

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

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



The First

February 2015

Volume II - N° 1

1. J Pain Symptom Manage. 2015 Jan 31. [Epub ahead of print]

Timing of Survey Administration After Hospice Patient Death: Stability of Bereaved Respondents.

DiBiasio EL¹, Clark MA¹, Gozalo PL¹, Spence C², Casarett DJ³, Teno JM⁴.

CONTEXT: The Centers for Medicare & Medicaid Services have elected to include a bereaved family member survey in public reporting of hospice quality data as mandated in the Affordable Care Act. However, it is not known what timepoint after death offers the most reliable responses. **OBJECTIVES:** To examine the stability of bereaved family members' survey responses when administered three, six and nine months after hospice patient death. **METHODS:** Bereaved family members from six geographically diverse hospices were interviewed three, six, and nine months after patient death. All respondents completed a core survey. Those whose family member died at home, in a free-standing inpatient unit, or in a nursing home also completed a site-specific module. Stability was based on top-box scoring of each item with kappa statistics, and multi-variable regression models were used to assess directionality and predictors of change. To analyze the effects of grief, we assessed response stability among respondents at least one standard deviation from the mean change in grief between three and six months. **RESULTS:** We had 1532 surveys (536 three-month surveys, 529 six-month surveys, and 467 nine-month surveys) returned by 643 respondents (average age 61.7 years, 17.4% Black, 50.5% a child respondent) about hospice decedents (55.3% female, average age 78.6 years, 57.0% non-cancer, 40.0% at home.) The average kappa for core items between three and nine months was 0.54 (range: 0.42-0.74), 0.58 (0.41-0.69) for home-specific items, and 0.54 (0.39-0.63) for nursing home. Even among individuals demonstrating large grief changes, core items demonstrated moderate to high stability over time. **CONCLUSION:** Bereaved family member responses are stable between three and nine months after the death of the patient.

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PMID: 25647420 [PubMed - as supplied by publisher]

2. Nurs Outlook. 2015 Jan-Feb;63(1):51-9.

Policy brief: The Institute of Medicine report Dying in America: Improving quality and honoring individual preferences near the end of life.

Meghani SH¹, Hinds PS².

The Institute of Medicine's 2014 report Dying in America: Improving quality and honoring individual preferences near the end of life provides recommendations for creating transformational change in the models of end-of-life care delivery, clinician-patient communication, and advance care planning; improving professional education, reforming policies, and payment systems; and engaging and educating the public toward high-quality, coordinated, and comprehensive care that is person centered and family oriented. This article provides a policy brief of this recently released report. The role of nursing in advancing these recommendations is discussed.

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PMID: 25645482 [PubMed - in process]

3. *Pediatr Blood Cancer*. 2015 Jan 13. [Epub ahead of print]

[Extreme doses of intravenous methadone for severe pain in two children with cancer.](#)

Rasmussen VF¹, Lundberg V, Jespersen TW, Hasle H.

We describe the effect and side effects in two children with cancer treated with intravenous methadone in extreme doses (>10 mg/kg/day) due to vincristine-induced neuropathy where surgical procedures provoked severe neuropathic pain. The maximum daily dose was 33 and 25 mg/kg/day. Methadone remained effective at adjusted doses. Few side effects were reported. No significant changes in paraclinical data were observed. Prolonged QTc-interval occurred only during concomitant treatment with fluconazole. In conclusion, methadone should be seen as a part of the armamentarium against cancer-related pain. Methadone can be used in extreme doses with appropriate monitoring by clinicians experienced in its use.

PMID: 25641929 [PubMed - as supplied by publisher]

4. *J Pain Symptom Manage*. 2015 Jan 29. [Epub ahead of print]

[Feasibility of Conducting a Palliative Care Randomized Controlled Trial in Children with Advanced Cancer: Assessment of the PediQUEST Study.](#)

Dussel V¹, Orellana L², Soto N³, Chen K⁴, Ullrich C⁵, Kang TT⁶, Geyer JR⁷, Feudtner C⁶, Wolfe J⁸.

CONTEXT: Pediatric palliative care randomized controlled trials (PPC-RCTs) are uncommon. **OBJECTIVES:** To evaluate the feasibility of conducting a PPC-RCT in pediatric cancer patients. **METHODS:** This was a cohort study embedded in the Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) Study (NCT01838564). This multicenter PPC-RCT evaluated an electronic patient-reported-outcomes system. Children ≥2-years-old, with advanced cancer, and potentially eligible for the study were included. Outcomes measured were: pre-inclusion attrition: patients not approached, refusals; post-inclusion attrition: drop-out, elimination, death, and intermittent attrition (missing surveys) over nine months; child/teenager self-report rates; and reasons to enroll/participate. **RESULTS:** Over five years, of the 339 identified patients, 231 were eligible (in 22 we could not verify eligibility); 87774 eligible patients were not approached and 43 declined participation. Patients not approached were more likely to die or have brain tumors. We enrolled 104 patients. Average enrollment rate was one patient/site/month; shortening follow-up from nine to three months (with optional re-enrollment) increased recruitment by 20%. Eighty-seven patients completed the study (24 died) and 17 dropped out. Median intermittent attrition was 41% in the first 20 weeks of follow-up, and over 60% in the eight weeks preceding death. Child/teenager self-report was 94%. Helping others, low burden procedures, incentives, and staff attitude were frequent reasons to enroll/participate. **CONCLUSION:** A PPC-RCT in children with advanced cancer was feasible, post-inclusion retention adequate; many families participated for altruistic reasons. Strategies that may further PPC-RCT feasibility include: increasing target population through large multicenter studies, approaching sicker patients, preventing exclusion of certain patient groups, and improving data collection at end of life.

PMID: 25640275

5. *Palliat Med*. 2015 Jan 29. [Epub ahead of print]

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

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

Abstract

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

PMID: 25634634 [PubMed - as supplied by publisher]

6. *Jpn J Clin Oncol*. 2015 Jan 26. [Epub ahead of print]

[Good death for children with cancer: a qualitative study.](#)

Ito Y¹, Okuyama T¹, Ito Y², Kamei M², Nakaguchi T¹, Sugano K¹, Kubota Y³, Sakamoto N⁴, Saitoh S², Akechi T⁵.

Abstract

OBJECTIVE: This study aims to explore the characteristics of a good death for children with cancer. **METHODS:** A total of 10 pediatric cancer survivors, 10 bereaved family members and 20 medical professionals participated in in-depth interviews. Qualitative content analysis was performed on the transcribed data obtained from semi-structured interviews. **RESULTS:** Thirteen characteristics including unique and specific for children of a good death were identified: (i) sufficient opportunities to play freely, (ii) peer supporters, (iii) continued access to the patient's usual activities and relationships, (iv)

assurance of privacy, (v) respect for the patient's decisions and preferences, (vi) a sense that others acknowledge and respect the patient's childhood, (vii) comfort care to minimize distressing symptoms, (viii) hope, (ix) not aware of the patient's own impending death, (x) constant dignity, (xi) strong family relationships, (xii) no sense of being a burden to family members and (xiii) good relationships with medical staffs. **CONCLUSIONS:** This study identifies important characteristics of a good death for children with cancer. These findings may help medical staffs provide optimal care for children with cancer and their families, enabling them to achieve a good death.

PMID: 25628351 [PubMed - as supplied by publisher]

7. Cancer Med. 2015 Jan 27. [Epub ahead of print]

Years of life lived with disease and years of potential life lost in children who die of cancer in the United States, 2009.

de Blank PM¹, Ostrom QT, Rouse C, Wolinsky Y, Kruchko C, Salcido J, Barnholtz-Sloan JS.

Abstract

Incidence and survival rates are commonly reported statistics, but these may fail to capture the full impact of childhood cancers. We describe the years of potential life lost (YPLL) and years of life lived with disease (YLLD) in children and adolescents who died of cancer in the United States to estimate the impact of childhood cancer in the United States in 2009. We examined mortality data in 2009 among children and adolescents <20 years old in both the National Vital Statistics System (NVSS) and the Surveillance, Epidemiology, and End Results (SEER) datasets. YPLL and YLLD were calculated for all deaths due to cancer. Histology-specific YPLL and YLLD of central nervous system (CNS) tumors, leukemia, and lymphoma were estimated using SEER. There were 2233 deaths and 153,390.4 YPLL due to neoplasm in 2009. CNS tumors were the largest cause of YPLL (31%) among deaths due to cancer and were the cause of 1.4% of YPLL due to all causes. For specific histologies, the greatest mean YPLL per death was due to atypical teratoid/rhabdoid tumor (78.0 years lost). The histology with the highest mean YLLD per death in children and adolescents who died of cancer was primitive neuroectodermal tumor (4.6 years lived). CNS tumors are the most common solid malignancy in individuals <20 years old and have the highest YPLL cost of all cancers. This offers the first histology-specific description of YPLL in children and adolescents and proposes a new measure of cancer impact, YLLD, in individuals who die of their disease. YPLL and YLLD complement traditional indicators of mortality and help place CNS tumors in the context of other childhood malignancies.

