

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

“Good information is the best medicine...”

Donald A.B. Lindberg



The second

This bimonthly newsletter contains a selection of the most recent articles published in the international scientific literature on the subject of palliative care and pain management in children.

Generated from the collaboration between the **Foundation 3Bi**, Biomedical Library Biella (www.3bi.info) and the **Maruzza Lefebvre d'Ovidio Foundation** (www.maruzza.org), the aim of this initiative is to improve the knowledge, skills and the quality of care offered to patients and their families by providing a constant update for professionals working in this complex field of medicine.

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June 2014

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*“Medicine and literature
have always been
good friends”*

Carlo Dossi

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1. Arch Dis Child Fetal Neonatal Ed. 2014 Jun 4. pii: fetalneonatal-2013-305845. doi: 10.1136/archdischild-2013-305845.

[Epub]

Managing palliation in the neonatal unit.

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

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

PMID: 24899052

2. J Paediatr Child Health. 2014 Jun 3. doi: 10.1111/jpc.12617. [Epub ahead of print]

Exploratory study of sleeping patterns in children admitted to hospital.

Herbert AR¹, 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

3. J Pain Symptom Manage. 2014 May 28. pii: S0885-3924(14)00266-8. [Epub ahead of print]

Long-Term Psychosocial Outcomes Among Bereaved Siblings of Children With Cancer.

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

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

PMID: 24880001

4. Lancet Oncol. 2014 Jun;15(7):e279-e289. doi: 10.1016/S1470-2045(13)70567-9.

Breast cancer in China.

Fan L¹, Strasser-Weippl K², Li JJ¹, St Louis J³, Finkelstein DM⁴, Yu KD⁵, Chen WQ⁶, Shao ZM⁵, Goss PE⁷.

ABSTRACT: The health burden of cancer is increasing in China, with more than 1.6 million people being diagnosed and 1.2 million people dying of the disease each year. As in most other countries, breast cancer is now the most common cancer in Chinese women; cases in China account for 12.2% of all newly diagnosed breast cancers and 9.6% of all deaths from breast cancer worldwide. China's proportional contribution to global rates is increasing rapidly because of the population's rising socioeconomic status and unique reproductive patterns. In this Review we present an overview of present control measures for breast cancer across China, and emphasise epidemiological and socioeconomic diversities and disparities in access to

care for various subpopulations. We describe demographic differences between China and high-income countries, and also within geographical and socioeconomic regions of China. These disparities between China and high-income countries include younger age at onset of breast cancer; the unique one-child policy; lower rates of provision and uptake for screening for breast cancer; delays in diagnosis that result in more advanced stage of disease at presentation; inadequate resources; and a lack of awareness about breast cancer in the Chinese population. Finally, we recommend key measures that could contribute to improved health outcomes for patients with breast cancer in China.

PMID: 24872111

5. J Palliat Med. 2014 May 28. [Epub ahead of print]

Impact of Research Participation on Parents of Seriously Ill Children.

Steele R¹, Cadell S, Siden H, Andrews G, Smit Ouosai 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

6. Am J Hosp Palliat Care. 2014 May 28. pii: 1049909114536922. [Epub ahead of print]

The Use of Emergency Medication Kits in Community Palliative Care: An Exploratory Survey of Views of Current Practice in Australian Home-Based Palliative Care Services.

Bullen T¹, Rosenberg JP², Smith B³, Maher K³.

ABSTRACT: Improving symptom management for palliative care patients has obvious benefits for patients and advantages for the clinicians, as workload demands and work-related stress can be reduced when the emergent symptoms of patients are managed in a timely manner. The use of emergency medication kits (EMKs) can provide such timely symptom relief. The purpose of this study was to conduct a survey of a local service to examine views on medication management before and after the implementation of an EMK and to conduct a nationwide prevalence survey examining the use of EMKs in Australia. Most respondents from community palliative care services indicated that EMKs were not being supplied to palliative care patients but believed such an intervention could improve patient care.

PMID: 24871345

7. Pediatr Hematol Oncol. 2014 May 22. [Epub ahead of print]

All Children with Malignant Rhabdoid Tumors Should Be Treated Initially with Intensive Chemotherapy.

Hernández-Marqués C¹, Lassaletta A, Cormenzana M, García-Esparza E, Madero-López L.

ABSTRACT: Malignant rhabdoid tumors (MRT) of soft tissues are aggressive tumors, which can be detected in almost any part of the body. MRT are rare, and very few cases have been reported in the literature. Prognosis of these tumors is extremely poor despite intensive therapy. Some risk factors such as young age or disseminated disease are associated with an aggressive and almost always lethal clinical course. Some clinicians even recommend initial palliative care due to this outcome. We report a case of metastatic MRT in a 6-month-old child with excellent initial response to chemotherapy.

PMID: 24852450

8. Enferm Intensiva. 2014 May 19. pii: S1130-2399(14)00031-5. doi: 10.1016/j.enfi.2014.02.002. [Epub]

[Non-invasive ventilation improves comfort in pediatric palliative care patients.] [Article in Spanish]

Bosch-Alcaraz A.

OBJECTIVE: To analyze the appropriate use of non-invasive ventilation and its contribution to improving comfort in pediatric palliative care patients. **PATIENTS AND METHOD:** This is a descriptive cross-sectional study comprising 55 palliative care patients from San Juan de Dios Hospital in Barcelona. The effectiveness was evaluated using a register of socio-demographic, clinical-ventilatory and oxymetric parameters, the comfort and dyspnea's grade using Silverman Anderson scale, and pain level using pediatric scales.

RESULTS: The effectiveness of the technique was proved by a decreased heart rate (133.53±25.8 vs. 111.04±23.1; p<0.0001), respiratory rate (35.02±12.9 vs. 25.63±5.7; p<0.0001) and an increase of partial oxygen saturation (95.7±2.9 vs. 96.87±7.2; p<0.0001) and partial oxygen saturation/fraction of inspired oxygen ratio (297.12±113.4 vs. 336.97±100.7; p<0.0001). Dyspnea and pain levels improved in 100% of the patients.

CONCLUSIONS: The therapy was effective and the comfort improved in 100% of the patients.

PMID: 24852378

9. Arch Dis Child. 2014 May 15. pii: archdischild-2013-305246. doi: 10.1136/archdischild-2013-305246. [Epub ahead of print] [Charting the territory: symptoms and functional assessment in children with progressive, non-curable conditions.](#) Steele R¹, Siden H², Cadell S³, Davies B⁴, Andrews G⁵, Feichtinger L⁵, Singh M¹.
Collaborators: 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

10. Clin Pediatr (Phila). 2014 May 9. [Epub ahead of print]

[Palliative Care Is Critical to the Changing Face of Child Mortality and Morbidity in the United States.](#)

Bogetz JF¹, Schroeder AR, Bergman DA, Cohen HJ, Sourkes B.

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

PMID: 24817074

11. Lancet. 2014 May 3;383(9928):1547-8. doi: 10.1016/S0140-6736(14)60746-7.

[A charter for the rights of the dying child.](#)

Benini F¹, Vecchi R², Orzalesi M³.

ABSTRACT: The death of a child is a devastating and tragic event for all those involved: the family members distraught by grief and the health-care providers who are called on to address the child's complex care needs, where professionalism, ethics, deontology, and practice must reckon with personal emotions, experiences, and fears. But, it is the children who pay the highest price, suffering, and coping directly with the burden of incurable illness and death, the trauma of separation, the loss of their future and often, in solitude, the consequences of their illness, fears, and emotions. Sometimes, the people closest to them refuse to accept the negative progression of the disease and, consequently, do not recognise terminal illness and death as real and imminent issues to be addressed. As a result, these children are subjected to unrealistic decisions and treatment choices. More frequently, although fully aware of the reality of the situation, those caring for the child try to protect the child from a truth that they consider too difficult and painful to cope with by avoiding it in conversation, justifying it as the price to pay for an imaginary better future or, despite the obvious state of affairs, blatantly denying it.

PMID: 24792853

12. MCN Am J Matern Child Nurs. 2014 May-Jun;39(3):189-97. doi: 10.1097/NMC.000000000000025.

[Impact of a pediatric quality of life program on providers' moral distress.](#)

Brandon D¹, Ryan D, Sloane R, Docherty SL.

PURPOSE: To evaluate the impact of the introduction of a new pediatric palliative care program on the pattern of moral distress in pediatric healthcare providers (HCPs). **STUDY DESIGN AND METHODS:** We used a before and after cross-sectional survey design to study the impact of the Pediatric Quality of Life (QoL) Program on the moral distress of pediatric HCPs at a single center. Moral distress is measured in both intensity and frequency. The sample came from lists of all pediatric providers (nurses, physicians, social workers, therapists, dietitians, chaplains, administrators) serving the inpatient and outpatient pediatric areas of a southeastern academic tertiary medical center. **RESULTS:** The intensity of moral distress from situations focused on "individual responsibility" and "not in the best interest of the patient" were similar before and after program implementation, but the intensity of distress related to "work quality of life" decreased after program implementation. Situations causing moral distress when the "care given was not in the patient's best interest" occurred less frequently after program implementation. Providers disagreed with statements that "work-related distress" impacted their personal or professional life. The number of providers who were considering leaving the institution within 6 months decreased following program implementation. **CLINICAL IMPLICATIONS:** After implementation of the Pediatric QoL Program, nurses and other providers encountered morally distressing situations less often. Providers also answered that they had greater comfort with and competence in providing care focused on patients' quality of life after completing the program. As palliative care programs include many activities that reduce moral distress, nurses should actively take advantage of participation in debriefing sessions and staff education to maximize their work quality of life. PMID: 24759312

13. JAMA. 2014 May 21;311(19):1963-4.

Pediatric euthanasia in Belgium: disturbing developments.

