

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

“La Buona informazione è la miglior medicina...”

Donald A.B. Lindberg



Terzo numero

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1. J Pediatr. 2015 May 28. [Epub ahead of print]

Research Priorities in Pediatric Palliative Care.

Baker JN¹, Levine DR², Hinds PS³, Weaver MS², Cunningham MJ⁴, Johnson L², Anghelescu D², Mandrell B⁵, Gibson DV², Jones B⁶, Wolfe J⁷, Feudtner C⁸, Friebert S⁹, Carter B¹⁰, Kane JR¹¹.

OBJECTIVE: To synthesize the perspectives of a broad range of pediatric palliative care (PPC) clinicians and parents, to formulate a consensus on prioritization of the PPC research agenda. **STUDY DESIGN:** A 4-round modified Delphi online survey was administered to PPC experts and to parents of children who had received PPC. In round 1, research priorities were generated spontaneously. Rounds 2 and 3 then served as convergence rounds to synthesize priorities. In round 4, participants were asked to rank the research priorities that had reached at least 80% consensus. **RESULTS:** A total of 3093 concepts were spontaneously generated by 170 experts and 72 parents in round 1 (65.8% response rate [RR]). These concepts were thematically organized into 78 priorities and recirculated for round 2 ratings (n = 130; 53.7% RR). Round 3 achieved response stability, with 31 consensus priorities oscillating within 10% of the mode (n = 98; 75.4% RR). Round 4 resulted in consensus recognition of 20 research priorities, which were thematically grouped as decision making, care coordination, symptom management, quality improvement, and education. **CONCLUSIONS:** This modified Delphi survey used professional and parental consensus to identify preeminent PPC research priorities. Attentiveness to these priorities may help direct resources and efforts toward building a formative evidence base. Investigating PPC implementation approaches and outcomes can help improve the quality of care services for children and families.

PMID: 26028284

2. Acta Paediatr. 2015 May 25. [Epub ahead of print]

Dutch neonatologists have adopted a more interventionist approach to neonatal care.

Koper JF¹, Bos AF¹, Janvier A², Verhagen AA¹.

AIM: This study investigated whether continuous improvements to neonatal care and the legalisation of newborn euthanasia in 2005 had changed end-of-life decisions by Dutch neonatologists. **METHODS:** We carried out a retrospective study of fetuses and neonates of more than 22 weeks' gestation that died in the delivery room or in the neonatal intensive care unit (NICU) of a tertiary referral hospital in the Netherlands, comparing end-of-life decisions and mortality in 2001-2003 and 2008-2010, before and after euthanasia legislation was introduced. **RESULTS:** In 2008-2010 there were more deaths in the delivery room due to termination of pregnancy than in 2001-2003 (17% versus 29%, p = 0.031) and fewer infants received comfort medication (12% versus 20%, p = 0.078). The main mode of death in the NICU was the withdrawal of life-sustaining therapy. The number of days that infants lived increased significantly between 2001-2003 (11.5 days) and 2008-2010 (18.4 days, p < 0.006). Most infants received comfort medication and neuromuscular blocking agents were administered incidentally. **CONCLUSION:** Terminations increased after changes in healthcare regulations. Modes of death in the NICU remained similar over 10 years. The increased duration of NICU treatment before dying suggests a more interventionist approach to treatment in 2008-2010. This article is protected by copyright. All rights reserved.

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PMID: 26014464

3. J Pediatr. 2015 May 23. [Epub ahead of print]

Sedatives and Analgesics Given to Infants in Neonatal Intensive Care Units at the End of Life.

Zimmerman KO¹, Hornik CP¹, Ku L¹, Watt K¹, Laughon MM², Bidegain M³, Clark RH⁴, Smith PB⁵.

OBJECTIVE: To describe the administration of sedatives and analgesics at the end of life in a large cohort of infants in North American neonatal intensive care units. **STUDY DESIGN:** Data on mortality and sedative and analgesic administration were from infants who died from 1997-2012 in 348 neonatal intensive care units managed by the Pediatrix Medical Group. Sedatives and analgesics of interest included opioids (fentanyl, methadone, morphine), benzodiazepines (clonazepam, diazepam, lorazepam, midazolam), central alpha-2 agonists (clonidine, dexmedetomidine), ketamine, and pentobarbital. We used multivariable logistic regression to evaluate the association between administration of these drugs on the day of death and infant demographics and illness severity. **RESULTS:** We identified 19 726 infants who died. Of these, 6188 (31%) received a sedative or analgesic on the day of death; opioids were most frequently administered, 5366/19 726 (27%). Administration of opioids and benzodiazepines increased during the study period, from 16/283 (6%) for both in 1997 to 523/1465 (36%) and 295/1465 (20%) in 2012, respectively. Increasing gestational age, increasing postnatal age, invasive procedure within 2 days of death, more recent year of death, mechanical ventilation, inotropic support, and antibiotics on the day of death were associated with exposure to sedatives or analgesics. **CONCLUSIONS:** Administration of sedatives and analgesics increased over time. Infants of older gestational age and those more critically ill were more likely to receive these drugs on the day of death. These findings suggest that drug administration may be driven by severity of illness.

PMID: 26012893

4. Indian J Palliat Care. 2015 May-Aug;21(2):158-63.

Continuing professional development for volunteers working in palliative care in a tertiary care cancer institute in India: a cross-sectional observational study of educational needs.

Deodhar JK¹, Muckaden MA¹.

CONTEXT: Training programs for volunteers prior to their working in palliative care are well-established in India. However, few studies report on continuing professional development programs for this group. **AIMS:** To conduct a preliminary assessment of educational needs of volunteers working in palliative care for developing a structured formal continuing professional development program for this group. **SETTINGS AND DESIGN:** Cross-sectional observational study conducted in the Department of Palliative Medicine of a tertiary care cancer institute in India. **MATERIALS AND METHODS:** Participant volunteers completed a questionnaire, noting previous training, years of experience, and a comprehensive list of topics for inclusion in this program, rated in order of importance according to them. **STATISTICAL ANALYSIS USED:** Descriptive statistics for overall data and Chi-square tests for categorical variables for group comparisons were applied using Statistical Package for Social Sciences version 18. **RESULTS:** Fourteen out of 17 volunteers completed the questionnaire, seven having 5-10-years experience in palliative care. A need for continuing professional development program was felt by all participants. Communication skills, more for children and elderly specific issues were given highest priority. Spiritual-existential aspects and self-care were rated lower in importance than psychological, physical, and social aspects in palliative care. More experienced volunteers (>5 years of experience) felt the need for self-care as a topic in the program than those with less (<5-years experience) ($P < 0.05$). **CONCLUSIONS:** Understanding palliative care volunteers' educational needs is essential for developing a structured formal continuing professional development program and should include self-care as a significant component.

PMID: 26009668

5. Palliat Support Care. 2015 May 22:1-7.

Listening to parents: The role of symptom perception in pediatric palliative home care.

Vollenbroich R¹, Borasio GD², Duroux A¹, Grasser M¹, Brandstätter M³, Führer M¹.