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PMID: 25627000

8. Ecancermedicallscience. 2014 Dec 11;8:492. eCollection 2014.

The current situation in education and training of health-care professionals across Africa to optimise the delivery of palliative care for cancer patients.

Rawlinson F¹, Gwyther L², Kiyange F³, Luyirika E³, Meiring M⁴, Downing J⁵.

Abstract

The need for palliative care education remains vital to contribute to the quality of life of patients, both adults and children, with cancer in Africa. The number of patients with cancer continues to rise, and with them the burden of palliative care needs. Palliative care has been present in Africa for nearly four decades, and a number of services are developing in response to the HIV/AIDS epidemic. However, the needs of cancer patients remain a challenge. Education and training initiatives have developed throughout this time, using a combination of educational methods, including, more recently, e-learning initiatives. The role of international and national organisations in supporting education has been pivotal in developing models of education and training that are robust, sustainable, and affordable. Developing a material for education and professional development needs to continue in close collaboration with that already in production in order to optimise available resources. Seeking ways to evaluate programmes in terms of their impact on patient care remains an important part of programme delivery. This article reviews the current situation.

PMID: 25624873 [PubMed]

9. Ecancermedicallscience. 2014 Dec 11;8:489. eCollection 2014.

Palliative care needs of HIV exposed and infected children admitted to the inpatient paediatric unit in Uganda.

Nakawesi J¹, Kasirye I¹, Kavuma D¹, Muziru B¹, Businge A¹, Naluwooza J¹, Kabunga G¹, Karamagi Y¹, Akankwasa E¹, Odiit M¹, Mukasa B¹.

Abstract

Paediatric palliative care is an emerging subspecialty that focuses on achieving the best possible quality of life for children with life-limiting conditions and also for their families. It is a response to the suffering and unique needs of such children. Globally there is limited documented data available on the palliative care needs of children with HIV. A retrospective review of data of all the HIV exposed and positive children who were admitted to the ward from January to December 2012 was done to document their palliative care needs. A total of 243 children were admitted to the ward during the stated period. Of these, 139 (57.2%) were female and 104 (42.8%) were male. Among them 131 (54%) were aged five years and below whereas 112 (46%) were above five years. Some of the identified palliative care needs documented included physical needs: pneumonia 46 (19%), severe acute malnutrition 38 (16%), mild and moderate acute malnutrition 23 (9.6%), and respiratory tract infections 22 (9.3%). Social needs: poor social support 21 (41%), financial instability 16 (31%), and child neglect 4 (8%). Psychological needs: antiretroviral treatment (ART) counselling 127 (36%), HIV counselling and testing for the child and family 63 (18%), adherence support 53 (15%), and others 11 (3%). Spiritual needs: discontinuing ART because of belief in spiritual healing 18 (81%), loss of hope because of severe ill health 1 (5%), and others 3 (14%). These results emphasise the need for palliative care in children with HIV even in the era of ART. The needs identified are in keeping with studies done elsewhere and are similar to the palliative care needs of children with other life-limiting illnesses such as cancer. **CONCLUSION:** HIV positive and exposed children plus their families have vast palliative care needs and a holistic approach is the key in their management. PMID: 25624870 [PubMed]

10. J Pediatr Oncol Nurs. 2015 Jan 26. [Epub ahead of print]

Evaluation of Physician and Nurse Dyad Training Procedures to Deliver a Palliative and End-of-Life Communication Intervention to Parents of Children with a Brain Tumor.

Hendricks-Ferguson VL¹, Kane JR², Pradhan KR³, Shih CS³, Gauvain KM⁴, Baker JN⁵, Haase JE⁶.

Abstract

When a child's prognosis is poor, physicians and nurses (MDs/RNs) often struggle with initiating discussions about palliative and end-of-life care (PC/EOL) early in the course of illness trajectory. We describe evaluation of training procedures used to prepare MD/RN dyads to deliver an intervention entitled: Communication Plan: Early Through End of Life (COMPLETE) intervention. Our training was delivered to 5 pediatric neuro-oncologists and 8 pediatric nurses by a team of expert consultants (i.e., in medical ethics, communication, and PC/EOL) and parent advisors. Although half of the group received training in a 1-day program and half in a 2-day program, content for all participants included 4 modules: family assessment, goal-directed treatment planning, anticipatory guidance, and staff communication and follow-up. Evaluations included dichotomous ratings and qualitative comments on content, reflection, and skills practice for each module. Positive aspects of our training included parent advisers' insights, emphasis on hope and non-abandonment messages, written materials to facilitate PC/EOL communication, and an MD/RN dyad approach. Lessons learned and challenges related to our training procedures will be described. Overall, the MDs and RNs reported that our PC/EOL communication-training procedures were helpful and useful. Future investigators should carefully plan training procedures for PC/EOL communication interventions.

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PMID: 25623029 [PubMed - as supplied by publisher]

11. BMC Palliat Care. 2015 Jan 13;14(1):1. eCollection 2015.

Initial development and psychometric testing of an instrument to measure the quality of children's end-of-life care.

Widger K¹, Tourangeau AE¹, Steele R², Streiner DL³.

Abstract

BACKGROUND: The field of pediatric palliative care is hindered by the lack of a well-defined, reliable, and valid method for measuring the quality of end-of-life care. **METHODS:** The study purpose was to develop and test an instrument to measure mothers' perspectives on the quality of care received before, at the time of, and following a child's death. In Phase 1, key components of quality end-of-life care for children were synthesized through a comprehensive review of research literature. These key components were validated in Phase 2 and then extended through focus groups with bereaved parents. In Phase 3, items were developed to assess structures, processes, and outcomes of quality end-of-life care then tested for content and face validity with health professionals. Cognitive testing was conducted through interviews with bereaved parents. In Phase 4, bereaved mothers were recruited through 10 children's hospitals/hospices in Canada to complete the instrument, and psychometric testing was conducted. **RESULTS:** Following review of 67 manuscripts and 3 focus groups with 10 parents, 141 items were initially developed. The overall content validity index for these items was 0.84 as rated by 7 health professionals. Based on feedback from health professionals and cognitive testing with 6 parents, a 144-item instrument was finalized for further testing. In Phase 4, 128 mothers completed the instrument, 31 of whom completed it twice. Test-retest reliability, internal consistency, and construct validity were demonstrated for six subscales: Connect With Families, Involve Parents, Share Information With Parents, Share Information Among Health Professionals, Support Parents, and Provide Care at Death. Additional items with content validity were grouped in four domains: Support the Child, Support Siblings, Provide Bereavement Follow-up, and Structures of Care. Forty-eight items were deleted through psychometric testing, leaving a 95-item instrument. **CONCLUSIONS:** There is good initial evidence for the reliability and validity of this new quality of end-of-life care instrument as a mechanism for evaluative feedback to health professionals, health systems, and policy makers to improve children's end-of-life care.

PMID: 25620884 [PubMed]

12. J Pediatr Oncol Nurs. 2015 Jan 23. [Epub ahead of print]

Establishing Feasibility of Early Palliative Care Consultation in Pediatric Hematopoietic Stem Cell Transplantation.

Lafond DA¹, Kelly KP², Hinds PS², Sill A³, Michael M⁴.

Abstract

Children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) encounter a number of distressing physical symptoms and existential distress but may not be afforded timely access to palliative care services to help ameliorate the distress. This feasibility study investigated the acceptability and outcomes of early palliative care consultation to promote comfort in this population. A longitudinal, descriptive cohort design examined both provider willingness to refer and willingness of families to receive palliative care interventions as well as satisfaction. Feasibility was demonstrated by 100% referral of eligible patients and 100% of patient and family recruitment (N = 12). Each family received 1 to 3 visits per week (ranging from 15 to 120 minutes) from the palliative care team. Interventions included supportive care counseling and integrative therapies. Families and providers reported high satisfaction with the nurse-led palliative care consultation. Outcomes included improvement or no significant change in comfort across the trajectory of HSCT, from the child and parental perspective. Early integration of palliative care in HSCT is feasible and acceptable to families and clinicians.

PMID: 25616372

13. J Pain Symptom Manage. 2015 Jan 12. [Epub ahead of print]

Independent Validation of the Japanese Version of the EORTC QLQ-C15-PAL for Patients with Advanced Cancer.

Miyashita M¹, Wada M², Morita T³, Ishida M², Onishi H², Sasaki Y⁴, Narabayashi M⁵, Wada T⁶, Matsubara M², Takigawa C⁷, Shinjo T⁸, Suga A⁹, Inoue S¹⁰, Ikenaga M¹¹, Kohara H¹², Tsuneto S¹³, Shima Y¹⁴.