Siegel AM, Sisti DA, Caplan AL.

ABSTRACT: On February 13, 2014, Belgium's Parliament approved an amendment of the 2002 Belgium Act on Euthanasia to allow euthanasia for chronically ill children. The amendment, supported by a majority of Belgians and recently signed into law by King Philippe, permits euthanasia for children who are experiencing "constant and unbearable suffering." In addition to requiring the child's own voluntary and explicit request for euthanasia, the new law requires parental consent, excludes children with an intellectual disability or mental illness, and mandates a multidisciplinary team carefully examine the child's capacity for discernment.

PMID: 24743867

14. J Child Neurol. 2014 Apr 9. [Epub ahead of print]

Mapping the Literature: Palliative Care Within Adult and Child Neurology.

Dallara A¹, Meret A, Saroyan J.

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

PMID: 24717986

15. J Clin Oncol. 2014 Apr 10;32(11):1119-26. doi: 10.1200/JCO.2013.51.5981. Epub 2014 Mar 10.

Improving the care of children with advanced cancer by using an electronic patient-reported feedback intervention: results from the PediQUEST randomized controlled trial.

Wolfe J¹, Orellana L, Cook EF, Ullrich C, Kang T, Geyer JR, Feudtner C, Weeks JC, Dussel V.

PURPOSE: This study aimed to determine whether feeding back patient-reported outcomes (PROs) to providers and families of children with advanced cancer improves symptom distress and health-related quality of life (HRQoL). **PATIENTS AND METHODS:** This study was a parallel, multicentered pilot randomized controlled trial. At most once per week, children age ≥ 2 years old with advanced cancer or their parent completed the computer-based Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) survey consisting of age- and respondent-adapted versions of the Memorial Symptom Assessment Scale (MSAS), Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL4.0), and an overall Sickness question. In the intervention group (n = 51), oncologists and families received printed reports summarizing PROs; e-mails were sent to oncologists and subspecialists when predetermined scores were exceeded. No feedback was provided in the control group (n = 53). Primary outcomes included linear trends of MSAS, PedsQL4.0 total and subscale scores, and Sickness scores during 20 weeks of follow-up, along with child, parent, and provider satisfaction with PediQUEST feedback. **RESULTS:** Feedback did not significantly affect average MSAS, PedsQL4.0, or Sickness score trends. Post hoc subgroup analyses among children age ≥ 8 years who survived 20 weeks showed that feedback improved PedsQL4.0 emotional (+8.1; 95% CI, 1.8 to 14.4) and Sickness (-8.2; 95% CI, -14.2 to -2.2) scores. PediQUEST reports were valued by children, parents, and providers and contributed at least sometimes to physician initiation of a psychosocial consult (56%). **CONCLUSION:** Although routine feedback of PROs did not significantly affect the child's symptoms or HRQoL, changes were in expected directions and improvements observed in emotional HRQoL through exploratory analyses were encouraging. Importantly, children, parents, and providers value PRO feedback.

PMID: 24616307

16. Pediatr Crit Care Med. 2014 May;15(4):336-42. doi: 10.1097/PCC.000000000000072.

Parental Perspectives on Suffering and Quality of Life at End-of-Life in Children With Advanced Heart Disease: An Exploratory Study*.

Blume ED¹, Balkin EM, Aiyagari R, Ziniel S, Beke DM, Thiagarajan R, Taylor L, Kulik T, Pituch K, Wolfe J.

OBJECTIVE: To describe parent perspectives regarding the end-of-life experience of children with advanced heart disease. **DESIGN:** Cross-sectional multicenter survey study of bereaved parents. **SETTING:** Two tertiary care pediatric hospitals. **SUBJECTS:** Parents of children younger than 21 years with primary cardiac diagnoses who died in the hospital 9 months to 4 years before the survey date. Parents were excluded if they were non-English speakers or had previously denied permission to contact. **INTERVENTION:** The Survey for Caring for Children with Advanced Heart Disease was developed, piloted, and then sent to parents of all children who died at two sites. **MEASUREMENTS AND MAIN RESULTS:** Fifty bereaved parents responded (39% response rate) a mean of 2.7 years after their child's death. Median age at death was 6 months (3.6 d to 20.4 yr). At end-of-life, 86% of children were intubated and 46% were receiving mechanical circulatory support. Seventy-eight percent died during withdrawal of life-sustaining interventions and 16% during resuscitative efforts. Parents realized that their child had no realistic chance of survival a median of 2 days prior to death (0-30 d). According to parents, 47% of children suffered "a great deal," "a lot," or "somewhat" during the end-of-life period. The symptoms parents perceived to be causing the most suffering were breathing and feeding difficulties in children under 2 years and fatigue and sleeping difficulties in older children. Seventy-one percent of parents described the quality of life of their child during the last month of life as "poor" or "fair." Most parents (84%) described the quality of care delivered as "very good" or "excellent". **CONCLUSIONS:** According to their parents, many children with advanced heart disease experience suffering

in the end-of-life care period. For most, realization that their child has no realistic chance of survival does not occur until late, some not until death is imminent. Once this realization occurs, however, parents perceive peacefulness, a "good death," and excellent quality of care. Strategies for improved communication around symptom management, quality of life, prognosis, and advance care planning are needed for families of children with advanced heart disease.

PMID: 24583501

17. MCN Am J Matern Child Nurs. 2014 May-Jun;39(3):148-54; quiz 155-6. doi: 10.1097/NMC.000000000000028.

[Leaning in and holding on: team support with unexpected death.](#)

[Kobler K.](#)

ABSTRACT: Integral to the care of medically fragile infants and children is the sobering reality that not all will survive. Supporting children and families through the dying process requires knowledge, skill, compassion, and a willingness to be present to the suffering of others. As healthcare professionals journey with a dying child, they experience an ongoing dual nature of their own grief, shifting between focusing on the loss at hand or avoiding the loss and refocusing their attention elsewhere. This internal conflict may be potentiated with the sudden, unexpected death of a patient, which affords little time for caregivers to process their own experience of the loss. When an unanticipated death occurs, a palpable grief ripples through the entire unit, impacting caregivers, the bereaved parents, and other patients and families. Such an event holds the potential for either team disorganization or growth. This article presents a case study of one unit's response to the unexpected death of a long-term patient, which caused caregivers to lean in to support each other. Using a case study approach, the author identifies strategies to best guide teams when death arrives without warning, and provides ideas for cocreating ritual to honor relationship in the midst of tragedy.

PMID: 24445436

18. Pediatr Blood Cancer. 2014 May;61(5):859-64. doi: 10.1002/pbc.24872. Epub 2013 Nov 21.

[Parent and clinician preferences for location of end-of-life care: home, hospital or freestanding hospice?](#)

[Kassam A¹](#), [Skiadaresis J](#), [Alexander S](#), [Wolfe J](#).

BACKGROUND: Current options for location of end-of-life (EOL) care for children with cancer include home, hospital, and freestanding pediatric hospice (FSPH). However, access to these options varies greatly depending on geographical location. We aimed to determine bereaved parent and clinician preferences for location to EOL care and death. **PROCEDURE:** We administered questionnaires to 75 bereaved parents (response rate 54%) and 48 pediatric oncology clinicians (response rate 91%) at a large teaching hospital. Main outcome measure was parent and clinician ranking for preferred location of EOL care and death if given the options of home, hospital or FSPH. **RESULTS:** Majority of parents and clinicians ranked home as their first choice for EOL care (70.2% and 87%, respectively) and death (70.8% and 89.1%, respectively). Compared to clinicians, parents gave a higher ranking to hospital ($P < 0.01$) and lower ranking to FSPH ($P < 0.01$) as the preferred location for EOL care and death. Congruence between actual and preferred location of EOL care was more likely when a palliative care team was involved ($P < 0.01$) and less likely for children with haematologic malignancies ($P = 0.03$). **CONCLUSIONS:** Parents and clinicians prefer home as the location for EOL care and death for children with cancer. Hospital based palliative care is a preferred alternative if home is not desired. FSPH is a relatively recent phenomena and further research needs to be directed towards understanding its cost benefit in comparison to home and hospital-based EOL care.

PMID: 24265171

19. BMC Med. 2014 May 21;12(1):83. doi: 10.1186/1741-7015-12-83.

[The 'placement' of people with profound impairments across the lifespan: re-thinking age criteria.](#)

[Gibson BE¹](#), [King G](#), [Kingsnorth S](#), [McKeever P](#).

BACKGROUND: Advances in lifesaving technologies and treatments make it possible for children with profound physical and cognitive impairments to survive into adulthood. Questions regarding how and where they should live are discussed rarely and, when they are, primarily focus on safety and/or containing costs. Since models of long-term care provision are age-based, children who reside in institutions are 'discharged' to adult facilities when they reach an arbitrary age. Such transfers may not be in the best interests of these young people or their families. Our aim in this debate is to highlight why age is a problematic criterion for placement decisions, with the goal of stimulating further research and inquiry.