OBJECTIVE: This study analyzes symptom perception by parents and healthcare professionals and the quality of symptom management in a pediatric palliative home care setting and identifies which factors contribute to a high quality of palliative and end-of-life care for children. **METHODS:** In this retrospective, cross-sectional study, parents were surveyed at the earliest three months after their child's death. All children were cared for by a specialized home pediatric palliative care team that provides a 24/7 medical on-call service. Questionnaires assessed symptom prevalence and intensity during the child's last month of life as perceived by parents, symptom perception, and treatment by medical staff. The responses were correlated with essential palliative care outcome measures (e.g., satisfaction with the care provided, quality-of-life of affected children and parents, and peacefulness of the dying phase). **RESULTS:** Thirty-eight parent dyads participated (return rate 84%; 35% oncological disorders). According to parental report, dyspnea (61%) and pain (58%) were the dominant symptoms with an overall high symptom load (83%). Pain, agitation, and seizures could be treated more successfully than other symptoms. Successful symptom perception was achieved in most cases and predicted the quality of symptom treatment (R^2 , 0.612). Concordant assessment of symptom severity between parents and healthcare professionals (HCPs) improved the satisfaction with the care provided ($p = 0.037$) as well as the parental quality-of-life ($p = 0.041$). Even in cases with unsuccessful symptom control, parents were very satisfied with the SHPPC team's care (median 10; numeric rating scale 0-10) and rated the child's death as highly peaceful (median 9). Significance of the results: The quality and the concordance of symptom perception between parents and HCPs essentially influence parental quality-of-life as well as parental satisfaction and constitute a predictive factor for the quality of symptom treatment and palliative care.

PMID: 25998176

6. PLoS One. 2015 May 15;10(5):e0126861. [Epub ahead of print]

Barriers in referring neonatal patients to perinatal palliative care: a French multicenter survey.

Tosello B¹, Dany L², Bétrémieux P³, Le Coz P⁴, Auquier P⁵, Gire C⁶, Einaudi MA⁴.

BACKGROUND: When an incurable fetal condition is detected, some women (or couples) would rather choose to continue with the pregnancy than opt for termination of pregnancy for medical reasons, which, in France, can be performed until full

term. Such situations are frequently occurring and sometimes leading to the implementation of neonatal palliative care. The objectives of this study were to evaluate the practices of perinatal care french professionals in this context; to identify the potential obstacles that might interfere with the provision of an appropriate neonatal palliative care; and, from an opposite perspective, to determine the criteria that led, in some cases, to offer this type of care for prenatally diagnosed lethal abnormality. **METHODS:** We used an email survey sent to 434 maternal-fetal medicine specialists (MFMs) and fetal care pediatric specialists (FCPs) at 48 multidisciplinary centers for prenatal diagnosis (MCPD). **RESULTS:** Forty-two multidisciplinary centers for prenatal diagnosis (87.5%) took part. In total, 102 MFMs and 112 FCPs completed the survey, yielding response rate of 49.3%. One quarter of professionals (26.2%) estimated that over 20% of fetal pathologies presenting in MCPD could correspond to a diagnosis categorized as lethal (FCPs versus MFMs: 24% vs 17.2%, $p = 0.04$). The mean proportion of fetal abnormalities eligible for palliative care at birth was estimated at 19.30% (± 2.4) (FCPs versus MFMs: 23.4% vs 15.2%, $p = 0.029$). The degree of diagnostic certainty appears to be the most influencing factor (98.1%, $n = 207$) in the information provided to the pregnant woman with regard to potential neonatal palliative care. The vast majority of professionals, 92.5%, supported considering the practice of palliative care as a regular option to propose antenatally. **CONCLUSIONS:** Our study reveals the clear need for training perinatal professionals in perinatal palliative care and for the standardization of practices in this field.

PMID: 25978417

7. BMJ Support Palliat Care. 2015 Apr;5 Suppl 1:A29.

PA32 Family centred health care: a palliative care approach to engage communities to address the burden of hiv in tanzania abstract.

Frank M¹, Msembo D², Muganyizi E³, Mbando P⁴, Kayange A⁵

BACKGROUND: Tanzania is one of the countries most devastated by HIV and AIDS in the sub Saharan Africa. The Government of Tanzania has called for a community participation to address the burden of HIV in Tanzania(1) however the uptake of this call has been minimal. This paper intends to describe the role of Palliative Medicine in engaging communities to address burden of HIV in Tanzania. **AIM:** We aim to improve health outcomes of HIV+ children by engaging families through utilisation of palliative care principles in a low resource setting Method Single child with recurrent illness, multiple social spiritual and psychological problems was purposely selected from a pool of HIV+ children attending a PASADA HIV clinic and was offered care through palliative care approach. An interdisciplinary team of health providers was formed, goals of care were identified and care plan developed. Family members empowered with knowledge and skills to live with a HIV+ child and assigned specific role to ensure the boy's physical, psychological and spiritual needs are met. Through retrospective chart review, clinical meetings, counselling sessions with the child, family and providers information was gathered to enrich our understanding of the process. **RESULTS:** Goals of care were met: cleared infections, tested for HIV, resumed school, and family unified. Hundreds of children benefited from the experience generated and expansion of the approach was governed by community engagement. **CONCLUSION:** Families when empowered have much potentials that can reverse sufferings due to diseases through application of Palliative Care Principles in practice. **REFERENCE:** Tanzania Commission for AIDS. 2008 Annual Report.

PMID: 25960518

8. J Palliat Med. 2015 Apr 30. [Epub ahead of print]

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

Flerlage JE¹, Baker JN.

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

PMID: 25927665

9. J Palliat Med. 2015 Apr 30. [Epub ahead of print]

Place of Death among Hospitalized Patients with Cancer at the End of Life.

Wallace SK¹, Waller DK, Tilley BC, Piller LB, Price KJ, Rathin N, Haque S, Nates JL.

BACKGROUND: The majority of hospital deaths in the United States occur after ICU admission. The characteristics associated with the place of death within the hospital are not known for patients with cancer. **OBJECTIVE:** The study objective was to identify patient characteristics associated with place of death among hospitalized patients with cancer who were at the end of life. **METHODS:** A retrospective cohort study design was implemented. Subjects were consecutive patients hospitalized between 2003 and 2007 at a large comprehensive cancer center in the United States. Multinomial logistic regression analysis was used to identify patient characteristics associated with place of death (ICU, hospital following ICU, hospital

without ICU) among hospital decedents. **RESULTS:** Among 105,157 hospital discharges, 3860 (3.7%) died in the hospital: 42% in the ICU, 14% in the hospital following an ICU stay, and 44% in the hospital without ICU services. Individuals with the following characteristics had an increased risk of dying in the ICU: nonlocal residence, newly diagnosed hematologic or nonmetastatic solid tumor malignancies, elective admission, surgical or pediatric services. A palliative care consultation on admission was associated with dying in the hospital without ICU services. **CONCLUSIONS:** Understanding existing patterns of care at the end of life will help guide decisions about resource allocation and palliative care programs. Patients who seek care at dedicated cancer centers may elect more aggressive care; thus the generalizability of this study is limited. Although dying in a hospital may be unavoidable for patients who have uncontrolled symptoms that cannot be managed at home, palliative care consultations with patients and their families in advance regarding end-of-life preferences may prevent unwanted admission to the ICU.

PMID: 25927588

10. Palliat Med. 2015 Apr 28. [Epub ahead of print]

Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review.

Weaver MS¹, Heinze KE², Bell CJ³, Wiener L⁴, Garee AM⁵, Kelly KP⁶, Casey RL⁷, Watson A⁸, Hinds PS; Pediatric Palliative Care Special Interest Group at Children's National Health System.

BACKGROUND: Despite standardization in disease assessments and curative interventions for childhood cancer, palliative assessments and psychosocial interventions remain diverse and disparate. **AIM:** Identify current approaches to palliative care in the pediatric oncology setting to inform development of comprehensive psychosocial palliative care standards for pediatric and adolescent patients with cancer and their families. Analyze barriers to implementation and enabling factors.

