Newsletter con aggiornamenti bibliografici sulla Terapia del dolore e sulle Cure Palliative Pediatriche

“La Buona informazione è la miglior medicina...”
Donald A.B. Lindberg

Quarto numero
Agosto 2015
Volume II - N° 4

Determining comorbidities and quality of life among pediatric survivors of extracorporeal life support.
Chandler HK¹, Teppa B², Johnson KA³, McCracken C⁴, Fortenberry JD², Paden ML².

PURPOSE: The purpose of this study is to describe health-related quality of life (HRQoL) and the prevalence of comorbidities in pediatric survivors of extracorporeal life support (ECLS) and to determine risk factors for poor HRQoL. MATERIALS: The study design was a retrospective cohort and prospective follow-up study of patients who received ECLS in the pediatric intensive care unit at Egleston Children’s Hospital from 2006 to 2013. Quality of life was measured using the Pediatric Quality of Life Inventory (PedsQL 4.0) completed by either parent proxies or the survivors themselves. Clinical data were obtained via review of electronic medical records. RESULTS: Surveys were sent to 37 parent proxies or survivors with a response rate of 43.2%. Survivors ranged in age from 2 to 21 years with follow-up range of 1 to 7.5 years. Primary respiratory failure due to pneumonia was the reason for ECLS in 81.3%. Mean total PedsQL scores were 73.9 (±21.3) with 11 survivors (69.8%) having a normal quality of life. None of the clinical characteristics (including age, ECLS length, or length of stay) correlated with PedsQL scores. The most commonly reported comorbidities included readmission less than 1 year after ECLS (46.7%) and “problems with school” (25%). CONCLUSIONS: Survivors of pediatric extracorporeal membrane oxygenation can exhibit good HRQoL scores yet may be at risk for long-term adverse effects, such as lower psychosocial functioning and problems with school. A rigorous prospective investigation of the long-term follow-up of this patient cohort is needed to further evaluate these conclusions and to work toward the best possible outcomes for recipients of this resource-intensive therapy. PMID: 26235652

Methicillin-resistant Staphylococcus aureus: Prevalence, incidence, risk factors, and effects on survival of patients in a specialist palliative care unit: A prospective observational study.
Gleeson A¹, Larkin P², Walsh C³, O'Sullivan N⁴.

BACKGROUND: Little is known about the impact of methicillin-resistant Staphylococcus aureus in palliative care settings. To date, the clinical impact of methicillin-resistant Staphylococcus aureus in palliative care is unknown. AIM: To determine prevalence and incidence of methicillin-resistant Staphylococcus aureus colonisation in a specialist palliative care setting, to identify risk factors for methicillin-resistant Staphylococcus aureus colonisation, to determine the eradication success rate and to determine the impact of methicillin-resistant Staphylococcus aureus on survival. DESIGN: Prospective cohort study. SETTING/PARTICIPANTS: Data were collected for consecutive admissions to an inpatient palliative care service. Patients were screened for methicillin-resistant Staphylococcus aureus colonisation on admission and 1 week post admission. Methicillin-resistant Staphylococcus aureus eradication was attempted in methicillin-resistant Staphylococcus aureus positive patients. RESULTS: Data were collected from 609 admissions for 466 individual patients. Admission screening data were available in 95.5%. Prevalence of methicillin-resistant Staphylococcus aureus colonisation was 11.59% (84 patients). One week incidence of methicillin-resistant Staphylococcus aureus colonisation was 1.2%. Risk factors for methicillin-resistant Staphylococcus aureus colonisation were determined using Chi-Squared test and included high Waterlow score (p < 0.01), high palliative performance scale score (p < 0.01), methicillin-resistant Staphylococcus aureus status prior to admission (p < 0.01), admission from hospital (p < 0.05), presence of urinary catheter or percutaneous endoscopic gastrostomy tube (p < 0.05) and poor dietary intake (p < 0.05). Regression analysis did not identify independent risk factors. Methicillin-resistant Staphylococcus aureus was eradicated in 8.1% of admissions, while 46 patients commenced on the protocol (82.2%) died
Palliative care (PC) is the most appropriate treatment for patients with life-limiting, incurable diseases, but it is a relatively new concept in sub-Saharan Africa (SSA). A lack of curative treatment options for some conditions creates a great need for PC, but such services are rarely provided in SSA. Hence, restricting methicillin-resistant Staphylococcus aureus screening to high-risk palliative care patients may be prudent.

PMID: 26231420


Experiences of Pediatric Oncology Patients and Their Parents at End of Life: A Systematic Review.

Montgomery K1, Sawin K1, Hendricks-Ferguson VL1.

Abstract Improvement in pediatric palliative and end-of-life care has been identified as an ongoing research priority. The child and parent experience provides valuable information to guide how health care professionals can improve the transition to end of life and the care provided to children and families during the vulnerable period. The purpose of this systematic review was to describe the experience of pediatric oncology patients and their parents during end of life, and identify gaps to be addressed with interventions. A literature search was completed using multiple databases, including CINAHL, PubMed, and PsycInfo. A total of 43 articles were included in the review. The analysis of the evidence revealed 5 themes: symptom prevalence and symptom management, parent and child perspectives of care, patterns of care, decision making, and parent and child outcomes of care. Guidelines for quality end-of-life care are needed. More research is needed to address methodological gaps that include the pediatric patient and their sibling’s experience.

PMID: 26219300


Symptom profiles in children with advanced cancer: Patient, family caregiver, and oncologist ratings.

Zhukovsky DS1,2, Rozmus CL1, Robert RS3, Bruera E3, Wells RJ4, Chisholm GB5, Allo JA6, Cohen MZ6.

BACKGROUND: Systematic symptom assessment is not routinely performed in pediatric oncology. The objectives of the current study were to characterize the symptoms of pediatric oncology outpatients and evaluate agreement between patient and proxy reports and the association between children’s ratings and oncologists’ treatment recommendations. METHODS: Two versions of the pediatric Memorial Symptom Assessment Scale (pMSAS) were translated into Spanish. An age-appropriate and language-appropriate pMSAS was administered independently before visits to the oncologist to patients and family caregivers (caregivers) and after visits to consenting oncologists. Statistical analysis included Spearman correlation coefficients and weighted kappa values. RESULTS: English and Spanish results were similar and were combined. A total of 60 children and their caregivers completed the pMSAS. The children had a median age of 10 years (range, 7-18 years); approximately 62% were male and 33% were Spanish-speaking. Fourteen oncologists completed the pMSAS for 25 patients. Nine patients (15%) had no symptoms and 38 patients (63%) reported ≥2 symptoms. The most common symptoms were fatigue (12 patients; 40%) and itch (9 patients; 30%) for the younger children and pain (15 patients; 50%) and lack of energy (13 patients; 45%) among the older children. Total and subscale score agreement varied by proxy type and subscale, ranging from fair to good for most comparisons. Agreement for individual symptoms between the patient and proxy ranged from a kappa of 0.30 (95% confidence interval, -0.43 to -0.01) to 0.91 (95% confidence interval, 0.75 to 1.00). Three of 51 symptomatic patients (6%) had treatment recommendations documented in the electronic health record. CONCLUSIONS: Symptoms are common and cross several functional domains. Proxy and child reports are often not congruent, possibly explaining apparent undertreatment among this group of patients. Cancer 2015. © 2015 American Cancer Society.

