

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

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



The Fourth

August 2015

Volume II - N° 4

1. J Crit Care. 2015 Jun 24. [Epub ahead of print]

Determining comorbidities and quality of life among pediatric survivors of extracorporeal life support.

Chandler HK¹, Teppa B², Johnson KA³, McCracken C⁴, Fortenberry JD², Paden MI².

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

2. Palliat Med. 2015 Jul 31. [Epub ahead of print]

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% (54 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 (62.2%) died

before completing it. Methicillin-resistant *Staphylococcus aureus* did not significantly impact survival but was significantly associated with having infection episodes and longer length of stay. **CONCLUSION:** This study identified risk factors for methicillin-resistant *Staphylococcus aureus* colonisation in palliative care patients. Methicillin-resistant *Staphylococcus aureus* was eradicated in 8.1% of patients. Hence, restricting methicillin-resistant *Staphylococcus aureus* screening to high-risk palliative care patients may be prudent.

PMID: 26231420

3. J Pediatr Oncol Nurs. 2015 Jul 27. [Epub ahead of print]

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

Montgomery K¹, Sawin KJ², Hendricks-Ferguson VL³.

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

4. Cancer. 2015 Jul 28. [Epub ahead of print]

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

Zhukovsky DS^{1,2}, Rozmus CL³, Robert RS², Bruera E¹, Wells RJ², Chisholm GB⁴, Allo JA¹, Cohen MZ⁵.

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

5. J Pediatr. 2015 Jul 23. [Epub ahead of print]

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

Morrison W¹, Womer J², Nathanson P³, Kersun L³, Hester DM⁴, Walsh C⁵, Feudtner C⁶.

OBJECTIVE: To conduct a national survey of pediatricians' access to and experience with clinical ethics consultation. **STUDY DESIGN:** We surveyed a randomly selected sample of 3687 physician members of 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 leading to consultation concerned end-of-life care and conflicts with patients/families or among the team. Intensive care unit physicians were more likely to have requested consultation. Mediation skills and ethics knowledge were the most highly valued consultant characteristics, and representing the official position of the hospital was the least-valued characteristic. **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: 26210945

6. Int J Palliat Nurs. 2015 Jul 2;21(7):331-7.

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

Tamannai M^{1,2}, Kaah J^{3,2}, Mbah G², Ndimba J², D'Souza C^{4,2}, Wharin P^{5,2}, Hesselting PB^{6,2}.

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.
PMID: 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 I^{1,2}, Carlander I^{3,4}, Holm M^{3,5}, James I⁶, Kenne Sarenmalm E^{3,7}, Lundh Hagelin C^{4,8,9}, Lind S^{3,5}, Sandgren A^{10,11}, Öhlén J

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.
PMID: 26190052

8. J Palliat Med. 2015 Jul 17. [Epub ahead of print]

The Language of End-of-Life Decision Making: A Simulation Study.

Lu A¹, Mohan D², Alexander SC³, Mescher C⁴, Barnato AE^{5,6}.

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 84 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.
PMID: 26186668

9. J Palliat Med. 2015 Jul 17. [Epub ahead of print]

Reliability and Validity of the Pediatric Palliative Care Questionnaire for Measuring Self-Efficacy, Knowledge, and Adequacy of Prior Medical Education among Pediatric Fellows.

Brock KE^{1,2}, Cohen H¹, Popat RA³, Halamek LP^{1,4,5}.

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 0.78 (item range 0.44-0.81) and 0.61 (item range 0.36-0.70), respectively. For the Adequacy of Medical Education Summary Score, ICC was 0.85 (item range 0.6-0.78) 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

10. Soins PEDIATR Pueric. 2015 Jul-Aug;36(285):40-2. [Article in French]

[\[The difficulties of staff retention in neonatal intensive care units\].](#)

Deparis C¹.