DESIGN: Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines framed the search strategy and reporting. Data analysis followed integrative review methodology. **DATA SOURCES:** Four databases were searched in May 2014 with date restrictions from 2000 to 2014: PubMed, Cochrane, PsycINFO, and Scopus. A total of 182 studies were included for synthesis. Types of studies included randomized and non-randomized trials with or without comparison groups, qualitative research, prior reviews, expert opinion, and consensus report. **RESULTS:** Integration of patient, parent, and clinician perspectives on end-of-life needs as gathered from primary manuscripts (using NVivo coding for first-order constructs) revealed mutual themes across stakeholders: holding to hope, communicating honestly, striving for relief from symptom burden, and caring for one another. Integration of themes from primary author palliative care outcome reports (second-order constructs) revealed the following shared priorities in cancer settings: care access; cost analysis; social support to include primary caregiver support, sibling care, bereavement outreach; symptom assessment and interventions to include both physical and psychological symptoms; communication approaches to include decision-making; and overall care quality. **CONCLUSION:** The study team coordinated landmark psychosocial palliative care papers into an informed conceptual model (third-order construct) for approaching pediatric palliative care and psychosocial support in oncology settings.

PMID: 25921709

11. Paediatr Child Health. 2015 Apr;20(3):159-65.

Challenging neurological symptoms in paediatric palliative care: An approach to symptom evaluation and management in children with neurological impairment.

Rasmussen LA¹, Grégoire MC².

Abstract: Neurological symptoms are very common in children with life-limiting conditions and are challenging in terms of burden of illness. Moreover, neurological symptoms can significantly impact the child's quality of life and contribute to distress among parents, families, caregivers and health care providers. Knowing how to manage and alleviate these symptoms is essential for providing good palliative care. In the present article, the more common neurological symptoms of agitation/irritability, spasticity and dystonia will be reviewed. The aim of the present brief review is to provide a basic approach to both the identification and treatment of these neurological symptoms. A medication table is provided for quick reference. A brief commentary and guidance for the management of pain are also incorporated, with reference to further literature sources.

PMID: 25914579

12. Paediatr Child Health. 2015 Apr;20(3):155-6.

Introducing a lexicon of terms for paediatric palliative care.

Spicer S¹, Macdonald ME², Davies D³, Vadeboncoeur C⁴, Siden H⁵.

PMID: 25914578

13. Paediatr Child Health. 2015 Apr;20(3):153-4.

Paediatric palliative care in Canada: A national survey of paediatricians.

Cyr C¹, Maisonneuve MH¹.

PMID: 25914577

14. Paediatr Child Health. 2015 Apr;20(3):149-50.

Case 1: A primary care provider enhances family support in perinatal palliative care.

Chamberlain C¹, Spicer S², Curiel Kd³.

PMID: 25914575

15. Paediatr Child Health. 2015 Apr;20(3):145-7.

Quality indicators for paediatric palliative care.

Charlebois J¹, Cyr C¹.

OBJECTIVES: To apply quality indicators for paediatric palliative care and evaluate performance in one service provision area. **METHODS:** After institutional review board approval, medical records were abstracted for well-defined and measurable quality indicators for children with chronic complex conditions (CCCs) between January 2006 and December 2011 (n=50) at a university medical centre. **RESULTS:** Of the 50 children with a CCC (mean age 64 months, 48% female), 39 (78%) died in hospital, 11 (22%) died at home and 13 (26%) were <1 month of age. In the final month of their life, 10 patients (20%) required an unplanned visit to the emergency department and seven (14%) were admitted. Only four patients (8%) were admitted for >14 days in their final month of life. Goals of care were addressed in a timely manner 60% of the time. An invasive procedure was performed in the final month of life in 27 (44%) patients. Bereavement follow-up was offered to 25 (50%) families. A palliative care consultant was involved with 17 (34%) patients. Palliative care was associated with less frequent invasive procedures in the final month of life and more frequent documentation of the preferred place of death. **CONCLUSION:** Performance on these particular quality indicators was unsatisfactory across a diverse group of children with CCCs, indicating important opportunities for improvement. Methods used to improve the quality of other aspects of paediatric care, including emphasis on efficient work systems, practical tools and interdisciplinary teamwork, should be used for ensuring delivery of high-quality palliative care.

PMID: 25914573

16. Paediatr Child Health. 2015 Apr;20(3):135-8.

When parents say "more" and health care professionals say "enough".

Davies D¹, Mack C².

PMID: 25914571

17. Paediatr Child Health. 2015 Apr;20(3):125.

Canadian paediatric palliative care: Challenges and promises.

Lynk A¹.

PMID: 25914568

18. Paediatr Child Health. 2015 Apr;20(3):123-4.

Paediatric palliative care: There is always more we can do.

Rapoport A¹, Liben S².

PMID: 25914567

19. Cardiol Young. 2015 Apr 23:1-10.

Does functional health status predict health-related quality of life in children after Fontan operation?

Dulfer K¹, Bossers SS², Utens EM¹, Duppen N², Kuipers IM³, Kapusta L⁴, van Iperen G⁵, Schokking M⁴, Ten Harkel AD⁶, Takken T⁷, Helbing WA².

Purpose It is important to identify those children with a Fontan circulation who are at risk for impaired health-related quality of life. We aimed to determine the predictive value of functional health status - medical history and present medical status - on both physical and psychosocial domains of health-related quality of life, as reported by patients themselves and their parents. **METHODS:** We carried out a prospective cross-sectional multi-centre study in Fontan patients aged between 8 and 15, who had undergone staged completion of total cavopulmonary connection according to a current technique before the age of 7 years. Functional health status was assessed as medical history - that is, age at Fontan, type of Fontan, ventricular dominance, and number of cardiac surgical procedures - and present medical status - assessed with magnetic resonance imaging, exercise testing, and rhythm assessment. Health-related quality of life was assessed with The TNO/AZL Child Questionnaire Child Form and Parent Form. **RESULTS:** In multivariate prediction models, several medical history variables, such as more operations post-Fontan completion, lower age at Fontan completion, and dominant right ventricle, and present medical status variables, such as smaller end-diastolic volume, a higher score for ventilatory efficiency, and the presence of sinus node dysfunction, predicted worse outcomes on several parent-reported and self-reported physical as well as psychosocial health-related quality of life domains. **CONCLUSIONS:** Medical history and worse present medical status not only predicted worse physical parent-reported and self-reported health-related quality of life but also worse psychosocial health-related quality of life and subjective cognitive functioning. These findings will help in identifying patients who are at risk for developing impaired health-related quality of life.

PMID: 25906441

20. J Pain Symptom Manage. 2015 Apr 16.

Parents' Experiences of Pediatric Palliative Transports: A Qualitative Case Series.

Nelson H¹, Mott S², Kleinman ME³, Goldstein RD⁴.

CONTEXT: Pediatric palliative transports, the practice of transporting critically ill children home for end-of-life care including extubation, are an option for children requiring high levels of medical support at end of life. Little is known about the experience from the perspective of the children and families. **OBJECTIVES:** To understand parents' perspectives on the experience of pediatric palliative transports. **METHODS:** Open-ended interviews were conducted using a qualitative descriptive design. Each parent was asked to reflect on the process of bringing their child home to die. Conventional content analysis was used for data analysis. **RESULTS:** Nine parents participated. The decision to transport the child home was a process motivated by promises to the child or a conviction that it was the right thing to do. The parents were gratified by the attention to safety and detail involved, but the actual transport home was stressful to them. The arrival home was typically recounted as a celebration. Being home provided time with the child in the context of their family and contributed to their lives. Memories of the experience brought comfort and a sense of fulfillment. **CONCLUSION:** Each parent found the experience positive and meaningful. The child's experiences when alive, not events at the time of death, were remembered. All

parents recommended palliative transports, emphasizing the importance of home and family, when desired. These interviews strongly suggest that palliative transports make a positive, important contribution to the care of at least some children facing end of life, and their families.

PMID: 25891665

21. J Pain Symptom Manage. 2015 Apr 16.

Patterns of End-of-Life Care in Children with Advanced Solid Tumor Malignancies Enrolled on a Palliative Care Service.