DISCUSSION: Transfers from pediatric to adult institutions are driven primarily by funding arrangements and underpinned by stage-based theories of human development. Arguments supporting such transfers point to the value of communal living with same age peers, and engagement in age-appropriate activities. These goals are questionable for individuals who are minimally interactive and/or where equally worthy interactions are feasible in intergenerational settings. Instead their accommodation needs might more closely align with palliative care principles of supporting individuals and families to enjoy what they bring to each other's lives and minimize suffering. Innovative models of 'vertical care' and 'lifetime homes', which enable continuous flexible services across the lifespan, are discussed as examples of alternative approaches requiring further debate and research. **SUMMARY:** Entrenched funding and service models that require the transfer of profoundly impaired young people from pediatric to adult facilities need to be re-examined with considerations of best interests, needs, and preferences of individuals and their families. Questions of what constitutes a 'good life' for these individuals are tenacious and require further thought and research. Nevertheless, they need to be regarded as citizens of our human community deserving of a good life in whatever form that may take, in settings that enable them to flourish.

PMID: 24885127

20. J Pain Symptom Manage. 2014 May 27. pii: S0885-3924(14)00261-9. doi: 10.1016/j.jpainsymman.2014.05.004. [Epub]

[Measuring the Quality of Dying and Death in the Pediatric Intensive Care Setting: The Clinician PICU-QODD.](#)

[Sellers DE¹](#), [Dawson R²](#), [Cohen-Bearak A³](#), [Solomond MZ⁴](#), [Truog RD⁵](#).

CONTEXT: In the pediatric intensive care setting, an accurate measure of the dying and death experience holds promise

for illuminating how critical care nurses, physicians, and allied psychosocial staff can better manage end-of-life care for the benefit of children and their families, as well as the caregivers. **OBJECTIVES:** To assess the reliability and validity of a clinician measure of the quality of dying and death (PICU-QODD-20) in the pediatric intensive care setting. **METHODS:** In a retrospective cohort study, five types of clinicians (primary nurse, bedside nurse, attending physician, and the psychosocial clinician and critical care fellow most involved in the case) were asked to complete a survey for each of the 94 children who died over a 12-month period in the pediatric intensive care units (PICUs) of two children's hospitals in the northeast U.S. Analyses were conducted within type of clinician. **RESULTS:** In total, 300 surveys were completed by 159 clinicians. Standard item analyses and substantive review led to the selection of 20 items for inclusion in the PICU-QODD-20. Cronbach's alpha for the PICU-QODD-20 ranged from 0.891 for bedside nurses to 0.959 for attending physicians. For each type of clinician, the PICU-QODD-20 was significantly correlated with the quality of end-of-life care and with meeting the family's needs. In addition, when patient/family or team barriers were encountered, the PICU-QODD-20 score tended to be significantly lower than for cases in which the barrier was not encountered. **CONCLUSION:** The PICU-QODD-20 shows promise as a valid and reliable measure of the quality of dying and death in pediatric intensive care.

PMID: 24878067

21. *J Palliat Med.* 2014 May 27. [Epub ahead of print]

What's Missing in Missing Data? Omissions in Survey Responses among Parents of Children with Advanced Cancer.

Rosenberg AR¹, Dussel V, Orellana L, Kang T, Geyer JR, Feudtner C, Wolfe J.

ABSTRACT: 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

22. *J Soc Work End Life Palliat Care.* 2014;10(2):170-85. doi: 10.1080/15524256.2014.906375.

Poverty and pediatric palliative care: what can we do?

Beaune L¹, Leavens A, Muskat B, Ford-Jones L, Rapoport A, Zlotnik Shaul R, Morinis J, Chapman LA.

ABSTRACT: It has been recognized that families of children with life-limiting health conditions struggle with significant financial demands, yet may not have awareness of resources available to them. Additionally, health care providers may not be aware of the socioeconomic needs of families they care for. This article describes a mixed-methods study examining the content validity and utility for health care providers of a poverty screening tool and companion resource guide for the pediatric palliative care population. The study found high relevance and validity of the tool. Significant barriers to implementing the screening tool in clinical practice were described by participants, including: concerns regarding time required, roles and responsibilities, and discomfort in asking about income. Implications for practice and suggestions for improving the tool are discussed. Screening and attention to the social determinants of health lie within the scope of practice of all health care providers. Social workers can play a leadership role in this work.

PMID: 24835385

23. *Am J Orthopsychiatry.* 2014 Mar;84(2):123-33. doi: 10.1037/h0099384.

Posttraumatic growth in parents caring for a child with a life-limiting illness: A structural equation model.

Cadell S¹, Hemsworth D², Smit Quosai T¹, Steele R³, Davies E⁴, Liben S⁵, Straatman L⁶, Siden H⁶.

ABSTRACT: When parents first meet their child, they take on the entwined joys and burdens of caring for another person. Providing care for their child becomes the basic expectation, during health and illness, through the developmental milestones, into adulthood and beyond. For those parents who have a child who is born with or is later diagnosed with a life-limiting illness, parents also become caregivers in ways that parents of predominantly well children do not. While the circumstances are undisputedly stressful, for some parents benefits can co-occur along with the negative outcomes. This article tests two structural equation models of possible factors that allow these parent caregivers to experience growth in the circumstances. The diagnosis and illness of a child in the context of pediatric palliative care is a very complex experience for parents. The stresses are numerous and life-changing and yet the parents in this research demonstrated growth as measured by the Post Traumatic Growth Inventory. It appears that particular personal resources reflected in personal well-being are a precursor to the process of positive meaning making, which then, in turn, contributes to growth. The path to posttraumatic growth is not a simple one, but this research contributes to further elucidating it. (PsycINFO Database Record (c) 2014 APA, all rights reserved).

PMID: 24826928

24. J Palliat Med. 2014 May 13. [Epub ahead of print]

Sexual History Taking: A Dying Skill?

Sargant NN¹, Smallwood N, Finlay F.

ABSTRACT: Many adolescents are having sex and adolescents with life-limiting illnesses are no exception. It is therefore important for health care professionals to take a sexual history and provide advice about sexually transmitted diseases, unintended pregnancies, and ways of reducing high-risk sexual behaviors. Consultations should provide a forum for discussion and education. A literature review revealed no previous studies on this topic. **Objective:** Our aim was to review medical consultations between adolescents with life-limiting illnesses and pediatricians to establish whether sex was discussed. **Methods:** The clinical medical notes of 25 adolescents aged 12 to 18 years, under the care of a community team specializing in patients with nonmalignant life-limiting conditions at a District General Hospital in the United Kingdom (UK) were selected at random. Researchers retrospectively reviewed handwritten notes and typed letters in the medical records with a view to establishing whether a sexual history was taken on any occasion. **Results:** None of the health care professionals took a sexual history from any of the adolescents on any occasion despite multiple clinic attendances. **Conclusion:** Sexual health is described by the World Health Organization as a basic human right. Clinicians may struggle to accept that adolescents with life-limiting illnesses may want to talk about sex, and this study has highlighted it as a topic that is generally ignored. Health professionals should include sexual health in routine palliative assessments. Adolescents with life-limiting illnesses should not be denied the right to holistic health care.

PMID: 24824776

25. J Palliat Med. 2014 May;17(5):500-1. doi: 10.1089/jpm.2014.9432.

Is there a "right way" to provide pediatric palliative care?

Jones E, Wolfe Associate Editor J.

ABSTRACT: As THE FIELD of pediatric palliative care (PPC) continues to grow and new programs are developed, the question of quality and standardization is beginning to emerge. Many in the field, from established groups to lone reeds struggling to introduce palliative care at their hospital or in the community, are seeking guidance. But is possible to define a "right way" for a field upon individualized care planning family-centeredness? Perhaps this individualization necessitates heterogeneity. The question of the "right way" brings to mind the adage, "if you have seen one pediatric palliative care program, you have seen ONE pediatric palliative care program"

PMID: 24809465

26. J Pain Symptom Manage. 2014 Apr 18. pii: S0885-3924(14)00194-8. [Epub ahead of print]

Palliative Sedation at Home for Terminally Ill Children With Cancer.

Korzeniewska-Eksterowicz A¹, Przyslo I², Fendler W³, Stolarska M⁴, Mlynarski W³.

CONTEXT: The presence of symptoms that are difficult to control always requires adjustment of treatment and palliative sedation should be considered. **OBJECTIVES:** We analyzed our experience in conducting palliative sedation at home for terminally ill children with cancer during a seven-year period. **METHODS:** We performed a retrospective analysis of medical records of children with cancer treated at home between the years 2005 and 2011. **RESULTS:** We analyzed the data of 42 cancer patients (18% of all patients); in 21 cases palliative sedation was initiated (solid tumors n=11, brain tumors (5), bone tumors (4), leukemia (1)). Sedation was introduced because of pain (n=13), dyspnea (9), anxiety (5) or two of those symptoms (6). The main drug used for sedation was midazolam; all patients received morphine. There were no significant differences in the dose of morphine or midazolam depending on the patient's sex; age was correlated with an increase of midazolam dose (R=0.68; P=0.005). Duration of sedation (R=0.61; P=0.003) and its later initiation (R=0.43; P=0.05) were correlated with an increase of the morphine dose. All patients received adjuvant treatment; in patients who required a morphine dose increase, metoclopramide was used more often (P=0.0002). Patients did not experience any adverse reactions. Later introduction of sedation was associated with a marginally higher number of intervention visits and a significantly higher number of planned visits (R=0.53; P=0.013). **CONCLUSION:** Sedation may be safely used at home. It requires close monitoring and full cooperation between the family and hospice team. Because of the limited data on home palliative sedation in pediatric populations, further studies are needed.

PMID: 24751437

27. Support Care Cancer. 2014 Apr 18. [Epub ahead of print]

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

Klosa PR¹, Klein C, Heckel M, Bronnhuber AC, Ostgathe C, Stiel S.