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 (KSPC) 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 KSPC, 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

13. World J Pediatr Congenit Heart Surg. 2015 Jul;6(3):431-7.

[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-specific volume, postoperative length of stay, and in-hospital mortality. **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 = 3,549), 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

14. Am J Hosp Palliat Care. 2015 Jul 12. [Epub ahead of print]

[Physician Communication in Pediatric End-of-Life Care: A Simulation Study.](#)

Bateman LB¹, Tofil NM², White ML², Dure LS², Clair JM³, 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: 26169522

15. J Pain Symptom Manage. 2015 Jul 9. [Epub ahead of print]

The Spirit of "Ubuntu" in Children's Palliative Care.

Marston JM¹.

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

16. J Pain Symptom Manage. 2015 Jul 8. [Epub ahead of print]

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

Hung YN¹, Liu TW², Tang ST³.

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: 26162507

17. Lancet. 2015 Jul 3.[Epub ahead of print]

Controversies in faith and health care.

Tomkins A¹, Duff J², Fitzgibbon A³, Karam A⁴, Mills EJ⁵, Munnings K⁶, Smith S⁷, Seshadri SR⁸, Steinberg A⁹, Vitillo R¹⁰, Yugi P¹¹.

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

18. Nurs Child Young People. 2015 Jul 9;27(6):7.

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

19. Crit Care Med. 2015 Jul 2. [Epub ahead of print]

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

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

Frontera JA¹, Curtis JR, Nelson JE, Campbell M, Gabriel M, Mosenthal AC, Mulkerin C, Puntillo KA, Ray DE, Bassett R, Boss RD, Lustbader DR, Brasel KJ, Weiss SP, Weissman DE; Improving Palliative Care in the ICU Project Advisory Board.

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 critical 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.

PMID: 26154929

20. PLoS One. 2015 Jul 8;10(7):e0132073. eCollection 2015.

The Brazilian Version of the Edmonton Symptom Assessment System (ESAS) Is a Feasible, Valid and Reliable Instrument for the Measurement of Symptoms in Advanced Cancer Patients.

Paiva CE¹, Manfredini LL², Paiva BS³, Hui D⁴, Bruera E⁴.

PURPOSES: To develop and validate a Portuguese version of the Edmonton Symptom Assessment System (ESAS) in Brazilian patients with advanced cancer. **METHODS:** The ESAS was translated and then back translated into Portuguese in accordance with international guidelines. The final version was approved by an Expert Committee after pilot testing on 24 advanced cancer patients. Subsequently, we evaluated the time to complete the assessment, the number of unanswered items, internal consistency, convergent validity, and known-group validity in a sample of 249 advanced cancer patients who completed the ESAS along with the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-C30), Hospital Anxiety and Depression Scale (HADS), and Epworth Sleepiness Scale (ESS). A total of 90 clinically stable patients were retested after 4 to 96 hours (test-retest reliability), and 80 patients answered the ESAS after 21 (± 7) days to measure scale responsiveness using an anchor-based method. **RESULTS:** The ESAS was completed in a mean time of only 2.2 minutes. The internal consistency was good (Cronbach's alpha = 0.861), and the removal of single items did not change the overall alpha value. For convergent validity, Spearman's correlation coefficients between the ESAS symptom scores and the corresponding EORTC QLQ-C30 and ESS symptom scores ranged between 0.520 (95% CI = 0.424-0.605) and 0.814 (95% CI = 0.760-0.856), indicating moderate to strong correlations. Test-retest reliability values were considered adequate, with intraclass correlation coefficients ranging from 0.758 (95% CI = 0.627-0.843) to 0.939 (95% CI = 0.905-0.960). **CONCLUSIONS:** ESAS is a feasible, valid and reliable multi-symptom assessment instrument for use in Brazil.

PMID: 26154288 **Free PMC Article**

21. Am J Hosp Palliat Care. 2015 Jul 6. [Epub ahead of print]

Predictors of Intention to Refer to Pediatric Palliative or Hospice Care.

