

# Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

*"Good information is the best medicine..."*

*Donald A.B. Lindberg*



## The Third

August 2014

N° 3

1. Palliat Support Care. 2014 Aug 4:1-6. [Epub ahead of print]

[What are the best terms in Portuguese to explain the concepts of "fatigue" and "depression" in cancer patients?](#)

[Paiva CE<sup>1</sup>, Manfredini LL<sup>2</sup>, Paiva BS<sup>3</sup>, Carnesecca EC<sup>3</sup>, Yennurajalingam S<sup>4</sup>, Bruera E<sup>4</sup>, Hui D<sup>4</sup>.](#)

**ABSTRACT OBJECTIVE:** Although "fatigue" and "depression" are well-accepted clinical terms in the English language, they are ill defined in many other languages, including Portuguese. We aimed to investigate the most appropriate words to describe cancer-related fatigue (CRF) and depression in Brazilian cancer patients. **METHOD:** The interviewers read to patients two clinical vignettes describing fatigued patients and two others describing depressed patients. Participants were asked to choose from among "fatigue," "tiredness," "weakness," "depression," and "sadness" the best and worst terms to explain the vignettes. In addition, they were administered an instrument containing numeric rating scales (NRSs), addressing common symptoms, including the aforementioned terms. Pearson correlation analysis and accuracy diagnostic tests were conducted using the Hospital Anxiety and Depression Scale (HADS) and the Functional Assessment of Cancer Treatment-Fatigue (FACT-F) as references. **Results:** Among the 80 participants, 40% reported that the best term to explain the concept of CRF was "tiredness," and 59% chose "sadness" as the best descriptor of depression. Regarding diagnostic accuracy, the areas under the curve (AUCs) for "fatigue," "weakness," and "tiredness" were 0.71, 0.81, and 0.76, respectively; the AUCs for "depression" and "sadness" ranged from 0.81 to 0.91 and 0.73 to 0.83, respectively. Negative correlations were found among FACT-F fatigue subscale scores and NRS scores for "fatigue" ( $r = -0.58$ ), "tiredness" ( $r = -0.67$ ), and "weakness" ( $r = -0.62$ ). Regarding depression, there were positive correlations between HADS-D scores and both NRS for "depression" ( $r = 0.61$ ) and "sadness" ( $r = 0.54$ ). **SIGNIFICANCE OF RESULTS:** "Tiredness" was considered the best descriptor of CRF. Taking into consideration the clinical correlation with depression scores, the term "depression" was accepted as the best term to explain the concept of depression.

PMID: 25088719

2. *Pediatr Rev.* 2014 Aug;35(8):318-26.

[Integration of palliative care into the care of children with serious illness.](#)

[Kang TI, Munson D, Hwang J, Feudtner C.](#)

**Practice Gap** The 2013 American Academy of Pediatrics (AAP) Policy Statement "Pediatric Palliative Care and Hospice Care: Commitments, Guidelines, and Recommendations" urges broader integration of palliative care into overall medical care plans not only for terminally ill infants and children but also for those with life-threatening or life-shortening illnesses. Despite supportive federal legislation, the AAP recommendations have not been implemented consistently because of inadequate training, lack of funding, entrenched professional attitudes, and lack of an evidence base for assessments and interventions. To overcome these barriers, pediatric health care clinicians should educate themselves, their patients, their practices, and their health care systems on the benefits of earlier palliative care intervention.

**Introduction** During the past decade the field of pediatric palliative care (PPC) has transformed. Palliative care services, once thought to be suitable only for patients in the last stages of life or reserved for patients engaging hospice services, are now being used much more broadly. No longer restricted to just the provision of end-of-life care, palliative care for children is now best understood as encompassing a combination of medical, psychosocial, and spiritual care that enables children with serious, life-threatening illnesses to maximize quality of life while making medical decisions based on the goals and values of the patient and family. Integrating palliative care into the overall plan of medical care for children with serious ill-

ness is a key therapeutic goal. In 2013, the American Academy of Pediatrics (AAP) published a policy statement entitled "Pediatric Palliative Care and Hospice Care: Commitments, Guidelines, and Recommendations" that aimed to promote the welfare of infants and children living with life-threatening or inevitably life-shortening conditions and their ...

PMID: 25086163

3. *Pediatr Clin North Am.* 2014 Aug;61(4):xvii-xviii. doi: 10.1016/j.pcl.2014.05.006. Epub 2014 Jun 3.

[Hospital medicine and pediatric palliative care.](#)

Stanton BF.

ABSTRACT Most pediatricians practice in the outpatient setting. The familiarity with hospital-based practices most pediatricians acquire through their residencies rapidly ebbs as policies and activities change. Therefore, this issue of *Pediatric Clinics of North America*, focusing on two emerging pediatric specialties with strong hospital foci—pediatric hospital medicine and pediatric palliative care (PPC)—should be of great interest and importance to all practicing pediatricians. "Born" in 2003, Pediatric Hospital Medicine (PHM) is the cornerstone of inpatient management in many pediatric wards and hospitals—and has a presence in most. In this issue, Mary Ottolini and colleagues clearly describe the range of clinical roles and activities conducted and overseen by today's PHM specialists, including communication and coordinating with primary care physicians and other specialists, facilitating shared decision-making with families, and carrying out hospital-based procedures, such as pediatric sedation. PHM specialists provide care to all hospitalized children, including children with chronic life-threatening illnesses. In their care of these children, they form close partnerships with PPC specialists. The discipline of PPC medicine has emerged with the growth of a bewildering array of clinical options and technologies that can extend life for children with life-threatening diseases. PPC specialists help the PHM specialists and primary care pediatric providers, and the families of children with life-threatening illnesses (as well as the children themselves), navigate through these options to assure that the child's needs and the families' desires are being met. In this issue, Ullrich and colleagues artfully describe their approach to optimizing the care and well-being of these children and their families, while prolonging life and providing end-of-life support. The PPC provider achieves these goals through continual learning of new advances, communication with and education of the family, child and hospital-based and community-based providers, and frequent reassessment of child and family. PPC specialists function inside and outside of the hospital setting, although often the family and primary care pediatric provider meet the PPC provider in the hospital setting. PHM and PPC specialists are critical members of the family of pediatric care providers. These articles provide a clear description of the great value they bring to our profession and to the children under our care.

PMID: 25084729

4. *Pediatr Clin North Am.* 2014 Aug;61(4):835-854. doi: 10.1016/j.pcl.2014.04.012.

[End-of-Life Care for Hospitalized Children.](#)

Johnson LM<sup>1</sup>, Snaman JM<sup>2</sup>, Cupit MC<sup>2</sup>, Baker JN<sup>2</sup>.

ABSTRACT High-quality palliative care is the standard for children with life-threatening illness, especially when a cure is not possible. This review outlines a model for clinical practice that integrates clinical, psychosocial, and ethical concerns at the end of life (EOL) into a standard operating procedure specifically focused on inpatient deaths. Palliative care for children at EOL in the hospital setting should encompass the personal, cultural, and spiritual needs of the child and family members and aim to minimize suffering and increase support for all who are involved, including hospital staff.

PMID: 25084727

5. *Pediatr Clin North Am.* 2014 Aug;61(4):823-834. doi: 10.1016/j.pcl.2014.04.009. Epub 2014 Jun 3.

[Interdisciplinary Care: Using Your Team.](#)

Ogelby M<sup>1</sup>, Goldstein RD<sup>2</sup>.

ABSTRACT The interdisciplinary approach is a cornerstone of a well-functioning pediatric palliative care team. These teams are most often available as an inpatient consultation service, are composed of professionals representing multiple disciplines, and are used during the illness course of a child with life-threatening and chronic complex conditions, especially during challenging health care decision-making near end of life. This article reviews the current structure of the palliative care team, explores opportunities for inclusion of other vital team members, and proactively identifies the challenges that may occur when involving more providers in a child's and family's care.

PMID: 25084726

6. *Pediatr Clin North Am.* 2014 Aug;61(4):797-821. doi: 10.1016/j.pcl.2014.04.011. Epub 2014 May 28.

[Pediatric Palliative Care for Children with Complex Chronic Medical Conditions.](#)

Schwantes S<sup>1</sup>, Wells O'Brien H<sup>2</sup>.