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

PMID: 24743852

28. Eur J Pediatr. 2014 Apr 11. [Epub ahead of print]

[Pain therapy, pediatric palliative care and end-of-life care: training, experience, and reactions of pediatric residents in Italy.](#)

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

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

PMID: 24718654

29. Pediatr Crit Care Med. 2014 Jun;15(5):435-42. doi: 10.1097/PCC.000000000000128.

[Perioperative steroids administration in pediatric cardiac surgery: a meta-analysis of randomized controlled trials*.](#)

Scrascia G¹, Rotunno C, Guida P, Amorese L, Polieri D, Codazzi D, Paparella D.

OBJECTIVE: To evaluate the effects of prophylactic perioperative corticosteroid administration, compared with placebo, on postoperative mortality and clinical outcomes (renal dysfunction, duration of mechanical ventilation, and ICU length of stay) in pediatric patients undergoing cardiac surgery with cardiopulmonary bypass. **DATA SOURCES:** MEDLINE and Cochrane Library were screened through August 2013 for randomized controlled trials in which perioperative steroid treatment was adopted. **STUDY SELECTION:** Included were randomized controlled trials conducted on pediatric population that reported clinical outcomes about mortality and morbidity. **DATA EXTRACTION:** -Eighty citations (PubMed, 48 citations; Cochrane, 32 citations) were identified, of which 14 articles were analyzed in depth and six articles fulfilled eligibility criteria and reported mortality data (232 patients), two studies reported ICU length of stay and mechanical ventilation duration (60 patients), and two studies reported renal dysfunction (49 patients). **DATA SYNTHESIS:** A nonsignificant trend of reduced mortality was observed in steroid-treated patients (11 [4.7%] vs 4 [1.7%] patients; odds ratio, 0.41; 95% CI, 0.14-1.15; p = 0.089). Steroids had no effects on mechanical ventilation time (117.4 ± 95.9 hr vs 137.3 ± 102.4 hr; p = 0.43) and ICU length of stay (9.6 ± 4.6 d vs 9.9 ± 5.9 d; p = 0.8). Perioperative steroid administration reduced the prevalence of renal dysfunction (13 [54.2%] vs 2 [8%] patients; odds ratio, 0.07; 95% CI, 0.01-0.38; p = 0.002). **CONCLUSION:** Despite a demonstrated attenuation of cardiopulmonary bypass-induced inflammatory response by steroid administration, a systematic review of randomized controlled trials performed so far reveals that steroid administration has potential clinical advantages (lower mortality and significant reduction of renal function deterioration). A larger prospective randomized study is needed to verify clearly the effects of steroid prophylaxis in pediatric patients.

PMID: 24717907

30. J Pain Symptom Manage. 2014 Apr 3. pii: S0885-3924(14)00151-1. [Epub ahead of print]

[Variation of Opioid Use in Pediatric Inpatients Across Hospitals in the U.S.](#)

Womer J¹, Zhong W¹, Kraemer FW², Maxwell LG², Ely EA³, Faerber JA¹, Dai D¹, Feudtner C⁴.

CONTEXT: Appropriate use of opioids is essential to manage moderate-to-severe pain in children safely and effectively, yet published guidance regarding opioid treatment for pediatric patients is limited, potentially resulting in excessive variation in opioid use in pediatric patients across hospitals in the U.S. **OBJECTIVES:** The aim was to evaluate hospital variation in opioid use in pediatric inpatients. **METHODS:** Using data from the Pediatric Health Information System and the Premier Perspective Database regarding all pediatric inpatients in 626 hospitals, we examined hospital variation in opioid use and the length of opioid use, adjusting for patient demographic and clinical characteristics and for hospital type (children's vs. general) and hospital patient volume, using multilevel generalized linear regression modeling. **RESULTS:** Overall, 41.2% of all pediatric hospitalizations were exposed to opioids. Among the exposed patients, the mean length of exposure was 4.6 days. Exposure proportion and exposure length varied substantially across hospitals, even after accounting for patient demographic and clinical characteristics, hospital type and hospital patient volume, especially among terminal hospitalizations. For patients discharged alive vs. died, the adjusted exposure percentage for each hospital ranged from 0.7% to 99.1% (interquartile range [IQR]: 35.3%-59.9%) vs. 0.1% to 100.0% (IQR: 29.2%-66.2%), respectively, and the adjusted exposure length ranged from 1.0 to 8.4 days (IQR: 2.2-2.7 days) vs. 0.9 to 35.2 days (IQR: 4.0-7.4 days). **CONCLUSION:** The substantial hospital-level variation in opioid use in pediatric inpatients suggests room for improvement in clinical practice.

PMID: 24703942

31. Rev Paul Pediatr. 2014 Mar;32(1):99-106.

[Assistance to children in palliative care in the Brazilian scientific literature.](#)

Garcia-Schinzari NR¹, Santos FS².

OBJECTIVE: To describe what has been published in Brazilian scientific literature regarding pediatric palliative care. **DATA SOURCES:** Bibliographic review with a descriptive approach. In LILACS and SciELO databases, the descriptors "palliative care", "child", "pediatrics", "terminal illness" and "death" were sought, from January 2002 to December 2011. The eight selected articles were analyzed according to year of publication, type of study, data collected, target population, pathology, professionals involved, types of care and main findings. **DATA SYNTHESIS:** Regarding the year of publication,

there was an increase in the number of publications related to pediatric palliative care. Regarding the type of study, four articles were literature reviews and four were qualitative researches. Data was collected mainly by semi-structured interviews. The participants of the majority of the studies were children's relatives and health professionals. The main pathology addressed was cancer and the nurses were the most frequently cited professionals. The types of care provided were related to physical aspects, general care and psychological, social and spiritual aspects (less emphasis). The main findings were: little emphasis on the children's needs, the importance of including the family in the care provided and the lack of preparation of the health team. **CONCLUSIONS:** Despite the difficulties and the challenges in establishing pediatric palliative care, many articles brought important considerations for the development of this practice in the country.

PMID: 24676197

32. J Pain. 2014 Apr;15(4):321-37. doi: 10.1016/j.jpain.2014.01.494.

Methadone safety: a clinical practice guideline from the American Pain Society and College on Problems of Drug Dependence, in collaboration with the Heart Rhythm Society.

Chou R¹, Cruciani RA², Fiellin DA³, Compton P⁴, Farrar JT⁵, Haigney MC⁶, Inturrisi C⁷, Knight JR⁸, Otis-Green S⁹, Marcus SM¹⁰, Mehta D¹¹, Meyer MC¹², Portenoy R², Savage S¹³, Strain E¹⁴, Walsh S¹⁵, Zeltzer L¹⁶.

ABSTRACT: Methadone is used for the treatment of opioid addiction and for treatment of chronic pain. The safety of methadone has been called into question by data indicating a large increase in the number of methadone-associated overdose deaths in recent years that has occurred in parallel with a dramatic rise in the use of methadone for chronic pain. The American Pain Society and the College on Problems of Drug Dependence, in collaboration with the Heart Rhythm Society, commissioned an interdisciplinary expert panel to develop a clinical practice guideline on safer prescribing of methadone for treatment of opioid addiction and chronic pain. As part of the guideline development process, the American Pain Society commissioned a systematic review of various aspects related to safety of methadone. After a review of the available evidence, the expert panel concluded that measures can be taken to promote safer use of methadone. Specific recommendations include the need to educate and counsel patients on methadone safety, use of electrocardiography to identify persons at greater risk for methadone-associated arrhythmia, use of alternative opioids in patients at high risk of complications related to corrected electrocardiographic QTc interval prolongation, careful dose initiation and titration of methadone, and diligent monitoring and follow-up. Although these guidelines are based on a systematic review, the panel identified numerous research gaps, most recommendations were based on low-quality evidence, and no recommendations were based on high-quality evidence. **PERSPECTIVE:** This guideline, based on a systematic review of the evidence on methadone safety, provides recommendations developed by a multidisciplinary expert panel. Safe use of methadone requires clinical skills and knowledge in use of methadone to mitigate potential risks, including serious risks related to risk of overdose and cardiac arrhythmias.

PMID: 24685458

33. Int J Palliat Nurs. 2014 Mar;20(3):143-8.

Perinatal palliative care: a developing specialty.

Kimman R1, Doumic L2.

ABSTRACT: Neonates and babies have the highest death rate in the paediatric population. Perinatal palliative care aims to enhance the quality of life of babies with a life-limiting condition and their families. However, very little data is available on perinatal palliative care and its impact on babies and families along their journey. End-of-life decision-making for babies with an adverse prognosis also remains ethically challenging. This paper provides an overview of perinatal palliative care and its development, and then considers some of the issues affecting this field by looking at single national, institutional, and patient case studies.

PMID: 24675541

34. Support Care Cancer. 2014 Mar 27. [Epub ahead of print]

Referral practices of pediatric oncologists to specialized palliative care.

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

PURPOSE: The aims of this study are to describe the attitudes and referral practices of pediatric oncologists (POs) to specialized palliative care (SPC), and to compare them with those of adult oncologists (AOs). **METHODS:** Canadian members of the American Society of Pediatric Hematology/Oncology (ASPHO), Canadian Association of Medical Oncologists (CAMO), Canadian Association of Radiation Oncologists (CARO), and the Canadian Society of Surgical Oncology (CSSO) participated in an anonymous survey assessing SPC referral practices. **RESULTS:** The response rate was 70 % (646/921), 52 % (43/82) for ASPHO members; 5 CARO members self-identified as POs, for a total of 48 POs and 595 AOs. Ninety-six percent of POs had access to inpatient SPC consultation services (vs. 48 % AOs), 31 % to a PCU (vs. 82 % AOs), and 27 % to an outpatient SPC clinic (vs. 73 % AOs). POs more often stated their SPC services accepted patients on chemotherapy than AOs (64 vs. 37 %, p = 0.0004). POs were less likely to refer only after chemotherapy had been stopped (13 vs. 29 % for AOs) and more likely to state that ideally referral should occur at the diagnosis of cancer/incurable cancer (73 vs. 43 %). POs were more likely to agree they would refer earlier if palliative care were renamed "supportive care" (58 vs. 33 %, p < 0.0001), that palliative care adds too many providers (17 vs. 7 %, p = 0.002), and that palliative care was perceived negatively by their patients (60 vs. 43 %, p = 0.02). **CONCLUSIONS:** Although POs acknowledge the importance of early referral to SPC for children with cancer, there remain resource and attitudinal barriers to overcome in this regard.