Abstract

CONTEXT.: Although the psychometric properties of the Japanese version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 15-Palliative Care (EORTC QLQ-C15-PAL) have been examined pre-

viously, that study had several limitations, e.g., small sample size. **OBJECTIVES:** To examine the validity and reliability, including test-retest reliability, of the Japanese version of EORTC QLQ-C15-PAL for cancer patients with metastasis or recurrence. **METHODS:** A cross-sectional anonymous questionnaire was administered to cancer patients who were being treated on an oncology inpatient ward, in an oncology outpatient clinic, and in seven inpatient palliative units in Japan, from August 2007 to March 2008. **RESULTS:** Data from a total of 312 cancer patients were analyzed. The proportion of missing values was less than 4% for all items. The factor structure was reproduced identically with the original EORTC QLQ-C15-PAL, English version. The correlation of subscales showed a reasonable matrix. Cronbach's alpha coefficients were 0.76 to 0.86 and intra-class correlation coefficients, which indicate test-retest reliability, ranged from 0.52 to 0.77. All subscales, especially physical functioning, fatigue, and pain, were significantly correlated with self-reported Eastern Cooperative Oncology Group performance status. **CONCLUSION:** The Japanese version of EORTC QLQ-C15-PAL has sufficient validity, acceptable reliability, and feasibility for patients with advanced cancer.

PMID: 25593101

14. Expert Rev Gastroenterol Hepatol. 2015 Jan 16:1-6. [Epub ahead of print]

The challenges of liver transplantation in children with primary sclerosing cholangitis.

Venkat VL¹, Ranganathan S, Sindhi R.

Abstract

Primary sclerosing cholangitis (PSC) in children can progress to end-stage liver disease requiring liver transplantation. PSC poses many challenges beginning with evaluation and classification of ductal involvement and overlap syndromes, few options for medical management and unique risks in the post-transplant period. The construct that PSC may be an autoimmune disease is based on positive autoantibodies, association with inflammatory bowel disease, linkage to HLA type and overlap/autoimmune sclerosing cholangitis; however, PSC is not responsive to standard immunosuppression. Study of PSC and post-transplant outcomes in children may provide a unique background in which to study this challenging disease. This is particularly intriguing in the subset of patients diagnosed in the first decade of life, suggesting a strong link to predisposing genetic susceptibility and immune dysregulation. Long-term, multicenter effort is likely to be the only mechanism to study this rare disease in children and to improve outcomes in the future.

PMID: 25592492

15. J Paediatr Child Health. 2015 Jan;51(1):8-11.

Fifty years of paediatric ethics.

Gillam L¹.

Abstract

In 1965, when the first issue of Journal of Paediatrics and Child Health appeared, medical ethics was just becoming established as a discipline. The sub-speciality of paediatric ethics did not make an appearance until the late 1980s, with the first key texts appearing in the 1990s. Professional concern to practice ethically in paediatrics obviously goes much further back than that, even if not named as such. In clinical areas of paediatrics, the story of the last 50 years is essentially a story of progress - better understanding of disease, better diagnosis, more effective treatment, better outcomes. In paediatric ethics, the story of the last 50 years is a bit more complicated. In ethics, the idea of progress, rather than just change, is not so straightforward and is sometimes hotly contested. There has certainly been change, including some quite radical shifts in attitudes and practices, but on some issues, the ethical debate now looks remarkably similar to that of 40-50 years ago. This is the story of some things that have changed in paediatric ethics, some things that have stayed the same and the key ethical ideas lying beneath the surface.

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PMID: 25586839

16. PLoS One. 2015 Jan 13;10(1):e0116913. eCollection 2015.

The Association between Individual Income and Aggressive End-of-Life Treatment in Older Cancer Decedents in Taiwan.

Huang CY¹, Hung YT², Chang CM³, Juang SY⁴, Lee CC⁵.

Abstract

OBJECTIVES: To examine the association of individual income and end of life (EOL) care in older cancer decedents in Taiwan. **DESIGN:** Retrospective cohort study. **SETTING:** National Health Insurance Research Database (NHIRD) in Taiwan. **PARTICIPANTS:** 28,978 decedents >65 years were diagnosed with cancer and died during 2009-2011 in Taiwan. Of these decedents, 10941, 16535, and 1502 were categorized by individual income as having low, moderate, and high SES, respectively. **MAIN OUTCOME MEASURES:** Indicators of aggressiveness of EOL care: chemotherapy use before EOL, more than one emergency department (ER) visit, more than one hospital admission, hospital length of stay >14 days, intensive care unit (ICU) admission, and dying in a hospital. **RESULTS:** Low individual income was associated with more aggressive EOL treatment (estimate -0.30 for moderate income, -0.27 for high income, both $p < 0.01$). The major source of aggressiveness was the tendency for older decedents with low income to die in the acute care hospital. The indicators had an increasing trend from 2009 to 2011, except for hospital stay >14 days. **CONCLUSIONS:** Low individual income is associated with more aggressive EOL treatment in older cancer decedents. Public health providers should make available appropriate education and hospice resources to these decedents and their families, to reduce the amount of aggressive terminal care such decedents receive.

PMID: 25585131 [PubMed - in process]

17. J Pain Palliat Care Pharmacother. 2015 Jan 12. [Epub ahead of print]

Evidence-based Pain Management and Palliative Care.

Wiffen PJ.

Abstract

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

PMID: 25580716

18. Clin Pediatr (Phila). 2015 Mar;54(3):222-7.

[Continuing education needs of pediatricians across diverse specialties caring for children with medical complexity.](#) [Bogetz JF](#)¹, [Bogetz AL](#)², [Gabhart JM](#)³, [Bergman DA](#)⁴, [Blankenburg RL](#)⁴, [Rassbach CE](#)⁴.

Abstract

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

PMID: 25561699

19. Pediatrics. 2015 Feb;135(2):e465-76.

[Talking With Parents About End-of-Life Decisions for Their Children.](#)

[de Vos MA](#)¹, [Bos AP](#)², [Plötz FB](#)³, [van Heerde M](#)⁴, [de Graaff BM](#)⁵, [Tates K](#)⁶, [Truog RD](#)⁷, [Willems DL](#)⁸.

Abstract

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

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PMID: 25560442

20. Cancer. 2014 Dec 29. doi: 10.1002/cncr.29230. [Epub ahead of print]

[Does phase 1 trial enrollment preclude quality end-of-life care? Phase 1 trial enrollment and end-of-life care characteristics in children with cancer.](#)

[Levine DR](#)¹, [Johnson LM](#), [Mandrell BN](#), [Yang J](#), [West NK](#), [Hinds PS](#), [Baker JN](#).

Abstract

BACKGROUND: End-of-life care (EOLC) discussions and treatment-related decisions, including phase 1 trial enrollment, in patients with incurable disease are complex and can influence the quality of EOLC received. The current study was conducted in pediatric oncology patients to determine whether end-of-life characteristics differed between those who were and were not enrolled in a phase 1 trial. **METHODS:** The authors reviewed the medical records of 380 pediatric oncology patients (aged <22 years at the time of death) who died during a 3.5-year period. Of these, 103 patients with hematologic malignancies were excluded. A total of 277 patients with a diagnosis of a brain tumor or other solid tumor malignancy were divided into 2 groups based on phase 1 trial enrollment: a phase 1 cohort (PIC; 120 patients) and a non-phase 1 cohort (NPIC; 157 patients). The EOLC characteristics of these 2 cohorts were compared using regression analysis and chi-square testing. **RESULTS:** A comparison of patients in the PIC and NPIC revealed no significant differences in either demographic characteristics (including sex, race, religious affiliation, referral origin, diagnosis, or age at diagnosis, with the exception of age at the time of death [P = .03]) or in EOLC indices (such as use or timing of do not attempt resuscitation orders, hospice use or length of stay, forgoing life-sustaining therapies, location of death, time from first EOLC discussion to death, and total number of EOLC discussions). **CONCLUSIONS:** The results of the current study of a large cohort of deceased pediatric cancer patients indicate that enrollment on a phase 1 trial does not affect EOLC characteristics, suggesting that quality EOLC can be delivered regardless of phase 1 trial participation. PMID: 25557437

21. Cancer. 2014 Dec 29.

Conditional survival in pediatric malignancies: Analysis of data from the Childhood Cancer Survivor Study and the Surveillance, Epidemiology, and End Results Program.

Mertens AC¹, Yong J, Dietz AC, Kreiter E, Yasui Y, Bleyer A, Armstrong GT, Robison LL, Wasilewski-Masker K.