Vern-Gross TZ¹, Lam CG², Graff Z³, Singhal S³, Levine DR³, Gibson D³, Sykes A⁴, Anghelescu DL⁵, Yuan Y⁴, Baker JN⁶.

CONTEXT: Pediatric patients with solid tumors can have a significant symptom burden that impacts quality of life (QoL) and end-of-life care needs. **OBJECTIVES:** We evaluated outcomes and symptoms in children with solid tumors and compared patterns of end-of-life care after implementation of a dedicated institutional pediatric palliative care (PC) service. **METHODS:** We performed a retrospective cohort study of children with solid tumors treated at St. Jude Children's Research Hospital, before and after implementation of the institutional QoL/PC service in January 2007. Patients who died between July 2001 and February 2005 (historical cohort; n = 134) were compared with those who died between January 2007 and January 2012 (QoL/PC cohort; n = 57). **RESULTS:** Median time to first QoL/PC consultation was 17.2 months (range 9-33). At consultation, 60% of children were not receiving or discontinued cancer-directed therapy. Within the QoL/PC cohort, 54 patients had documented symptoms, 94% required intervention for ≥3 symptoms, and 76% received intervention for ≥5 symptoms. Eighty-three percent achieved their preferred place of death. Compared with the historical cohort, the QoL/PC cohort had more end-of-life discussions per patient (median 12 vs. 3; P < 0.001), earlier end-of-life discussions, with longer times before do-not-resuscitate orders (median 195 vs. 2 days; P < 0.001), and greater hospice enrollment (71% vs. 46%, P = 0.002).

CONCLUSION: Although children with solid tumor malignancies may have significant symptom burden toward the end of life, positive changes were documented in communication and in places of care and death after implementation of a pediatric PC service.

PMID: 25891664

22. J Pain Symptom Manage. 2015 Apr 16.

Correlates and Predictors of Conflict at the End of Life Among Families Enrolled in Hospice.

Kramer BJ¹, Boelk AZ².

CONTEXT: Despite the palliative care mandate to view family as the unit of care, and the high prevalence and detrimental consequences of conflict at the end of life, little research has been conducted with hospice families to understand what contributes to family conflict. **OBJECTIVES:** Using a recently generated explanatory matrix of family conflict at the end of life, this study sought to identify the correlates and predictors of family conflict. **METHODS:** As part of a larger mixed methods cross-sectional study, a 100-item survey was administered to 161 hospice family caregivers enrolled in a Medicare/Medicaid certified non-profit hospice organization located in the Midwest U.S. **RESULTS:** Although overall levels of conflict were relatively low, 57% of hospice caregivers reported experiencing some family conflict at the end of life. Contextual variables associated with family conflict included a history of family conflict, female gender, younger caregiver age, presence of children in the home, and less advance care planning discussions. Significant main effects in the prediction of family conflict in the final hierarchical multiple regression model included prior family conflict, caregiver age, caregiver gender, advance care planning discussions, family "coming out of the woodwork," communication constraints, and family members asserting control. The model explained 59% of the variance in family conflict. **CONCLUSION:** Results support the multidimensional theoretical model of family conflict specifying the importance of the family context, key conditions that set the stage for conflict, and essential contributing factors. Implications for routine assessment and screening to identify families at risk and recommendations for future research are highlighted.

PMID: 25891662

23. Pediatr Blood Cancer. 2015 Apr 16.

Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team.

Kassam A¹, Skiadaresis J, Alexander S, Wolfe J.

BACKGROUND: There is a general consensus that involving a specialized palliative care team in the care of children with advanced cancer can help optimize end-of-life communication; however, how this compares to standard oncology care is still unknown. We aimed to determine whether there was an association between specialist palliative care involvement and improved end-of-life communication for children with advanced cancer and their families. **PROCEDURE:** We administered questionnaires to 75 bereaved parents (response rate 54%). Outcome measures were presence or absence of 11 elements related to end-of-life communication. **RESULTS:** Parents were significantly more likely to receive five communication elements if their child was referred to a palliative care team. These elements are: discussion of death and dying with parents by the healthcare team (P < 0.01); discussion of death and dying with child by the healthcare team when appropriate (P < 0.01); providing parents with guidance on how to talk to their child about death and dying when appropriate (P < 0.01); preparing parents for medical aspects surrounding death (P = 0.02) and sibling support (P = 0.02). Children were less likely to be referred to a palliative care team if they had a hematologic malignancy. **CONCLUSIONS:** Children who receive standard oncology care are at higher risk of not receiving critical communication elements at end of life. Strategies to optimize end-of-life communication for children who are not referred to a palliative care team are needed.

PMID: 25882665

24. Cancer. 2015 Apr 14. [Epub ahead of print]

Practical communication guidance to improve phase 1 informed consent conversations and decision-making in pediatric oncology.

Johnson LM¹, Leek AC², Drotar D³, Noll RB⁴, Rheingold SR⁵, Kodish ED⁶, Baker JN^{1,7}.

BACKGROUND: It can be difficult to explain pediatric phase 1 oncology trials to families of children with refractory cancer. Parents may misunderstand the information presented to them, and physicians may assume that certain topics are covered in the informed consent document and need not be discussed. Communication models can help to ensure effective discussions. **METHODS:** Suggestions for improving the informed consent process were first solicited from phase 1 study clinicians via questionnaire. Eight parents who had enrolled their child on a phase 1 pediatric oncology trial were recruited for an advisory group designed to assess the clinicians' suggestions and make additional recommendations for improving informed consent for pediatric phase 1 trials. **RESULTS:** A phase 1 communication model was designed to incorporate the suggestions of clinicians and families. It focused on educating parents/families about phase 1 trials at specific time points during a child's illness, but specifically at the point of disease recurrence. An informative phase 1 fact sheet that can be distributed to families was also presented. **CONCLUSIONS:** Families who will be offered information regarding phase 1 clinical trials can first receive a standardized fact sheet explaining the general purpose of these early-phase clinical trials. Parental understanding may be enhanced further when oncologists address key themes, beginning at the time of diagnosis and continuing through important decision points during the child's illness. This model should be prospectively evaluated.

PMID: 25873253

25. Pediatrics. 2015 May;135(5):868-74.

Parental hope for children with advanced cancer.

Kamihara J¹, Nyborn JA¹, Olcese ME², Nickerson T³, Mack JW⁴.

BACKGROUND: Previous work suggests that parents of children with cancer can remain hopeful despite receiving prognostic information, but we know little about what hope means to such parents, or the extent to which parents can feel hopeful even while facing the child's impending death. **METHODS:** We audiotaped conversations between clinicians and parents of 32 children with relapsed or refractory cancer, and then interviewed parents about their hopes and expectations for their child. **RESULTS:** Parent statements about prognosis in interviews mirrored those made by clinicians during discussions about the child's diagnosis with refractory or relapsed cancer. Clinicians used language referring to hope during these conversations but did not ask parents directly about their hopes. Parents expressed a range of hopes for their children, from hopes related to cure or treatment response, to quality of life, normalcy, and love and relationships for the child. For most parents, expectations about prognosis were not aligned with their hopes for the child; for example, many parents hoped for a cure and also reported that they did not believe cure was possible. Many parents were able to acknowledge this incongruence. **CONCLUSIONS:** Parents accurately conveyed the reality of their child's serious condition in the setting of advanced cancer, and yet maintained hope. Hopes were not limited to hope for cure/treatment response. Clinicians should be encouraged to engage in direct conversations about hope with parents as a means to elicit realistic hopes that can help to focus the most meaningful plans for the child and family.

PMID: 25847801

26. Pediatrics. 2015 May;135(5):796-797. Epub 2015 Apr 6.

Learning to Care at the End.

MacDonell-Yilmaz RE¹.