PMID: 26218240


Pediatricians’ Experience with Clinical Ethics Consultation: A National Survey.

Morrison W1, Womer J1, Nathanson P1, Kersun L1, Hester DM1, Walsh C1, Feudtner C1.

OBJECTIVE: To conduct a national survey of pediatricians’ access to and experience with clinical ethics consultation. STUDY DESIGN: We surveyed 3687 pediatric physicians in the American Academy of Pediatrics. We asked about their experiences with ethics consultation, the helpfulness of and barriers to consultation, and ethics education. Using a discrete choice experiment with maximum difference scaling, we evaluated which traits of ethics consultants were most valuable. RESULTS: Of the total sample of 3687 physicians, 659 (18%) responded to the survey. One-third of the respondents had no experience with clinical ethics consultation, and 16% reported no access to consultation. General pediatricians were less likely to have access. The vast majority (90%) who had experience with consultation had found it helpful. Those with fewer years in practice were more likely to have training in ethics. The most frequently reported issues were fatigue (12 patients; 40%) and itch (9 patients; 30%) for the younger children and pain (15 patients; 50%) and lack of energy (13 patients; 45%) among the older children. Total and subscale score agreement varied by proxy type and subscale, ranging from fair to good for most comparisons. Agreement for individual symptoms between the patient and proxy ranged from a kappa of 0.30 (95% confidence interval, -0.43 to -0.01) to 0.91 (95% confidence interval, 0.75 to 1.00). Three of 51 symptomatic patients (6%) had treatment recommendations documented in the electronic health record. CONCLUSION: There is variability in pediatricians’ access to ethics consultation. Most respondents reported that consultation had been helpful in the past. Determining ethically appropriate end-of-life care and mediation of disagreements are common reasons that pediatricians request consultation.

PMID: 26210846


An evaluation of a palliative care outreach programme for children with Burkitt lymphoma in rural Cameroon.

Tamnanai M1,2, Kaah F3, Mbah G2, Ndimba F1, D'Souza C1,2, Wharin F3,4, Hesseling PB5,6.

BACKGROUND: Palliative care (PC) is the most appropriate treatment for patients with life-limiting, incurable diseases, but it is a relatively new concept in sub-Saharan Africa (SSA). A lack of curative treatment options for some conditions creates a great need for PC, but such services are rarely provided in SSA. More research into PC in SSA is urgently needed to create...
an evidence base to confirm the importance of appropriate PC services. **OBJECTIVES:** To gain a better understanding of the needs of patients and their families visited by a children's PC nurse in Cameroon and to identify aspects of the service that can be improved. **METHODOLOGY:** A qualitative study design with semi-structured interviews was used. Tape-recorded interviews were transcribed and thematically analysed. **RESULTS:** Twelve interviews were conducted with patients, carers and nurses. Financial aid, general disease improvement and prayers were the directly expressed needs of service recipients. Specialist training in children's PC was the main need expressed by the nurses. Open communication about clinical status and treatment failure, more detailed counselling, more distraction for patients and respite for carers were identified as underlying needs. **CONCLUSION:** It is possible to provide an effective children's PC service that meets the most urgent needs of recipients in a rural setting in SSA. Recommendations include improved counselling, specialist education for staff, expansion of local support networks and more frequent home visits. More studies are needed to help define the need for PC in children with life-limiting diseases.

**PMD:** 26203953

7. Scand J Caring Sci. 2015 Jul 17. [Epub ahead of print] Palliative Care Research - A Systematic Review of foci, designs and methods of research conducted in Sweden between 2007 and 2012. Henoch I1,2, Carlander H3,4, Holm M5,5, James I6, Kenne Sarenalm C6,7, Lundh Hagelin C8,8,9, Lind G8,9, Sandgren A10,11, Ohlén J1

**BACKGROUND:** In 2007, a literature review was undertaken of palliative care research from Sweden during the 1970s-2006, paving the way for a follow-up study to explore the recent developments. The aim was to systematically examine palliative care research from Sweden between 2007 and 2012, with special attention to methods, designs and research foci. **METHODS:** A literature review was undertaken. The databases Academic search elite, Age line, Ahmed, Cinahl, PsychInfo, PubMed, Scopus, Soc abstracts, Web of science and Libris were reviewed for Swedish palliative care research studies published from 2007 to 2012, applying the search criteria 'palliative care OR palliative medicine OR end-of-life care OR terminal care OR hospice care OR dying OR death'. **RESULTS:** A total of 263 papers met the inclusion criteria, indicating an increased volume of research compared to the 133 articles identified in the previous review. Common study foci were symptom assessment and management, experiences of illness and care planning. Targeting non-cancer-specific populations and utilisation of population-based register studies were identified as new features. There was continued domination of cross-sectional, qualitative and mono-disciplinary studies, not including ethnic minority groups, nonverbally communicable people or children <18 years of age. **CONCLUSIONS:** The trend is that Swedish palliative care research has expanded in volume from 2007 to 2012 compared to during the 1970s to 2006, with increasing participation of non-cancer-specific populations. A domination of qualitative approaches and small, cross-sectional studies with few interventions is still characteristic. Still more strategies are needed to expand the knowledge development of palliative care to respond to demographical, epidemiological, therapeutic and healthcare structure changes.