ABSTRACT Children with complex chronic medical conditions are at risk for significant distress during multiple points in their life. Pediatric palliative care can meaningfully assist in providing support to the child and family throughout their complex care, managing distressing symptoms, anticipating future decision points, and helping the child and family to thrive in their local community.

PMID: 25084725 [PubMed - as supplied by publisher]

7. *Pediatr Clin North Am.* 2014 Aug;61(4):785-796.

[Adolescents and Young Adults with Life-Threatening Illness: Special Considerations, Transitions in Care, and the Role of Pediatric Palliative Care.](#)

Linebarger JS<sup>1</sup>, Ajayi TA<sup>2</sup>, Jones BL<sup>3</sup>.

ABSTRACT This article will cover the special considerations, challenges, and opportunities presented by caring for adoles-

cents and young adults with life-threatening illnesses when the possibility of transition to an adult care setting arises.  
PMID: 25084724

8. *Pediatr Clin North Am.* 2014 Aug;61(4):761-783. doi: 10.1016/j.pcl.2014.04.008. Epub 2014 Jun 3.

[Transitions to and from the Acute Inpatient Care Setting for Children with Life-Threatening Illness.](#)

[Nageswaran S](#)<sup>1</sup>, [Radulovic A](#)<sup>2</sup>, [Anania A](#)<sup>3</sup>.

**ABSTRACT** Children with life-threatening illnesses (LTIs) are hospitalized more often and spend more days in the hospital than children without LTIs. Hospitalizations may be associated with changes in health status of children with LTIs and thus alter their care needs significantly. Transitional care is particularly relevant for this population. Pediatric palliative care clinicians and teams are well-positioned to improve transitional care of children with LTIs by facilitating communication between clinicians and educating clinicians about issues related to children with LTIs.

PMID: 25084723

9. *Pediatr Clin North Am.* 2014 Aug;61(4):749-760. doi: 10.1016/j.pcl.2014.04.010. Epub 2014 Jun 3.

[Improving Quality of life in Hospitalized Children.](#)

[Rapoport A](#)<sup>1</sup>, [Weingarten K](#)<sup>2</sup>.

**ABSTRACT** There are many ways to add to children's quality of life within the hospital environment. Inpatient settings offer both opportunities and challenges with respect to providing care to children with life-threatening illnesses. The barriers to pediatric palliative care (PPC) on hospital wards, as with those in other settings, frequently stem from misconceptions. However, some barriers are intensified by characteristics of acute inpatient centers. Yet some characteristics of the inpatient setting, including the availability of human resources and unique interventions, offer creative ways to ease distress and improve quality of life for children and their families.

PMID: 25084722

10. *Pediatr Clin North Am.* 2014 Aug;61(4):735-747. doi: 10.1016/j.pcl.2014.04.007. Epub 2014 Jun 4.

[Pediatric Palliative Care Consultation.](#)

[Moore D](#)<sup>1</sup>, [Sheetz J](#)<sup>2</sup>.

**ABSTRACT** Pediatric palliative care (PPC) is a relatively new and quickly growing pediatric subspecialty. It is generally provided using a consultative model, and is available in most specialized pediatric hospitals. This article discusses PPC consultation with specific focus on the added value of PPC, elements of a PPC consultation, and challenges to and opportunities for PPC consultation. Ongoing research, current publication, expert opinion, and institutional experience were compiled for this article.

PMID: 25084721

11. *Pediatr Clin North Am.* 2014 Aug;61(4):719-733. doi: 10.1016/j.pcl.2014.05.002.

[Pediatric Hospital Care for Children with Life-threatening Illness and the Role of Palliative Care.](#)

[Bogetz JF](#)<sup>1</sup>, [Ullrich CK](#)<sup>2</sup>, [Berry JC](#)<sup>3</sup>.

**ABSTRACT** Under increasing pressure to contain costs, hospitals are challenged to provide high-quality care to an increasingly complex group of children with life-threatening illness (LTI) that often worsen over time. Pediatric palliative care is an essential component of optimal hospital care delivery for these children and their families. This article describes (1) the current landscape of pediatric hospital care for children with LTI, (2) the connection between palliative care and hospital care for such children, and (3) the relationship between health care reform and palliative care for children with LTI.

PMID: 25084720

12. *Pediatr Crit Care Med.* 2014 Jul 30. [Epub ahead of print]

[Integrating Palliative Care Into the PICU: A Report From the Improving Palliative Care in the ICU Advisory Board.](#)

[Boss R](#)<sup>1</sup>, [Nelson J](#), [Weissman D](#), [Campbell M](#), [Curtis R](#), [Frontera J](#), [Gabriel M](#), [Lustbader D](#), [Mosenthal A](#), [Mulkerin C](#), [Puntillo K](#), [Ray D](#), [Bassett R](#), [Brasel K](#), [Hays R](#).

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

PMID: 25080152

13. N C Med J. 2014 Jul-Aug;75(4):276-7.

[Pediatric oncology and palliative care.](#)

[Barfield R.](#)

**ABSTRACT:** Overall, we now cure 70% of the children who are diagnosed with cancer, and in the 30% of cases that are still not curable, we can almost always add time to the child's life. As our ability to cure cancer has improved, we are now paying increased attention to the goal of avoiding or alleviating the suffering associated with cancer and its therapy. Risk stratification aims to avoid undertreatment of children with high-risk cancers and to avoid overtreatment (with all of the associated side effects of therapy) of children with lower-risk cancers. This goal has become an important part of designing treatment protocols over the past 15 years. Whether or not a child will be cured, we know that all children with cancer suffer, as do their families. Pediatric oncology is committed to curing cancer, but palliative care is committed to improving a child's quality of life, irrespective of the potential for cure. Oncology and palliative care are thus twin endeavors, both of which seek what is best for a child and his or her family [1]. Within the 2 broad categories of curing disease and alleviating suffering, there are many specific goals unique to each patient. Palliative care seeks to relieve the physical, emotional, social, and spiritual distress produced by complex, chronic, or life-limiting conditions; to assist in making difficult decisions and setting goals; and to enhance children's quality of life [2]. More than a decade has passed since the American Academy of Pediatrics [3] and the Institute of Medicine of the National Academies [4] called for the integration of palliative care into ongoing medical management of life-threatening illnesses (such as cancer) in children, from diagnosis to the end of life. Since these calls were issued, models of integrated pediatric palliative care have been developed in which curative therapy and palliative care coexist. For children whose lives are going to be short, adding a few months of good-quality life can be transformative. Adding 6 months to the life of a child who would otherwise have died at 3.5 years of age is extending his or her life by nearly 15%. To help maximize both quantity and quality of life for children with terminal illnesses, the Patient Protection and Affordable Care Act of 2010 contains the Concurrent Care for Children Requirement [5]. This provision states that palliative and hospice care services must be reimbursed if they are administered to a child with a life-limiting illness who is eligible for Medicaid or the Children's Health Insurance Program, even if the child is still receiving disease-modifying treatments. In this context, concurrent care is defined as the introduction of palliative care principles at the time of a life-threatening diagnosis, with increasing support over time as the disease progresses; this approach includes a multidimensional assessment to identify, prevent, and alleviate suffering [6]. At the end of life, the model allows for hospice services without requiring the patient to stop all traditional medicine, which may include antibiotics, transfusions, and palliative chemotherapy. Such models have been supported by studies of adult patients that have demonstrated that palliative care prolongs life [7], is effective in improving quality of life and mood [8], and decreases caregiver burden [9, 10]. In 2012 the American Society of Clinical Oncology released a provisional clinical opinion, based on available evidence from clinical trials, advocating for the early integration of palliative care into standard cancer treatment for malignancies with high symptom burden [11]. However, many challenges exist in the implementation of these integrated models, including the pressure to reduce overall health care costs, lack of necessary tools and skills on the part of health care providers, and the mistaken tendency to equate palliative care with end-of-life care. The Concurrent Care for Children Requirement has been challenging to implement in many states, including North Carolina. Despite the fact that palliative care is now widely recognized as a critical part of excellent care for children with life-limiting diseases such as cancer, patients continue to receive this care very late in their illness trajectory [12, 13]. In 1 study, the median time between palliative care consultation and death was only 8 days [14]. However, as evidence grows that introducing palliative care early in the course of therapy benefits children with cancer, and as the medical culture becomes more aware of the evidence demonstrating the value of such an approach, pediatric oncology and palliative care will continue to become more integrated. This will benefit children, their families, and the staff members who care for them.