Abstract

BACKGROUND: Long-term survivors of pediatric cancer are at risk of life-threatening late effects of their cancer. Previous studies have shown excesses in long-term mortality within high-risk groups defined by demographic and treatment characteristics. **METHODS:** To investigate conditional survival in a pediatric cancer population, the authors performed an analysis of conditional survival in the original Childhood Cancer Survivor Study (CCSS) cohort and the Surveillance, Epidemiology, and End Results (SEER) database registry. The overall probability of death for patients at 5 years and 10 years after they survived 5, 10, 15, and 20 years since cancer diagnosis and cause-specific death in 10 years for 5-year survivors were estimated using the cumulative incidence method. **RESULTS:** Among patients in the CCSS and SEER cohorts who were alive 5 years after their cancer diagnosis, within each diagnosis group at least 92% were alive in the subsequent 5 years, except for patients with leukemia, of whom only 88% of 5-year survivors remained alive in the subsequent 5 years. The probability of all-cause mortality in the next 10 years among patients who survived at least 5 years after diagnosis was 8.8% in CCSS and 10.6% in SEER, approximately 75% of which was due to neoplasms as the cause of death. **CONCLUSIONS:** The risk of death among survivors of pediatric cancer in 10 years can vary between diagnosis groups by at most 12%, even up to 20 years after diagnosis. This information is clinically significant when counseling patients regarding their conditional survival, particularly when survivors are seen in long-term follow-up. Cancer 2014. © 2014 American Cancer Society.

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PMID: 25557134

22. J Pediatr Oncol Nurs. 2015 Jan 2. [Epub ahead of print]

Parents' Experience With Their Child's Cancer Diagnosis: Do Hopefulness, Family Functioning, and Perceptions of Care Matter?

Popp JM¹, Conway M², Pantaleao A³.

Abstract

OBJECTIVES: This study assessed the experience of parents who have a child diagnosed with cancer and whether parental hope, family functioning, and perceptions of care distinguish those parents who have adapted to the diagnosis versus those who have not adapted. **METHODS:** Fifty parents completed an interview about the diagnosis experience and questionnaires about hopefulness, family functioning, and family-centered care. **RESULTS:** A majority of parents had come to terms with the diagnosis; however, a subset indicated feeling emotionally disengaged from the experience and having persistent thoughts about why this had happened to them. In addition, parents who were having a difficult time adapting reported lower hopefulness and felt that they received more information about support services from medical providers compared with parents who had come to terms with the diagnosis. **CONCLUSIONS:** By recognizing families who continue to struggle with the diagnosis, nurses may be better equipped to approach families and evaluate their needs, including coping and adaptation. Asking parents about their experience can also lead to more appropriate and timely care and referral and allows nurses to provide care that engenders hopefulness.

PMID: 25556107

23. J Pediatr Oncol Nurs. 2015 Jan 2. [Epub ahead of print]

Novice Nurses' Experiences With Palliative and End-of-Life Communication.

Hendricks-Ferguson VL¹, Sawin KJ², Montgomery K³, Dupree C⁴, Phillips-Salimi CR⁵, Carr B⁶, Haase JE⁵.

Abstract

Health care providers recognize that delivery of effective communication with family members of children with life-threatening illnesses is essential to palliative and end-of-life care (PC/EOL). Parents value the presence of nurses during PC/EOL of their dying child. It is vital that nurses, regardless of their years of work experience, are competent and feel comfortable engaging family members of dying children in PC/EOL discussions. This qualitative-descriptive study used focus groups to explore the PC/EOL communication perspectives of 14 novice pediatric oncology nurses (eg, with less than 1 year of experience). Audio-taped focus group discussions were reviewed to develop the following 6 theme categories: (a) Sacred Trust to Care for the Child and Family, (b) An Elephant in the Room, (c) Struggling with Emotional Unknowns, (d) Kaleidoscope of Death: Patterns and Complexity, (e) Training Wheels for Connectedness: Critical Mentors during PC/EOL of Children, and (f) Being Present with an Open Heart: Ways to Maintain Hope and Minimize Emotional Distress. To date, this is the first study to focus on PC/EOL communication perspectives of novice pediatric oncology nurses.

PMID: 25556105

24. Pain Manag Nurs. 2014 Dec 23. [Epub ahead of print]

Families' Views of Pediatric Palliative Aquatics: A Qualitative Study.

Gaab E¹, Steinhorn DM².

Abstract

Although pediatric palliative care policies and services have been developed, research in this area continues to lag. An integrated model of palliative care has been suggested by the American Academy of Pediatrics and includes complementary and alternative services aimed at improving the well-being of children and their families. The first-known pediatric palliative aquatics program (PPAP) in California uses several techniques to decrease pain and promote well-being through relaxation and interaction between patients, specialists, and family members. This study investigates the perceptions of family members of their children's experiences with a PPAP. Researchers from an outside institution conducted focus groups and interviews. Themes were extracted from the focus group transcripts using Braun and Clarke's method of inductive thematic analysis. Data were collected at the host site, local libraries, and participant homes. Participants were primary caregivers and sib-

lings (n = 23) of children in a PPAP, an independent children's respite, transitional, and end-of-life care facility in California. The research described and drew implications from the diverse perceptions that family members expressed about the benefits of having a child in the PPAP, including sensory, physical, and social experiences. Although the PPAP aims to promote well-being through relaxation, several other benefits were expressed by family members of children going through the program, including pain relief.

PMID: 25547919

25. J Pain Symptom Manage. 2014 Dec 26. [Epub ahead of print]

Patient-Controlled Analgesia for Children at Home.

Mherekumombe MF¹, Collins JJ².

Abstract

CONTEXT: Pain is a common and significant symptom experienced by children with advanced malignant disease. There is limited research on pain management of these children at home. **OBJECTIVES:** To describe and review the indications for using patient-controlled analgesia (PCA) in the form of a Computerized Ambulatory Drug Delivery device (CADD®) in the home setting. **METHODS:** A retrospective chart review was conducted in children discharged home with opioid infusions using a CADD. Charts from January 2008 to February 2012 were surveyed. **RESULTS:** Thirty-seven CADDs were dispensed during the study period and of these, 33 were prescribed for patients with cancer-related pain. A third of these were commenced at home and almost all PCA CADDs were used for end-of-life care. Hydromorphone was the most commonly prescribed opioid. Patients remained at home and pain control was achieved by either increasing the opioid dose or switching the opioid and using adjuvant therapy. Sixteen patients were readmitted to hospital from home and three admissions were related to pain. The median duration on a PCA CADD at home was 33.7 days (range 1 to 150 days) and the mean morphine equivalent dose was 2.13mg/kg/day. **CONCLUSION:** PCA with a CADD can be used to manage pain in the home setting. Dose adjustments and opioid switches were performed with no adverse incidents.

PMID: 25546288

26. Pediatr Blood Cancer. 2014 Dec 24. [Epub ahead of print]

Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer.

Jacobs S¹, Perez J, Cheng YI, Sill A, Wang J, Lyon ME.

Abstract

BACKGROUND: Little is known about how well family members accurately represent adolescents when making EOL decisions on their behalf. This study reports on surveys given to adolescents with cancer and their parents as part of a larger study facilitating advanced care discussions, as well as the results of a survey for health care providers. **PROCEDURE:** Trained facilitators administered surveys orally to adolescents and families in the intervention arm of the Family CEntered Advance Care Planning (ACP) for Teens with Cancer (FACE-TC) study. In addition, a post-hoc survey was sent to oncology providers. **RESULTS:** Seventeen adolescent/family dyads completed this survey. Seventy five percent of adolescents believed it was appropriate to discuss EOL decisions early and only 12% were not comfortable discussing death. Most preferred to be at home if dying. There were substantial areas of congruence between adolescents and their surrogates, but lower agreement on the importance of dying a natural death, dying at home and "wanting to know if I were dying." Among providers, 83% felt their patients' participation in the study was helpful to the patients and 78% felt it was helpful to them as providers. **CONCLUSIONS:** Adolescents with cancer were comfortable discussing EOL, and the majority preferred to talk about EOL issues before they are facing EOL. There were substantive areas of agreement between adolescents and their surrogates, but important facets of adolescents' EOL wishes were not known by their families, reinforcing the importance of eliciting individual preferences and engaging dyads so parents can understand their children's wishes. Pediatr Blood Cancer 2014;9999:1-5.

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PMID: 25545105 [PubMed - as supplied by publisher]

27. Cancer Nurs. 2014 Dec 23. [Epub ahead of print]

Self-reported Pain in Adolescents With Leukemia or a Brain Tumor: A Systematic Review.

Olson K¹, Amari A.