**PMD:** 26190052


**BACKGROUND:** Framing is known to influence decision making. **OBJECTIVE:** The study objective was to describe language used by physicians when discussing treatment options with a critically and terminally ill elder. **METHODS:** High-fidelity simulation was used, involving an elder with end-stage cancer and life-threatening hypoxia, followed by a debriefing interview. Subjects were hospitalist, emergency medicine, and critical care physicians from three academic medical centers. Measures were observation of encounters in real time followed by content analysis of simulation and debriefing interview transcripts. During the simulation we identified the first mention (“broaching”) of principal treatment options-intubation and mechanical ventilation (life-sustaining treatment [LST]) and palliation in anticipation of death (palliation)—and used constant comparative methods to identify language used. We identified physician opinions about the use of LST in this clinical context during the debriefing interviews, and compared language used with opinions. **RESULTS:** Among 114 physician subjects, 106 discussed LST, 86 discussed palliation, and 94 discussed both. We identified five frames: will (decided), must (necessary), should (convention), could (option), and ask (elicitation of preferences). Physicians broached LST differently than palliation (p<0.01), most commonly framing LST as necessary (53%), while framing palliation as optional (49%). Among physicians who framed LST as imperative (will or must), 16 (30%) felt intubation would be inappropriate in this clinical situation. **CONCLUSIONS:** In this high-fidelity simulation experiment involving a critically and terminally ill elder, the majority of physicians framed the available options in ways implying LST was the expected or preferred choice. Framing of treatment options could influence ultimate treatment decisions. **PMD:** 26186668


**BACKGROUND:** Interventions to improve pediatric trainee education in palliative care have been limited by a lack of reliable and valid tools for measuring effectiveness. **OBJECTIVE:** We developed a questionnaire to measure pediatric fellows’ self-efficacy (comfort), knowledge, and perceived adequacy of prior medical education. We measured the questionnaire’s reliability and validity. **METHODS:** The questionnaire contains questions regarding self-efficacy (23), knowledge (10), fellow’s perceived adequacy of prior medical education (6), and demographics. The survey was developed with palliative care experts, and sent to fellows in U.S. pediatric cardiology, critical care, hematology/oncology, and neonatal-perinatal medicine programs. Measures of reliability, internal consistency, and validity were calculated. **RESULTS:** One hundred forty-seven fellows completed the survey at test and retest. The self-efficacy and medical education questionnaires showed high
internal consistency of 0.95 and 0.84. The test-retest reliability for the Self-Efficacy Summary Score, measured by intraclass correlation coefficient (ICC) and weighted kappa, was 0.79 (item range 0.44-0.81) and 0.81 (item range 0.36-0.70), respectively. For the Adequacy of Medical Education Summary Score, ICC was 0.88 (item range 0.5-0.78) and weighted kappa was 0.63 (item range 0.47-0.62). Validity coefficients for these two questionnaires were 0.88 and 0.92. Fellows answered a mean of 8.8/10 knowledge questions correctly; percentage agreement ranged from 65% to 99%. **CONCLUSIONS:** This questionnaire is capable of assessing self-efficacy and fellow-perceived adequacy of their prior palliative care training. We recommend use of this tool for fellowship programs seeking to evaluate fellow education in palliative care, or for research studies assessing the effectiveness of a palliative care educational intervention.

**PMID:** 26185912


**Abstract** Neonatal intensive care units attract nurses due to the technical and highly specific nature of the work. However, there is a high turnover in these departments. Work-related distress and the lack of team cohesion are the two main causes of this problem. Support from the health care manager is essential in this context.

**PMID:** 26183101

11. JAMA Oncol. 2015 Jul 9. [Epub ahead of print]

**End-of-Life Care Intensity Among Adolescent and Young Adult Patients With Cancer in Kaiser Permanente Southern California.**

Mack JW1, Chen LH2, Cannavale K3, Sattayapiwat O3, Cooper RM4, Chao CR2

**Importance:** Cancer is the leading disease-related cause of death among adolescents and young adults (AYAs), but little is known about the care that AYA patients with cancer receive at the end of life (EOL). **Objective:** To evaluate the intensity of EOL care among AYA patients with cancer. **Design, Setting, and Participants:** Cross-sectional study of Kaiser Permanente Southern California (KPSC) cancer registry data and electronic health records for 663 AYA patients with either stage I to III cancer and evidence of cancer recurrence or stage IV cancer at diagnosis. All patients were treated within KSPEC, an integrated health care delivery system, and died between 2001 and 2010 before age 40 years (age range at time of death, 15-39 years). **Main Outcomes and Measures:** (1) Chemotherapy use in the last 14 days of life; (2) intensive care unit (ICU) care in the last 30 days of life; (3) more than 1 emergency department (ED) visit in the last 30 days of life; (4) hospitalization in the last 30 days of life; and (5) a composite measure of medically intensive EOL care including any of the aforementioned measures. **Results:** Eleven percent of patients (72 of 663) received chemotherapy within 14 days of death. In the last 30 days of life, 22% of patients (144 of 663) were admitted to the ICU; 22% (147 of 663) had more than 1 ED visit; and 62% (413 of 663) were hospitalized. Overall, 68% of patients (449 of 663) received at least 1 medically intensive EOL care measure. **Conclusions and Relevance:** Most AYA patients received at least 1 form of medically intensive EOL care. These findings suggest the need to better understand EOL care preferences and decision making in this young population.

**PMID:** 26181778

12. JAMA Oncol. 2015 Jul 9. [Epub ahead of print]

**The Death Burden and End-of-Life Care Intensity Among Adolescent and Young Adult Patients With Cancer.**

Bleyer A1

**PMID:** 26181237


**Mortality and Operative Management for Patients Undergoing Repair of Coarctation of the Aorta: A Retrospective Review of the Pediatric Cardiac Care Consortium.**

**BACKGROUND:** The surgical mortality associated with repair of coarctation of the aorta (CoA) over a 25-year period was examined. Risk factors for discharge mortality were evaluated as well as the surgical techniques and its evolution over the period studied. **METHODS:** Utilizing the pediatric cardiac care consortium, we conducted a retrospective review of patients less than 18 years of age submitted between 1982 and 2007. Variables reviewed included weight at birth, age and weight at the operation, type of coarctation repair, associated cardiac anomalies, year of repair, center period studied.

**RESULTS:** There were 7,860 patients submitted with the procedural code for repair of CoA. Forty-five percent underwent repair within 30 days of life (n = 3,984), including 1,444 patients who were operated upon within the first 7 days of life (18% of all patients). Seventy percent (n = 5,528) of patients had an isolated CoA (iCoA). The overall mortality for the entire group was 4.2% (n = 331), decreasing to 2.0% (n = 114) for iCoA (P < .0001). A hypoplastic aortic arch occurred in 4.6%, with a mortality of 10.6%. Coarctectomy with an end-to-end reconstruction was the most common procedure performed. Multivariable modeling for discharge mortality was significant for diagnosis of ventricular septal defect, operative weight, operative year, and diagnosis of aortic arch hypoplasia. **CONCLUSIONS:** Operative repair of CoA is accomplished with a low mortality, although certain subgroups have persistently inferior outcomes. The techniques utilized for aortic reconstruction have evolved, with coarctectomy and an end-to-end anastomosis becoming the dominant surgical procedures.