Conner NE¹, Uddin N².

Abstract The purpose of this descriptive correlational study was to determine whether nurse characteristics, level of comfort with care of the dying, and spirituality predict intention to refer and timing of referral to pediatric palliative/hospice care. The Behavioral Model of Health Services Use served as the framework for this study. Data were collected from 105 pediatric nurses recruited from 7 patient units of one pediatric hospital. Regression analysis revealed several nurse factors (practice unit, years of experience, age, race/ethnicity) that predicted intent to refer and timing of referral to pediatric palliative/hospice care. The relationship between nurse characteristics and intent to refer was specific to certain medical conditions (HIV, extreme prematurity, brain injuries). Healthcare providers can use these findings to improve care for children with life-limiting illnesses. PMID: 26150677

22. J Paediatr Child Health. 2015 Jul 6. [Epub ahead of print]

Managing paediatric death in the emergency department.

O'Meara M^{1,2}, Trethewie S¹.

Author information:

¹Pain and Palliative Care, Sydney Children's Hospital, Sydney, New South Wales, Australia.

²Paediatric Emergency Department, Sydney Children's Hospital, Sydney, New South Wales, Australia.

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

23. Am J Hosp Palliat Care. 2015 Jul 2. [Epub ahead of print]

Provider Difficulties With Spiritual and Forgiveness Communication at the End of Life.

Wittenberg E¹, Ferrell B¹, Goldsmith J², Buller H³.

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.

PMID: 26139631

24. Palliat Support Care. 2015 Jul 1:1-10.

Two worlds: Adolescents' strategies for managing life with a parent in hospice.

Sheehan DK¹, Mayo MM², Christ GH³, Heim K⁴, Parish S¹, Shahrour G¹, Draucker CB⁵.

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. **METHOD:** 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 audiotaped, 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.

PMID: 26126748

25. Int J Palliat Nurs. 2015 Jun 2;21(6):294-301.

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 consistent 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.

PMID: 26126678

26. Int J Palliat Nurs. 2015 Jun 2;21(6):287-91.

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

27. Int J Palliat Nurs. 2015 Jun 2;21(6):281-6.

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

28. Int J Palliat Nurs. 2015 Jun 2;21(6):263.

Developing palliative care for children globally.

[No authors listed]

PMID: 26126672

29. Clin Pediatr (Phila). 2015 Jun 26. [Epub ahead of print]

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

Hinson AP¹, Rosoff PM².

PMID: 26116346

30. Am J Hosp Palliat Care. 2015 Jun 21. [Epub ahead of print]

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

Barnett MD¹, Maurer SH², Wood GJ³.

BACKGROUND: Prior research has shown that less than 40% of pediatric program directors believe their graduating residents competent in palliative care. While many curricula have been developed to address this need, few have demonstrated improved comfort and/or knowledge with palliative care principles. The purpose of this study was to test a pocket card educational intervention regarding resident knowledge and comfort with palliative care principles. **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: 26101349

31. J Pediatr Hematol Oncol. 2015 Jul;37(5):373-7.

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 ‡Department of Clinical Sciences §Harold C. Simmons Cancer Center, University of Texas Southwestern Medical Center ¶Children's Medical Center Dallas ¶Department of Pediatrics, Pauline Allen Gill 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 an inpatient hospice unit, 15 (18%) died in the oncology unit, 5 (6%) died in the intensive care unit, and 2 (2%) died in the emergency department. The median length of hospice services was 41 days, twice the national median of 21 days reported in adults. One quarter of children disenrolled from hospice care, ultimately dying in an acute care setting. Further studies are warranted to explore the hospice experience in children, and to address modifiable factors that may impact a family's choice to withdraw from hospice care.