PMID: 25046095

14. Child Care Health Dev. 2014 Jul 16. [Epub ahead of print]

[Limitations in the approach health caregivers can take in end-of-life care decisions.](#)

[Bülbül S<sup>1</sup>, Sürücü M, Karavaizoğlu C, Eke M.](#)

**BACKGROUND:** In the terminal stages of neuro-metabolic diseases, parents can begin to experience a sense of loss even before the child dies, and might accept death prematurely. **CASES:** A 2.5-year-old female patient with Sandoff Disease (diagnosed at 9 months of age), and a 17-month-old male Krabbe patient (diagnosed at 5 months of age) were admitted to the hospital with hypernatraemic dehydration and bronchopneumonia, respectively, within 10 days of each other. Both patients developed respiratory arrest short after admission and were supported with mechanical ventilation. Both families gave written consent to end life support, but their wishes could not be accepted according to Turkish law. **CONCLUSIONS:** Specialists are expected to communicate well with families and give continuous care while respecting the opinions of patients' families on the timing of the withdrawal of life support. However, ethical and legal regulations on the conduct of health care professionals in these circumstances are unclear in Turkey and should be developed rapidly.

PMID: 25039488

15. J Pediatr Nurs. 2014 Jun 26. pii: S0882-5963(14)00192-4. doi: 10.1016/j.pedn.2014.06.009. [Epub ahead of print]

[When a Child Dies: Parents' Experiences of Palliative Care-An Integrative Literature Review.](#)

[Melin-Johansson C<sup>1</sup>, Axelsson I<sup>2</sup>, Jonsson Grundberg M<sup>3</sup>, Hallqvist F<sup>3</sup>.](#)

**ABSTRACT** The aim of this integrative review was to increase knowledge about parents' experiences of palliative care when their child is dying or has died due to illness using Whitemore and Knafelz (2005) analysis process. Computerized databases were used to search the literature. Nine papers met the inclusion criteria. The analysis resulted in five categories: genuine communication, sincere relationships, respect as an expert, and alleviation of suffering and need of support, including 15 subcategories. Health professionals need education to provide high-quality pediatric palliative care. They especially need

training concerning existential issues, and further studies need to be performed.  
 PMID: 25038375

16. *Comput Inform Nurs.* 2014 Jul;32(7):299-302.  
[Pediatric hospice and palliative care: designing a mobile app for clinical practice.](#)  
 Lindley LC<sup>1</sup>, Zhou W, Mack JW, Li X.

**ABSTRACT** Most children who die of health-related conditions spend their brief lives encountering a wide variety of clinicians, from primary physicians and nurse practitioners to oncologists and neurologists. Many of these providers act as gate keepers to hospice care through the referral process. One of the barriers to pediatric hospice and palliative care use is that pediatric clinicians generally lack an understanding of and experience with this service, which influences their decision to refer children to hospice. In fact, most physicians have limited or no training in core end-of-life competencies, less than 50% of residents are taught how to hold conversations about pediatric end of life, and more than 25% of pediatricians do not even know whether local hospice services even exist. Although there have been significant strides to increase formal end-of-life educational opportunities for clinicians, improved training in communications between clinicians and families about end of life, and increased understanding of clinicians hospice referral practices, very few children access hospice and palliative care at end of life. Perhaps it is time to try something completely different. What if we provided clinicians with a technological tool to assist the misunderstanding and experiencing pediatric hospice care, all in the palm of their hands? Along with formal education and training, information on pediatric hospice care could be accessible 24/7 when clinicians need it, whether in the examination room with children and their families, in the office while reviewing tests, or in the clinical conference with the care team. Although the evidence is in its infancy, the cutting edge technology associated with smart phones and tablets (eg, iPads) may have the potential to significantly influence healthcare. By providing a powerful platform, mobile applications (apps) may increase awareness of pediatric hospice care, assist clinicians' discussions with children and families about it, and create a seamless referral to hospice that would ultimately improve access to pediatric hospice and palliative care. **MOBILE APP DESIGN** Our design team, which consisted of a nurse, information systems engineer, physician, and Big Data analyst, is designing a Key Points: Assemble an interdisciplinary team to design the mobile app to meet the needs of clinical users. Plan for marketing, "keeping it fresh," and large data volumes when implementing a mobile app.  
 PMID: 25032671

17. *Am J Hosp Palliat Care.* 2014 Jul 15. [Epub ahead of print]  
[Ketamine PCA for Treatment of End-of-Life Neuropathic Pain in Pediatrics.](#)  
 Taylor M<sup>1</sup>, Jakacki R<sup>2</sup>, May C<sup>3</sup>, Howrie D<sup>4</sup>, Maurer S<sup>5</sup>.

**ABSTRACT** Control of neuropathic pain (NP) for children at end of life is challenging. Ketamine improves control of NP, but its use in children is not well described. We describe a retrospective case review of 14 children with terminal prognoses treated with ketamine patient-controlled analgesia (PCA) for management of opioid-refractory NP at the end of life. Median ketamine dose was 0.06 mg/kg/h (range 0.014-0.308 mg/kg/h) with a 0.05 mg/kg (range 0.03-0.5mg/kg) demand dose available every 15 minutes (range 10-60 minutes). All patients noted subjective pain relief with ketamine, and 79% had no adverse effects. Benzodiazepines limited neuropsychiatric side effects. Ketamine treatment arrested dose escalation of opioids in 64% of patients, and 79% were discharged to home hospice. Ketamine PCA is an effective, well-tolerated therapy for opioid-refractory NP in pediatric end-of-life care.  
 PMID: 25028743

18. *Adv Neonatal Care.* 2014 Jul 11. [Epub ahead of print]  
[The Relationship Between Providing Neonatal Palliative Care and Nurses' Moral Distress: An Integrative Review.](#)  
 Cavinder C.

**ABSTRACT** Moral distress has been identified in multiple clinical settings especially in critical care areas. The neonatal intensive care unit (NICU) has frequent situations in which moral distress may occur including providing palliative care. The purpose of this integrative review was to determine the relationship between the provision of palliative care in a NICU and nurses' moral distress. The evidence reviewed supports that moral distress does occur with the provision of neonatal palliative care. An interdisciplinary care team, an established protocol, and educational interventions may decrease moral distress in nurses providing end-of-life care to infants in the NICU.  
 PMID: 25022749

19. *Am J Hosp Palliat Care.* 2014 Jul 9. [Epub ahead of print]  
[Why Palliative Care for Children is Preferable to Euthanasia.](#)  
 Carter BS.

**ABSTRACT** Recent laws in Europe now allow for pediatric euthanasia. The author reviews some rationale for caution, and addresses why ensuring the availability of pediatric palliative care is an important step before allowing pediatric euthanasia.  
 PMID: 25007796

20. *J Palliat Med.* 2014 Jul 9. [Epub ahead of print]  
[Components and Principles of a Pediatric Palliative Care Consultation: Results of a Delphi Study.](#)  
 Bradford N<sup>1</sup>, Herbert A, Mott C, Armfield N, Young J, Smith A.

**ABSTRACT BACKGROUND:** Pediatric palliative care is a distinct specialty that requires input from pediatric and palliative medicine specialists to provide comprehensive high-quality care. Consultations undertaken early in a child's illness trajectory, when end-of-life care is not anticipated to be required, enables relationships to be established and may enhance the

quality of care provided. **OBJECTIVE:** To define optimal components of an early pediatric palliative care consultation. **DESIGN:** Consensus of an expert group was sought in a five-round Delphi study. **SETTING/PARTICIPANTS:** Based on the literature and existing standards for specialist palliative care, components of an early pediatric palliative care consultation were derived. In rounds 2 and 3, experts from around Australia participated in online surveys to review and prioritize the components and principles. Consensus of survey items was determined by defined criteria. A flowchart was developed in the fourth round and the final round involved review and refinement of the flowchart by the expert group. **RESULTS:** Nineteen experts participated and prioritized 34 components and principles in the first survey round, and 36 statements in the second survey round. There was consensus from all participants that the first priority of a consultation was to establish rapport with the family, and examples of how to achieve this were defined. Other components of a consultation included: establishing the family's understanding of palliative care; symptom management; an emergency plan; discussion of choices for location of care, and a management plan. Components considered suitable to defer to later consultations, or appropriate to address if initiated by family members, included: spiritual or religious issues; discussion around resuscitation and life-sustaining therapies; end-of-life care; and the dying process. **CONCLUSION:** We have provided the first published framework from expert consensus that defines the components and principles of an early pediatric palliative care consultation. This framework will provide guidance for clinical practice as well as being useful for education and research in this area.

