four report versions with a 5-choice response scale created. Parent mean scores for importance, understandability, and sensitivity of wording ranged from 4.29 (SD = 0.52) to 4.66 (SD = 0.50). The CVI ranged from 95% to 100%. These steps resulted in reductions of the PAC-QoL to 57-65 items, as well as a modification of the response scale to a 4-choice option with new anchors. **CONCLUSIONS:** The next phase of this study will be to conduct cognitive probing with the intended population to further modify and reduce candidate items prior to psychometric evaluation. **KEYWORDS:** measure; oncology; palliative; pediatric; quality of life

PMID: 24947134

30. Pediatr Blood Cancer. 2014 Oct;61(10):1835-9.

[Development of the Pediatric Advanced Care Quality of Life Scale \(PAC-QoL\): evaluating comprehension of items and response options.](#)

[Morley TE1](#), [Cataudella D](#), [Fernandez CV](#), [Sung L](#), [Johnston DL](#), [Nesin A](#), [Zelcer S](#).

BACKGROUND: Validated tools that measure quality of life (QoL) for children with poor prognosis malignancies are not

available. We are developing a novel instrument, The Pediatric Advanced Care-Quality of Life Scale (PAC-QoL), in order to address this gap. Instrument development requires a phase of item reduction and assessment of item comprehension in the target population. This manuscript provides a report on this phase in the development of the PAC-QoL. **PROCEDURE:** Children with poor prognosis cancer and/or their parents were invited to participate in cognitive probing interviews. Participants' understanding of each item was rated from 0 (did not understand) to 4 (completely understood). To evaluate the response scale, an overall percentage of respondents' ability to accurately distinguish between the four response options was calculated. **RESULTS:** Four age- and reporter-specific versions of the PAC-QoL were tested with 74 participants. Mean (\pm SD) comprehension scores across versions ranged from 3.40 ± 0.30 (child self-report) to 3.69 ± 0.23 (parent of toddler report). The number of items deleted or modified to improve understandability ranged from 46% of all items on the parent-of-child report to 56% for the child and adolescent self-reports. Respondent's abilities to accurately distinguish between response-scale options ranged from 84% (child-report) to 98% (parent-toddler report). **CONCLUSIONS:** We demonstrate a high degree item understandability and response-scale separation in the current version of the PAC-QoL. The scale is ready for psychometric evaluation in its target population. **KEYWORDS:** oncology; palliative; pediatric; quality of life; scale development

PMID:24947009

31. Arch Dis Child Fetal Neonatal Ed. 2014 Sep;99(5):F349-52.

Managing palliation in the neonatal unit.

Uthaya S1, Mancini A2, Beardsley C2, Wood D3, Ranmal R4, Modi N5.

Professionals working in neonatology have a duty to act in the best interests of the infant. Normally, the goal of care is to sustain life and restore health. However, there are circumstances in which treatments that sustain life are not considered to be in the infant's best interests. The Royal College of Paediatrics and Child Health (RCPCH) guidance, *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice*,¹ focuses on the decision making process. The British Association of Perinatal Medicine guidance, *Palliative Care (Supportive and End of Life Care) A Framework for Clinical Practice in Perinatal Medicine*,² sets out the principles of palliative care for infants. Following a systematic review of the literature we have developed evidence-based guidance for the practical aspects of caring for an infant receiving palliative and end of life care.³ We define palliative care as the 'the active, total care of infants whose disease is not responsive to curative treatment; the goal of palliative care is achievement of the best possible quality of life for infants and their families'. Here we summarise the Guidance, a publication from Chelsea and Westminster NHS Foundation Trust developed in collaboration with the RCPCH. **KEYWORDS:** End of Life; Infant; Neonatology; Palliative Care

PMID: 24899052

32. J Anal Toxicol. 2014 Sep;38(7):421-6.

Evaluation of concomitant methylphenidate and opioid use in patients with pain.

Jiang JY1, Best BM2, Morello CM3, Atayee RS4, Ma JD5.