Abstract

BACKGROUND:: Given the changes adolescents experience in psychosocial domains as they transition from childhood to young adulthood, the experience of cancer at this time of life is likely to differ in regard to symptom manifestation and relative distress. **OBJECTIVE::** The purpose of this systematic review is to examine self-reported pain among adolescents diagnosed with leukemia or a brain tumor. **METHODS::** Electronic searches of MEDLINE, PubMed, and the Cochrane Database of Systematic Reviews since inception to May 2014 were conducted. Search terms included pain; a second term including adolescent, juvenile, youth, child, or childhood; and a third term including cancer, leukemia, or brain tumor. Adolescents were defined as being 10 to 19 years of age. **RESULTS::** A total of 30 articles met inclusion criteria. Pain was reported associated with the cancer itself, with treatments, and with procedures and was assessed via a variety of measures and methods. Pain was also found to persist long after treatment completion. **CONCLUSION:** Pain is a frequently reported symptom among adolescents with leukemia or a brain tumor. More consistent inclusion of established measures across studies could increase the availability of data suitable for meta-analyses while also providing information on which aspects of the pain experience are understudied. **IMPLICATIONS FOR PRACTICE:** Rigorous assessment of pain should be conducted from diagnosis throughout the cancer continuum into long-term survivorship or end of life, with particular attention paid to before and after treatment procedures. Improved pain management incorporating behavioral and/or pharmacological strategies may result in improved quality of life for adolescents with cancer.

PMID: 25539166 [PubMed - as supplied by publisher]

28. Anesthesiology. 2014 Dec 23. [Epub ahead of print]

Invasive Treatments for Complex Regional Pain Syndrome in Children and Adolescents: A Scoping Review.

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

Abstract

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

PMID: 25539076

29. Pain Manag. 2015 Jan;5(1):23-35.

Pediatric pain management in palliative care.

Downing J¹, Jassal SS, Mathews L, Brits H, Friedrichsdorf SJ.

Abstract

SUMMARY The management of pain in pediatric palliative care (PPC) is essential. Whilst the field of pain management has developed over the years, much of what is done in PPC is based on anecdotal evidence or adult studies. This review explores recent developments in pain management in PPC, in particular the WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. Key issues discussed include the definition, assessment, pharmacological and integrative management of pain, availability of medications, education and research. Whilst advances have been made, including publication of the guidelines, significant gaps exist in terms of the evidence base, education and access to essential medications and both interdisciplinary and international collaboration are required to meet these gaps.

PMID: 25537696 [PubMed - in process]

30. J Pediatr. 2015 Jan;166(1):4-5. [PubMed - in process]

Recent experience establishing a new pediatric palliative care team.

No Abstract

Miller EG¹, Frizzola MA², Levy C², Greenspan JS².

PMID: 25527850

31. Int J Palliat Nurs. 2014 Dec;20(12):584-90.

Grief experiences of nurses in Ireland who have cared for children with an intellectual disability who have died.

MacDermott C¹, Keenan PM.

Abstract

BACKGROUND: The personal grief experience of nurses who have cared for children with an intellectual disability who have died is little understood. **METHOD:** This descriptive qualitative study was initiated to ascertain nurses' knowledge and personal experience of grief and how this is managed. Semi-structured interview was the method used to collect data from eight nurses who had cared for a child with an intellectual disability who had died. A pragmatic approach to qualitative data analysis was adopted. **RESULTS:** Of the eight main themes identified, the four most prevalent are discussed in detail: grief, relationship with the child, end of life, and support. The findings demonstrate that nurses have a good understanding of grief, but the way they experience and manage it varies. **CONCLUSION:** The study suggests that nurses who have cared for children with an intellectual disability who have died may experience disenfranchised grief. Nurses seek support from a variety of sources. Organisational support is important for nurses following the death of a child for whom they have provided care.

PMID: 25526287

32. J Palliat Med. 2014 Dec 18. [Epub ahead of print]

Complex Chronic Conditions in Rhode Island's Pediatric Populace: Implications for Palliative and Hospice Services, 2000-2012.

Jamorabo DS¹, Belani CP, Martin EW.

Abstract

Abstract Background: Pediatric patients with complex chronic conditions (CCC) can benefit from pediatric palliative and hospice care (PP/HC) services. PP/HC can be delivered in a variety of health care settings and for a multitude of conditions, but data on hospitalization patterns and on secondary illnesses in pediatric CCC patients remains scant. **Objective:** The study objective was to describe mortality trends for Rhode Island resident children aged 0-17 years, along with the demographics, subtypes, sites of death, and comorbidities of those with CCC. **Methods:** This was a retrospective cohort study using demographic, hospitalization, and clinical data from all Rhode Island Department of Health death certificates from 2000 to 2012. **Results:** Among the 1422 Rhode Island children aged 0-17 years old who died from 2000 to 2012, CCCs accounted for 27% (279/1049) of medically related deaths and 62% (145/233) of such deaths after infancy. CCC deaths were more likely at home (OR 5.202, 95% CI 2.984-9.203, p<0.001) and to have had a secondary cause of death documented (OR 3.032, 95% CI 2.259-4.067, p<0.001) than were other medically related deaths. Infants with CCCs were more likely to die in an inpatient setting (OR 5.141, 95% CI 2.718-10.026, p<0.001), whereas 1-17 year-olds with CCCs were more likely to die at home (OR 5.346, 95% CI 2.200-14.811, p<0.001) or in an emergency department (OR 3.281, 95% CI 1.363-8.721, p<0.040). **Conclusions:** CCCs constitute a significant proportion of medically related pediatric deaths in Rhode Island and are associated with both

secondary comorbidities and death at home. Specialized, multidisciplinary services are warranted and PP/HC is crucial for patient and family support.

PMID: 25522161

33. Am J Perinatol. 2014 Dec 17. [Epub ahead of print]

End-of-Life Care in the Neonatal Intensive Care Unit: Experiences of Staff and Parents.

Cortezzo DE¹, Sanders MR², Brownell EA³, Moss K⁴.

Abstract

Objective The aim of the study is to determine the perceptions of end-of-life care practices and experience with infants who have died in the NICU among neonatologists, advanced practitioners, nurses, and parents, and also to determine perceived areas for improvement and the perceived value of a palliative care team. **Study Design** This descriptive, exploratory cross-sectional study using surveys consisting of 7-point Likert scales and free response comments was sent to all neonatologists ($n = 14$), advanced practitioners ($n = 40$), and nurses ($n = 184$) at Connecticut Children's Medical Center's neonatal intensive care units (NICUs) in April 2013 and to all parents whose infants died in these NICUs from July 1, 2011, to December 31, 2012 ($n = 28$). **Results** The response rates were 64.3% for physicians; 50.0% for practitioners; 40.8% for nurses; and 30.4% for parents. Most providers reported they feel comfortable delivering end-of-life care. Bereavement support, debriefing/closure conferences, and education did not occur routinely. Families stressed the importance of memory making and bereavement/follow-up. Consistent themes of free responses include modalities for improving end-of-life care, inconsistency of care delivery among providers, and the importance of memory making and follow-up. **Conclusion** End-of-life experiences in the NICU were perceived as variable and end-of-life practices were, at times, perceived as inconsistent among providers. There are areas for improvement, and participants reported that a formalized palliative care team could help. Families desire memory making, follow-up, and bereavement support.

Thieme Medical Publishers 333 Seventh Avenue, New York, NY 10001, USA.

PMID: 25519196

34. Palliat Med. 2014 Dec 17. pii: 0269216314560803. [Epub ahead of print]

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

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

Abstract

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

PMID: 25519146

35. Support Care Cancer. 2014 Dec 18. [Epub ahead of print]

Development of clinical practice guidelines for supportive care in childhood cancer-prioritization of topics using a Delphi approach.

Loeffen EA¹, Mulder RL, Kremer LC, Michiels EM, Abbink FC, Ball LM, Segers H, Mavinkurve-Groothuis AM, Smit FJ, Vonk JJ, Vd Wetering MD, Tissing WJ.

Abstract

INTRODUCTION: Currently, very few guidelines for supportive care for children with cancer exist. In the Netherlands, nationwide guidelines are over 10 years old and mostly based on expert opinion. Consequently, there is growing support and need for clinical practice guidelines (CPGs), which ought to be developed with a well-defined methodology and include a systematic search of literature, evidence summaries, and a transparent description of the decision process for the final recommendations. Development of CPGs is time consuming; therefore, it is important to prioritize topics for which there is the greatest clinical demand. **OBJECTIVES:** This study aims to prioritize childhood cancer supportive care topics for development of CPGs. **METHODS:** A Delphi survey consisting of two rounds was conducted to prioritize relevant childhood cancer supportive care topics for the development of CPGs. A group of experts comprising 15 pediatric oncologists, 15 pediatric oncology nurses, and 15 general pediatricians involved in care for childhood cancer patients were invited to participate. All relevant supportive care topics in childhood cancer were rated. **RESULTS:** In both rounds, 36 panellists (82 %) responded. Agreement between panellists was very good, with an intraclass correlation coefficient of 0.918 (95 % confidence interval (CI) = 0.849-0.966, $p < 0.001$) in round 2. The ten topics with the highest score in the final round were infection, sepsis, febrile neutropenia, pain, nausea/vomiting, restrictions in daily life and activities, palliative care, procedural sedation, terminal care, and oral mucositis. **CONCLUSION:** We successfully used a Delphi survey to prioritize childhood cancer supportive care topics for the development of CPGs. This is a first step towards uniform and evidence-based Dutch guidelines in supportive care in childhood cancer. Even though performed nationally, we believe that this study can also be regarded as an

example starting point for international development of CPGs in the field of supportive care in cancer or any other field for that matter.