PMID: 25847796

27. Arch Pediatr. 2015 May;22(5):498-504.

[Development, implementation, and analysis of a "collaborative decision-making for reasonable care" document in pediatric palliative care].

[Article in French]

Paoletti M¹, Litnhouvongs MN², Tandonnet J².

INTRODUCTION: In France, a legal framework and guidelines state that decisions to limit treatments (DLT) require a collaborative decision meeting and a transcription of decisions in the patient's file. The do-not-attempt-resuscitation order involves the same decision-making process for children in palliative care. To fulfill the law's requirements and encourage communication within the teams, the Resource Team in Pediatric Palliative Care in Aquitaine created a document shared by all children's hospital units, tracing the decision-making process. This study analyzed the decision-making process, quality of information transmission, and most particularly the relevance of this new "collaborative decision-making for reasonable care" card. **MATERIAL AND METHODS:** Retrospective study evaluating the implementation of a traceable document relating the DLT process. All the data sheets collected between January and December 2013 were analyzed. **RESULTS:** A total of 58 data sheets were completed between January and December 2013. We chose to collect the most relevant data to evaluate the relevance of the items to be completed and the transmission of the document, to draw up the patients' profile, and the contents of discussions with families. Of the 58 children for whom DLT was discussed, 41 data sheets were drawn up in the pediatric intensive care unit, seven in the oncology and hematology unit, five in the neonatology unit, four in the neurology unit, and one in the pneumology unit. For 30 children, one sheet was created, for 11 children, two sheets and for two children, three sheets were filled out. Thirty-nine decisions were made for withholding lifesaving treatment, 11 withdrawing treatment, and for five children, no limitation was set. Nine children survived after DLT. Of the 58 data sheets, only 31 discussions with families were related to the content of the data sheet. Of the 14 children transferred out of the unit with a completed data sheet, it was transmitted to the new unit for 11 children (79 %). **DISCUSSION:** The number of data sheets collected in 1 year shows the value of this document. The participation of several pediatric specialities' referents in its creation, then its progressive presentation in the children's hospital units, were essential steps in introducing and establishing its use. Items describing the situation, management proposals, and adaptation of the children's supportive care were completed in the majority of cases. They correspond to a clinical description, the object of the discussion, and the daily caregiver's practices, respectively. On the other hand, discussions with families were related to the card's contents in only 53 % of the cases. This can be explained by the time required to complete the DLT process. It is difficult for referring doctors to

systematically, faithfully, and objectively transcribe discussions with parents. Although this process has been used for a long time in intensive care units, this document made possible an indispensable formalisation in the decision-making process. In other pediatric specialities, the sheet allowed introducing the palliative approach and was a starter and a tool for reflection on the do-not-attempt-resuscitation order, thus suggesting the need for anticipation in these situations. **CONCLUSION:** With the implementation of this new document, the DLT, data transmission, and continuity of care conditions were improved in the children's hospital units. Sharing this sheet with all professionals in charge of these children would support homogeneity and quality of management and care for children and their parents.

PMID: 25840464

28. Health Psychol. 2015 Apr;34(4):446-52. doi: 10.1037/hea0000166.

The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase.

Kars MC¹, Grypdonck MH², de Bock LC¹, van Delden JJ¹.

OBJECTIVE: In pediatric oncology, parents want, and are expected, to act and decide in the best interest of their child. A recent qualitative study (PRESENCE study) indicated that parents had difficulty in doing so. The aim of this subanalysis was to describe and offer an explanation for the parents' actions in expressing and handling of "the voice of the child." **METHOD:** A multicenter, qualitative research study comprising 37 interviews conducted with 34 parents of 17 children with incurable cancer, cared for at home, during the palliative phase. A thematic analysis was conducted. **RESULTS:** The "voice of the child" becomes manifest in the parents' expressions of the child's needs and perceptions. Parents who actively searched to understand their child's inner perspective used direct and indirect strategies. Parents preferred indirect strategies when their child avoided talking or when they considered the conversation as threatening for the child, or for themselves. Even if the parents show an intense involvement in the care and support of their child; they can still have difficulty acknowledging the child's perspective. An inability to take into account the child's perspective was largely due to the parents' own struggle to cope with loss. **CONCLUSIONS:** Whether or not the voice of children approaching the end-of-life is heard, often depends on their parents' ability to give them a voice. Professional caregivers have a difficult task in supporting parents in giving their child his or her voice, while at the same time preserving their, and their parents', ability to cope.

PMID: 25822058

29. Pediatrics. 2015 Apr;135(4):694-700.

Pediatric palliative care and inpatient hospital costs: a longitudinal cohort study.

Smith AG¹, Andrews S², Bratton SL³, Sheetz J³, Feudtner C⁴, Zhong W⁵, Maloney CG³.

BACKGROUND: Pediatric palliative care (PPC) improves the quality of life for children with life-limiting conditions, but the cost of care associated with PPC has not been quantified. This study examined the association between inpatient cost and receipt of PPC among high-cost inpatients. **METHODS:** The 10% most costly inpatients treated at a children's hospital in 2010 were studied, and factors associated with receipt of PPC were determined. Among patients dying during 2010, we compared 2010 inpatient costs between PPC recipients and nonrecipients. Inpatient costs during the 2-year follow-up period between PPC recipients and nonrecipients were also compared. Patients were analyzed in 2 groups: those who died and those who survived the 2-year follow-up. **RESULTS:** Of 902 patients, 86 (10%) received PPC. Technology dependence, older age, multiple chronic conditions, PICU admission, and death in 2010 were independently associated with receipt of PPC. PPC recipients had increased inpatient costs compared with nonrecipients during 2010. Among patients who died during the 2-year follow-up, PPC recipients had significantly lower inpatient costs. Among survivors, PPC recipients had greater inpatient costs. When controlling for patient complexity, differences in inpatient costs were not significant. **CONCLUSIONS:** The relationship of PPC to inpatient costs is complex. PPC seems to lower costs among patients approaching death. Patients selectively referred to PPC who survive most often do so with chronic serious illnesses that predispose them to remain life-long high-resource utilizers.

PMID: 25802343

30. Arch Dis Child. 2015 May;100 Suppl 2:s3-23.

Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice.

Larcher V¹, Craig F², Bhogal K³, Wilkinson D⁴, Brierley J⁵; Royal College of Paediatrics and Child Health.

PMID: 25802250

31. Pain. 2015 Apr;156 Suppl 1:S115-8.

Palliative care and pain treatment in the global health agenda.

De Lima L¹.

Abstract The Global Atlas of Palliative Care at the End of Life, published by the Worldwide Palliative Care Alliance (WPCA) jointly with the World Health Organization (WHO) estimated that every year >20 million patients need palliative care (PC) at the end of life. Six percent of these are children. According to the Atlas, in 2011, approximately 3 million patients received PC and only 1 in 10 people in need is currently receiving it. Although most PC is provided in high-income countries (HIC), almost 80% of the global need is in low- and middle-income countries (LMIC). Only 20 countries have PC well integrated into their health-care systems. In regards to opioids, >5 billion people (83% of the world's population) live in countries with low to nonexistent access, 250 million (4%) have moderate access, and only 460 million (7%) have adequate access. In order for PC and pain treatment strategies to be effective, they must be incorporated by governments into all levels of their health care systems. In 1990, the WHO pioneered a public health strategy to integrate PC into existing health care systems which includes four components: (1) appropriate policies, (2) adequate availability of medications, (3) education of health care workers and the public, and (4) implementation of PC services at all levels throughout the society. This topical review describes the current status of the field, and presents several initiatives by United Nations (UN) organizations and the civil society to improve access to PC and to pain treatment for patients in need. PMID: 25789428

32. Palliat Med. 2015 Apr;29(4):371-9.

Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff.