ABSTRACT Methylphenidate is a central nervous system stimulant that is used for management of opioid-induced sedation. Sparse data exist regarding use patterns of methylphenidate and opioids in patients with pain. This retrospective data analysis evaluated concomitant methylphenidate and opioid use from physician-reported medication lists and in urine specimens of patients with pain. All specimens were analyzed and quantified with LC-MS-MS. Concomitant methylphenidate and opioid use (e.g., sample population) were compared with a baseline population of patients taking opioids. There were 3,326 patients with physician-reported use of methylphenidate. Of these, 1,089 patients were tested for the presence of methylphenidate in urine. Methylphenidate was positive in urine for 551 patients (detection rate of 50.6%). Ritalinic acid was positive in 776 patients (detection rate of 71.3%). The current study observed differences in the use pattern of methylphenidate based on opioid type. Physician-reported use revealed methadone had the highest percent difference between the sample and baseline populations (77%, $P \leq 0.05$). Fentanyl, morphine and hydromorphone also had higher percent differences of 19.6, 25.3 and 32.3%, respectively. Further studies need to examine the apparent discrepancies between the physician-reported medication lists and urine drug testing of concomitant methylphenidate and opioid use in patients with pain. Published by Oxford University Press. All rights reserved. For Permissions, please email: journals.permissions@oup.com.

PMID:24907143

33. J Anal Toxicol. 2014 Sep;38(7):404-9.

Urinary hydrocodone and metabolite distributions in pain patients.

Barakat NH1, Atayee RS2, Best BM3, Ma JD4.

ABSTRACT Hydrocodone combined with acetaminophen is commonly used for moderate pain. Hydrocodone is metabolized by cytochrome P450 (CYP) 2D6 into hydromorphone and by CYP3A4 into norhydrocodone. This was a retrospective study evaluating hydrocodone, hydromorphone and norhydrocodone distributions in urine. Urine specimens ($n = 76,924$) were obtained from patients on chronic opioid therapy during their first or single visit and were analyzed by liquid chromatography-tandem mass spectrometry (LC-MS-MS). The patients were at least 16 years of age and had documented hydrocodone use via a medication list. There were 48,710 specimens that were positive for all three analytes. Mean hydrocodone, hydromorphone and norhydrocodone mole fractions (95% confidence interval) were 0.39 (0.38-0.39), 0.12 (0.11-0.12) and 0.49 (0.48-0.49), respectively. Hydromorphone fractions were lower in women compared with men (0.11 versus 0.13; $P < 0.0001$). Hydrocodone mole fractions were higher in the 65-year and older age group compared with the 16- to 39-year age group (0.4 versus 0.36; $P \leq 0.005$). Concurrent use of a CYP2D6 and/or CYP3A4 inhibitor altered hydromorphone and norhydrocodone mole fractions, compared with the control group. Patient factors affect hydrocodone and metabolite mole fractions and suggest increased awareness of their contribution when attempting to interpret urine drug testing results.

PMID:24836897

34. Palliat Med. 2014 Sep;28(8):1026-35.

Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012.

Lovell A1, Yates P2.

BACKGROUND: Advance Care Planning is an iterative process of discussion, decision-making and documentation about end-of-life care. Advance Care Planning is highly relevant in palliative care due to intersecting clinical needs. To enhance the implementation of Advance Care Planning, the contextual factors influencing its uptake need to be better understood.

AIM: To identify the contextual factors influencing the uptake of Advance Care Planning in palliative care as published between January 2008 and December 2012. **METHODS:** Databases were systematically searched for studies about Advance Care Planning in palliative care published between January 2008 and December 2012. This yielded 27 eligible studies, which were appraised using National Institute of Health and Care Excellence Quality Appraisal Checklists. Iterative thematic synthesis was used to group results. **RESULTS:** Factors associated with greater uptake included older age, a college degree, a diagnosis of cancer, greater functional impairment, being white, greater understanding of poor prognosis and receiving or working in specialist palliative care. Barriers included having non-malignant diagnoses, having dependent children, being African American, and uncertainty about Advance Care Planning and its legal status. Individuals' previous illness experiences, preferences and attitudes also influenced their participation. **CONCLUSION:** Factors influencing the uptake of Advance Care Planning in palliative care are complex and multifaceted reflecting the diverse and often competing needs of patients, health professionals, legislature and health systems. Large population-based studies of palliative care patients are required to develop the sound theoretical and empirical foundation needed to improve uptake of Advance Care Planning in this setting. **KEYWORDS:** Advance Care Planning; Advance Directives; Living Wills; palliative care; palliative therapy; terminal care

PMID:24821708

35. Clin Pediatr (Phila). 2014 Oct;53(11):1030-1.

Palliative care is critical to the changing face of child mortality and morbidity in the United States.