PMID: 24671435

35. South Asian J Cancer. 2014 Jan;3(1):78-82. doi: 10.4103/2278-330X.126548.

Overview of pediatric oncology and hematology in Myanmar.

Halbert J¹, Khaing AA².

ABSTRACT: Myanmar is a country in southeast Asia in political, economic and healthcare transition. There are currently only two pediatric oncology centers serving a population of almost 19 million children. An estimated 85-92% of children with cancer are undiagnosed or not receiving treatment. Abandonment of treatment is as high as 60%. Although a number of chemotherapy agents are available, difficulties remain concerning treatment costs, quality control and the availability of supportive care. Radiotherapy services are also limited and not usually included in pediatric protocols. Healthcare professional training, improved diagnostics, strategies to tackle abandonment of treatment and the development of a parents' support group are major priorities. Local and international partnerships including a recent partnership with world child cancer are essential in the interim to support the development of pediatric oncology and hematology in Myanmar. A unique opportunity exists to support the development of preventive, diagnostic, curative and palliative care for children's cancer in Myanmar from the outset.

PMID: 24665454

36. J Palliat Med. 2014 May;17(5):589-91. doi: 10.1089/jpm.2013.0576. Epub 2014 Mar 14.

End-of-Life Care for Children Enrolled in a Community-Based Pediatric Palliative Care Program.

Niswander LM¹, Cromwell P, Chirico J, Gupton A, Korones DN.

ABSTRACT BACKGROUND: Despite recent strides in pediatric palliative care (PPC), there are few published data on community-based care of dying children. **OBJECTIVE:** Our aim was to describe end-of-life care during the last 6 months of life for children on a community-based PPC program. **Methods:** We conducted a retrospective review of children <21 years old who died while enrolled in a community-based PPC program (CompassionNet) from December 2004 through May 2008. Data were extracted on the last 6 months of life from hospital records (University of Rochester) and records of CompassionNet and its home-nursing team. **RESULTS:** Thirty-six children died while enrolled in the CompassionNet program; diagnoses included cancer 20 (56%), genetic/neurologic disorders 7 (19%), cardiac anomalies 6 (17%), and other 3 (8%). In the last 6 months of life, there were a median of 2 emergency room visits (range 0-12) and 2 unplanned hospitalizations (range 0-6). Home visits by CompassionNet (case manager, physician, nurse) ranged from 1 to 121 (median 24). A "goals of care" discussion was documented for 29 children (81%), occurring a median of 16 days before death (range 0-118). Sixteen children died at home (44%); 20 died in the hospital (56%). Of the 16 families with a documented preference for location of death, 14 children died in this location (88%). Thirty-two families (89%) had bereavement support through CompassionNet. **CONCLUSIONS:** Children who die of complex chronic conditions spend the majority of their last 6 months of life at home. Community-based PPC can contribute substantially to their care and comfort.

PMID: 24628107

37. BMC Palliat Care. 2014 Mar 13;13(1):9. doi: 10.1186/1472-684X-13-9.

Regoaling: a conceptual model of how parents of children with serious illness change medical care goals.

Hill DL, Miller V, Walter JK, Carroll KW, Morrison WE, Munson DA, Kang TI, Hinds PS, Feudtner C¹.

BACKGROUND: Parents of seriously ill children participate in making difficult medical decisions for their child. In some cases, parents face situations where their initial goals, such as curing the condition, may have become exceedingly unlikely. While some parents continue to pursue these goals, others relinquish their initial goals and generate new goals such as maintaining the child's quality of life. We call this process of transitioning from one set of goals to another regoaling. **DISCUSSION:** Regoaling involves factors that either promote or inhibit the regoaling process, including disengagement from goals, reengagement in new goals, positive and negative affect, and hopeful thinking. We examine these factors in the context of parental decision making for a seriously ill child, presenting a dynamic conceptual model of regoaling. This model highlights four research questions that will be empirically tested in an ongoing longitudinal study of medical decision making among parents of children with serious illness. Additionally, we consider potential clinical implications of regoaling for the practice of pediatric palliative care. **SUMMARY:** The psychosocial model of regoaling by parents of children with a serious illness predicts that parents who experience both positive and negative affect and hopeful patterns of thought will be more likely to relinquish one set of goals and pursue a new set of goals. A greater understanding of how parents undergo this transition may enable clinicians to better support them through this difficult process.

PMID: 24625345

38. Adv Neonatal Care. 2014 Feb;14(1):7.

Pediatric palliative care.

[No authors listed]

Pediatric palliative care programs are becoming more common in children's hospitals, a positive development. A recent survey found that approximately 70% of children's hospitals have pediatric palliative care programs, although there is marked variation in how the programs operate, suggesting a need for formal guidance on how to deliver high-quality pediatric palliative care.

PMID: 24616938

39. J Palliat Med. 2014 May;17(5):585-8. doi: 10.1089/jpm.2013.0206. Epub 2014 Feb 27.

Referrals to a new pediatric palliative care team: details of the first 12 months of operation.

Frizzola M¹, Miller EG.

ABSTRACT: Although the field of pediatric palliative care (PPC) remains in its infancy, over the past decade it has grown in practice and scope. We report on patient referral patterns to a new PPC team at a free-standing children's hospital. **Objective:** Our aim is to provide a descriptive comparison of the patient population seen by our new program as compared to existing literature. **Methods:** We examined our database of patient referral and demographic data and compared our data with published reports. **Conclusions:** Our team was operating beyond its predicted year-one volume with a patient population that mirrored larger, more established programs. In an era of growth and acceptance of PPC, hospitals that have undergone

a strong needs assessment, significant educational effort, and have a strong prediction of patient volume should expect to be operating at projected capacity quickly.

PMID: 24576099

40. Indian J Pediatr. 2014 May;81(5):455-9. doi: 10.1007/s12098-013-1295-1. Epub 2014 Jan 11.

The need of pediatric palliative care education among pediatric postgraduates in South India.

Latha MS¹, Thirugnanasambandam RP, Balakrishnan N, Meghanathan HS, Moorthy A, Venkatraman P, Paramasivam V, Scott JX.

OBJECTIVES: To assess the status of Pediatric Palliative care education among the pediatric postgraduates in South India and reinforce the need to introduce a targeted curriculum to improve their skills and confidence levels in handling terminally ill children. **METHODS:** The study was conducted in a 2 d workshop attended by 180 pediatric postgraduates from South India. An 18 point questionnaire was given to the participants and the questions were to test their clinical knowledge and confidence levels in treating terminally ill children. SPSS 18.V software was used for statistical analysis. **RESULTS:** Eighty eight percent of the postgraduates had never received any training in any aspect of palliative care. 77.3 % felt uncomfortable in initiating a discussion about palliative care with the family members. 60.7 % were not comfortable with the care of the dying patient. 87.3 % strongly supported that a formal training in palliative care would improve their competence in this field. **CONCLUSIONS:** There is a huge lacunae in the delivery of palliative care services and hence an urgent need to inculcate targeted curriculum to provide focused skills and training for the pediatric postgraduates.

PMID: 24408397

41. Psychooncology. 2014 May;23(5):592-6. doi: 10.1002/pon.3469. Epub 2013 Dec 27.

Changes in self-reported distress in end-of-life pediatric cancer patients and their parents using the pediatric distress thermometer.

Patel SK¹, Fernandez N, Wong AL, Mullins W, Turk A, Dekel N, Smith M, Ferrell B.:

ABSTRACT: The majority of children who are diagnosed with cancer survive; however, 20% will die from the disease. Assessment of cancer-related quality of life in children may occur at many points following diagnosis, but typically neglected towards the end-of-life phase. This appears counterintuitive given that suffering becomes more severe as death approaches and the subsequent need for clinical services may be at its highest. Fortunately, with increased national attention to palliative care, the research and clinical focus on understanding the end-of-life issues faced by patients and caregivers is increasing, with beneficial impact on quality of supportive care.

PMID: 24375665

42. MCN Am J Matern Child Nurs. 2014 May-Jun;39(3):198-204. doi: 10.1097/NMC.000000000000026.

Combining regional expertise to form a bereavement support alliance.

Friedrichs JB¹, Kobler K, Roose RE, Meyer C, Schmitz N, Kavanaugh K.

ABSTRACT: Providing compassionate bereavement care for families experiencing perinatal loss is a standard of care in most healthcare organizations. In this article, we describe the development of The Alliance of Perinatal Bereavement Support Facilitators, begun over 25 years ago in Chicago by staff who identified the need to reach out to colleagues at other area institutions for advice and support in this work. This collaboration created a regional support network that has resulted in a long-lasting, active, sustainable organization of excellence focused on enhancing practice, education, and perinatal bereavement care. Alliance activities center around four main areas: education, networking/support, policy, and recognizing outstanding service to families. By continuing to draw upon the collective talent, wisdom, and expertise of its members, The Alliance still serves grieving families and provides mentoring for future interdisciplinary team members engaged in this work. The path taken to build this organization can be used by professionals in other specialties who are looking to create their own alliance infrastructure based on mutual benefit and interest.