PMID: 25516211

36. MCN Am J Matern Child Nurs. 2015 Jan-Feb;40(1):44-50.

[Clinician perspectives of barriers in perinatal palliative care.](#)

Wool C¹.

Abstract

PURPOSE: Perinatal palliative care (PPC) is a developing model of care aimed at providing supportive services to families anticipating fetal or neonatal demise. This study measured barriers physicians and advance practice nurses report in providing and referring patients to PPC. **STUDY DESIGN AND METHODS:** A cross-sectional survey design using the Perinatal Palliative Care Perceptions and Barriers Scale © was administered using a Web-based tool. Recruitment was completed via email and flyer invitations and list serves. Physicians (n = 66) and advance practice nurses (n = 146) participated. T-test and Mann-Whitney U were used to examine differences in clinician-reported barriers to PPC. **RESULTS:** Physicians and nurses differ significantly in the barriers they report. Nurses expressed more obstacles at the healthcare systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians are more confident in their ability to counsel patients than nurses. Members of both disciplines express similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. They also report a lack of societal support and understanding about PPC. **CLINICAL IMPLICATIONS:** Cultivating an environment of collaboration and interdisciplinary communication can benefit both caregivers and patients. Nurses have an opportunity to lead and promote PPC endeavors through participating in advantageous partnerships and research. Both disciplines may benefit from interventions directed at increasing their comfort in caring for patients in a palliative setting through targeted education and supportive staff services.

PMID: 25503834

37. J Palliat Med. 2014 Dec 10. [Epub ahead of print]

[Physician and Parent Perceptions of Prognosis and End-of-Life Experience in Children with Advanced Heart Disease.](#)

Balkin EM¹, Wolfe J, Ziniel SI, Lang P, Thiagarajan R, Dillis S, Fynn-Thompson F, Blume ED.

Abstract

Abstract Background: Little is known about how physician and parent perspectives compare regarding the prognosis and end-of-life (EOL) experience of children with advanced heart disease (AHD). **Objective:** The study's objective was to describe and compare parent and physician perceptions regarding prognosis and EOL experience in children with AHD. **Methods:** This was a cross-sectional survey study of cardiologists and bereaved parents. Study subjects were parents and cardiologists of children with primary cardiac diagnoses who died in a tertiary care pediatric hospital between January 2007 and December 2009. Inclusion required both physician and parent to have completed surveys respective to the same patient. A total of 31 parent/physician pairs formed the analytic sample. Perceptions were measured of cardiologists and bereaved parents regarding the EOL experience of children with AHD. **Results:** Nearly half of parents and physicians felt that patients suffered 'a great deal,' 'a lot,' or 'somewhat' at EOL, but there was no agreement between them. At diagnosis, parents more often expected complete repair and normal lifespan while the majority of physicians expected shortened lifespan without normal quality of life. Parents who expected complete repair with normal life were more likely to report 'a lot' of suffering at EOL (p=0.002). In 43% of cases, physicians reported that the parents were prepared for the way in which their child died, while the parents reported feeling unprepared. **Conclusion:** Both parents and physicians perceive suffering at EOL in patients who die of AHD. Moreover, parent expectations at diagnosis may influence perceptions of suffering at EOL. Physicians overestimate the degree of parent preparedness for their child's death.

PMID: 25493354 [PubMed - as supplied by publisher]

38. Nurs Child Young People. 2014 Dec 9;26(10):14.

[Student voice - The end of training but life is wide open.](#)

Kirwan L¹.

Abstract

I AM SO relieved that I have nearly finished my internship and my training. I am looking forward to the day when I can say that I am registered as a children's and general nurse.

PMID: 25487397 [PubMed - in process]

39. Nurs Child Young People. 2014 Dec 9;26(10):6.

[Young people falling into gap between child and adult care.](#)

[No authors listed]

Abstract

THE GAP between children's and adult palliative care services is too wide to negotiate for some young people, according to a study of the experiences of young people with life-limiting conditions and their families.

PMID: 25487377 [PubMed - in process]

40. Health Commun. 2015;30(2):144-53.

[Communication nonaccommodation in family conversations about end-of-life health decisions.](#)

Scott AM¹, Caughlin JP.

Abstract

Furthering our understanding of how communication can improve end-of-life decision making requires a shift in focus from whether people talk to how people talk about end-of-life health decisions. This study used communication accommodation theory to examine the extent to which communication nonaccommodation distinguished more from less successful end-of-

life conversations among family members. We analyzed elicited conversations about end-of-life health decisions from 121 older parent/adult child dyads using outside ratings of communication over- and underaccommodation and self-reported conversational outcomes. Results of multilevel linear modeling revealed that outside ratings of underaccommodation predicted self-reported and partner-reported uncertainty, and ratings of overaccommodation predicted self-reported decision-making efficacy and change in concordance accuracy. We discuss the methodological, theoretical, and practical implications of these findings.

PMID: 25470439

41. *Acta Oncol.* 2014 Dec 3:1-7. [Epub ahead of print]

Teenagers want to be told when a parent's death is near: A nationwide study of cancer-bereaved youths' opinions and experiences.

Bylund-Grenklo T¹, Kreichbergs U, Ugglä C, Valdimarsdóttir UA, Nyberg T, Steineck G, Fürst CJ.

Abstract

Background. We aimed to investigate cancer-bereaved youths' opinions and experiences of being told about a parent's imminent death from cancer and of barriers to this communication. **Material and methods.** This nationwide population-based survey included 622/851 (73%) youths (aged 18-26) who at age 13-16, 6-9 years earlier had lost a parent to cancer. **Results.** In total 595 of 610 (98%) of the participants stated that teenage children should be informed when the parent's death was imminent (i.e. a matter of hours or days, not weeks). 59% stated that they themselves had been told this, 37% by the parents, 7% by parents and healthcare professionals together and 8% by professionals only. Frequent reasons for why the teenager and parents did not talk about imminent death before loss were that one (n = 106) or both (n = 25) of the parents together with the teenage child had pretended that the illness was not that serious, or that none of the parents had been aware that death was imminent (n = 80). Up to a couple of hours before the loss, 43% of participants had not realized that death was imminent. **Conclusion.** In this population-based study virtually all youth who at ages 13-16 had lost a parent to cancer afterwards stated that teenagers should be told when loss is near, i.e. a matter of hours or days, not weeks. Many stated that they had not been given this information and few were informed by professionals, with implications for future improvements in end-of-life care of patients with teenage children.

PMID: 25467964

42. *J Spec Pediatr Nurs.* 2015 Jan;20(1):5-20.

Parents' experiences of healthcare provider actions when their child dies: An integrative review of the literature.

Butler A¹, Hall H, Willetts G, Copnell B.

Abstract

PURPOSE: To review, critique and synthesise current research studies that examine parental perceptions of healthcare provider actions during and after the death of a child. **CONCLUSIONS:** Five main themes were synthesised from the literature: staff attitudes and affect; follow-up care and ongoing contact; communication; attending to the parents; and continuity of care. **PRACTICE IMPLICATIONS:** This review helps to identify important aspects of paediatric end-of-life care as recognised by parents, with the intention of placing the family at the centre of any future end-of-life care education or policy/protocol development. © 2014, Wiley Periodicals, Inc.

PMID: 25443391

43. *Clin Oncol (R Coll Radiol).* 2014 Dec;26(12):806.

Patients' acceptability of different fentanyl products for breakthrough cancer pain.

No Abstract

Mercadante S¹, Caruselli A², Meli MR³, Bellavia G², Tuttolomondo A⁴, Casuccio A⁵.

PMID: 25439311

44. *Res Gerontol Nurs.* 2015 Jan-Feb;8(1):29-38.

A portrait of resilience in caregiving.

Ewen HH, Chahal JK, Fenster ES.

Abstract

The current study investigated biopsychosocial resilience in an older adult caregiver. A case study was selected for in-depth exploration of resilience in caregiving identified through biopsychosocial (i.e., salivary cortisol) methods. An exemplar of a woman caring for an adult child dying from a genetic disease is presented in the context of multiple stressors. Significant stress was found to be buffered by cognitive reframing and acceptance of interpersonal limits. Early experiences in caregiving for others with terminal illnesses provided a frame of reference, and difficult family dynamics added a layer of complexity. During periods identified as stressful, cortisol levels rose outside of normal bounds. The study implications are that mixed-methods (i.e., biopsychosocial) studies yield important results on individual differences within similar contexts.