Bogetz JF1, Schroeder AR2, Bergman DA3, Cohen HJ3, Sourkes B3.

I have had to watch my child die twice, once when he was diagnosed and now the slow death from his disease.—Mother of a 9-year-old boy with lissencephaly, developmental delay, epilepsy, gastrostomy feeding tube, and wheelchair dependence

Children With a Pressing Need

In hospitals around the nation, children with medical complexity (CMC) receive life-prolonging interventions for debilitating diseases. These children are alive because of disease-focused interventions including multiple medications, innovative procedures, durable medical equipment, and continuous care. Their lives depend on an intricate dance of family caregivers—along with health care providers—who must manage long-term illnesses in their homes and communities in the context of a health care system that is only beginning to address the challenges of complex chronic disease care for ...

PMID:24817074

36. Eur J Pediatr. 2014 Sep;173(9):1201-7.

Pain therapy, pediatric palliative care and end-of-life care: training, experience, and reactions of pediatric residents in Italy.

Rusalen F1, Ferrante A, Pò C, Salata M, Agosto C, Benini F.

ABSTRACT Pediatric palliative care represents the ideal response to life-limiting and life-threatening diseases and requires a specific and multidisciplinary training. This study aims at evaluating in Italy the training programs offered in pain therapy and pediatric palliative care, the exposure, and the personal experience concerning end-of-life care management. The data have been obtained through a survey addressed to all the residents specializing in pediatrics in Italy. Three hundred forty-eight of 1,200 residents from 33 of the 41 schools of pediatrics existing in Italy responded to the questionnaire. One hundred seventy-four of them (50 %) declared they received training in end-of-life care at least once: 146 during their graduation course of medicine, 84 during the pediatric residency, and 54 in both occasions. Sixty percent of respondents were present at one death at least, with an increasing percentage in the last years of residency (91.5 % in the fifth year) but only 12 % were directly involved in the management (36.2 % in the fifth year); 5.7 % managed at least one communication of death; 12.6 % followed sedo-analgesia protocols. Only 11 % of residents felt ready to face end-of-life care management. **CONCLUSION:** The training in end-of-life care in Italy is not currently satisfactory. Further efforts are therefore required to create a comprehensive and multidisciplinary training.

PMID:24718654

37. Support Care Cancer. 2014 Sep;22(9):2315-22.

Referral practices of pediatric oncologists to specialized palliative care.

Wentlandt K1, Krzyzanowska MK, Swami N, Rodin G, Le LW, Sung L, Zimmermann C.

PURPOSE: The aims of this study are to describe the attitudes and referral practices of pediatric oncologists (POs) to specialized palliative care (SPC), and to compare them with those of adult oncologists (AOs). **METHODS:** Canadian members of the American Society of Pediatric Hematology/Oncology (ASPHO), Canadian Association of Medical Oncologists (CAMO), Canadian Association of Radiation Oncologists (CARO), and the Canadian Society of Surgical Oncology (CSSO) participated in an anonymous survey assessing SPC referral practices. **RESULTS:** The response rate was 70 % (646/921), 52 % (43/82) for ASPHO members; 5 CARO members self-identified as POs, for a total of 48 POs and 595 AOs. Ninety-six percent of POs had access to inpatient SPC consultation services (vs. 48 % AOs), 31 % to a PCU (vs. 82 % AOs), and 27 % to an outpatient SPC clinic (vs. 73 % AOs). POs more often stated their SPC services accepted patients on chemotherapy than AOs (64 vs. 37 %, $p = 0.0004$). POs were less likely to refer only after chemotherapy had been stopped (13 vs. 29 % for AOs) and more likely to state that ideally referral should occur at the diagnosis of cancer/incurable cancer (73 vs. 43 %). POs were more likely to agree they would refer earlier if palliative care were renamed "supportive care" (58 vs. 33 %, $p <$

0.0001), that palliative care adds too many providers (17 vs. 7 %, $p = 0.002$), and that palliative care was perceived negatively by their patients (60 vs. 43 %, $p = 0.02$). **CONCLUSIONS:** Although POs acknowledge the importance of early referral to SPC for children with cancer, there remain resource and attitudinal barriers to overcome in this regard.