**PMID:** 26180161


**Physician Communication in Pediatric End-of-Life Care: A Simulation Study.**

Bateman LB1, Tofil NM2, White ML2, Dure LS3, Clair JM4, Needham BL4

**OBJECTIVE:** The objective of this exploratory study is to describe communication between physicians and the actor parent of a standardized 8-year-old patient in respiratory distress who was nearing the end of life. **METHODS:** Thirteen pediatric
emergency medicine and pediatric critical care fellows and attendings participated in a high-fidelity simulation to assess physician communication with an actor-parent. **RESULTS:** Fifteen percent of the participants decided not to initiate life-sustaining technology (intubation), and 23% of participants offered alternatives to life-sustaining care, such as comfort measures. Although 92% of the participants initiated an end-of-life conversation, the quality of that discussion varied widely. **CONCLUSION:** Findings indicate that effective physician-parent communication may not consistently occur in cases involving the treatment of pediatric patients at the end of life in emergency and critical care units. **PRACTICE IMPLICATIONS:** The findings in this study, particularly that physician-parent end-of-life communication is often unclear and that alternatives to life-sustaining technology are often not offered, suggest that physicians need more training in both communication and end-of-life care.

PMID: 26169822

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**The Spirit of "Ubuntu" in Children’s Palliative Care.**

Marston JM.

**Abstract** The concept of "Ubuntu", a Nguni word, is found in many Southern African cultures and means that we are part of all humanity and we are who we are through our interconnectedness with others. Children with life-limiting conditions often become isolated and take on a new identity in the eyes of others, linked to their illness and treatment. Terms that are used can de-humanize the child. The concept of Ubuntu can help the child, the family and the community to ensure the child remains connected to society. Programs providing palliative care for children often say they feel isolated; Ubuntu principles are relevant to effective network development.

PMID: 26166185

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**Determinants of Hospital Death for Taiwanese Pediatric Cancer Decedents, 2001-2010.**

Hung YN1, Liu TW2, Tang ST.

**CONTEXT:** Factors influencing pediatric cancer patients' place of death may have evolved with advances in medical and hospice care since earlier studies were done. **OBJECTIVES:** To comprehensively analyze factors associated with hospital death in an unbiased population of pediatric cancer patients in Taiwan. **METHODS:** This was a retrospective cohort study using administrative data for 1603 Taiwanese pediatric cancer patients who died in 2001-2010. Place of death was hypothesized to be associated with 1) patient sociodemographics and disease characteristics, 2) primary physician’s specialty, 3) characteristics and health care resources at both the hospital and regional levels, and 4) historical trends. **RESULTS:** Most Taiwanese pediatric cancer patients (87.4%) died in an acute care hospital. The probability of dying in hospital increased slightly over time, reaching significance only in 2009 (adjusted odds ratio [AOR], 95% CI: 2.84 [1.32-6.11]). Children were more likely to die in an acute care hospital if they resided in the most urbanized area, were diagnosed with leukemia or lymphoma (2.32 [1.39-3.87]), and received care from a pediatrician (1.58 [1.01-2.47]) in a nonprofit proprietary hospital (1.50 [1.01-2.24]) or large hospital, reaching significance for the third quartile (2.57 [1.28-5.18]) of acute care hospital beds. **CONCLUSION:** Taiwanese pediatric cancer patients predominantly died in an acute care hospital with a slightly increasing trend of shifting place of death from home to hospital. Propensity for hospital death was determined by residential urbanization level, diagnosis, primary physician’s specialty, and the primary hospital’s characteristics and health care resources. Clinical interventions and health policies should ensure that resources are allocated to allow pediatric cancer patients to die in the place they and their parents prefer to achieve a good death and promote their parents’ bereavement adjustment.

PMID: 26162607

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**Controversies in faith and health care.**

Todrick A,1 Duff T,1 Pittsibgood A,2 Khan A,4 Mills E,1 Munnings K,1 Smith S,5 Seshadri S,6 Steinberg A,7 Vittillo P,8 Yugi P.1

**Abstract** Differences in religious faith-based viewpoints (controversies) on the sanctity of human life, acceptable behaviour, health-care technologies and health-care services contribute to the widespread variations in health care worldwide. Faith-linked controversies include family planning, child protection (especially child marriage, female genital mutilation, and immunisation), stigma and harm reduction, violence against women, sexual and reproductive health and HIV, gender, end-of-life issues, and faith activities including prayer. Buddhism, Christianity, Hinduism, Islam, Judaism, and traditional beliefs have similarities and differences in their viewpoints. Improved understanding by health-care providers of the heterogeneity of viewpoints, both within and between faiths, and their effect on health care is important for clinical medicine, public-health programmes, and health-care policy. Increased appreciation in faith leaders of the effect of their teachings on health care is also crucial. This Series paper outlines some faith-related controversies, describes how they influence health-care provision and uptake, and identifies opportunities for research and increased interaction between faith leaders and health-care providers to improve health care.

PMID: 26159392

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**Lack of resources hinders palliative care.**

Mulholland H.

**Abstract** Many terminally ill children are not being given the choice to die at home because of a lack of staff training and resources to provide 24/7 care in the community, according to a UK-wide survey conducted by the RCN.

PMID: 26156599

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**Integrating Palliative Care Into the Care of Neurocritically Ill Patients: A Report From the Improving Palliative Care
Abstract

Managing paediatric death in the emergency department.

O'Meara M1, Trethieve S2.

Abstract

Death of a child in an emergency department is a rare occurrence, but one with significant impact on the family and staff involved. The rarity means few emergency department clinicians feel ‘expert’ in the overall management process. However, most have some knowledge and experience which can be augmented by collaborating with other health professionals. By exploring some of the main management issues and challenges for the emergency department, key aspects of care are identified for emergency department clinicians to consider in reviewing local procedures and guidelines.

PMID: 26147905

in the ICU Project Advisory Board and the Center to Advance Palliative Care.


OBJECTIVES: To describe unique features of neurocritical illness that are relevant to provision of high-quality palliative care; to discuss key prognostic aids and their limitations for neurocritical illnesses; to review challenges and strategies for establishing realistic goals of care for patients in the neuro-ICU; and to describe elements of best practice concerning symptom management, limitation of life support, and organ donation for the neurocritically ill. DATA SOURCES: A search of PubMed and MEDLINE was conducted from inception through January 2015 for all English-language articles using the term "palliative care," "supportive care," "end-of-life care," "withdrawal of life-sustaining therapy," "limitation of life support," "prognosis," or "goals of care" together with "neurocritical care," "neurointensive care," "neurological," "stroke," "subarachnoid hemorrhage," "intracerebral hemorrhage," or "brain injury." DATA EXTRACTION AND SYNTHESIS: We reviewed the existing literature on delivery of palliative care in the neurointensive care unit setting, focusing on challenges and strategies for establishing realistic and appropriate goals of care, symptom management, organ donation, and other considerations related to use and limitation of life-sustaining therapies for neurocritically ill patients. Based on review of these articles and the experiences of our interdisciplinary/interprofessional expert advisory board, this report was prepared to guide clinical care staff, palliative care specialists, and others who practice in this setting. CONCLUSIONS: Most neurocritically ill patients and their families face the sudden onset of devastating cognitive and functional changes that challenge clinicians to provide patient-centered palliative care within a complex and often uncertain prognostic environment. Application of palliative care principles concerning symptom relief, goal setting, and family emotional support will provide clinicians a framework to address decision making at a time of crisis that enhances patient/family autonomy and clinician professionalism.