PMID: 25006759

21. Nurs Child Young People. 2014 Jul 8;26(6):35-9. doi: 10.7748/ncyp.26.6.35.e451.

[Family-focused children's end of life care in hospital and at home.](#)

[Parker H<sup>1</sup>, Farrell M, Ryder A, Fernley K, Cox C, Farasat H, Hewitt-Taylor J.](#)

**ABSTRACT** An increasing number of children and young people require end of life care, and providing them and their families with optimum support at this time is crucial. This article describes how nurses working with children and families in home, hospital and community settings used the principles of practice development methodology to develop end of life care provision and follow-up bereavement support. It outlines the 'ways of knowing' that informed developments and how parents' priorities were kept central to the process. Finally, it discusses how the approach taken to practice development reflected the value of compassion in nursing practice.

PMID: 25004049

22. Nurs Child Young People. 2014 Jul 8;26(6):27-34. doi: 10.7748/ncyp.26.6.27.e445.

[Innovative approach to providing 24/7 palliative care for children.](#)

[Maynard L<sup>1</sup>, Lynn D.](#)

**ABSTRACT** This study outlines an innovative, English hospice-based service that provides 24/7 care for children with life-limiting conditions and their families. Operational objectives were: symptom management; open access to families and professionals; choice in place of care and of death; and collaboration to develop shared pathways and management plans. Service standards were audited through questionnaires completed by professionals and families. Findings demonstrated that the nursing team filled a critical gap and met its pre-set standards. Keys to success were: having the right level and mix of specialist and advanced skills; funded on-call arrangements; anticipatory planning; symptom management plans; and clinical supervision. Further recommendations were to develop a multi-agency workforce strategy, and to increase capacity in the children's sector to undertake academic research measuring the impacts of interventions.

PMID: 25004048

23. Pediatrics. 2014 Aug;134(2):e436-43. doi: 10.1542/peds.2013-3124. Epub 2014 Jul 7.

[Pediatric advance directives: parents' knowledge, experience, and preferences.](#)

[Lieberman DB<sup>1</sup>, Pham PK<sup>2</sup>, Nager AI<sup>3</sup>.](#)

**OBJECTIVES:** To explore parents' and caregivers' experience, knowledge, and preferences regarding advance directives (ADs) for children who have chronic illness. **METHODS:** We conducted a prospective, cross-sectional survey of parents and caregivers of children who have chronic illness. During ambulatory medical visits, participants were asked about previous AD experience and knowledge, future preferences regarding AD discussions, their child's past and current health status, and family demographics. **RESULTS:** Among 307 participants surveyed, previous AD experience was low, with 117 (38.1%) having heard of an AD, 54 (17.6%) having discussed one, and 77 (25.1%) having known someone who had an AD. Furthermore, 27 (8.8%) participants had an AD or living will of their own, and 8 (2.6%) reported that their chronically ill child had an AD. Previous AD knowledge was significantly more likely among parents and caregivers who had a college degree than those who did not have a high school diploma, yet significantly less likely among primarily Spanish-speaking parents and caregivers than those primarily English-speaking. Interest in creating an AD for the child was reported by 151 (49.2%) participants, and was significantly more likely among families who had more frequent emergency department visits over the previous year. **CONCLUSIONS:** The limited AD experience and knowledge of parents and caregivers of children who have chronic illness and their interest in creating an AD suggest an unmet need among families of children who have chronic illness, and an opportunity to enhance communication between families and medical teams regarding ADs and end-of-life care.

PMID: 25002672

24. Arch Pediatr. 2014 Aug;21(8):834-44. doi: 10.1016/j.arcped.2014.05.012. Epub 2014 Jun 30.

[\[Pediatric palliative care: A national survey of French pediatric residents' knowledge, education, and clinical experience\].](#)  
[Article in French]

[Lefeuvre C<sup>1</sup>, Viillard ML<sup>2</sup>, Schell M<sup>3</sup>.](#)

**BACKGROUND:** The need for educational training of healthcare professionals in palliative care is an important issue. Training and practice of pediatric residents in the field of pediatric palliative care (PPC) has never been assessed, although the organization of the medical curriculum in France is currently being revised. **MATERIALS AND METHODS:** This study presents

a national survey of pediatric residents, using a computerized anonymous questionnaire. Four different areas were studied: epidemiological data, theoretical and practical knowledge, education, and clinical experience in PPC. RESULTS: The response rate was 39% (n=365/927). Whatever their age or regional location, 25% of residents did not know any details of the French law concerning patients' rights and the end of life. Experience with PPC starts very early since 77% of the first-year pediatric residents experienced at least one child in a palliative care and/or end-of-life situation. During their entire residency, 87% of the residents had experience with PPC and nearly all (96%) end-of-life care. Furthermore, 76% had participated in announcing palliative care (cancer, ICU, etc.) or a serious illness, and 45% had met and discussed with bereaved parents. Furthermore, while 97% of the pediatric residents received training in adult palliative care, mainly before their residency, only 60% received specific PPC training. DISCUSSION AND CONCLUSION: Ninety-six percent of all French pediatric residents encountered a PPC situation during their residency. That 77% of them had experienced PPC during their first year of residency shows the importance of early training in PPC for pediatric residents. Furthermore, this study points out that there is a significant lack in PPC training since 40% of all residents in the study received no specific PPC training. Progress in education remains insufficient in the dissemination of knowledge on the legal framework and concepts of palliative medicine: while the medical curriculum is being revised, we suggest that training in medical ethics and PPC should be introduced very early and systematically.

PMID: 24993148

25. J Perinat Neonatal Nurs. 2014 Jul 2. [Epub ahead of print]

[A Descriptive Study Evaluating Perinatal Healthcare Providers' Perspectives of Palliative Programming in 3 Canadian Institutions.](#)

[Steneke S](#)<sup>1</sup>, [Ens CD](#), [Harlos M](#), [Chochinov HM](#), [Mytopher K](#).

ABSTRACT: A paucity of research has evaluated the perspectives of the broader healthcare team regarding perinatal palliative care. This study examines the views of healthcare providers involved in perinatal palliative care in 3 tertiary care hospitals in Canada. Developing an understanding of their perspectives of care provision, as well as the interactions that took place with families and other teams while providing perinatal palliative care, was of interest. Twenty-nine healthcare providers were involved in 4 focus groups and 5 individual interviews. Data were transcribed and content analysis was undertaken. The overarching theme of communication materialized from the data. Within this theme were 3 subthemes, each highlighting an aspect of communication that impacted care provision: connecting through proximity, protected time and dedicated space, and flexibility and formality. The study also describes a model of integrated perinatal palliative care program development and explains where each of the 3 sites falls along this continuum. The development of formal programs in these facilities is varied and recommendations are included to enhance communication and assist in providing improved and integrated programming.

PMID: 24992245

26. Crit Care Med. 2014 Jun 27. [Epub ahead of print]

[Epidemiology of Death in the PICU at Five U.S. Teaching Hospitals.](#)

[Burns JP](#)<sup>1</sup>, [Sellers DE](#), [Meyer EC](#), [Lewis-Newby M](#), [Truog RD](#).

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

PMID: 24979486

27. Dev Med Child Neurol. 2014 Jun 25. doi: 10.1111/dmcn.12530. [Epub ahead of print]

[Sleep disturbances in children, adolescents, and young adults with severe psychomotor impairment: impact on parental quality of life and sleep.](#)

[Tietze AL](#)<sup>1</sup>, [Zernikow B](#), [Michel E](#), [Blankenburg M](#).