Mitchell S¹, Dale J².

BACKGROUND: The majority of children and young people who die in the United Kingdom have pre-existing life-limiting illness. Currently, most such deaths occur in hospital, most frequently within the intensive care environment. **AIM:** To explore the experiences of senior medical and nursing staff regarding the challenges associated with Advance Care Planning in relation to children and young people with life-limiting illnesses in the Paediatric Intensive Care Unit environment and opportunities for improvement. **DESIGN:** Qualitative one-to-one, semi-structured interviews were conducted with Paediatric Intensive Care Unit consultants and senior nurses, to gain rich, contextual data. Thematic content analysis was carried out. **SETTING/PARTICIPANTS:** UK tertiary referral centre Paediatric Intensive Care Unit. Eight Paediatric Intensive Care Unit consultants and six senior nurses participated. **FINDINGS:** Four main themes emerged: recognition of an illness as 'life-limiting'; Advance Care Planning as a multi-disciplinary, structured process; the value of Advance Care Planning and adverse consequences of inadequate Advance Care Planning. Potential benefits of Advance Care Planning include providing the opportunity to make decisions regarding end-of-life care in a timely fashion and in partnership with patients, where possible, and their families. Barriers to the process include the recognition of the life-limiting nature of an illness and gaining consensus of medical opinion. Organisational improvements towards earlier recognition of life-limiting illness and subsequent Advance Care Planning were recommended, including education and training, as well as the need for wider societal debate. **CONCLUSIONS:** Advance Care Planning for children and young people with life-limiting conditions has the potential to improve care for patients and their families, providing the opportunity to make decisions based on clear information at an appropriate time, and avoid potentially harmful intensive clinical interventions at the end of life.

PMID: 25721360

33. Palliat Med. 2015 Apr;29(4):346-53.

Novel legislation for pediatric advance directives: surveys and focus groups capture parent and clinician perspectives.

Boss RD¹, Hutton N², Griffin PL², Wiecek BH², Donohue PK³.

BACKGROUND: Legislative measures increasingly require consideration of pediatric inpatients for Medical Orders for Life-Sustaining Treatment. **AIM:** To explore pediatric clinicians' experiences with life-sustaining treatments prior to the Medical Orders for Life-Sustaining Treatment mandate and to describe clinician and family concerns and preferences regarding pediatric Medical Orders for Life-Sustaining Treatment. **DESIGN:** Clinician surveys and clinician and parent focus groups. **SETTING/PARTICIPANTS:** Pediatric clinicians and parents from one of Maryland's largest health systems. **RESULTS:** Of 96 survey respondents, 72% were physicians and 28% were nurse practitioners. A total of 73% of physicians and 34% of nurse practitioners felt able to lead discussions about limiting therapies "most" or "all" of the time. A total of 75% of physicians and 37% of nurse practitioners led such a discussion in the prior year. A total of 55% of physicians and 96% of nurse practitioners had written no order to limit therapies in the past year. Only for children predicted to die within 30 days did >80% of clinicians agree that limitation discussions were warranted. A total of 100% of parent focus group participants, but 17% of physicians and 33% of nurse practitioners, thought that all pediatric inpatients warranted Medical Orders for Life-Sustaining Treatment discussions. Parents felt that universal Medical Orders for Life-Sustaining Treatment would decrease the stigma of limitation discussions. Participants believed that Medical Orders for Life-Sustaining Treatment would clarify decision making and increase utilization of palliative care. Medical Orders for Life-Sustaining Treatment communication skills training was recommended by all. **CONCLUSION:** A minority of clinicians, but all parents, support universal pediatric Medical Orders for Life-Sustaining Treatment. Immediately prior to the Medical Orders for Life-Sustaining Treatment mandate, many clinicians felt unprepared to lead limitation discussions, and few had written relevant orders in the prior year. Communication training is perceived essential to successful Medical Orders for Life-Sustaining Treatment conversations.

PMID: 25670471

34. Jpn J Clin Oncol. 2015 Apr;45(4):349-55.

Good death for children with cancer: a qualitative study.

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

OBJECTIVE: This study aims to explore the characteristics of a good death for children with cancer. **METHODS:** A total of 10 pediatric cancer survivors, 10 bereaved family members and 20 medical professionals participated in in-depth interviews. Qualitative content analysis was performed on the transcribed data obtained from semi-structured interviews. **RESULTS:** Thirteen characteristics including unique and specific for children of a good death were identified: (i) sufficient opportunities to play freely, (ii) peer supporters, (iii) continued access to the patient's usual activities and relationships, (iv) assurance of privacy, (v) respect for the patient's decisions and preferences, (vi) a sense that others acknowledge and respect the patient's childhood, (vii) comfort care to minimize distressing symptoms, (viii) hope, (ix) not aware of the patient's own impending death, (x) constant dignity, (xi) strong family relationships, (xii) no sense of being a burden to family members and (xiii) good relationships with medical staffs. **CONCLUSIONS:** This study identifies important characteristics of a good death for children with cancer. These findings may help medical staffs provide optimal care for children with cancer and their families, enabling them to achieve a good death.

PMID: 25628351

35. J Pain Symptom Manage. 2015 May;49(5):923-7.

Patient-controlled analgesia for children at home.

Mherekumombe MF¹, Collins JJ².

CONTEXT: Pain is a common and significant symptom experienced by children with advanced malignant disease. There is limited research on pain management of these children at home. **OBJECTIVES:** To describe and review the indications for

using patient-controlled analgesia (PCA) in the form of a Computerized Ambulatory Drug Delivery device (CADD®) in the home setting. **METHODS:** A retrospective chart review was conducted in children discharged home with opioid infusions using a CADD. Charts from January 2008 to February 2012 were surveyed. **RESULTS:** Thirty-seven CADDs were dispensed during the study period, and of these, 33 were prescribed for patients with cancer-related pain. A third of the CADDs were commenced at home and almost all PCA CADDs were used for end-of-life care. Hydromorphone was the most commonly prescribed opioid. Patients remained at home and pain control was achieved by either increasing the opioid dose or switching the opioid and using adjuvant therapy. Sixteen patients were readmitted to hospital from home and three admissions were related to pain. The median duration on a PCA CADD at home was 33.7 days (range, 1-150 days), and the mean morphine equivalent dose was 2.13 mg/kg/day. **CONCLUSION:** PCA with a CADD can be used to manage pain in the home setting. Dose adjustments and opioid switches were performed with no adverse incidents.
PMID: 25546288

36. Cancer. 2015 May 1;121(9):1508-12..

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

Levine DR¹, Johnson LM, Mandrell BN, Yang J, West NK, Hinds PS, Baker JN.

BACKGROUND:End-of-life care (EOLC) discussions and treatment-related decisions, including phase 1 trial enrollment, in patients with incurable disease are complex and can influence the quality of EOLC received. The current study was conducted in pediatric oncology patients to determine whether end-of-life characteristics differed between those who were and were not enrolled in a phase 1 trial. **METHODS:**The authors reviewed the medical records of 380 pediatric oncology patients (aged <22 years at the time of death) who died during a 3.5-year period. Of these, 103 patients with hematologic malignancies were excluded. A total of 277 patients with a diagnosis of a brain tumor or other solid tumor malignancy were divided into 2 groups based on phase 1 trial enrollment: a phase 1 cohort (PIC; 120 patients) and a non-phase 1 cohort (NPIC; 157 patients). The EOLC characteristics of these 2 cohorts were compared using regression analysis and chi-square testing. **RESULTS:**A comparison of patients in the PIC and NPIC revealed no significant differences in either demographic characteristics (including sex, race, religious affiliation, referral origin, diagnosis, or age at diagnosis, with the exception of age at the time of death [P =.03]) or in EOLC indices (such as use or timing of do not attempt resuscitation orders, hospice use or length of stay, forgoing life-sustaining therapies, location of death, time from first EOLC discussion to death, and total number of EOLC discussions). **CONCLUSIONS:** The results of the current study of a large cohort of deceased pediatric cancer patients indicate that enrollment on a phase 1 trial does not affect EOLC characteristics, suggesting that quality EOLC can be delivered regardless of phase 1 trial participation. Cancer 2015;121:1508-1512. © 2014 American Cancer Society.
PMID: 25557437

37. J Palliat Med. 2015 Apr;18(4):350-7.

Complex chronic conditions in Rhode Island's pediatric populace: implications for palliative and hospice services, 2000-2012.