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PMID: 26154929
Provider Difficulties With Spiritual and Forgiveness Communication at the End of Life.
Wittenberg E1, Ferrell B1, Goldsmith J2, Buller H1

BACKGROUND: Due to an absence of communication training, provider responses to patient/family spiritual distress are highly variable. Assessing spiritual and forgiveness concerns are important to ensuring quality holistic care. METHODS: Cross-sectional survey data were collected from providers attending 1 of 2 continuing education courses. The survey measured the frequency and initiation of communication about spirituality and forgiveness with patients/families, the perceived difficulty in communication across topics, and preparation and resources for these discussions. RESULTS: Most participants (n = 124) were nurses followed by social workers with over half of providers having 10 years or more of clinical experience. Participants reported the highest level of difficulty in spiritual communication when talking with family after the death of a patient, followed by conducting a spiritual history with a patient. Facilitating forgiveness communication between parent and adult child, followed by facilitating forgiveness between partners was most difficult for all participants. Social workers reported much lower difficulty than nurses on all items of spiritual and forgiveness communication. CONCLUSION: The majority of participants indicated they were involved in spiritual and forgiveness communication. The most difficult communication included talking with family after death and facilitating forgiveness between patients and families. These findings support the importance of spiritual communication in clinical practice, and the need for clinician training in communicating about spirituality and forgiveness with patients and families.
PMD: 26139631

Two worlds: Adolescents’ strategies for managing life with a parent in hospice.
Sheehan DK1, Mayo MM2, Christ GH3, Heim K4, Parish S5, Shahroug G6, Draucker CB7

OBJECTIVE: This study aimed to generate an explanatory model of the coping strategies that adolescents employ to manage the stressors they experience in the final months of their ill parent's life and shortly after their death. METHODS: The sample included 26 families of adolescents with a parent receiving care in a large hospice program in northeastern Ohio. A semistructured interview was conducted with 14 ill parents, 17 well parents/guardians, and 30 of their adolescent children before the parent's death and, additionally, with 6 of these families after the death. The interviews were audiotaaped, transcribed verbatim, and analyzed using a grounded-theory approach. RESULTS: The participants described two worlds that constituted the lives of the adolescents: the well world of normal adolescence and the ill world of having a parent near the end of life. The adolescents experienced a common challenge of living in two worlds and responded to the challenge with a process we labeled “managing two worlds.” Five stages through which adolescents manage their worlds were identified: keeping the ill world and the well world separate; having the ill world intrude into the well world; moving between the ill world and the well world; being immersed in the ill world; and returning to the well world having been changed by the ill world. SIGNIFICANCE OF RESULTS: The explanatory model of “managing two worlds” outlines a complex and nuanced process that changes over time. The model can be used by health professionals who seek to help adolescents navigate this critical time when their parents are dying or have recently died. These results can also be used to inform the development of interventions that assist families with strategies tailored to an adolescent's specific needs. Future research should investigate associations among the process of “managing two worlds” and outcomes related to adolescent bereavement.
PMD: 26126748

Paediatric death and dying: exploring coping strategies of health professionals and perceptions of support provision.
Forster E1, Hafiz A2

Abstract Without question a child’s death is a devastating event for parents and families. Health professionals working with the dying child and family draw upon their expertise and experience to engage with children, parents and families on this painful journey. This is a delicate and sensitive area of practice and has strong and penetrating effects on health professionals. They employ physical, emotional, spiritual and problem solving strategies to continue to perform this role effectively and to protect their continued sense of wellbeing. AIM: To explore health professionals' perceptions of bereavement support surrounding the loss of a child. METHODS: The research was underpinned by social constructionism. Semi-structured interviews were held with 10 health professionals including doctors, nurses and social workers who were directly involved in the care of the dying child and family in 7 cases of paediatric death. Health professional narratives were analysed consistently with Charmaz’s (2006) approach. RESULTS: For health professionals, constructions around coping emerged as peer support, personal coping strategies, family support, physical impact of support and spiritual beliefs. Analysis of the narratives also revealed health professionals’ perceptions of their support provision. CONCLUSION: Health professionals involved in caring for dying children and their families use a variety of strategies to cope with the emotional and physical toll of providing support. They also engage in self-assessment to evaluate their support provision and this highlights the need for self-evaluation tools in paediatric palliative care.
PMD: 26126678

We are not alone: international learning for professionals caring for children requiring palliative care.
Price J1, Quinn K2, McNeilly P3, Heywood M4

BACKGROUND: Educational opportunities for professionals working with children requiring palliative care are central to future development within the specialty across countries. International educational initiatives involving a range of professionals are important for learning with and from others working within the field. AIM: To explore the experiences and value to students from participating in an international online discussion forum. METHOD: This article examines one such initiative; the use of an international asynchronous discussion forum with students in Melbourne, Australia and Belfast, UK who work with children and families. The innovation is examined and student perspectives of the forum’s value are presented.
RESULTS: Students endorsed the value of the forum, identifying three main areas of learning: differences across locations within countries, respecting different views and being open, and need for continued learning within children's palliative care. The overarching theme 'we are not alone' supported the idea that participation in the international discussion forum enabled students to see a broader perspective. Ideas for future developments of similar forums are also explored.

PMID: 26126677


Outcomes of children with advanced HIV initiated on antiretroviral therapy in a South African hospice.

Brits H1, Joubert G2.

BACKGROUND: Little is known about the long-term outcome of antiretroviral therapy (ART) for children with advanced-stage HIV. AIM: To assess the outcome in children with advanced HIV initiated on ART. The predictors for survival, general wellbeing and the role of palliative care were assessed. METHODS: Patient files, retained patient records and personal follow-up were used for data collection. Data on baseline characteristics, ART treatment and progress were collected at baseline, 6, 12 and 48 months. Information regarding general wellbeing and school attendance and performance were collected. RESULTS: 37 children were started on ART. At 48 months there were 18 known survivors and 7 known to have died. Another 12 were transferred to another programme or lost to follow-up. There was no significant difference in baseline characteristics between groups. All eligible children attended school and all received medical care. The hospice programme offered holistic care and support. CONCLUSIONS: No baseline characteristic could predict the outcome of children with advanced HIV initiated on ART. A hospice support programme can contribute to positive outcomes even when ART is initiated in children with advanced disease.