AIM: In childhood, severe psychomotor impairment (SPMI) is associated with profound sleep disturbances. With the help of newly developed and validated measures, we systematically assessed how much a child's sleep disturbance affects parental sleep and quality of life (QoL) in this specific patient group. METHOD: Parents and their children with SPMI were enrolled from three outpatient centers and one in-patient center in Germany. We administered a set of questionnaires to the parents that addressed their child's sleep quality, the sleep disturbance-related parental burden, and the impact on both parental

sleep and QoL. Additional questionnaires were used to gather data describing our sample group to allow for comparison with published norms. RESULTS: Parents of 214 children, adolescents, and young adults with SPMI (114 males, 100 females; mean age 10y 5mo, SD 5y 6mo, range 0.1-25y) responded to the questionnaire set (response rate of 66%). We found severe impairment of parental health status and QoL. More than 50% of the parents suffered from a sleep disorder (e.g. prolonged sleep latency, shortened sleep duration). Sleep disturbances in children, adolescents, and young adults correlated strongly with parental sleep disturbances, parental impairment of physical and mental functioning, parental social functioning, and parental working ability. INTERPRETATION: Sleep-related difficulties have a significant sociomedical impact on the parents of children, adolescents, and young adults with complex neurological diseases. Typically, parents are severely affected in various aspects of daily living. There is a need for novel diagnostic and therapeutic approaches that match the complex sociomedical needs of these patients and their families.

PMID: 24962083

28. J Palliat Med. 2014 Jun 23. [Epub ahead of print]

[Advance Care Planning: Challenges and Approaches for Pediatricians.](#)

Heckford E<sup>1</sup>, Beringer AJ.

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

PMID: 24955940

29. Lancet Oncol. 2014 Jul;15(8):841-51. doi: 10.1016/S1470-2045(14)70265-7. Epub 2014 Jun 19.

[Risk of late effects of treatment in children newly diagnosed with standard-risk acute lymphoblastic leukaemia: a report from the Childhood Cancer Survivor Study cohort.](#)

Essig S<sup>1</sup>, Li Q<sup>2</sup>, Chen Y<sup>2</sup>, Hitzler J<sup>3</sup>, Leisenring W<sup>4</sup>, Greenberg M<sup>3</sup>, Sklar C<sup>5</sup>, Hudson MM<sup>6</sup>, Armstrong GT<sup>7</sup>, Krull KR<sup>8</sup>, Neglia JP<sup>9</sup>, Oeffinger KC<sup>5</sup>, Robison LL<sup>7</sup>, Kuehni CE<sup>1</sup>, Yasui Y<sup>2</sup>, Nathan PC<sup>10</sup>.

BACKGROUND: Treatment of patients with paediatric acute lymphoblastic leukaemia has evolved such that the risk of late effects in survivors treated in accordance with contemporary protocols could be different from that noted in those treated decades ago. We aimed to estimate the risk of late effects in children with standard-risk acute lymphoblastic leukaemia treated with contemporary protocols. METHODS: We used data from similarly treated members of the Childhood Cancer Survivor Study cohort. The Childhood Cancer Survivor Study is a multicentre, North American study of 5-year survivors of childhood cancer diagnosed between 1970 and 1986. We included cohort members if they were aged 1.0-9.9 years at the time of diagnosis of acute lymphoblastic leukaemia and had received treatment consistent with contemporary standard-risk protocols for acute lymphoblastic leukaemia. We calculated mortality rates and standardised mortality ratios, stratified by sex and survival time, after diagnosis of acute lymphoblastic leukaemia. We calculated standardised incidence ratios and absolute excess risk for subsequent neoplasms with age-specific, sex-specific, and calendar-year-specific rates from the Surveillance, Epidemiology and End Results Program. Outcomes were compared with a sibling cohort and the general US population. FINDINGS: We included 556 (13%) of 4329 cohort members treated for acute lymphoblastic leukaemia. Median follow-up of the survivors from 5 years after diagnosis was 18.4 years (range 0.0-33.0). 28 (5%) of 556 participants had died (standardised mortality ratio 3.5, 95% CI 2.3-5.0). 16 (57%) deaths were due to causes other than recurrence of acute lymphoblastic leukaemia. Six (1%) survivors developed a subsequent malignant neoplasm (standardised incidence ratio 2.6, 95% CI 1.0-5.7). 107 participants (95% CI 81-193) in each group would need to be followed-up for 1 year to observe one extra chronic health disorder in the survivor group compared with the sibling group. 415 participants (376-939) in each group would need to be followed-up for 1 year to observe one extra severe, life-threatening, or fatal disorder in the group of survivors. Survivors did not differ from siblings in their educational attainment, rate of marriage, or independent living. INTERPRETATION: The prevalence of adverse long-term outcomes in children treated for standard risk acute lymphoblastic leukaemia according to contemporary protocols is low, but regular care from a knowledgeable primary-care practitioner is warranted. FUNDING: National Cancer Institute, American Lebanese-Syrian Associated Charities, Swiss Cancer Research.

PMID: 24954778

30. Arch Dis Child. 2014 Jun 20. pii: archdischild-2013-305492. doi: 10.1136/archdischild-2013-305492. [Epub ahead of print]

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

Laddie J<sup>1</sup>, Craig F<sup>2</sup>, Brierley J<sup>3</sup>, Kelly P<sup>4</sup>, Bluebond-Langner M<sup>5</sup>.

OBJECTIVE: To review the work of one tertiary paediatric palliative care service in facilitating planned withdrawal of ventilatory support outside the intensive care setting, with the purpose of developing local guidance for practice. METHODS: Retrospective 10-year (2003-2012) case note review of intensive care patients whose parents elected to withdraw ventilation in another setting. Demographic and clinical data revealed common themes and specific incidents relevant to local guideline

development. **RESULTS:** 18 children (aged 2 weeks to 16 years) were considered. Three died prior to transfer. Transfer locations included home (5), hospice (8) and other (2). Primary pathologies included malignant, neurological, renal and respiratory diseases. Collaborative working was evidenced in the review including multidisciplinary team meetings with the palliative care team prior to discharge. Planning included development of symptom management plans and emergency care plans in the event of longer than anticipated survival. Transfer of children and management of extubations demonstrated the benefits of planning and recognition that unexpected events occur despite detailed planning. We identified the need for local written guidance supporting healthcare professionals planning and undertaking extubation outside the intensive care setting, addressing the following phases: (i) introduction of withdrawal, (ii) preparation pretransfer, (iii) extubation, (iv) care postextubation and (v) care postdeath. **CONCLUSIONS:** Planned withdrawal of ventilatory support outside the intensive care setting is challenging and resource intensive. The development of local collaborations and guidance can enable parents of children dependent on intensive care to consider a preferred place of death for their child, which may be outside the intensive care unit.

PMID: 24951460

31. *Pediatr Blood Cancer*. 2014 Jun 19. doi: 10.1002/pbc.25115. [Epub ahead of print]

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

[Cataudella D<sup>1</sup>, Morley TE, Nesin A, Fernandez CV, Johnston DL, Sung I, Zelcer S.](#)

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

PMID: 24947134

32. *Pediatr Blood Cancer*. 2014 Jun 19. doi: 10.1002/pbc.25111. [Epub ahead of print]

[Development of the pediatric advanced care quality of life scale \(PAC-QoL\): Evaluating comprehension of items and response options.](#)

[Morley TE<sup>1</sup>, Cataudella D, Fernandez CV, Sung I, Johnston DL, Nesin A, Zelcer S.](#)

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

PMID: 24947009

33. *Cancer Nurs*. 2014 Jun 18. [Epub ahead of print]

[Facebook Advertisements Recruit Parents of Children With Cancer for an Online Survey of Web-Based Research Preferences.](#)

[Akard TF<sup>1</sup>, Wray S, Gilmer MJ.](#)

**BACKGROUND:** Studies involving samples of children with life-threatening illnesses and their families face significant challenges, including inadequate sample sizes and limited diversity. Social media recruitment and Web-based research methods may help address such challenges yet have not been explored in pediatric cancer populations. **OBJECTIVE:** This study examined the feasibility of using Facebook advertisements to recruit parent caregivers of children and teenagers with cancer. We also explored the feasibility of Web-based video recording in pediatric palliative care populations by surveying parents of children with cancer regarding (a) their preferences for research methods and (b) technological capabilities of their computers and phones. **METHODS:** Facebook's paid advertising program was used to recruit parent caregivers of children currently living with cancer to complete an electronic survey about research preferences and technological capabilities.

ties. RESULTS: The advertising campaign generated 3 897 981 impressions, which resulted in 1050 clicks at a total cost of \$1129.88. Of 284 screened individuals, 106 were eligible. Forty-five caregivers of children with cancer completed the entire electronic survey. Parents preferred and had technological capabilities for Web-based and electronic research methods. Participant survey responses are reported. CONCLUSION: Facebook was a useful, cost-effective method to recruit a diverse sample of parent caregivers of children with cancer. Web-based video recording and data collection may be feasible and desirable in samples of children with cancer and their families. IMPLICATIONS FOR PRACTICE: Web-based methods (eg, Facebook, Skype) may enhance communication and access between nurses and pediatric oncology patients and their families.