PMID: 26090871

32. Eur J Cancer. 2015 Aug;51(12):1618-29.

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, Yamaguchi T⁸, Hirohashi T⁹, Tajima T¹⁰, Tatara R¹¹, Watanabe H¹², Otani H¹³, Takigawa C¹⁴, Matsuda Y, Nagaoka 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 (D-PaP score), Palliative Prognostic Index (PPI) and modified Prognosis in Palliative Care Study predictor model (PiPS model). **PATIENTS AND 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 ≥69% 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 groups 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

33. Am J Hosp Palliat Care. 2015 Jun 11. [Epub ahead of print]

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

Park NS¹, Jang Y², Ko JE³, 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 9;112(12):1845-56.

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

Weaver MS¹, Yao AJ², Renner LA³, Harif M⁴, Lam CG⁵.

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 Worldwide Palliative Care Alliance. **RESULTS:** Eighteen national plans and one Africa-wide plan (10 English, 9 French) were accessible, representing 9 low-, 4 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

35. Childs Nerv Syst. 2015 Aug;31(8):1227-37.

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

Chan MH¹, Boop F, Oaddoumi 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

36. J Pediatr Hematol Oncol. 2015 Jul;37(5):378-82.

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

Anghelescu DL¹, 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

37. Nursing. 2015 Jun;45(6):30-7; quiz 37-8.

Applying the evidence to help caregivers torn in two.

Beach PR¹, White BE.

Author information:

¹Patricia Ringos Beach is a patient navigator and clinical nurse specialist in oncology and palliative care at Mercy Cancer Center, Mercy St. Vincent Medical Center, in Toledo, Ohio. Beth E. White is a pediatric clinical nurse specialist and quality improvement consultant living in Sylvania, Ohio.

PMID: 25973758

38. CA Cancer J Clin. 2015 Jul;65(4):315-33.

Pediatric palliative care in the community.

Kaye EC¹, Rubenstein J², Levine D³, Baker JN⁴, Dabbs D⁵, Friebert SE⁶.

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 patients 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: 25955682

39. J Palliat Med. 2015 Jul;18(7):631-3. Epub 2015 Apr 30.

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

Flerlage JE¹, Baker JN¹.

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-

veloped OIC, 7 (78%) had laxation after methylaltrexone administration (0.15 mg/kg/dose). Of these 7 patients, 5 (71%) had laxation with the first dose, and 5 (71%) who responded had a continued response to repeated doses. The longest a patient regularly received methylaltrexone was 9 months. Of 5 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:** Methylaltrexone appears to be safe and efficacious in treating OIC in children and AYA with progressive incurable cancer. Methylaltrexone was tolerated in both the inpatient and outpatient settings and with repeated dosing.

PMCID: PMC4492591 [Available on 2016-07-01] PMID: 25927665

40. J Clin Oncol. 2015 Jun 10;33(17):1928-35.

Symptoms and Distress in Children With Advanced Cancer: Prospective Patient-Reported Outcomes From the PediQUEST Study.

Wolfe J¹, Orellana L², Ullrich C², Cook EF², Kang TI², Rosenberg A², Geyer R², Feudtner C², Dussel V².

PURPOSE: 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

41. Pediatr Blood Cancer. 2015 Jul;62(7):1237-44.

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

Anghelescu DL¹, Snaman JM², Trujillo L¹, Sykes AD³, Yuan Y³, Baker JN².

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

PMID: 25820345

42. J Pediatr. 2015 Jun;166(6):1536-40. Epub 2015 Mar 19.

Pediatric palliative care: current evidence and evidence gaps.

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

PMID: 25799195 [PubMed - indexed for MEDLINE]

43. Nurse Educ Today. 2015 Jun;35(6):765-70.

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

O'Shea ER¹, Campbell SH², Engler AJ³, Beauregard R⁴, Chamberlin EC⁶, Currie LM⁶.