PMID: 26126676


Developing palliative care for children globally.

[No authors listed]

PMID: 26126672


Where Children Die: Obstacles to Quality End-of-Life Care.

Hinson AP1, Rosoff PM2.

PMID: 26116346


Pediatric Palliative Care Pilot Curriculum: Impact of “Pain Cards” on Resident Education.

Barnett MD1, Maurer SH2, Wood GJ3.

METHODS: Pocket reference cards were created to deliver fundamentals of pediatric palliative care to resident learners; didactics and case studies emphasized principles on the cards. Self-reported comfort and objective knowledge were measured before and after the curriculum among residents. RESULTS: Of 32 post-graduate year 2 (PGY2) residents, 23 (72%) completed the pre-test survey. The post-test was completed by 14 PGY2 residents (44%) and 16 of 39 PGY3/4 residents (41%). There was improvement in comfort with communication, as well as pain and symptom management among the residents. Knowledge of palliative care principles improved in part, with only a few survey questions reaching statistical significance. 100% of respondents recommended the cards be provided to their colleagues. CONCLUSION: This longitudinal curriculum, designed specifically for pediatric residents, was built into an existing training program and proved to be popular, feasible, and effective at improving comfort with basic palliative care principles.

PMID: 26101344


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

Thienprayoon R1, Lee SC, Leonard D, Winick N.

Author information: 1 Department of Anesthesiology & Cancer and Blood Disease Institute, Cincinnati Children's Hospital Medical Center, Cincinnati, OH 2 Department of Clinical Sciences & Harold C. Simmons Cancer Center, University of Texas Southwestern Medical Center 3 Children's Medical Center Dallas 4 Department of Pediatrics, Paul D. Goldreyer Center for Cancer and Blood Disorders, Division of Hematology-Oncology, University of Texas at Southwestern Medical Center, Dallas, TX.

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

PMID: 26090871

**Survival prediction for advanced cancer patients in the real world: A comparison of the Palliative Prognostic Score, Delirium-Palliative Prognostic Score, Palliative Prognostic Index and modified Prognosis in Palliative Care Study predictor model.**

Baba M1, Maeda I2, Morita T3, Inoue S4, Ikenaga M5, Matsumoto Y6, Sekine R7, Yamauchi T8, Hirohashi T9, Taitima M10, Tataru R11, Watanabe H12, Otani H13, Takigawa C14, Matsuda Y, Nagaoa H, Mori M, Tei Y, Hiramoto S, Suga A, Kinoshita H.

**PURPOSE:** The aim of this study was to investigate the feasibility and accuracy of the Palliative Prognostic Score (PaP score), Delirium-Palliative Prognostic Score (DPaP score), Palliative Prognostic Index (PPI) and modified Prognosis in Palliative Care Study predictor model (PiPS model).

**METHODS:** This multicentre prospective cohort study involved 58 palliative care services, including 19 hospital palliative care teams, 16 palliative care units and 23 home palliative care services, in Japan from September 2012 to April 2014. Analyses were performed involving four patient groups: those treated by palliative care teams, those in palliative care units, those at home and those receiving chemotherapy.

**RESULTS:** We recruited 2426 participants, and 2361 patients were finally analysed. Risk groups based on these instruments successfully identified patients with different survival profiles in all groups. The feasibility of PPI and modified PiPS-A was more than 90% in all groups, followed by PaP and D-PaP scores; modified PiPS-B had the lowest feasibility. The accuracy of prognostic scores was >60% in all groups and the difference was within 13%, while c-statistics were significantly lower with the PPI than PaP and D-PaP scores.

**CONCLUSION:** The PaP score, D-PaP score, PPI and modified PiPS model provided distinct survival profiles for patients in the three palliative care settings and those receiving chemotherapy. The PPI seems to be suitable for routine clinical use for situations where rough estimates of prognosis are sufficient and/or patients do not want invasive procedure. If clinicians can address more items, the modified PiPS-A would be a non-invasive alternative. In cases where blood samples are available or those requiring more accurate prediction, the PaP and D-PaP scores and modified PiPS-B would be more appropriate.

PMID: 26074396


**Factors Affecting Willingness to Use Hospice in Racially/Ethnically Diverse Older Men and Women.**

Park NS1, Jang Y2, Ko IE3, Chiriboga DA4.

**Abstract** Racial/ethnic minorities tend to underutilize hospice services. Guided by Andersen behavioral health model, the purpose of this study was to explore the predictors of the willingness to use hospice services in racially/ethnically diverse older men and women. Data were drawn from the Survey of Older Floridians: 504 non-Hispanic whites, 360 African Americans, 328 Cuban Americans, and 241 non-Cuban Hispanics. In each group, logistic regression models of the willingness to use hospice were estimated. A greater likelihood of willingness was observed among younger non-Hispanic whites and among African Americans with fewer functional disabilities. In non-Cuban Hispanics, English proficiency increased the willingness by 3.1 times. Findings of the study identified group-specific factors contributing to the willingness to use hospice services and hold implications for tailored intervention programs.

PMID: 26071499

34. Br J Cancer. 2015 Jun;112(12):1846-56.

**The prioritisation of paediatrics and palliative care in cancer control plans in Africa.**

Weaver MS1, Yao AJ2, Renner LA3, Harif M4, Lam C5.

**BACKGROUND:** Given the burden of childhood cancer and palliative care need in Africa, this paper investigated the paediatric and palliative care elements in cancer control plans. **METHODS:** We conducted a comparative content analysis of accessible national cancer control plans in Africa, using a health systems perspective attentive to context, development, scope, and monitoring/evaluation. Burden estimates were derived from World Bank, World Health Organisation, and World-wide Palliative Care Alliance. **RESULTS:** Eighteen national plans and one Africa-wide plan (10 English, 9 French) were accessed, from 9 low-, 6 lower-middle-, and 5 upper-middle-income settings. Ten plans discussed cancer control in the context of noncommunicable diseases. Paediatric cancer was mentioned in 7 national plans, representing 5127 children, or 13% of the estimated continental burden for children aged 0-14 years. Palliative care needs were recognised in 11 national plans, representing 157 490 children, or 24% of the estimated Africa-wide burden for children aged 0-14 years; four plans specified paediatric palliative needs. Palliative care was itemised in four budgets. Sample indicators and equity measures were identified, including those highlighting contextual needs for treatment access and completion. **CONCLUSIONS:** Recognising explicit strategies and funding for paediatric and palliative services may guide prioritised cancer control efforts in resource-limited settings.

PMID: 26042935


**Challenges and opportunities to advance pediatric neuro-oncology care in the developing world.**

Chan MH1, Boop F, Qaddoumi I.