PMID: 24945264

34. J Palliat Med. 2014 Jul;17(7):803-10.

[Specialized home palliative care for adults and children: differences and similarities.](#)

[Groh G<sup>1</sup>, Feddersen B, Führer M, Borasio GD.](#)

ABSTRACT OBJECTIVE: To compare the provision of specialized home palliative care (SHPC) by the adult and pediatric SHPC teams at the Munich University Hospital. METHODS: All patients treated by one of the SHPC teams and their primary caregivers were eligible for the prospective nonrandomized survey. We analyzed the demographics, the underlying diseases, duration and impact of SHPC on symptom control and quality of life (QOL) as well as the caregivers' burden and QOL. RESULTS: Between April 2011 and June 2012, 100 adult and 43 pediatric patients were treated consecutively; 60 adults (median age, 67.5 years; 55% male) and 40 children (median age, 6 years, 57% male) were included in the study. Oncologic diseases were dominant only in the adult cohort (87 versus 25%,  $p < 0.001$ ). The median period of care was higher in the pediatric sample (11.8 versus 4.3 weeks; NS). Ninety-five percent of adult and 45% of pediatric patients died by the end of the study ( $p < 0.001$ ), 75% and 90% of them at home, respectively. The numbers of significant others directly affected by the patient's disease was higher in children (mean 3.4 versus 1.2;  $p < 0.001$ ). The QOL of adult patients and children ( $p < 0.05$  for both), as well as of their primary caregivers ( $p < 0.001$  for both) improved during SHPC, while the caregivers' burden was lowered ( $p < 0.001$  for both). CONCLUSIONS: Our results show important differences in several clinically relevant parameters between adults and children receiving SHPC. This should assist in the development of age-group specific SHPC concepts that effectively address the specific needs of each patient population.

PMID: 24926957

35. J Paediatr Child Health. 2014 Aug;50(8):632-8.

[Exploratory study of sleeping patterns in children admitted to hospital.](#)

[Herbert AR<sup>1</sup>, de Lima J, Fitzgerald DA, Seton C, Waters KA, Collins JJ.](#)

AIMS: Sleep is considered an important time of healing and restoration during illness. The primary aim of this study was to determine the prevalence of self-reported sleep disturbance in children admitted to a tertiary children's hospital with a variety of medical diagnoses. METHODS: Parents of children admitted to the hospital, aged between 1 and 18 years, were asked to complete a sleep diary during one night of their child's hospital stay. Children older than 12 years were asked to complete a diary independently. Descriptive statistics were used to summarise the data. RESULTS: Overall, 107 children were surveyed for one hospital inpatient night. The overall prevalence of poor sleep was 52.3%. The wide age range and variety of diagnosis limited further detailed analysis of specific causes of this problem. Poor sleep prior to admission was the strongest predictor of poor sleep in hospital suggesting that these children already had an underlying sleep problem. Unprompted awakenings were predominantly due to toileting (17.8%) or were spontaneous (17.8%). Factors specific to the hospital environment that woke children were nursing cares (25.2%), alarms (12.1%) and pain (12.1%). CONCLUSIONS: Children admitted to hospital have a higher prevalence of poor sleep compared with healthy children in the community. Children were woken frequently by both external noise and attention provided by hospital staff. Education of hospital staff about the importance of sleep for children and factors that affect children's sleep may reduce the negative impact of hospitalisation on children's sleep.

PMID: 24893889

36. J Palliat Med. 2014 Jul;17(7):788-96. doi: 10.1089/jpm.2013.0529. Epub 2014 May 28.

[Impact of research participation on parents of seriously ill children.](#)

[Steele R<sup>1</sup>, Cadell S, Siden H, Andrews G, Smit Quosai T, Feichtinger L.](#)

ABSTRACT BACKGROUND: There is a paucity of research evidence to guide health care providers' practice in pediatric palliative care. At the same time, some clinicians and Institutional Review Boards are reluctant to approve such studies because of concerns about further burdening families. Yet, there is some evidence that research participation can have positive effects for families. OBJECTIVE: To obtain parents' perceptions about their experience of participating in one of two research studies. DESIGN: Descriptive, quantitative survey. SETTING/SUBJECTS: Caregivers of children with life-threatening conditions ( $n = 323$ ) who were caring for the child at home. MEASUREMENTS: Researcher-designed Impact of Participation questionnaire. RESULTS: Few differences between the two groups were found on Impact responses. Not a single parent reported regretting participating in their study and almost all (96.3%) reported that conducting research about family's experiences in pediatric palliative care had value. Just over three-quarters (76.2%) did not find participation at all painful, and 73.7% reported that participation was about as painful as expected, with 23.2% reporting less painful. Approximately half (50.5%) said that participation had at least some positive effect and only three parents reported any negative effect. An overwhelming majority (93.4%) would recommend participation to other parents in a similar situation. CONCLUSIONS: Participation in research for families with children who have a life-threatening condition is not only acceptable to parents, but may in fact have a positive effect. Although clinicians and Institutional Review Boards may be hesitant to fully support such research, it is

clear that conducting research in the field of pediatric palliative care is important.

PMID: 24871891

37. J Palliat Med. 2014 Aug;17(8):953-6. doi: 10.1089/jpm.2013.0663. Epub 2014 May 27.

[What's Missing in Missing Data? Omissions in Survey Responses among Parents of Children with Advanced Cancer.](#)

Rosenberg AR<sup>1</sup>, Dussel V, Orellana L, Kang T, Geyer JR, Feudtner C, Wolfe J.

ABSTRACT BACKGROUND: Missing data is a common phenomenon with survey-based research; patterns of missing data may elucidate why participants decline to answer certain questions. OBJECTIVE: To describe patterns of missing data in the Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) study, and highlight challenges in asking sensitive research questions. DESIGN: Cross-sectional, survey-based study embedded within a randomized controlled trial. SETTING: Three large children's hospitals: Dana-Farber/Boston Children's Cancer and Blood Disorders Center (DF/BCCDC); Children's Hospital of Philadelphia (CHOP); and Seattle Children's Hospital (SCH). MEASUREMENTS: At the time of their child's enrollment, parents completed the Survey about Caring for Children with Cancer (SCCC), including demographics, perceptions of prognosis, treatment goals, quality of life, and psychological distress. RESULTS: Eighty-six of 104 parents completed surveys (83% response). The proportion of missing data varied by question type. While 14 parents (16%) left demographic fields blank, over half (n=48; 56%) declined to answer at least one question about their child's prognosis, especially life expectancy. The presence of missing data was unrelated to the child's diagnosis, time from progression, time to death, or parent distress (p>0.3 for each). Written explanations in survey margins suggested that addressing a child's life expectancy is particularly challenging for parents. CONCLUSIONS AND RELEVANCE: Parents of children with cancer commonly refrain from answering questions about their child's prognosis, however, they may be more likely to address general cure likelihood than explicit life expectancy. Understanding acceptability of sensitive questions in survey-based research will foster higher quality palliative care research.

PMID: 24865204

38. J Palliat Med. 2014 Aug;17(8):924-30. doi: 10.1089/jpm.2014.0023. Epub 2014 May 22.

[Perceptions of Lethal Fetal Abnormality among Perinatal Professionals and the Challenges of Neonatal Palliative Care.](#)

Tosello B<sup>1</sup>, Dany L, Gire C, Bétrémieux P, Vriet-Ndour ME, Le Coz P, D'Ercole C, Siméoni U, Einaudi MA.