Jamorabo DS¹, Belani CP, Martin EW.

BACKGROUND: Pediatric patients with complex chronic conditions (CCC) can benefit from pediatric palliative and hospice care (PP/HC) services. PP/HC can be delivered in a variety of health care settings and for a multitude of conditions, but data on hospitalization patterns and on secondary illnesses in pediatric CCC patients remains scant. **OBJECTIVE:** The study objective was to describe mortality trends for Rhode Island resident children aged 0-17 years, along with the demographics, subtypes, sites of death, and comorbidities of those with CCC. **METHODS:**This was a retrospective cohort study using demographic, hospitalization, and clinical data from all Rhode Island Department of Health death certificates from 2000 to 2012. **RESULTS:** Among the 1422 Rhode Island children aged 0-17 years old who died from 2000 to 2012, CCCs accounted for 27% (279/1049) of medically related deaths and 62% (145/233) of such deaths after infancy. CCC deaths were more likely at home (OR 5.202, 95% CI 2.984-9.203, p<0.001) and to have had a secondary cause of death documented (OR 3.032, 95% CI 2.259-4.067, p<0.001) than were other medically related deaths. Infants with CCCs were more likely to die in an inpatient setting (OR 5.141, 95% CI 2.718-10.026, p<0.001), whereas 1-17 year-olds with CCCs were more likely to die at home (OR 5.346, 95% CI 2.200-14.811, p<0.001) or in an emergency department (OR 3.281, 95% CI 1.363-8.721, p<0.040). **CONCLUSIONS:**CCCs constitute a significant proportion of medically related pediatric deaths in Rhode Island and are associated with both secondary comorbidities and death at home. Specialized, multidisciplinary services are warranted and PP/HC is crucial for patient and family support.
PMID: 25522161

38. J Palliat Med. 2015 Apr;18(4):318-23.

Physician and parent perceptions of prognosis and end-of-life experience in children with advanced heart disease.

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

BACKGROUND: Little is known about how physician and parent perspectives compare regarding the prognosis and end-of-life (EOL) experience of children with advanced heart disease (AHD). **OBJECTIVE:** The study's objective was to describe and compare parent and physician perceptions regarding prognosis and EOL experience in children with AHD. **METHODS:** This was a cross-sectional survey study of cardiologists and bereaved parents. Study subjects were parents and cardiologists of children with primary cardiac diagnoses who died in a tertiary care pediatric hospital between January 2007 and December 2009. Inclusion required both physician and parent to have completed surveys respective to the same patient. A total of 31 parent/physician pairs formed the analytic sample. Perceptions were measured of cardiologists and bereaved parents regarding the EOL experience of children with AHD. **RESULTS:** Nearly half of parents and physicians felt that patients suffered 'a great deal,' 'a lot,' or 'somewhat' at EOL, but there was no agreement between them. At diagnosis, parents more often expected complete repair and normal lifespan while the majority of physicians expected shortened lifespan without normal quality of life. Parents who expected complete repair with normal life were more likely to report 'a lot' of suf-

fering at EOL (p=0.002). In 43% of cases, physicians reported that the parents were prepared for the way in which their child died, while the parents reported feeling unprepared. **CONCLUSION:** Both parents and physicians perceive suffering at EOL in patients who die of AHD. Moreover, parent expectations at diagnosis may influence perceptions of suffering at EOL. Physicians overestimate the degree of parent preparedness for their child's death.
PMID: 25493354

39. *Am J Hosp Palliat Care*. 2015 May;32(3):253-61. Epub 2014 Apr 16.

A Structured End-of-Life Curriculum for Neonatal-Perinatal Postdoctoral Fellows.

Harris LL¹, Placencia FX², Arnold JL², Minard CG³, Harris TB⁴, Haidet PM⁵.

Abstract Death in tertiary care neonatal intensive care units is a common occurrence. Despite recent advances in pediatric palliative education, evidence indicates that physicians are poorly prepared to care for dying infants and their families. Numerous organizations recommend increased training in palliative and end-of-life care for pediatric physicians. The purpose of this study is to develop a structured end-of-life curriculum for neonatal-perinatal postdoctoral fellows based on previously established principles and curricular guidelines on end-of-life care in the pediatric setting. Results demonstrate statistically significant curriculum effectiveness in increasing fellow knowledge regarding patient qualification for comfort care and withdrawal of support (P = .03). Although not statistically significant, results suggest the curriculum may have improved fellows' knowledge of appropriate end-of-life medical management, comfort with addressing the family, and patient pain assessment and control.

PMID: 24744397

40. *Palliat Support Care*. 2015 Apr;13(2):313-7.

Palliative care in children with spinal muscular atrophy type I: What do they need?

García-Salido A¹, de Paso-Mora MC², Monleón-Luque M², Martino-Alba R².

OBJECTIVE: Our aim was to describe the clinical evolution and needs of children with spinal muscular atrophy type I treated in a domiciliary palliative care program. **METHOD:** We undertook a retrospective chart review of nine consecutive patients. Descriptions of the clinical and demographic profile of children with spinal muscular atrophy (SMA) type I were referred to a pediatric palliative care team (PPCT). **RESULTS:** Six males and three females were admitted to the PPCT, all before six months of age, except for one afflicted with SMA type I with respiratory distress. The median time of attention was 57 days (range 1-150). The domiciliary attention mainly consisted of respiratory care. The patient with SMA type I with respiratory distress required domiciliary mechanical ventilation by tracheotomy. In all cases, a nasogastric tube (NT) was indicated. As end-of-life care, eight required morphine to manage the dyspnea, four received it only by enteral (oral or NT) administration, and four received it first by enteral administration with continuous subcutaneous infusion (CSI) later. Three of the four patients with CSI also received benzodiazepines. While they were attended by the PPCT, none required hospital admission. All the patients died at home except for the one attended to for just one day. **SIGNIFICANCE OF RESULTS:** Domiciliary care for these patients is possible. The respiratory morbidity and its management are the main issues. Application of an NT is useful to maintain nutritional balance. Morphine administration is necessary to manage the dyspnea. Palliative sedation is not always necessary.

PMID: 24565112

41. *Palliat Support Care*. 2015 Apr;13(2):179-86.

The clinical, operational, and financial worlds of neonatal palliative care: A focused ethnography.

Williams-Reade J¹, Lamson AL², Knight SM², White MB², Ballard SM², Desai PP².

OBJECTIVE: Due to multiple issues, integrated interdisciplinary palliative care teams in a neonatal intensive care unit (NICU) may be difficult to access, sometimes fail to be implemented, or provide inconsistent or poorly coordinated care. When implementing an effective institution-specific neonatal palliative care program, it is critical to include stakeholders from the clinical, operational, and financial worlds of healthcare. In this study, researchers sought to gain a multidisciplinary perspective into issues that may impact the implementation of a formal neonatal palliative care program at a tertiary regional academic medical center. **METHOD:** In this focused ethnography, the primary researcher conducted semistructured interviews that explored the perspectives of healthcare administrators, finance officers, and clinicians about neonatal palliative care. The perspectives of 39 study participants informed the identification of institutional, financial, and clinical issues that impact the implementation of neonatal palliative care services at the medical center and the planning process for a formal palliative care program on behalf of neonates and their families. **RESULTS:** Healthcare professionals described experiences that influenced their views on neonatal palliative care. Key themes included: (a) uniqueness of neonatal palliative care, (b) communication and conflict among providers, (c) policy and protocol discrepancies, and (d) lack of administrative support. **SIGNIFICANCE OF RESULTS:** The present study highlighted several areas that are challenging in the provision of neonatal palliative care. Our findings underscored the importance of recognizing and procuring resources needed simultaneously from the clinical, operational, and financial worlds in order to implement and sustain a successful neonatal palliative care program.