**PURPOSE:** As the morbidity and mortality associated with communicable diseases continue to decrease in the developing world, the medical burden of childhood cancer continues to expand. Although international aid and relief groups such as the World Health Organization recognize the importance of childhood cancer, their main emphasis is on the more easily treated malignancies, such as leukemias and lymphomas, and not pediatric brain tumors, which are the second most common malignancy in children and the leading cause of cancer-related deaths in the pediatric population. Addressing the needs of these children is a growing concern of several professional neuro-oncology-related societies. Thus, the goal of this review is to describe the current state of pediatric neuro-oncology care in the developing world, address the current and future needs of the field, and help guide professional societies’ efforts to contribute in a more holistic and multidisciplinary manner.

**METHODS:** We reviewed the literature to compare the availability of neuro-oncology care in various regions of the developing world with that in higher income nations, to describe examples of successful initiatives, and to present opportunities...
to improve care. RESULTS: The current challenges, previous successes, and future opportunities to improve neuro-oncology care are presented. The multidisciplinary nature of neuro-oncology depends on large teams of highly specialized individuals, including neuro-oncologists, neurosurgeons, neurologists, radiologists, radiation oncologists, pathologists, palliative care specialists, oncology nurses, physical therapists, occupational therapists, speech therapists, pediatric intensivists, and social workers, among others. CONCLUSION: Pediatric neuro-oncology is one of the most complex types of medical care to deliver, as it relies on numerous specialists, subspecialists, support staff, and physical resources and infrastructure. However, with increasing collaboration and advancing technologies, developed nations can help substantially improve neuro-oncology care for children in developing nations.

PMID: 26040936


The Safety and Effectiveness of Patient-controlled Analgesia in Outpatient Children and Young Adults With Cancer: A Retrospective Study.
Anghelescu DL, Zhang K, Faughnan LG, Pei D.

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

PMID: 26018808


Applying the evidence to help caregivers torn in two.
Beach PR, White BE.

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PMID: 25973758


Pediatric palliative care in the community.
Kaye EC, Rubenstein E, Levine D, Baker JN, Dabbs D, Friebert SE.

Abstract Answer questions and earn CME/CNE Early integration of pediatric palliative care (PPC) for children with life-threatening conditions and their families enhances the provision of holistic care, addressing psychological, social, spiritual, and physical concerns, without precluding treatment with the goal of cure. PPC involvement ideally extends throughout the illness trajectory to improve continuity of care for children and families. Although current PPC models focus primarily on the hospital setting, community-based PPC (CBPPC) programs are increasingly integral to the coordination, continuity, and provision of quality care. In this review, the authors examine the purpose, design, and infrastructure of CBPPC in the United States, highlighting eligibility criteria, optimal referral models to enhance early involvement, and fundamental tenets of CBPPC. This article also appraises the role of CBPPC in promoting family-centered care. This model strives to enhance shared decision making, facilitate seamless handoffs of care, maintain desired locations of care, and ease the end of life for children who die at home. The effect of legislation on the advent and evolution of CBPPC also is discussed, as is an assessment of the current status of state-specific CBPPC programs and barriers to implementation of CBPPC. Finally, strategies and resources for designing, implementing, and maintaining quality standards in CBPPC programs are reviewed. CA Cancer J Clin 2015;65:315-333.

PMID: 25995682


Methylnaltrexone for Opioid-Induced Constipation in Children and Adolescents and Young Adults with Progressive Incurable Cancer at the End of Life.
Flierlage JE, Baker JN.

BACKGROUND: Opioid-induced constipation (OIC) is common among children and adolescents and young adults (AYA) with progressive incurable cancer. Although methylnaltrexone is a successful treatment for OIC in adult cancer patients, no case series has established its safety and efficacy in pediatric cancer patients. OBJECTIVES: The aim of the study was to describe the safety and efficacy of methylnaltrexone use for OIC in children and AYA with progressive incurable cancer at the end of life in the inpatient and outpatient settings. METHODS: We conducted a retrospective review of medical records of children and AYA with progressive incurable cancer who received methylnaltrexone at our institution from May 2008 to June 2013. Pharmacy data were reviewed for each patient and a chart review was performed for documentation of laxation and side effects. RESULTS: Of the 9 patients (age range: 17 months to 21 years) with progressive incurable cancer who de-
developed OIC, 7 (78%) had laxation after methylnaltrexone administration (0.15 mg/kg/dose). Of these 7 patients, 5 (71%) had laxation with the first dose, and 6 (71%) who responded had a continued response to repeated doses. The longest a patient regularly received methylnaltrexone was 9 months. Of 8 patients with intraabdominal disease, 4 (80%) had laxation. There were no negative side effects in any of the patients. Also, there was no increase in pain either qualitatively or by pain score.

CONCLUSIONS: Methylnaltrexone appears to be safe and efficacious in treating OIC in children and AYA with progressive incurable cancer. Methylnaltrexone was tolerated in both the inpatient and outpatient settings and with repeated dosing.


BACKGROUND: Thousands of children are living with advanced cancer; yet patient-reported outcomes (PROs) have rarely been used to describe their experiences. We aimed to describe symptom distress in 104 children age 2 years or older with advanced cancer enrolled onto the Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) Study (multisite clinical trial evaluating an electronic PRO system).

METHODS: Symptom data were collected using age- and respondent-adapted versions of the PediQUEST Memorial Symptom Assessment Scale (PQ-MSAS) at most once per week. Clinical and treatment data were obtained from medical records. Individual symptom scores were dichotomized into high/low distress. Determinants of PQ-MSAS scores were explored using linear mixed-effects models.

RESULTS: During 9 months of follow-up, PQ-MSAS was administered 920 times: 459 times in teens (99% self-report), 249 times in children ages 7 to 12 years (96% child/parent report), and 212 times in those ages 2 to 6 years (parent reports). Common symptoms included pain (48%), fatigue (46%), drowsiness (39%), and irritability (37%); most scores indicated high distress. Among the 73 PQ-MSAS surveys administered in the last 12 weeks of life, pain was highly prevalent (62%; 58% with high distress). Being female, having a brain tumor, experiencing recent disease progression, and receiving moderate- or high-intensity cancer-directed therapy in the prior 10 days were associated with worse PQ-MSAS scores. In the final 12 weeks of life, receiving mild cancer-directed therapy was associated with improved psychological PQ-MSAS scores.

CONCLUSION: Children with advanced cancer experience high symptom distress. Strategies to promote intensive symptom management are indicated, especially with disease progression or administration of intensive treatments.

PMID: 25918277


Angelescu DL1, Snaman IM2, Trujillo L3, Sykes AD1, Yuan Y4, Baker IN5.