ABSTRACT BACKGROUND: After prenatal diagnosis of lethal fetal abnormality (LFA), some couples choose to continue the pregnancy rather than opt for termination of the pregnancy. This may result in the requirement for neonatal palliative care, which in France is prescribed by the Leonetti Law. These rare situations raise various questions about when and how palliative care is provided in cases of LFA. OBJECTIVE: The main goal of the study was to clarify the place given to the concept of perinatal palliative care within the antenatal information provided by perinatal professionals. This work was specifically aimed at revealing caregivers' perceptions of and attitudes toward LFA, how it is managed, and procedures for decision making and providing information. METHODS: This is a qualitative study using focus groups from two French Multidisciplinary Centers for Prenatal Diagnosis. All verbal production (individual statements, verbal exchanges, etc.) produced during the two focus groups was fully transcribed and the content analyzed. RESULTS: Content analysis revealed four main themes: (1) defining LFA; (2) the source and nature of information about LFA and how it is communicated; (3) therapeutic options and decisions in the management of LFA; and (4) palliative care (limits and criteria) in the context of LFA. CONCLUSIONS: Consistency as regards the perceived intention of care among all members of the health care team is essential to support parents facing a possible fatal outcome. Attitudes and practices at Multidisciplinary Centers for Prenatal Diagnosis need to be shaped on a national basis.

PMID: 24854190

39. Arch Dis Child. 2014 Aug;99(8):754-762.

[Charting the territory: symptoms and functional assessment in children with progressive, non-curable conditions.](#)

Steele R<sup>1</sup>, Siden H<sup>2</sup>, Cadell S<sup>3</sup>, Davies B<sup>4</sup>, Andrews G<sup>5</sup>, Feichtinger L<sup>5</sup>, Singh M<sup>1</sup>.

Collaborat.: Spicer S, Goetz H, Davies D, Rapoport A, Vadeboncoeur C, Liben S, Gregoire MC, Schwantes S, Friedrichsdorf SJ.

BACKGROUND: Children with progressive, non-curable genetic, metabolic, or neurological conditions require specialised care to enhance their quality of life. Prevention and relief of physical symptoms for these children needs to begin at diagnosis, yet, little is known about their patterns of symptoms and functional abilities. AIM: To describe these children's symptoms, as well as how the children's condition affects them physically. DESIGN: Cross-sectional, baseline results from an observational, longitudinal study, Charting the Territory, that followed 275 children and their families. SETTING/PARTICIPANTS: Seven tertiary care children's hospitals in Canada, 2 in the USA. Families were eligible based on the child's condition. A total of 275 children from 258 families participated. RESULTS: The 3 most common symptoms in these children were pain, sleep problems, and feeding difficulties; on average, they had 3.2 symptoms of concern. There was a pattern of under-reporting of children's symptoms for clinicians compared with parents. Regardless of use of associated medications, pain, feeding and constipation symptoms were often frequent and distressing. Children with a G/J tube had a higher total number of symptoms, and respiratory problems, pain, feeding difficulties and constipation were more likely to occur. They also tended to have frequent and distressing symptoms, and to need extensive mobility modifications which, in turn, were associated with higher numbers of symptoms. CONCLUSIONS: These children experience multiple symptoms that have been previously documented individually, but not collectively. Effective interventions are needed to reduce their symptom burden. Future longitudinal analyses will examine which disease-modifying interventions improve, or do not improve, symptom burden.

PMID: 24833792

40. J Clin Endocrinol Metab. 2014 Aug;99(8):2932-41.

[Initial presentation and late results of treatment of post-chernobyl papillary thyroid carcinoma in children and adolescents of belarus.](#)

Fridman M<sup>1</sup>, Savva N, Krasko O, Mankovskaya S, Branovan DI, Schmid KW, Demidchik Y.

BACKGROUND: The aim of this population-based study was to evaluate the clinical and pathological characteristics and outcome of papillary thyroid carcinoma (PTC) that have arisen in the Belarusian childhood population exposed to the radioactive fallout from the Chernobyl accident within a long-term period. PATIENTS AND METHODS: The long-term treatment results were investigated in 1078 children and adolescents (<19 years old) with PTC who were surgically treated during the years 1990 through 2005. RESULTS: Patients had high rates of metastatic PTC at presentation, with 73.8% of cases having lymph node involvement and 11.1% having distant spread. The most influential factor for lymph node metastases at initial treatment was lymphatic vessel invasion ( $P < .0001$ ) and for distant metastases, lateral lymph node involvement ( $P < .0001$ ). The overall survival was  $96.9\% \pm 0.9\%$  with a median follow-up of 16.21 years, and 20-year event-free survival and relapse-free survival were  $87.8\% \pm 1.6\%$  and  $92.3\% \pm 0.9\%$ , respectively. Patients had significantly lower probability of both loco-regional ( $P < .001$ ) and distant relapses ( $P = .005$ ) after total thyroidectomy (TT) and radioactive iodine therapy (RAI). For loco-regional relapses after TT, only RAI influenced the prognosis significantly ( $P < .001$ ). For distant relapses after TT, the refusal to treat with RAI (hazard ratio [HR] = 9.26), vascular invasion (HR = 8.68), and age at presentation (HR = 6.13) were significant risk factors. For loco-regional relapses after non-TT, the principal risk factors were age less than 15 years old at presentation (HR = 5.34) and multifocal growth of tumor (HR = 5.19). For distant relapses after non-TT, the lateral neck metastases were the only unfavorable factor (HR = 9.26). CONCLUSION: The outcome of PTC both in children and in adolescents exposed to the post-Chernobyl radioiodine fallout was rather favorable. TT with RAI is recommended for minimizing loco-regional or distant relapses.

PMID: 24823453

41. J Pain. 2014 Jul;15(7):756-70.

[Validation of the Short-Form McGill Pain Questionnaire-2 in Younger and Older People With Cancer Pain.](#)

Gauthier LR<sup>1</sup>, Young A<sup>1</sup>, Dworkin RH<sup>2</sup>, Rodin G<sup>3</sup>, Zimmermann C<sup>4</sup>, Warr D<sup>5</sup>, Librach SL<sup>6</sup>, Moore M<sup>5</sup>, Shepherd FA<sup>5</sup>, Pillai Riddell R<sup>7</sup>, Macpherson A<sup>1</sup>, Melzack R<sup>8</sup>, Gagliese I<sup>9</sup>.

ABSTRACT Pain is among the most common symptoms of cancer. Because cancer can occur at any age, it is imperative that pain assessment tools are valid for use across the adult lifespan. The Short-Form McGill Pain Questionnaire-2 (SF-MPQ-2) is a valid and reliable tool for the assessment of the multidimensional qualities of pain in people with chronic nonmalignant pain, but its psychometric properties in people with cancer pain and in older versus younger people require investigation. This study evaluated age differences in the validity, reliability, and use of the SF-MPQ-2 in 244 people with advanced cancer and pain. We confirmed the previously reported 4-factor solution in older ( $\geq 60$  years) and younger (<60 years) patients. Internal consistency reliability and convergent validity were similar across age groups, although the SF-MPQ-2 sensory subscales were correlated with mental health quality of life in older, but not younger, patients. Older and younger patients selected the same words with the same intensity to describe their pain. The most commonly selected words in both age groups were aching, tiring-exhausting, sharp, and dull. These results demonstrate that the SF-MPQ-2 is appropriate for use across the adult lifespan in people with cancer pain. PERSPECTIVE: This study demonstrated that the SF-MPQ-2 is valid for use in older and younger people with advanced cancer and pain. This measure could improve cancer pain assessment across the adult lifespan, which may lead to improved pain management.

PMID: 24780200

42. Pediatr Blood Cancer. 2014 Jul;61(7):1162-7.

[Brachytherapy in children with rhabdomyosarcomas of the nasolabial fold.](#)

Mazon R<sup>1</sup>, Oberlin O, Dumas I, Kolb F, Goulart J, Rivin E, Haie-Méder C.

Comment in

[Braching news about rhabdomyosarcoma.](#) [Pediatr Blood Cancer. 2014]

Braching news about rhabdomyosarcoma. Marcus KJ. Pediatr Blood Cancer. 2014 Jul; 61(7):1151. Epub 2014 Mar 9.