PMID: 24759313

43. Journal of Palliative Medicine (J PALLIAT MED), 2014 May; 17 (5): 521-6.

Assessing Prognostic Documentation and Accuracy among Palliative Care Clinicians.

Zibelman, Matthew; Xiang, Oun; Muchka, Sandra; Nickoloff, Sarah; Marks, Sean

BACKGROUND: Prognostication is an important element of palliative care consultations. Research has shown that estimated survivals offered by clinicians are often inaccurate; however, few of these studies have focused on the documentation and prognostic accuracy of palliative care providers. **OBJECTIVE:** Our aim was to determine whether palliative care clinicians document specific estimates of survival in the electronic medical record and whether these survival estimates are accurate.

METHODS: We retrospectively analyzed 400 consecutive, new palliative care consults at an urban, academic medical center from October 1, 2009 to December 31, 2010. Descriptive statistics were used to summarize patient demographics, median patient survival, documented estimated survival, agreement between estimated and actual survival, and agreement differences among disease groups. **RESULTS:** The inpatient consult note template was utilized by the clinicians in 94.2% of the patients analyzed, and 69.4% of the patients analyzed had a specific survival estimate documented. Of the patients with specific survival estimates documented, 42.6% died in the time frame estimated. Weighted kappa coefficients and Kaplan survival estimators showed fair to moderate agreement between actual survival and estimated survival offered by palliative care clinicians. Survival groups with the shortest prognosis had the most accurate estimates of prognosis. Cancer had the least agreement between estimated and actual survival among disease types. Overestimation of survival was the most common prognostic error. Use of a template resulted in significantly greater documentation of a specific estimated survival.

CONCLUSIONS: The prognostic accuracy of palliative care physicians in this study was similar to physician accuracy in other studies. Trends toward overestimation were also similar to those seen in previous research. Use of a template in the

electronic medical record (EMR) increases documentation of estimated prognosis.

PMID: 24720384

44. Palliative Medicine (PALLIAT MED), 2014 Jun; 28 (6): 530-3.

[The Paediatric Palliative Screening Scale: Further validity testing.](#)

[Bergstraesser, Eva; Paul, Michaela; Rufibach, Kaspar; Hain, Richard D; Held, Leonhard](#)

BACKGROUND: Paediatric palliative care is still often introduced late in the illness trajectory of children with life-limiting diseases. Translating palliative care into practice continues to be a challenge. **AIM:** To validate the Paediatric Palliative Screening Scale further by defining attributes that predict the need for palliative care in children between 1 and 18 years. **DESIGN:** Proportional-odds logistic regression analysis was performed to investigate the relationship between the attributes of the Paediatric Palliative Screening Scale and the experts' assessment of case vignettes with various combinations of different attribute characteristics. Estimates from regression analysis were transformed to empirical weightings of the Paediatric Palliative Screening Scale attribute characteristics. **SETTING/PARTICIPANTS:** Online questionnaires with case vignettes were sent to 33 paediatric palliative care experts from Europe, the United States, Canada, Australia and New Zealand. **RESULTS:** The highest weightings among the five previously defined attributes were estimated life expectancy <12 months (40% of maximum score) and preferences of the child/parents received (24%). Trajectory of disease and impact on daily activities of the child, expected outcome of treatment directed at the disease and burden of treatment, and symptom or problem burden were weighted less. **CONCLUSIONS:** According to this second step of psychometric testing of the Paediatric Palliative Screening Scale, the strongest and most urgent necessity indicators for a palliative care approach are life expectancy and child/family preferences. These results are somewhat discrepant with results from the previous validation of the instrument as well as previous research findings.

PMID: 24280277

45. Indian Journal of Palliative Care (INDIAN J PALLIAT CARE), 2014 May-Aug; 20 (2): 112-5.

[Palliative Approach in Advanced Pelvic Osteosarcoma: A Single Centre Experience of a Rare Disease.](#)

[Kumar, Ritesh; Kapoor, Rakesh; Khosla, Divya; Kumar, Narendra; Singh, Pramod Kumar; Kumar, Mahendra; Sharma, S. C.](#)

BACKGROUND: Pelvic osteosarcoma is a rare and aggressive malignant neoplasm with poor outcomes. It represents only 5% of all osteosarcomas. The authors present our institute's experience in management and outcomes of five successive patients of pelvic osteosarcoma. **MATERIALS AND METHODS:** We retrospectively reviewed five patients of pelvis osteosarcoma treated in our institute from September 2008 to December 2010. Clinical characteristics and treatment (CCT) modality in form of surgery and chemotherapy were noted. Statistical analysis was done with regards to progression-free survival (PFS) using Kaplan-Meier survival analysis. **RESULTS:** The median age of the patients was 16.0 years. The median duration of symptoms was 9 months. One patient had lung metastases at presentation. All patients received systemic chemotherapy. One patient underwent surgery in the form of limb sparing approach. Three patients had partial response to treatment, one had complete response, and one had progressive disease. Median duration of PFS was 7 months only. **CONCLUSIONS:** Pelvic osteosarcomas are rare neoplasms with aggressive growth patterns. Survival results are poor in view of advanced stage of presentation and difficult surgical approaches. The combined modality approach is needed to improve the results.

NLM UID: 101261221

46. International Journal of Palliative Nursing (INT J PALLIAT NURS), 2014 Apr; 20 (4): 165-71. (15 ref)

[Sharing the care: the key-working experiences of professionals and the parents of life-limited children.](#)

[Rodriguez, Alison; King, Nigel](#)

AIMS: To explore the lived experience of caring and care planning for a child with a life-limiting condition (LLC). **METHOD:** Using van Manen's conceptualisation of hermeneutic phenomenology, three focus groups were conducted with 21 paediatric palliative care professionals, and interviews were conducted with 20 parents of children with LLCs. **FINDINGS:** Parents' expectations for support were raised by the diagnosis, but the reality could disappoint, which put pressures on professionals. Current service designs with respect to key working did not always coincide with family preferences. Both parents and professionals found that the care journey required them to shift personas to respond to different contexts. **CONCLUSIONS:** The findings are limited by the sample characteristics, but they provide insight for current policy and practice initiatives. The key worker needs to be mindful of historical care arrangements and be prepared to step into the family 'team' arrangements.

PMID: 24763324

47. Journal of Palliative Medicine (J PALLIAT MED), 2014 Apr; 17 (4): 475-81.

[Comparing Unmet Needs between Community-Based Palliative Care Patients with Heart Failure and Patients with Cancer.](#)

[Kavalieratos, Dio; Kamal, Arif H.; Abernethy, Amy P.; Biddle, Andrea K.; Carey, Timothy S.; Dev, Sandesh; Reeve, Bryce B.; Weinberger, Morris](#)

BACKGROUND: As the role of palliative care (PC) has yet to be clearly defined in patients with heart failure (HF), such patients may face barriers regarding PC referral. In order to maximally meet the needs of HF patients, it is necessary to understand how they compare to the classic PC population: patients with cancer. **OBJECTIVE:** To characterize the unresolved symptom and treatment needs with which patients with HF and those with cancer present to PC. **METHODS:** We used data from the Palliative Care Research Registry (PCRR), a repository of quality improvement data from three community-based PC organizations. We abstracted first PC visit data from the PCRR for patients with primary diagnoses of HF or cancer seen between 2008 and 2012. We assessed the association of primary diagnosis (i.e., HF or cancer) on three outcomes: unresolved symptoms, treatment gaps, and a composite indicator of symptom control and quality of life. Analyses included descriptive statistics and multivariate Poisson regression. **RESULTS:** Our analytic sample comprised 334 patients with HF and

697 patients with cancer, the majority of whom were white and male. Compared to patients with cancer, patients with HF presented with fewer unresolved symptoms, both overall and at moderate/severe distress levels. Patients with HF more commonly reported moderately/severely distressful dyspnea (25% versus 18%, $p=0.02$), and more commonly experienced dyspnea-related treatment gaps (17% versus 8%, $p<0.001$). **CONCLUSIONS:** Patients with HF possess care needs that are squarely within the purview of PC. Future work is needed to delineate how PC referral policies should be refined to optimize PC access for patients with HF.

PMID: 24588568

48. Palliative Medicine (PALLIAT MED), 2014 Jun; 28 (6): 461-2.

To check or not to check: The role of checklists in children's palliative care.

Knapp, Caprice

Children's palliative care is somewhat of a paradox. It was patient-centered long before patient-centered became a popular term for funders and policymakers. It began as multidisciplinary, collaborative, and comprehensive as opposed to other areas in medicine that until recently were far from being teams based. It seeks to address the mind, body, and spirit in an era when most pediatric care is defined by 15-min intervals in which addressing the body is all that can be managed. It transcends cultures, as the death of a child is a loss that no parent would ever want to face. Yet, if children's palliative care is all of these things, why does it seem that something is holding us back?

NLM UID: 8704926

49. Journal of Palliative Medicine (J PALLIAT MED), 2014 Apr; 17 (4): 469-71.

Palliative Care Answers the Challenges of Transitioning Serious Illness of Childhood to Adult Medicine.

Ajayi, Toluwalase A.; Edmonds, Kyle P.