BACKGROUND: Educational practices and national guidelines for best practices of providing palliative care to children and their families have been developed and are gaining support; however, the dissemination of those practices lags behind expectations. Incorporating education for pediatric palliative care into nursing pre-licensure programs will provide guidelines for best practices with opportunities to enact them prior to graduation. **OBJECTIVE:** To evaluate the effect of an integrated curriculum for palliative care on nursing students' knowledge. **DESIGN:** Matched pretest-posttest. **SETTING:** One private and one public university in the northeastern United States. **PARTICIPANTS:** Two groups of baccalaureate nursing students, one exposed to an integrated curriculum for palliative care and one without the same exposure. **METHODS:** Pre-testing of the students with a 50-item multiple choice instrument prior to curriculum integration and post-testing with the same instrument at the end of the term. **RESULTS:** This analysis demonstrated changes in knowledge scores among the experimental ($n=40$) and control ($n=19$) groups that were statistically significant by time (Wilks' Lambda=.90, $F(1, 57)=6.70$, $p=.012$) and study group (Wilks' Lambda=.83, $F(1, 57)=11.79$, $p=.001$). **CONCLUSIONS:** An integrated curriculum for pedi-

atric 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

44. Cancer. 2015 Jun 1;121(11):1891-7. Epub 2015 Feb 11.

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

Mack JW^{1,2}, Walling A^{3,4}, Dy S⁵, Antonio AL^{3,4,6}, Adams J^{3,4}, Keating NL^{7,8}, Tisnado D⁹.

BACKGROUND: Many patients with incurable cancer inaccurately believe that chemotherapy may cure them. Little is known about how such beliefs affect choices for care at the end of life. This study assessed whether patients with advanced cancer who believed that chemotherapy might offer a cure were more likely to receive chemotherapy in the last month of life and less likely to enroll in hospice care before death. **METHODS:** This study examined patients diagnosed with stage IV lung or colorectal cancer in the Cancer Care Outcomes Research and Surveillance consortium, a population- and health system-based prospective cohort study. Among 722 patients who completed a baseline survey and died during the study period, logistic regression was used to assess the association of understanding goals of chemotherapy with chemotherapy use in the last month of life and hospice enrollment before death; adjustments were made for patient and tumor characteristics.

RESULTS: One-third of the patients (33%) recognized that chemotherapy was "not at all" likely to cure their cancer. After adjustments, such patients were no less likely than other patients to receive end-of-life chemotherapy (odds ratio [OR], 1.32; 95% confidence interval [CI], 0.84-2.09), but they were more likely than other patients to enroll in hospice (OR, 1.97; 95% CI, 1.37-2.82). **CONCLUSIONS:** An understanding of the purpose of chemotherapy for incurable cancer is a critical aspect of informed consent. Still, advanced cancer patients who were well informed about chemotherapy's goals received late-life chemotherapy at rates similar to those for other patients. An understanding of the incurable nature of cancer, however, is associated with increased hospice enrollment before death, and this suggests important care outcomes beyond chemotherapy use. PMID: PMC4441582 [Available on 2016-06-01]

PMID: 25677655

45. J Pain Symptom Manage. 2015 Jun;49(6):1059-69.

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 TI⁶, 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 Study (NCT01838564). This multicenter PPC-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 participation. 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 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. Copyright © 2015 American Academy of Hospice and Palliative Medicine.

PMCID: PMC4530789 [Available on 2016-06-01] PMID: 25640275

46. J Pediatr Oncol Nurs. 2015 Jul;32(4):253-60. Epub 2015 Jan 2.

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

Popp JM¹, Conway M², 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: 25556107

47. J Pediatr Oncol Nurs. 2015 Jul;32(4):240-52. Epub 2015 Jan 2.

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 JE⁶.

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

48. Am J Perinatol. 2015 Jul;32(8):713-24. Epub 2014 Dec 17.

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

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

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: 25519196

49. Acta Oncol. 2015 Jun;54(6):944-50. Epub 2014 Dec 3.

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, Kreicbergs U, Uggla C, Valdimarsdóttir UA, Nyberg T, Steineck G, Fürst CJ.