PMID:24671435

38. Palliat Support Care. 2014 Oct;12(5):387-92.

Understanding communication among health care professionals regarding death and dying in pediatrics.

Harrison J1, Evan E2, Hughes A2, Yazdani S3, Federman M1, Harrison R1.

OBJECTIVE: Effective communication regarding death and dying in pediatrics is a vital component of any quality palliative care service. The goal of the current study is to understand communication among health care professionals regarding death and dying in children. The three hypotheses tested were: (1) hospital staff (physicians of all disciplines, nurses, and psychosocial clinicians) that utilize consultation services are more comfortable communicating about death and dying than those who do not use such services, (2) different disciplines of health care providers demonstrate varying levels of comfort communicating about a range of areas pertaining to death and dying, and (3) health care staff that have had some type of formal training in death and dying are more comfortable communicating about these issues. **METHODS:** A primary analysis of a survey conducted in a tertiary care teaching children's hospital. **RESULTS:** Health care professionals who felt comfortable discussing options for end of life care with colleagues also felt more comfortable: initiating a discussion regarding a child's impending death with his/her family ($r = 0.42$), discussing options for terminal care with a family ($r = 0.58$), discussing death with families from a variety of ethnic/cultural backgrounds ($r = 0.51$), guiding parents in developmentally age-appropriate discussions of death with their children ($r = 0.43$), identifying and seeking advice from a professional role model regarding management concerns ($r = 0.40$), or interacting with a family following the death of a child ($r = 0.51$). Among all three disciplines, physicians were more likely to initiate discussions with regards to a child's impending death ($F = 13.07$; $p = 0.007$). Health care professionals that received formal grief and bereavement training were more comfortable discussing death. Significance of the results: The results demonstrated that consultation practices are associated with a higher level of comfort in discussing death and dying in pediatrics.

PMID:23916065

39. J Pediatr Hematol Oncol. 2014 Oct;36(7):545-51.

Supporting adolescents and young adults with cancer through transitions: position statement from the canadian task force on adolescents and young adults with cancer.

Wilkins KL1, D'Agostino N, Penney AM, Barr RD, Nathan PC.

OBJECTIVE: This position statement from the Canadian Task Force on Adolescents and Young Adults with cancer aims to (1) conceptualize the numerous transition experiences encountered by adolescents and young adults (AYA) with cancer; and (2) provide recommendations on how to help the AYA regain a sense of control over their lives as they adjust to these transition experiences. **METHODS:** We reviewed and synthesized a heterogeneous sample of studies and recommendations, ranging from well-designed case-controlled investigations to opinions of respected authorities based on clinical experience, and reports of expert committees. **RESULTS:** We describe the key factors that have an impact on different transitions during the cancer journey, and the need for developmentally appropriate services for AYA with cancer that consider both the system issues and individual transition issues. Our recommendations are not intended to be prescriptive, but they are broad enough to be applicable in different types of settings (eg, family doctor, cancer center, specialty service) and systems beyond health care (eg, school system, social system). **CONCLUSIONS:** The Task Force urges health care providers, parents, and AYA with cancer to work together in planning and implementing strategies that will enable individuals to navigate the transitions they encounter along the cancer journey successfully, and strive for meaningful participation in life situations, achieving their potential as fully functional members of society.

PMID:24390448

40. J Child Health Care. 2014 Sep;18(3):230-40.

A relational understanding of sibling experiences of children with rare life-limiting conditions: findings from a qualitative study.

Malcolm C1, Gibson F2, Adams S3, Anderson G3, Forbat L4.

ABSTRACT: Mucopolysaccharidoses (MPS) and Batten disease are rare life-limiting conditions (LLCs) characterised by progressive and permanent physical and cognitive decline. The impact of such conditions on families, and notably on siblings, has not yet been described or documented. This paper presents data from a UK-wide study that sought to understand the family experience of supporting a child with the rare degenerative LLCs of MPS and Batten disease. The aim of this paper is to report sibling experiences related to these rare degenerative and progressive conditions, in order to inform the future development of supportive interventions. Eight siblings of children with MPS ($n = 7$) and Batten Disease ($n = 1$) participated in semi-structured qualitative interviews. A card sort technique was utilised to support and engage the children. Siblings are clearly impacted emotionally, pragmatically and relationally by the ill health of another child in the family. The data indicate four key themes which demonstrate impacts on siblings: perceptions of the condition and its symptoms, impact on daily life, emotional consequences and ways of coping. Siblings often had considerable knowledge of the condition and took on important roles in symptom management. However, these experiences were in the context of managing relationships within the family (often protecting parents from an awareness of how much they knew) and relationships at school (including distraction from learning and being bullied by peers). The data highlight how sibling experiences are generated through a combination of negative disability discourses and support through peers and family members. The data indicate how these features shift as a consequence of witnessing the advancement of their brother's or sister's condition and the emotional sequelae of disease progression. Exploration of siblings' experiences of living with such rare progressive and degenerative LLCs suggest the focus of interventions to support this group should address their emotional health and ways to overcome isolation and build connections with other siblings who share their unique experiences. Critically, the data suggest that sib-