BACKGROUND: Patient-controlled analgesia (PCA) is increasingly used to manage pain in pediatric cancer patients and is important in the treatment of escalating pain at the end of life. The description of the use of opioid PCA in this population has been limited.

PROCEDURE: This retrospective chart review of the last 2 weeks of life addressed the following objectives: (1) to describe the patient population treated with opioid PCA; (2) to describe the morphine-equivalent doses (MED) (mg/kg/day); and (3) to describe the pain scores (PS).

RESULTS: Twenty-eight percent of patients used opioid PCA for pain control during the last 2 weeks of life. The mean MED (mg/kg/day) (SD) at 2 weeks prior and the day of death were 10.7 (17.9) and 19 (25.8). The mean MED increased over the last 2 weeks of life for all patients and across age groups and cancer diagnoses (all P < 0.05). The mean MED was significantly higher in the younger age group (age < 13 vs. age ≥ 13) on the day of death (P < 0.04). There was a significant change in mean PS over the last 2 weeks of life (P < 0.001), with the highest PS on the day before death. The most frequently used concurrent medications were benzodiazepines (91%).

CONCLUSIONS: Children and young adults with cancer experience high opioid requirements and significant dose increases during the last 2 weeks of life. Additionally, PS increase toward the end of life. Opioid rotation and addition of adjuvant medications merit consideration in the context of escalating opioid requirements.

PMID: 25820345


Miller EC1, Levy C2, Linebarger JS3, Klick JC4, Carter BS5.

PMID: 25799195 [PubMed - indexed for MEDLINE]


O’Shea ER1, Campbell SH1, Engler AI1, Beauregard R4, Chamberlin EC1, Currie LM6.

BACKGROUND: Educational practices and national guidelines for best practices of providing palliative care to children and their families have been developed and are gaining support; however, the dissemination of those practices lags behind expectations. Incorporating education for pediatric palliative care into nursing pre-licensure programs will provide guidelines for best practices with opportunities to enact them prior to graduation. OBJECTIVE: To evaluate the effect of an integrated curriculum for palliative care on nursing students’ knowledge.

DESIGN: Matched pre-posttest. SETTING: One private and one public university in the northeastern United States.

PARTICIPANTS: Two groups of baccalaureate nursing students, one exposed to an integrated curriculum for palliative care and one without the same exposure.

METHODS: Pre-testing of the students with a 50-item multiple choice instrument prior to curriculum integration and post-testing with the same instrument at the end of the term.

RESULTS: This analysis demonstrated changes in knowledge scores among the experimental (n=40) and control (n=19) groups that were statistically significant by time (Wilks’ Lambda=.90, F(1, 57)=6.70, p=.012) and study group (Wilks’ Lambda=.83, F(1, 57)=11.79, p=.001).

CONCLUSIONS: An integrated curriculum for pedi-
atic and perinatal palliative and end-of-life care can demonstrate an increased knowledge in a small convenience sample of pre-licensure baccalaureate nursing students when compared to a control group not exposed to the same curriculum. Future research can examine the effect on graduates’ satisfaction with program preparation for this specialty area; the role of the use of the curriculum with practice-partners to strengthen transfer of knowledge to the clinical environment; and the use of this curriculum interprofessionally.

PMID: 25771263


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

Mack IW1,2, Walling A3,4, Dy S5, Antonio AL3,4, Adams F4, Keating NL4,7, Tisdale D6.

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

PMCID: PMC4441582 [Available on 2016-06-01]
PMID: 25677685


Feasibility of Conducting a Palliative Care Randomized Controlled Trial in Children With Advanced Cancer: Assessment of the PediQUEST Study.


CONTEXT: Pediatric palliative care randomized controlled trials (PCC-RCTs) are uncommon. OBJECTIVES: To evaluate the feasibility of conducting a PCC-RCT in pediatric cancer patients. METHODS: This was a cohort study embedded in the Pediatric Quality of Life and Evaluation of Symptoms Technology Study (NCT01838564). This multicenter PCC-RCT evaluated an electronic patient-reported outcomes system. Children aged two years and older, with advanced cancer, and potentially eligible for the study were included. Outcomes included: pre-inclusion attrition (patients not approached, refusals); post-inclusion attrition (drop-out, elimination, death, and intermittent attrition [IA; missing surveys] over nine months of follow-up); 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); 84 eligible patients were not approached and 43 declined enrollment. Patients not approached were more likely to die or have brain tumors. We enrolled 104 patients. Average enrollment rate was one patient per site per month; shortening follow-up from nine to three months (with optional re-enrollment) increased recruitment by 20%. A total of 87 patients completed the study (24 died) and 17 dropped out. Median IA was 41% in the first 20 weeks of follow-up and more than 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 PCC-RCT in children with advanced cancer was feasible, post-inclusion retention adequate; many families participated for altruistic reasons. Strategies that may further PCC-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. Copyright © 2015 American Academy of Hospice and Palliative Medicine.


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

Popp IM4, Conway M5, Pantaleao A3.

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. © 2015 by Association of Pediatric Hematology/Oncology Nurses.

PMID: 25565107
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.

PMID: 25591916

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

Cortezzo DE, Sanders MF, Brownell EA, Moss K.

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 622/881 (73%) youths (aged 18-26) who at age 13-16, 6-9 years earlier had lost a parent to cancer. RESULTS: In total 955 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 was/ were unaware of 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

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**Successful**
OBJECTIVE: Control over place of death is deemed important, not only in providing a “good death,” but also in offering person-centered palliative care. Despite the wish to die at home being endorsed by many, few achieve it. The present study aimed to explore the reasons why this wish is not fulfilled by examining the stories of ten individuals who lost a loved one to cancer.

METHOD: We adopted a narrative approach, with stories synthesized to create one metastory depicting plot similarities and differences.

RESULTS: Stories were divided into four chapters: (1) the cancer diagnosis, (2) the terminal stage and advancement of death, (3) death itself, and (4) reflections on the whole experience. Additionally, several reasons for cessation of home care were uncovered, including the need to consider children's welfare, exhaustion, and admission of the loved one by professionals due to a medical emergency. Some participants described adverse effects as a result of being unable to continue to support their loved one's wish to remain at home.

SIGNIFICANCE OF RESULTS: Reflections upon the accounts are provided with a discussion around potential clinical implications.

PMID: 24621995


Family stories of end-of-life cancer care when unable to fulfill a loved one’s wish to die at home.

Seal K1, Murray CD1, Seddon L1.

OBJECTIVE: Control over place of death is deemed important, not only in providing a “good death,” but also in offering person-centered palliative care. Despite the wish to die at home being endorsed by many, few achieve it. The present study aimed to explore the reasons why this wish is not fulfilled by examining the stories of ten individuals who lost a loved one to cancer.

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PMID: 24621995