PMID: 25420182

45. *J Pediatr Oncol Nurs.* 2015 Jan-Feb;32(1):32-9. doi: 10.1177/1043454214555195. Epub 2014 Nov 21.

Contributions of advanced practice nurses with a DNP degree during palliative and end-of-life care of children with cancer.

Hendricks-Ferguson VL¹, Akard TF², Madden JR³, Peters-Herron A⁴, Levy R⁵.

Abstract

The doctorate in nursing practice (DNP) degree is recommended as the terminal degree for advanced practice nurses by 2015. Improvement in the quality of palliative and end-of-life care for children with cancer is recognized as a health care priority. The purpose of this article is to describe: (a) how the American Association of Colleges of Nursing's 8 core elements

and competencies can be used by DNP-advanced practice nurses in pediatric oncology settings and (b) the DNP-advanced practice nurses' leadership role to advocate translation of evidence in the care of pediatric oncology patients and to promote interdisciplinary collaboration to improve health care outcomes for pediatric oncology patients.

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PMID: 25416517

46. Pediatrics. 2014 Dec;134(6):e1670-7.

Developing competencies for pediatric hospice and palliative medicine.

Klick JC¹, Friebert S², Hutton N³, Osenga K⁴, Pituch KJ⁵, Vesel T⁶, Weidner N⁷, Block SD⁸, Morrison LJ⁹; American Board of Hospice and Palliative Medicine Competencies Work Group.

Collaborators: Arnold R, Billings J, Block SD, Goldstein NE, Morrison LJ, Okon T, Sanchez-Reilly S, Tucker R, Tulsy JA, von Gunten C, Weissman D.

Abstract

In 2006, hospice and palliative medicine (HPM) became an officially recognized subspecialty. This designation helped initiate the Accreditation Council of Graduate Medical Education Outcomes Project in HPM. As part of this process, a group of expert clinician-educators in HPM defined the initial competency-based outcomes for HPM fellows (General HPM Competencies). Concurrently, these experts recognized and acknowledged that additional expertise in pediatric HPM would ensure that the competencies for pediatric HPM were optimally represented. To fill this gap, a group of pediatric HPM experts used a product development method to define specific Pediatric HPM Competencies. This article describes the development process. With the ongoing evolution of HPM, these competencies will evolve. As part of the Next Accreditation System, the Accreditation Council of Graduate Medical Education uses milestones as a framework to better define competency-based, measurable outcomes for trainees. Currently, there are no milestones specific to HPM, although the field is designing curricular milestones with multispecialty involvement, including pediatrics. These competencies are the conceptual framework for the pediatric content in the HPM milestones. They are specific to the pediatric HPM subspecialist and should be integrated into the training of pediatric HPM subspecialists. They will serve a foundational role in HPM and should inform a wide range of emerging innovations, including the next evolution of HPM Competencies, development of HPM curricular milestones, and training of adult HPM and other pediatric subspecialists. They may also inform pediatric HPM outcome measures, as well as standards of practice and performance for pediatric HPM interdisciplinary teams.

PMID: 25404726

47. Pediatrics. 2014 Dec;134(6):e1678-85.

Preventing CLABSIs among pediatric hematology/oncology inpatients: national collaborative results.

Bundy DG¹, Gaur AH², Billett AL³, He B⁴, Colantuoni EA⁴, Miller MR⁵; Children's Hospital Association Hematology/Oncology CLABSI Collaborative.

Abstract

OBJECTIVES: Central lines (CLs) are essential for the delivery of modern cancer care to children. Nonetheless, CLs are subject to potentially life-threatening complications, including central line-associated bloodstream infections (CLABSIs). The objective of this study was to assess the feasibility of a multicenter effort to standardize CL care and CLABSI tracking, and to quantify the impact of standardizing these processes on CLABSI rates among pediatric hematology/oncology inpatients. **METHODS:** We conducted a multicenter quality improvement collaborative starting in November 2009. Multidisciplinary teams at participating sites implemented a standardized bundle of CL care practices and adopted a common approach to CLABSI surveillance. **RESULTS:** Thirty-two units participated in the collaborative and reported a mean, precollaborative CLABSI rate of 2.85 CLABSIs per 1000 CL-days. Self-reported adoption of the CL care bundle was brisk, with average compliance approaching 80% by the end of the first year of the collaborative and exceeding 80% thereafter. As of August 2012, the mean CLABSI rate during the collaborative was 2.04 CLABSIs per 1000 CL-days, a reduction of 28% (relative risk: 0.71 [95% confidence interval: 0.55-0.92]). Changes in self-reported CL care bundle compliance were not statistically associated with changes in CLABSI rates, although there was little variability in bundle compliance rates after the first year of the collaborative. **CONCLUSIONS:** A multicenter quality improvement collaborative found significant reductions in observed CLABSI rates in pediatric hematology/oncology inpatients. Additional interventions will likely be required to bring and sustain CLABSI rates closer to zero for this high-risk population.

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PMID: 25404721

48. Nurs Crit Care. 2015 Jan;20(1):41-51.

Caring until the end: a systematic literature review exploring Paediatric Intensive Care Unit end-of-life care.

Howes C¹.

Abstract

AIMS AND OBJECTIVES: A systematic review of the literature focusing on the provision of end-of-life care (EOLC) on Paediatric Intensive Care Units (PICUs) and the options available to children and families within contemporary clinical practice. **BACKGROUND:** The death of a child is recognized as a uniquely traumatic experience for a parent. The care delivered to a child and family surrounding death can have a lasting effect on the grieving process. The majority of paediatric deaths occur within PICUs, often as a result of withdrawing or withholding treatment. Withdrawal of intensive care is becoming more common within UK PICUs, and this review will focus on the options available when a child's on-going treatment is deemed to be futile. **SEARCH STRATEGIES:** Literature published from 2002 to 2013 was obtained from a range of sources and critically reviewed. Cormack's (2000) framework for systematic literature review was utilized to critically review literature before analysis and synthesis of the literature was undertaken within the qualitative approach. **INCLUSION/EXCLUSION CRITERIA:** Each article focused on issues surrounding the topic area, excluded adult and neonatal intensive care and was published in English. **CONCLUSIONS:** Eight papers met the inclusion criteria and were suitable for review (highlighting diffi-

culties in reviewing a small, complex subject area). Key themes identified included family views, staff views, decision-making, medico-legal issues and resources. **RELEVANCE TO CLINICAL PRACTICE:** Although the number of relevant articles is limited, a wide range of challenges facing children, parents and staff are highlighted, whilst generally supporting the facilitation of transferring children to their homes or hospice for withdrawal of intensive care and continuing EOLC. Further research is required, particularly regarding long-term implications, legal issues and the effectiveness of clinical protocols. © 2014 British Association of Critical Care Nurses.

PMID: 25378129 [PubMed - in process]

49. Patient Educ Couns. 2015 Jan;98(1):49-54.

"Doctor, what would you do?": physicians' responses to patient inquiries about periviable delivery.

Tucker Edmonds B¹, McKenzie F², Panoch JE³, Wocial LD⁴, Barnato AE⁵, Frankel RM⁶.

Abstract

OBJECTIVE: To qualitatively assess obstetricians' and neonatologists' responses to standardized patients (SPs) asking "What would you do?" during periviable counseling encounters. **METHODS:** An exploratory single-center simulation study. SPs, portraying a pregnant woman presenting with ruptured membranes at 23 weeks, were instructed to ask, "What would you do?" if presented options regarding delivery management or resuscitation. Responses were independently reviewed and classified. **RESULTS:** We identified five response patterns: 'Disclose' (9/28), 'Don't Know' (11/28), 'Deflect' (23/28), 'Decline' (2/28), and 'Ignore' (2/28). Most physicians utilized more than one response pattern (22/28). Physicians 'deflected' the question by: restating or offering additional medical information; answering with a question; evoking a hypothetical patient; or redirecting the SP to other sources of support. When compared with neonatologists, obstetricians (40% vs. 15%) made personal or professional disclosures more often. Though both specialties readily acknowledged the importance of values in making a decision, only one physician attempted to elicit the patient's values. **CONCLUSION:** "What would you do?" represented a missed opportunity for values elicitation. Interventions are needed to facilitate values elicitation and shared decision-making in periviable care.

PRACTICE IMPLICATIONS: If physicians fail to address patients' values and goals, they lack the information needed to develop patient-centered plans of care.

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PMID: 25373527 [PubMed - in process]

50. J Pain Palliat Care Pharmacother. 2014 Dec;28(4):412-4.

Systematic reviews published in the July 2014 issue of the Cochrane Library.

Wiffen PJ.