ling support should be cognisant of the trajectory of the illness as well as the family, school and peer relational contexts that siblings inhabit. **KEYWORDS:** Palliative care; qualitative approaches; sibling(s)
PMID:23754839

41. J Palliat Med. 2014 Oct 10. [Epub ahead of print]

Evaluating Palliative Care Needs in Middle Eastern Countries.

Silbermann M1, Fink RM, Min SJ, Mancuso MP, Brant J, Hajjar R, Al-Alfi N, Baider L, Turker I, ElShamy K, Ghrayeb I, Al-Jadiry M, Khader K, Kav S, Charalambous H, Uslu R, Kebudi R, Barsela G, Kuruku N, Mutafoglu K, Ozalp-Senel G, Oberman A, Kislew L, Khleif M, Keoppi N, Nestoros S, Abdalla RF, Rassouli M, Morag A, Sabar R, Nimri O, Al-Qadire M, Al-Khalailah M, Tayyem M, Doumit M, Punjwani R, Rasheed O, Fallatah F, Can G, Ahmed J, Strode D.

ABSTRACT BACKGROUND: Cancer incidence in Middle Eastern countries, most categorized as low- and middle-income, is predicted to double in the next 10 years, greater than in any other part of the world. While progress has been made in cancer diagnosis/treatment, much remains to be done to improve palliative care for the majority of patients with cancer who present with advanced disease. **OBJECTIVE:** To determine knowledge, beliefs, barriers, and resources regarding palliative care services in Middle Eastern countries and use findings to inform future educational and training activities. Design: Descriptive survey. **SETTING/SUBJECTS:** Fifteen Middle Eastern countries; convenience sample of 776 nurses (44.3%), physicians (38.3%) and psychosocial, academic, and other health care professionals (17.4%) employed in varied settings. **MEASUREMENTS:** Palliative care needs assessment. **RESULTS:** Improved pain management services are key facilitators. Top barriers include lack of designated palliative care beds/services, community awareness, staff training, access to hospice services, and personnel/time. The nonexistence of functioning home-based and hospice services leaves families/providers unable to honor patient wishes. Respondents were least satisfied with discussions around advance directives and wish to learn more about palliative care focusing on communication techniques. Populations requiring special consideration comprise: patients with ethnic diversity, language barriers, and low literacy; pediatric and young adults; and the elderly. **CONCLUSIONS:** The majority of Middle Eastern patients with cancer are treated in outlying regions; the community is pivotal and must be incorporated into future plans for developing palliative care services. Promoting palliative care education and certification for physicians and nurses is crucial; home-based and hospice services must be sustained.

PMID:25302525

42. J Palliat Care. 2014 Autumn;30(3):179-87. EPUB

An integrative approach to music therapy in pediatric palliative care.

Clark BA, Siden H, Straatman L.

PMID:25265742

43. Pediatr Neurol. 2014 Oct;51(4):527-31.

Adjunctive levetiracetam treatment in pediatric lennox-gastaut syndrome.

Kim HJ1, Kim SH2, Kang HC3, Lee JS3, Chung HJ4, Kim HD5.