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

50. Palliat Support Care. 2015 Jun;13(3):591-9. Epub 2014 Mar 13.

Opening end-of-life discussions: how to introduce Voicing My CHOICES™, an advance care planning guide for adolescents and young adults.

Zadeh S¹, Pao M², Wiener L¹.

OBJECTIVE: Each year, more than 11,000 adolescents and young adults (AYAs), aged 15-34, die from cancer and other life-threatening conditions. In order to facilitate the transition from curative to end-of-life (EoL) care, it is recommended that EoL discussions be routine, begin close to the time of diagnosis, and continue throughout the illness trajectory. However, due largely to discomfort with the topic of EoL and how to approach the conversation, healthcare providers have largely avoided these discussions. **METHOD:** We conducted a two-phase study through the National Cancer Institute with AYAs living with cancer or pediatric HIV to assess AYA interest in EoL planning and to determine in which aspects of EoL planning AYAs wanted to participate. These results provided insight regarding what EoL concepts were important to AYAs, as well as preferences in terms of content, design, format, and style. The findings from this research led to the development of an age-appropriate advance care planning guide, Voicing My CHOICES™. **RESULTS:** Voicing My CHOICES™: An Advanced Care Planning Guide for AYA became available in November 2012. This manuscript provides guidelines on how to introduce and utilize an advance care planning guide for AYAs and discusses potential barriers. **SIGNIFICANCE OF RESULTS:** Successful

use of Voicing My CHOICES™ will depend on the comfort and skills of the healthcare provider. The present paper is intended to introduce the guide to providers who may utilize it as a resource in their practice, including physicians, nurses, social workers, chaplains, psychiatrists, and psychologists. We suggest guidelines on how to: incorporate EoL planning into the practice setting, identify timepoints at which a patient's goals of care are discussed, and address how to empower the patient and incorporate the family in EoL planning. Recommendations for introducing Voicing My CHOICES™ and on how to work through each section alongside the patient are provided.

PMID: 24622210

51. Am J Hosp Palliat Care. 2015 Jun;32(4):464-9. Epub 2014 Mar 4.

Mortality trends for pediatric life-threatening conditions.

Chavoshi N¹, Miller T², Siden H³.

Abstract Internal data from the sole pediatric hospice in British Columbia were utilized to investigate mortality trends among children dying from life-threatening conditions. Characteristics of the sample (hospice) were compared to that of the population (province) for individuals aged 0 to 18 years from 2002 to 2011. The provincial death rate was 2.30 per 10 000. The sample did not significantly vary with respect to sex and geographic distribution when compared to the population. Infants contributed to a significantly larger proportion of pediatric deaths in the population. Children referred to the hospice were more likely to be diagnosed with cancer and diseases of the nervous system. Only 15% of all pediatric deaths due to disease in the province were cared for by the hospice, calling for the strengthening of interdisciplinary palliative care programs. © The Author(s) 2014.

PMID: 24595320

52. Palliat Support Care. 2015 Jun;13(3):473-83. Epub 2014 Mar 13.

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

Seal K¹, Murray CD², 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. **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

53. J Pain Symptom Manage. 2015 Jul;50(1):17-27. Epub 2015 Jan 31.

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 time point 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 freestanding 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 multivariable 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 SD 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, and 50.5% a child respondent) about hospice decedents (55.3% females, average age 78.6 years, 57.0% noncancer, and 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.

PMID: 25647420

**Fondazione 3BI
Biblioteca Biomedica Biellese**

Sito: www.3bi.info
tel.: 015-15153132

Dott.sa Roberta Maoret
Responsabile Documentalista biomedico
biblioteca@3bi.info

**Maruzza Lefebvre d'Ovidio
Foundation**

Site: www.maruzza.org
tel.: 06-3290609

info@maruzza.org