BACKGROUND: Rhabdomyosarcomas (RMS) of the nasolabial fold can be difficult to manage surgically due to functional and cosmetic limitations. Therefore, brachytherapy (BT) has been proposed to improve local control while limiting the volume of irradiation as well as the extent of the surgical excision. MATERIALS AND METHODS: Sixteen pediatric cases with RMS of the nasolabial fold treated from 1971 to 2005 were retrospectively reviewed. RESULTS: Median follow-up was 4.4 years (1.7-33). Half of the patients were male and their age at diagnosis ranged from 4 months to 13.5 years. Histological subtypes included 10 embryonal and 6 alveolar RMS. Initial treatment consisted of induction multi-agent chemotherapy in all cases. In 12 patients, BT was combined with local excision (4 complete resections, 1 with macroscopic residual disease, and 7 with microscopic disease). Low dose-rate brachytherapy was performed in all cases according to the Paris system, using plastic catheters implanted per-operatively. The doses delivered ranged from 50 to 70 Gy, depending on chemotherapy response, and surgical margin status. 10 patients relapsed: 4 local, 6 regional, and 2 metastatic failures were reported. The median time to relapse was 6.5 months. At the time of analysis eight patients were alive and four had died. Four cases, under palliative care at last check-up, were lost to follow-up. CONCLUSION: BT provided an acceptable local control rate, but the poor regional control of these cases may suggest a need for more aggressive management of cervical regional lymph node regions in RMS of the nasolabial fold.

PMID: 24740487

43. Am J Kidney Dis. 2014 Jul;64(1):128-42.

[Optimal care of the infant, child, and adolescent on dialysis: 2014 update.](#)

Warady BA<sup>1</sup>, Neu AM<sup>2</sup>, Schaefer F<sup>3</sup>.

ABSTRACT Providing optimal care to the infant, child, and adolescent patient who is treated with long-term dialysis therapy mandates that attention be directed to a variety of clinical issues in addition to those related to solute removal and fluid management. Therapeutic plans must be formulated by a multidisciplinary team of pediatric specialists to address the clinical parameters of growth, anemia and osteodystrophy management, cardiovascular health, nutritional adequacy, education, cognitive development, quality of life, preparation for transplantation, and transition to adult care. This review highlights key components of current management recommendations based on a combination of published guidelines, pediatric registry data, and the combined clinical experience of the authors. Whereas some components of this review reflect a modification of the content and recommendations contained in the original publication from more than a decade ago, the contrast emphasizes the advances in understanding and therapeutics of many aspects of pediatric dialysis care that have taken place in the interim. In turn, the content of this article should provide the reader with valuable guidance toward the goal of providing optimal care to patients receiving dialysis.  
 PMID: 24717681

44. J Pediatr Nurs. 2014 Jul-Aug;29(4):e11-8. ....

[Parents' experiences of their premature infants' transportation from a university hospital NICU to the NICU at two local hospitals.](#)

Granrud MD<sup>1</sup>, Ludvigsen E<sup>2</sup>, Andershed B<sup>3</sup>.

ABSTRACT The aim of this study was to describe how the parents of premature infants experience the transportation of their baby from the neonatal intensive care unit at a university hospital (NICU-U) to such a unit at a local hospital (NICU-L). This descriptive qualitative study comprises interviews with nine sets of parents and two mothers. The qualitative content analysis resulted in one theme: living in uncertainty about whether the baby will survive, and three categories: being distanced from the baby; fearing that something would happen to the baby during transportation; and experiencing closeness to the baby. The results also revealed that the parents experienced developmental, situational and health-illness transitions.  
 PMID: 24582644

45. Palliat Support Care. 2014 Aug;12(4):317-29. ....

[Balance artistry: The healthy parent's role in the family when the other parent is in the palliative phase of cancer - Challenges and coping in parenting young children.](#)

Aamotsmo T<sup>1</sup>, Bugge KE<sup>2</sup>.

OBJECTIVES: The aim of this review was to provide a systematic overview of knowledge on how advanced cancer in a parent impacts the healthy parent's role in a family with children aged 6-12 years, and the types of help that they require in order to cope. Despite the large number of families living with a parent affected by cancer, the literature is limited concerning the needs and outcomes for the healthy parents and their need for support in managing their children's needs, when the partner is seriously ill or is in the palliative phase of cancer. METHOD: Comprehensive literature searches were undertaken by systematically searching for qualitative articles published during the period 1989-2009. The quality assessment was evaluated using a predefined "checklist to assess qualitative research." RESULTS: Seven articles met our eligibility criteria. Four distinct themes emerged that describe the healthy parent's role in the family, whose life is now characterized by uncertainty and who is attempting to maintain a balance between the needs of their children, the patient, and themselves: (1) new roles without a script, (2) attempting to maintain a safe and normal life, (3) feeling alone even within the family, and (4) support to help young family members. SIGNIFICANCE OF RESULTS: The present review provides new knowledge and insight into how healthy parents manage the challenges in parenting young children, coping with their everyday lives, and taking on new roles when their partner has advanced cancer or is dying. The healthy parent cannot balance the needs of all family members. To reach the goals of palliative care, nurses and other health professionals are encouraged to offer the patient, the healthy parent, and the children practical and emotional support.  
 PMID: 24103392

46. Nurs Child Young People. 2014 Jul 8;26(6):27-34. ....

[Innovative approach to providing 24/7 palliative care for children.](#)

Maynard L<sup>1</sup>, Lynn D.

ABSTRACT This study outlines an innovative, English hospice-based service that provides 24/7 care for children with life-limiting conditions and their families. Operational objectives were: symptom management; open access to families and professionals; choice in place of care and of death; and collaboration to develop shared pathways and management plans. Service standards were audited through questionnaires completed by professionals and families. Findings demonstrated that the nursing team filled a critical gap and met its pre-set standards. Keys to success were: having the right level and mix of specialist and advanced skills; funded on-call arrangements; anticipatory planning; symptom management plans; and clinical supervision. Further recommendations were to develop a multi-agency workforce strategy, and to increase capacity in the children's sector to undertake academic research measuring the impacts of interventions.  
 PMID: 25004048

47. Palliative Medicine. 2014 Jun;28(6):501-12. ....

[Prognostic indicators for children and young people at the end of life: A Delphi study.](#)

Shaw, Karen L; Brook, Lynda; Cuddeford, Lisa; Fitzmaurice, Nicki; Thomas, Claire; Thompson, Angela; Wallis, Maybelle;

ABSTRACT BACKGROUND: Recognizing transitions in end of life care for children is difficult and hinders communication and care planning. AIM: To identify the signs and symptoms that are most useful in signalling which children may have end of life care needs. METHODS: A Delphi study was undertaken with palliative care professionals who rated the extent to which 75 symptoms alerted them that a child/young person may have moved into his or her last (a) weeks/days, (b) 6-12 months of



life using a 7-point response scale. Level of support for items was indicated by the median, and consensus was shown by the mean absolute deviation from the median. The impact of the Delphi on final agreement and consensus was also assessed. RESULTS: Second-round questionnaires were completed by 49 (89%) individuals. It was easier to identify prognostic items in the last weeks/days than earlier in the end of life trajectory. Items most indicative included failure of physiological systems, deteriorating level of consciousness, loss of autonomic control (e.g. breathing and peripheral circulation), together with a feeling of the professional that life is ending and an agreement that resuscitation would be futile. Items most indicative of last 6/12 months suggest a progressive decline in disease trajectory, increased chest infections or other complications from which the child has difficulty in making a full recovery and which may require high dependency or critical care. CONCLUSION: This study provides important insight into which signs and symptoms are considered most valuable in identifying children approaching the end of the life.



**Fondation 3BI  
Biomedical Library Biella**

Site: [www.3bi.info](http://www.3bi.info)  
tel.: 015-15153132

**Dott.sa Roberta Maoret**  
Director  
Biomedical Librarian  
[biblioteca@3bi.info](mailto:biblioteca@3bi.info)

**Maruzza Lefebvre d'Ovidio  
Foundation**

Site: [www.maruzza.org](http://www.maruzza.org)  
tel.: 06-3290609  
[info@maruzza.org](mailto:info@maruzza.org)