Abstract

The Cochrane Library of Systematic Reviews is published quarterly as a DVD and monthly online (<http://www.thecochranelibrary.com>). The July 2014 issue (3rd DVD for 2014) contains 6050 complete reviews, 2,359 protocols for reviews in production, and 31,000 short summaries of systematic reviews published in the general medical literature. In addition, there are citations of 789,000 randomized controlled trials, and 15,700 cited papers in the Cochrane Methodology Register. The Health Technology Assessment database contains some 14,000 citations. Ninety-six new reviews have been published in the previous 3 months of which five have potential relevance for practitioners in pain and palliative medicine. The impact factor of the Cochrane Library stands at 5.715. Readers are encouraged to access the full report for any articles of interest as only a brief commentary is provided.

PMID: 25338103 [PubMed - in process]

51. J Palliat Med. 2015 Jan;18(1):18-25.

Evaluating palliative care needs in middle eastern countries.

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

Abstract

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 [PubMed - in process]

52. J Pediatr Nurs. 2015 Jan-Feb;30(1):45-53.

Exploring the perceived met and unmet need of life-limited children, young people and families.

Coad J¹, Kaur J², Ashley N², Owens C³, 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.

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PMID: 25301028 [PubMed - in process]

53. J Palliat Med. 2014 Dec;17(12):1306-10.

Pediatric palliative care consultation services in California hospitals.

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

BACKGROUND: 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 [PubMed - in process]

54. Jpn J Clin Oncol. 2014 Dec;44(12):1181-8.

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.

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PMID: 25249378 [PubMed - in process]

55. J Palliat Med. 2014 Dec;17(12):1369-83.

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

BACKGROUND: 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 [PubMed - in process]

56. J Palliat Med. 2014 Dec;17(12):1311-6.

[A statewide survey of adult and pediatric outpatient palliative care services.](#)

Rabow MW¹, O'Riordan DL, Pantilat SZ.

Abstract

BACKGROUND: 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 [PubMed - in process]

57. J Adv Nurs. 2015 Jan;71(1):204-13.

[Paediatric end-of-life care in the home care setting \(PELICAN HOME\)--a mixed methods study protocol.](#)

Eskola K¹, Bergstraesser E, Zimmermann K, Cignacco E.

Abstract

AIMS: (a) To explore parental experiences and needs during their child's end-of-life care at home; (b) to explore patient's characteristics and current provision of paediatric end-of-life care in the home care setting in Switzerland; and (c) to determine influencing system factors impacting end-of-life care at home.

BACKGROUND: Parental experiences/needs and paediatric end-of-life care services in the home care setting are influenced by national healthcare policy, determinants of the family and the individual patient. In Switzerland, there is a lack of information about the provision of paediatric end-of-life care at home and related parent's experiences/needs.

DESIGN: Sub-study of the nationwide multicenter study 'Paediatric End-of-Life Care Needs in Switzerland' using a concurrent qualitative embedded mixed methods design.

METHODS: Data will be collected from January-May 2014 through community care organizations and children's hospitals. The study includes approximately 40-50 families whose child (0-18 years) died in the years 2011-2012 due to a cardiological, neurological or oncological condition and spent at least 21 days at home during the last 4 weeks of life. Qualitative data will be collected through semi-structured interviews with parents and analysed by 'thematic analysis'. Quantitative data about patient's characteristics will be obtained from patient's medical charts and parental experiences/needs through the parental questionnaire. Appropriate descriptive and inference statistical methods will be used for data analysis.

DISCUSSION: This study will provide comprehensive basic information about parental needs and patient characteristics for the provision of paediatric end-of-life care and may promote the development of family-centred paediatric end-of-life care services at home.

STUDY REGISTRATION: The PELICAN-study is registered in the database of Clinical Trial gov. Study ID-number: NCT 01983852.

PMID: 24909918

58. J Pain Symptom Manage. 2015 Jan;49(1):55-65.

Long-term psychosocial outcomes among bereaved siblings of children with cancer.

Rosenberg AR¹, Postier A², Osenga K², Kreicbergs U³, Neville B⁴, Dussel V⁵, Wolfe J⁶.

Abstract

CONTEXT: The death of a child from cancer affects the entire family. Little is known about the long-term psychosocial outcomes of bereaved siblings. **OBJECTIVES:** To describe 1) the prevalence of risky health behaviors, psychological distress, and social support among bereaved siblings and 2) potentially modifiable factors associated with poor outcomes. **METHODS:** Bereaved siblings were eligible for this dual-center, cross-sectional, survey-based study if they were 16 years or older and their parents had enrolled in one of three prior studies about caring for children with cancer at the end of life. Linear regression models identified associations between personal perspectives before, during, and after the family's cancer experience and outcomes (health behaviors, psychological distress, and social support). **RESULTS:** Fifty-eight siblings completed surveys (62% response rate). They were approximately 12 years bereaved, with a mean age of 26 years at the time of the survey (SD 7.8). Anxiety, depression, and illicit substance use increased during the year after their brother/sister's death but then returned to baseline. Siblings who reported dissatisfaction with communication, poor preparation for death, missed opportunities to say goodbye, and/or a perceived negative impact of the cancer experience on relationships tended to have higher distress and lower social support scores ($P < 0.001-0.031$). Almost all siblings reported that their loss still affected them; half stated that the experience impacted current educational and career goals. **CONCLUSION:** How siblings experience the death of a child with cancer may impact their long-term psychosocial well-being. Sibling-directed communication and concurrent supportive care during the cancer experience and the year after the sibling death may mitigate poor long-term outcomes.

PMID: 24880001

59. J Pain Symptom Manage. 2015 Jan;49(1):66-78.

Measuring the Quality of Dying and Death in the Pediatric Intensive Care Setting: The Clinician PICU-QODD.

Sellers DE¹, Dawson R², Cohen-Bearak A³, Solomond MZ⁴, Truog RD⁵.

Abstract

CONTEXT: In the pediatric intensive care setting, an accurate measure of the dying and death experience holds promise for illuminating how critical care nurses, physicians, and allied psychosocial staff can better manage end-of-life care for the benefit of children and their families, as well as the caregivers.

OBJECTIVES: The aim was to assess the reliability and validity of a clinician measure of the quality of dying and death (Pediatric Intensive Care Unit-Quality of Dying and Death 20 [PICU-QODD-20]) in the pediatric intensive care setting.

METHODS: In a retrospective cohort study, five types of clinicians (primary nurse, bedside nurse, attending physician, and the psychosocial clinician and critical care fellow most involved in the case) were asked to complete a survey for each of the 94 children who died over a 12 month period in the pediatric intensive care units of two children's hospitals in the northeast U.S. Analyses were conducted within type of clinician.

RESULTS: In total, 300 surveys were completed by 159 clinicians. Standard item analyses and substantive review led to the selection of 20 items for inclusion in the PICU-QODD-20. Cronbach alpha for the PICU-QODD-20 ranged from 0.891 for bedside nurses to 0.959 for attending physicians. For each type of clinician, the PICU-QODD-20 was significantly correlated with the quality of end-of-life care and with meeting the family's needs. In addition, when patient/family or team barriers were encountered, the PICU-QODD-20 score tended to be significantly lower than for cases in which the barrier was not encountered.

CONCLUSION: The PICU-QODD-20 shows promise as a valid and reliable measure of the quality of dying and death in pediatric intensive care.

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PMID: 24878067 [PubMed - in process]

60. J Child Neurol. 2014 Dec;29(12):1728-38.

Mapping the literature: palliative care within adult and child neurology.

Dallara A¹, Meret A², Saroyan J³.

Abstract

Objectives of this review were to examine definitions and background of palliative care, as well as address whether there is an increased need for palliative care education among neurologists. The review also explores what literature exists regarding palliative care within general neurology and child neurology. A literature review was conducted examining use of palliative care within child neurology. More than 100 articles and textbooks were retrieved and reviewed. Expert guidelines stress the importance of expertise in palliative care among neurologists. Subspecialties written about in child neurology include that of peripheral nervous system disorders, neurodegenerative diseases, and metabolic disorders. Adult and child neurology patients have a great need for improved palliative care services, as they frequently develop cumulative physical and cognitive disabilities over time and cope with decreasing quality of life before reaching the terminal stage of their illness. PMID: 24717986

61. Am J Hosp Palliat Care. 2014 Dec;31(8):833-5.

Pediatric palliative care: using miniature chairs to facilitate communication.

Chin LE¹, Loong LC², Ngen CC³, Beng TS², Shireen C⁴, Kuan WS⁵, Shaw R⁶.

Abstract

Good communication is essential but sometimes challenging in pediatric palliative care. We describe 3 cases whereby miniature chairs made of various materials and colors were used successfully to encourage communication among pediatric patients, family, and health care professionals. This chair-inspired model may serve as a simple tool to facilitate complex discussions and to enable self-expression by children in the pediatric palliative care setting.

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PMID: 24150973 [PubMed - in process]



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