BACKGROUND: Our aim was to investigate the efficacy and tolerability of levetiracetam as an add-on treatment in pediatric patients with Lennox-Gastaut syndrome. **METHODS:** The study was an open-label, multicenter, observational clinical trial of levetiracetam as an add-on treatment in Lennox-Gastaut syndrome. Fifty-five patients aged 1.1-18.6 years (mean, 10.0 years) were enrolled. The study included a 4-8-week titration period and an 8-week maintenance period. The maintenance dose of levetiracetam was 20-80 mg/kg/day, according to its effectiveness and tolerability. The primary end point was reduction in seizure frequency, and related variables were also evaluated. **RESULTS:** Among 55 patents, 51 patients (92.7%) completed the study. Thirty-two patients (58.2%) experienced a more than 50% reduction in seizure frequency, and 15 patients (27.3%) became seizure free. A reduction in seizure frequency of more than 50% was observed in 21 of 36 patients (58.3%) with convulsive seizures, 7 of 12 patients (58.3%) with drop attacks, 2 of 4 patients (50.0%) with myoclonic seizures, and 2 of 3 patients (66.7%) with epileptic spasms. Overall, 34.5% of patients reported adverse events. None of the adverse events were life threatening, and the most common adverse event was hyperactivity (12.7%). **CONCLUSIONS:** This study suggests that levetiracetam is a safe and effective treatment in pediatric patients with Lennox-Gastaut syndrome. **KEYWORDS:** Lennox-Gastaut syndrome; child; efficacy; levetiracetam; tolerability

PMID:25266616

44. Arch Dis Child Fetal Neonatal Ed. 2014 Sep 26. [Epub ahead of print]

European neonatal intensive care nursing research priorities: an e-Delphi study.

Wielenga JM1, Tume LN2, Latour JM3, van den Hoogen A4.

OBJECTIVE: This study aimed to identify and prioritize neonatal intensive care nursing research topics across Europe using an e-Delphi technique. **DESIGN:** An e-Delphi technique with three questionnaire rounds was performed. Qualitative responses of round one were analysed by content analysis and research statements were generated to be ranked on importance on a scale of 1-6 (not important to most important). **SETTING:** Neonatal intensive care units (NICUs) in 17 European countries. **POPULATION:** NICU clinical nurses, managers, educators and researchers (n=75). **INTERVENTION:** None. **MAIN OUTCOME MEASURES:** A list of 43 research statements in eight domains. **RESULTS:** The six highest ranking statements (≥ 5.0 mean score) were related to prevention and reduction of pain (mean 5.49; SD 1.07), medication errors (mean 5.20; SD 1.13), end-of-life care (mean 5.05; SD 1.18), needs of parents and family (mean 5.04; SD 1.23), implementing evidence into nursing practice (mean 5.02; SD 1.03), and pain assessment (mean 5.02; SD 1.11). The research domains were prioritised and ranked: (1) pain and stress; (2) family centred care; (3) clinical nursing care practices; (4) quality and safety; (5) ethics; (6) respiratory and ventilation; (7) infection and inflammation; and (8) professional issues in neonatal intensive care nursing. **CONCLUSIONS:** The results of this study might support developing a nursing research strategy for the nursing section of the European Society of Paediatric and Neonatal Intensive Care. In addition, this may promote more European researcher collaboratives for neonatal nursing research. **KEYWORDS:** Evidence Based Medicine; Neonatology; Nurs-

ing Care
PMID:25260359

45. *Curr Med Res Opin.* 2014 Sep 22:1-71. [Epub ahead of print]

Patients with Chronic Pain and Dysphagia (CPD): Unmet Medical Need and Pharmacologic Treatment Options.
Argoff CE¹, Kopecky EA.