ABSTRACT Advances in the field of medicine have improved the overall life expectancy in children. Consequently, many children with previously lethal diseases now live into adulthood. There is an urgent need to develop approaches that assist with the transition of care from pediatrics to adult medicine. Palliative care, by virtue of its unique skills, is ideally positioned to play a part in this transition. This report will summarize the urgency for proper transition modalities and then introduce palliative care as a proposed solution for current challenges in transition. Along the way, it will touch on financial and workforce obstacles to this solution and will offer a potential funding option.

PMID: 24380449 NLM UID: 9808462

50. Palliative Medicine (PALLIAT MED), 2014 May; 28 (5): 412-21.

End-of-life care and achieving preferences for place of death in England: Results of a population-based survey using the VOICES-SF questionnaire.

Hunt, Katherine J; Shlomo, Natalie; Addington-Hall, Julia

BACKGROUND/AIM: Health policy places emphasis on enabling patients to die in their place of choice, and increasing the proportion of home deaths. In this article, we seek to explore reported preferences for place of death and experiences of care in a population-based sample of deaths from all causes. **DESIGN:** Self-completion post-bereavement survey. **SETTING/PARTICIPANTS:** Census of deaths registered in two health districts between October 2009 and April 2010. Views of Informal Carers - Evaluation of Services Short Form was sent to each informant ($n = 1422$; usually bereaved relative) 6-12 months post-bereavement. **RESULTS:** Response was 33%. In all, 35.7% of respondents reported that the deceased said where they wanted to die, and 49.3% of these were reported to achieve this. Whilst 73.9% of those who were reported to have a preference cited home as the preferred place, only 13.3% of the sample died at home. Cancer patients were more likely to be reported to achieve preferences than patients with other conditions ($p < .01$). Being reported to have a record of preferences for place of death increased the likelihood of dying at home (odds ratio = 22.10). When rating care in the last 2 days, respondents were more likely to rate 'excellent' or 'good' for nursing care ($p < .01$), relief of pain ($p < .01$) and other symptoms ($p < .01$), emotional support ($p < .01$) and privacy of patient's environment ($p < .01$) if their relative died in their preferred place. **CONCLUSIONS:** More work is needed to encourage people to talk about their preferences at the end of life: this should not be restricted to those known to be dying. Increasing knowledge and achievement of preferences for place of death may also improve end-of-life care.

PMID: 24292157 NLM UID: 8704926

51. International Journal of Palliative Nursing (INT J PALLIAT NURS), 2014 Apr; 20 (4): 173-8. (23 ref)

Bereavement support used by mothers in Ireland following the death of their child from a life-limiting condition.

Jennings, Valerie; Nicholl, Honor

BACKGROUND: Children's palliative care is a rapidly developing specialism internationally. Bereavement support is an integral component of children's palliative care but to date little research has investigated the bereavement support that mothers in Ireland use following the death of their child. **OBJECTIVE:** The aim of this study was to explore mothers' experiences of bereavement support in Ireland following the death of their child from a life-limiting condition. **METHOD:** A descriptive qualitative design was used. The study sample was ten mothers who had been bereaved in the previous 5 years. All mothers were recruited to the study by a gatekeeper from a voluntary organisation. Data were obtained through unstructured single interviews and analysed using conventional content analysis. **RESULTS:** The findings indicate that the mothers relied on a combination of informal and formal bereavement support. In addition to depending on others to provide support, the mothers described their ability to self-support. **CONCLUSIONS:** The findings show that mothers in Ireland use a variety of sources of support following the death of their child from a life-limiting condition. Health professionals involved in caring for families and children with a life-limiting condition should have an understanding of these sources.

PMID: 24763325 NLM UID: 9506762

52. Palliative Medicine (PALLIAT MED), 2014 Apr; 28 (4): 342-52.

Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study.

Kirk, Susan; Fraser, Claire

BACKGROUND: Transition to adult services and adulthood is now a prospect for young people with life limiting conditions requiring palliative care. Little is known about their transition experiences or how children's hospices can support a young adult population during/following transition. **AIMS:** (1) To examine how young people with life-limiting conditions and their parents experience transition. (2) To identify families' and hospice staff's perceptions of family support needs during transition. (3) To identify the implications for children's hospices. **DESIGN:** Qualitative study using in-depth, semi-structured interviews. Analysis used a grounded theory approach. **SETTING/PARTICIPANTS:** A total of 39 participants recruited from one children's hospice in the United Kingdom. **RESULTS:** Transition planning was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. Consequently, it was a time of uncertainty and anxiety for families. Moving to a young adult unit was a positive experience for young people as the building/support model recognised their adult status. However, they had unmet needs for emotional support and accessing information/services to realise their aspirations. Parents had unmet emotional needs and were unclear of support available once their children reached adulthood. Staff identified training needs in relation to working with adults, providing emotional support and acting as an advocate/key worker. **CONCLUSIONS:** Providing an appropriate building is only one aspect of developing support for young adults. A different model of support is needed, one which promotes young people's independence and provides emotional support while continuing to support parents and siblings. Hospices could play a role in transition support and coordination.

PMID: 24142761

53. Palliative Medicine (PALLIAT MED), 2014 Jun; 28 (6): 513-20.

Patterns of diagnoses among children and young adults with life-limiting conditions: A secondary analysis of a national dataset.

Fraser, Lorna K; Lidstone, Victoria; Miller, Michael; Aldridge, Jan; Norman, Paul; McKinney, Patricia A; Parslow, Roger C

BACKGROUND: Numbers of children and young people with life-limiting conditions are rising, and increasing lifespans require young adults with life-limiting condition to transit to appropriate adult services. **AIM:** To describe the prevalence of life-limiting condition in children and young adults by age, sex, diagnostic group, ethnicity and deprivation. **DESIGN:** A secondary analysis of the English Hospital Episode Statistics dataset was undertaken to calculate prevalence per 10,000 population. **SETTING/PARTICIPANTS:** Individuals (0-40 years) with life-limiting conditions were identified within an English Hospital Episode Statistics dataset by applying a customised coding framework of International Classification of Diseases, 10th Edition, disease codes. **RESULTS:** There were 462,962 inpatient hospital admissions for 92,129 individual patients with a life-limiting condition. Prevalence-by-age group curve is U shaped with the highest overall prevalence in the under 1-year age group (127.3 per 10,000), decreasing until age 21-25 years (21.1 per 10,000) before rising steeply to reach 55.5 per 10,000 in the 36-40 -year age group. The distribution by diagnostic group varies by age: congenital anomalies are most prevalent in children until age 16-20 years with oncology diagnoses then becoming the most prevalent. **CONCLUSION:** Non-malignant diagnoses are common in children and young adults, and services that have historically focussed on oncological care will need to widen their remit to serve this population of life-limited patients. The diagnosis determining a patient's life-limiting condition will strongly influence their palliative care service needs. Therefore, understanding the diagnostic and demographic breakdown of this population of teenagers and young adults is crucial for planning future service provision.

PMID: 24699788

54. Palliative Medicine (PALLIAT MED), 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

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

PMID: 24577064

55. International Journal of Palliative Nursing (INT J PALLIAT NURS), 2014 Apr; 20 (4): 201. (1 ref)

Corrigendum... Stephen R Connor, Chenjari Sisimayi, Julia Downing, Evelyn King, Patricia Lim Ah Ken, Rachel Yates, Barbara Ikin, Joan Marston (2014) *Assessment of the need for palliative care for children in South Africa.*

Int J Palliat Nurs 20(3): 130–4.

ABSTRACT: UNICEF and the International Children's Palliative Care Network undertook a joint analysis in three sub-Saharan countries—Zimbabwe, South Africa, and Kenya—to estimate the palliative care need among their children and to explore these countries' capacities to deliver children's palliative care (CPC). This report concerns the findings from South Africa. The study adopted a cross-sectional mixed-methods approach using both quantitative and qualitative data obtained from primary and secondary sources. CPC need was estimated using prevalence and mortality statistics. The response to the need and existing gaps were analysed using data obtained from a literature review, interviews with key persons, and survey data from service providers. The findings show very limited CPC service coverage for children in the public sector. In addition, services are mainly localised, with minimal reach. Less than 5% of the children needing care in South Africa are receiving it, with those receiving it being closer to the end of life. Barriers to the delivery of CPC include fear of opioid use, lack of education on CPC, lack of integration into the primary care system, lack of policies on CPC, and lack of community and health professional awareness of CPC needs and services. Estimating the need for CPC is a critical step in meeting the needs of children with life-threatening conditions and provides a sound platform to advocate for closure of the unacceptably wide gaps in coverage

PMID: 24763329

56. Death Studies (DEATH STUD), 2014 May; 38 (5): 302-7.

[Disclosing Terminal Diagnosis to Children and Their Families: Palliative Professionals' Communication Barriers.](#)

[Coad, Jane; Patel, Reena; Murray, Sarah](#)

ABSTRACT Few studies have fully explored the problem of communication barriers in pediatric palliative care, particularly the detrimental effects of poor interaction between staff and families on children's health and well-being. A literature review was undertaken to expand the current body of knowledge about staff to patient communications. Articles meeting the inclusion criteria (N = 15) were systematically read and summarized using a data extraction sheet. A narrative synthesis identified 5 overarching themes as barriers to communication. Improvements in staff education and individualized palliative care plans for children and their families may help to overcome communication barriers.

PMID: 24593008 NLM UID: 8506890

57. Archives of Disease in Childhood (ARCH DIS CHILD), 2014 Apr; 99 (4): 327-30.

[Use of formal advance care planning documents: a national survey of UK Paediatric Intensive Care Units.](#)

[Mitchell, Sarah; Plunkett, Adrian; Dale, Jeremy](#)

OBJECTIVE: Advance Care Planning (ACP) is nationally a core element of adult and paediatric palliative care strategies. It is defined as a process of discussion between an individual, their care providers and those close to them, about future care. Formal procedures and processes can help with some of the most difficult elements of communication related to ACP. The majority of children who die do so in a Paediatric Intensive Care Unit (PICU). This survey aimed to identify and compare paediatric ACP documents that are in use within UK hospitals with a PICU. **DESIGN:** Email survey of lead clinicians from UK PICUs (n=28). **RESULTS:** 24 (86%) questionnaires were returned. 14 (58%) responded that formal ACP documents were currently in use within their hospital trust. Of the remainder, 2 (8%) detailed plans to launch local ACP documents in the near future, 1 (4%) had a 'Children and Young Persons Deterioration Management (CAYPDM) Document' and 3 (12%) listed rapid discharge and extubation pathways. 6 (25%) provided details of the document in use. They varied widely in terms of their presentation, content and intended use with some having been developed locally and others having been adopted across regions. **CONCLUSIONS:** There is variation around the UK in the existence of formal ACP documents for paediatric patients with palliative care needs, as well as variation in the type of document that is used. Consideration of a national policy should be informed by further review and evaluation of these documents, as well as current practice in ACP.

PMID: 24336425 NLM UID: 0372434

58. Home Healthcare Nurse (HOME HEALTHC NURSE), 2014 May; 32 (5): 268.

[NIH Makes Palliative Care More Attainable for Pediatric Patients and Their Families.](#)

[\(No author listed\)](#)

A campaign just launched by the National Institute of Nursing Research (NINR) aims to increase the use of palliative care — comprehensive treatment of the discomfort, symptoms, and stress of serious illness — for children with serious illness. Palliative care can reduce a child's pain, help manage other distressing symptoms, and provide important emotional support to the child and family throughout the course of an illness.

Research has shown that pediatric palliative care services may also increase overall satisfaction with care for patients and their families. Yet, many health care providers hesitate to recommend palliative care for their youngest patients, and parents and caregivers are often unaware of its benefits.

NLM UID: 8403379

59. International Journal of Palliative Nursing (INT J PALLIAT NURS), 2014 May; 20 (5): 211.

[Euthanasia for children and young people?](#)

[Kelly, Daniel](#)

Abstract In February 2014 the Belgian parliament voted to extend the existing euthanasia law to cover children under the age of 18. The law sanctions euthanasia for children with terminal or incurable conditions who are near death, suffering 'constant and unbearable pain', and whose parents and health professionals agree with the decision. The child also has to be interviewed by a psychologist or psychiatrist to ascertain and certify their 'capacity of discernment'.

PMID: 24852024

60. *Oncologist (ONCOLOGIST)*, 2014; 19 (5): 515-22.

An Ethnographic Study of Barriers to Cancer Pain Management and Opioid Availability in India.

Lebaron, Virginia; Beck, Susan L.; Maurer, Martha; Black, Fraser; Palat, Gayatri

BACKGROUND. The world's global cancer burden disproportionately affects lower income countries, where 80% of patients present with late-stage disease and have limited access to palliative care and effective pain-relieving medications, such as morphine. Consequently, millions die each year with unrelieved pain. **OBJECTIVE.** The objective of this study was to examine barriers to opioid availability and cancer pain management in India, with an emphasis on the experiences of nurses, who are often the front-line providers of palliative care. **METHODS.** Fifty-nine participants were recruited using a purposive, snowball sampling strategy. Ethnographic data collection included in-depth, semistructured interviews (n = 54), 400+ hours of participant observation, and review of documents over 9 months at a government cancer hospital in South India. Systematic qualitative analysis led to identification of key barriers that are exemplified by representative quotes. Results. Morphine is more available at this study site than in most of India, but access is limited to patients seen by the palliative care service, and significant gaps in supply still occur. Systems to measure and improve pain outcomes are largely absent. Key barriers related to pain management include the role of nursing, opioid misperceptions, bureaucratic hurdles, and sociocultural/infrastructure challenges. **IMPLICATIONS.** Interventions must streamline process details of morphine procurement, work within the existing sociocultural infrastructure to ensure opioids reach patients most in need, target unexpected audiences for symptom management education, and account for role expectations of health care providers.

CONCLUSION. Macro- and micro-level policy and practice changes are needed to improve opioid availability and cancer pain management in India.

PMID: 24755460 NLM UID: 9607837

61. *Nursing Children & Young People (NURS CHILD YOUNG PEOPLE)*, 2014 Apr; 26 (3): 16-20. (19 ref)

Meeting the needs of siblings of children with life-limiting illnesses.

Lane, Catherine; Mason, Joanne

ABSTRACT: Siblings of children with life-threatening or life-limiting illnesses can face a number of challenges, yet this is a group that is often unacknowledged as needing specific support. It is essential that the needs of siblings are recognised and addressed as part of a family-centred approach. This article discusses the experiences and challenges faced by siblings in such families and what children's nurses can do to help. In particular, it outlines a group intervention offered by a community children's palliative care service.

PMID: 24708334 NLM UID: 101554473

62. *BMJ: British Medical Journal (BMJ BR MED J)*, 2014 May 3; 348 (7956): 40.

Minerva.

Comment on Palliative care

63. *Indian Journal of Palliative Care (INDIAN J PALLIAT CARE)*, 2014 May-Aug; 20 (2): 101-6.

Preference of the Place of Death Among People of Pune.

Kulkarni, Priyadarshini; Kulkarni, Pradeep; Anavkar, Vrushali; Ghooi, Ravindra

AIM: Provision of end-of-life care requires that we have adequate information about the preferred place of death in the population. Since no such study is reported in India, this study was taken up in and around Pune, a large cosmopolitan city. **SETTING AND DESIGN:** A questionnaire was designed in three parts and distributed among the people above the age of 18 in and around Pune. **MATERIALS AND METHODS:** The questionnaire had three parts the first being a consent form, followed by one for collection of personal information and lastly questions specific to the subject matter. Filled forms were screened for inconsistencies, gaps of information and errors. **RESULTS:** The population survey was mixed, both urban and rural, men and women, educated and uneducated, young and old. Despite this heterogeneity, the results were consistent to the point that most of the people surveyed preferred home as the place of death. This preference cuts across all barriers, the only difference being that women had a stronger preference for home death compared to men. **CONCLUSIONS:** Helping people to die at their preferred place is a part of end-of-life care. Majority of people surveyed by us, prefer to die at home, where they are relatively more comfortable. Public and governmental policies should be directed toward facilitating home deaths.

NLM UID: 101261221

64. *International Journal of Palliative Nursing (INT J PALLIAT NURS)*, 2014 Apr; 20 (4): 194-200. (27 ref)

Swedish nursing students' reasoning about emotionally demanding issues in caring for dying patients.

Strang, Susann; Bergh, Ingrid; Ek, Kristina; Hammarlund, Kina; Pahl, Charlotte; Westin, Lars; Österlind, Jane; Henoch, Ingela

AIM: To describe nursing students' reasoning about emotionally demanding questions concerning the care of dying patients. **METHODS:** The Frommelt Attitude Toward Care of the Dying (FATCOD) Scale was completed by students at the beginning of their education, and there was great variation in the responses to five items. At a follow-up measurement in the second year, an open-ended question, 'How did you reason when completing this question?', was added to each of the these five items. Qualitative content analysis was used to analyse the responses. Results: Of 140 students who completed the FATCOD, 111 provided free-text responses. The analysis of these responses revealed three themes: death perceptions, the students' understanding of their current situation, and the nurse's responsibility. **CONCLUSION:** This study provides useful information on students' reasoning about emotionally demanding questions relating to the care of dying patients. Such knowledge is valuable in helping students to overcome their fear and fulfil their expectations concerning their future proficiency.

PMID: 24763328 NLM UID: 9506762

65. Journal of Advanced Nursing (J ADV NURS), 2014 Jun; 70 (6): 1243-53. (66 ref)

Spiritual care of the child with cancer at the end of life: a concept analysis.

Petersen, Cheryl L.

AIM The aim of this paper is to report an analysis of the concept of spiritual care of a child with cancer at the end of life.

BACKGROUND Spirituality is a vital dimension of a child's experience at the end of life; providing comfort; support; and a sense of connection. Spiritual care is paramount to address the substantial spiritual distress that may develop. Design Rodgers' method of evolutionary concept analysis guided the review process. **DATA SOURCES** The literature search was not limited by start date and literature through the end of 2012 was included. English, peer-reviewed texts in the databases CINAHL, ATLA and PubMed were included. **METHODS** Critical analysis of the literature identified surrogate terms, related concepts, attributes, antecedents and consequences. **RESULTS** The analysis identified six attributes: assessing spiritual needs; assisting the child to express feelings; guiding the child in strengthening relationships; helping the child to be remembered; assisting the child to find meaning; and aiding the child to find hope. Antecedents include existential questions and spiritual distress. **CONSEQUENCES** include a peaceful death, spiritual growth, a relationship of trust and enhanced end-of-life care. **CONCLUSION** Spiritual care is a vital aspect of holistic nursing care; however, gaps in knowledge and practice prevent children from receiving adequate spiritual care at the end of life. Nurses would benefit from increased awareness, skills and knowledge about spiritual care. Research is needed to identify interventions that exert the greatest effect on patient care outcomes.

PMID: 24102699 NLM UID: 7609811

66. Nursing Standard (NURS STAND), 2014 Apr 30; 28 (35): 71.

Personalised approach.

Lyon, Fiona

ABSTRACT Hospice nurse and clinical team leader Fiona Lyon describes the attractions and challenges of providing respite and end of life care for children and young people.

NLM UID: 8508427