ABSTRACT BACKGROUND: For properly selected patients experiencing chronic pain, extended-release opioid formulations may represent an appropriate pain management choice. For the many adults, elderly, and children who have medical conditions that make swallowing solid, oral-dose formulations difficult (dysphagia) or painful (odynophagia), this option may be limited. The combination of chronic pain with dysphagia (CPD) presents a challenge to physicians and patients alike when oral opioid analgesia is needed to control pain, but patients are unable to swallow solid, oral dosage forms. **METHODS:** A Medline search was performed (1990 to 2013) using search terms swallowing difficulties, dysphagia, odynophagia, adults, pediatrics, elderly, chronic pain, pain, and opioids. The following websites were searched: American Dysphagia Network, Dysphagia Research Society, World Health Organization, American Pain Society, International Association for the Study of Pain, American Academy of Pain Medicine, and American Society of Interventional Pain Physicians. Chronic pain guidelines from the following professional organizations were searched: American Pain Society, National Comprehensive Cancer Network, American Society of Interventional Pain Physicians, British Geriatric Society, European Society of Medical Oncology, World Health Organization, and the European Association for Palliative Care. **FINDINGS:** There is an unmet medical need for greater recognition of dysphagia, awareness of potential problems with medication administration in these patients, recognition of alternative drug formulations that are available for use in CPD, and an appreciation that there are new, solid, oral-dose, opioid formulations in development that can mitigate these issues associated with swallowing difficulty while still providing practical, effective analgesia. Current pharmacologic treatments have limitations; new, prospective opioid formulations in clinical development may offer physicians and patients with CPD effective treatment options while mitigating accidental exposure and abuse liability. **CONCLUSIONS:** The number of patients with CPD may be larger than is currently anticipated by healthcare providers. Physicians should proactively include a discussion of dysphagia as part of the patient examination. CPD is an unmet medical need. There are novel opioid formulations in clinical development that address the limitations of current opioid treatments. This manuscript reviews the problems associated with dysphagia on medication administration and adherence, currently available treatment options, and opioid analgesic formulations currently in clinical development. **KEYWORDS:** abuse-deterrent; analgesics; chronic pain; chronic pain with dysphagia; dysphagia; odynophagia; opioid; opioid formulations; swallowing difficulty

PMID:25244248

46. *J Perinatol.* 2014 Sep 18. [Epub ahead of print]

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.

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47. *Arch Dis Child.* 2014 Sep;99(9):795-7.

Redirection in treatment goals: withdrawal of mechanical ventilation outside of the intensive care unit.

Mayer AP.

Despite extensive technological advances and improved survival in paediatric intensive care unit (PICU) patients, many families are faced with a redirection in the aims of treatment to a journey of palliation. This transition in care from cure to palliation is difficult (and sometimes unimaginable) for the families involved, and it is also challenging for professionals, technically and emotionally. There are no 'second chances' in end-of-life care. The experience and memories of that journey will remain with the relatives forever. There is increasing objective evidence of the importance of parental choice during the end-of-life care of their child, and this is no less so in the choices surrounding place of death.¹ Laddie *et al*² describe their experience of withdrawal of mechanical ventilation outside the PICU, with a view to providing guidance for professionals who may be involved in such terminal care. In the report, dividing the process into five phases provides a practical framework, and the importance of experience and training is highlighted at all stages. Preparation End of life is unpredictable, and withdrawal of mechanical ventilation outside the PIC means that the team embarking on this redirection-in-care will be working in an unfamiliar environment. Although the local palliative care team is familiar with the surroundings, it may be less familiar with the process of endotracheal tube extubation. Early liaison with the local team should be undertaken. Families must never be promised an option at the end of life that is not guaranteed to be available. Many other teams are often involved, including the team transporting the child from the PICU. **KEYWORDS:** End of Life Care; Paediatric Intensive Care; Palliative Care

Comment on [Withdrawal of ventilatory support outside the intensive care unit: guidance for practice.](#) [Arch Dis Child. 2014] PMID:24994862

48. Support Care Cancer. 2014 Oct;22(10):2621-8.

The EAPC framework on palliative sedation and clinical practice-a questionnaire-based survey in Germany.

[Klosa PR1](#), [Klein C](#), [Heckel M](#), [Bronnhuber AC](#), [Ostgathe C](#), [Stiel S](#).

BACKGROUND: Palliative sedation (PS) can be offered to patients with intolerable symptom burden refractory to comprehensive palliative care (PC) treatment. Little is known about the daily practice of using PS in German specialized PC institutions in the context of existing national and international recommendations. **PURPOSE:** This study's primary objective is to explore how PS is used in German specialized PC institutions with reference to the EAPC framework. **METHODS:** The heads of all palliative care units, hospices, specialized palliative home care teams, and specialized pediatric palliative home care teams listed in the official address registers were invited to take part in a questionnaire survey about the clinical practice of PS in their institution. **RESULTS:** Considerable differences of the frequency of PS exist between institutions. The estimated frequency of PS ranges from 0 to 80 % of all patients treated per year (mean 6.7 %). Some PC specialists report to discuss PS as treatment option for every patient they encounter. Specific evaluation and documentation tools are rare. Of the study participants, 36.2 % are not familiar with international and national recommendations. **CONCLUSION:** Many differences exist in frequency and clinical handling of PS in Germany. Implementation of international and national recommendations into clinical practice remains inconsistent.

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