PMID: 24168724

42. *Palliat Support Care*. 2015 Apr;13(2):145-55. Epub 2013 Nov 4.

Perinatal palliative care: Parent perceptions of caring in interactions surrounding counseling for risk of delivering an extremely premature infant.

Kavanaugh K¹, Roscigno CI², Swanson KM², Savage TA³, Kimura RE⁴, Kilpatrick SJ⁵.

OBJECTIVE: When infants are at risk of being born at a very premature gestation (22-25 weeks), parents face important life-support decisions because of the high mortality for such infants. Concurrently, providers are challenged with providing parents a supportive environment within which to make these decisions. Practice guidelines for medical care of these infants and the principles of perinatal palliative care for families can be resources for providers, but there is limited research to

bridge these medical and humanistic approaches to infant and family care. The purpose of this article is to describe how parents at risk of delivering their infant prior to 26 weeks gestation interpreted the quality of their interpersonal interactions with healthcare providers. **METHODS:** Directed content analysis was employed to perform secondary analysis of data from 54 parents (40 mothers and 14 fathers) from the previously coded theme "Quality of Interactions." These categorized data described parents' encounters, expectations, and experiences of interactions that occurred prenatally with care providers. For this analysis, Swanson's theory of caring was selected to guide analysis and to delineate parents' descriptions of caring and uncaring interactions. **RESULTS:** Parents' expectations for caring included: (a) respecting parents and believing in their capacity to make the best decisions for their family (maintaining belief); (b) understanding parents' experiences and their continued need to protect their infant (knowing); (c) physically and emotionally engaging with the parents (being with); (d) providing unbiased information describing all possibilities (enabling); and (e) helping parents navigate the system and creating a therapeutic environment for them in which to make decisions (doing for). **SIGNIFICANCE OF RESULTS:** Understanding parents' prenatal caring expectations through Swanson's theory gives deeper insights, aligning their expectations with the palliative care movement.
PMID: 24183005

43. BMJ Support Palliat Care. 2015 Apr;5 Suppl 1:A28.

PA29 How has the natural death movement has been lifting the lid on dying and funerals for 25 years?

Morris S¹, Inman-Cook R¹.

BACKGROUND: 'Birth' was reclaimed through the natural child birth movement in the 1970s and went on to inspire the origins of the natural death movement in the UK. The Natural Death Centre charity was launched in 1991 to reclaim death. However with any people's movement it responded to demand from the public into funerals. Until the last decade the funeral industry was a closed shop and the natural death movement has led consumer driven demand for change. The conference presentation will apply academic scrutiny to the history of the movement. **AIM:**As an anarchist movement the aims of the Natural Death Centre are fluid and ever evolving. **METHOD:** The conference presentation involves identifying key milestones in the natural death movement and the influences for change. Audio interviews with key leaders in the UK natural death movement will be transcribed and a content analysis will draw themes applied to the four concepts of a public health approach to palliative care. **RESULTS:** The results will allow an academic scrutiny to the UK natural death movement to act as a catalyst for change and creating new visions to share with the wider public health approach to palliative care community. **CONCLUSION:** The natural death movement is embracing and evolved away from traditional structures of health and palliative care. It complements more traditional methods for change.
PMID: 25960515

44. CA Cancer J Clin. 2015 May 7. [Epub ahead of print]

Pediatric palliative care in the community.

Kaye EC¹, Rubenstein J, Levine D, Baker JN, Dabbs D, Friebert SE.

Abstract Answer questions and earn CME/CNE Early integration of pediatric palliative care (PPC) for children with life-threatening conditions and their families enhances the provision of holistic care, addressing psychological, social, spiritual, and physical concerns, without precluding treatment with the goal of cure. PPC involvement ideally extends throughout the illness trajectory to improve continuity of care for patients and families. Although current PPC models focus primarily on the hospital setting, community-based PPC (CBPPC) programs are increasingly integral to the coordination, continuity, and provision of quality care. In this review, the authors examine the purpose, design, and infrastructure of CBPPC in the United States, highlighting eligibility criteria, optimal referral models to enhance early involvement, and fundamental tenets of CBPPC. This article also appraises the role of CBPPC in promoting family-centered care. This model strives to enhance shared decision making, facilitate seamless handoffs of care, maintain desired locations of care, and ease the end of life for children who die at home. The effect of legislation on the advent and evolution of CBPPC also is discussed, as is an assessment of the current status of state-specific CBPPC programs and barriers to implementation of CBPPC. Finally, strategies and resources for designing, implementing, and maintaining quality standards in CBPPC programs are reviewed.
PMID: 25955682

45. BMC Palliat Care. 2015 Apr 30;14:19.

What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback.

Xafis V¹, Wilkinson D^{2,3}, Sullivan J^{4,5}.

BACKGROUND: The information needs of parents facing end-of-life decisions for their child are complex due to the wide-ranging dimensions within which such significant events unfold. While parents acknowledge that healthcare professionals are their main source of information, they also turn to a variety of additional sources of written information in an attempt to source facts, discover solutions, and find hope. Much has been written about the needs of parents faced with end-of-life decisions for their child but little is known about the written information needs such parents have. Research in the adult intensive care context has shown that written resources impact positively on the understanding of medical facts, including diagnoses and prognoses, communication between families and healthcare professionals, and the emotional wellbeing of families after their relative's death. **METHODS:** A meta-synthesis of predominantly empirical research pertaining to features which assist or impede parental end-of-life decisions was undertaken to provide insight and guidance in our development of written resources (short print and online comprehensive version) for parents. **RESULTS:** The most prominently cited needs in the literature related to numerous aspects of information provision; the quantity, quality, delivery, and timing of information and its provision impacted not only on parents' ability to make end-of-life decisions but also on their emotional wellbeing. The meta-synthesis supports the value of written materials, as these provide guidance for both parents and healthcare professionals in pertinent content areas. **CONCLUSIONS:** Further research is required to determine the impact that written resources have on parental end-of-life decision-making and on parents' wellbeing during and after their experience and time in the hospital environment. PMID: 25924893

46. Lancet. 2015 Apr 24. [Epub ahead of print]

[Surgical palliative care in resource-limited settings.](#)

Riesel JN¹, Mandigo M², Gillies R³, Damuse R⁴, Farmer PE⁵, Cusack JC⁶, Krakauer EL⁷, Shulman LN⁸.

PMID: 25924837

47. Paediatr Child Health. 2015 Apr;20(3):139-44.

[Charting the Territory: Children and families living with progressive life-threatening conditions.](#)

Siden H¹, Steele R².

OBJECTIVES: To increase awareness of the topic of paediatric palliative care among practicing physicians in Canada by exploring the impact of a child's neurological or rare genetic life-threatening condition on the affected child and his/her parents. **METHODS:** Cross-sectional, baseline results from an observational, longitudinal study, Charting the Territory, which followed 275 children and 390 parents from 258 families. Parents completed multiple surveys, for themselves and their child.

RESULTS: These children had a high symptom burden. The three most common symptoms were pain, sleep problems and feeding difficulties; on average, they had 3.2 symptoms of concern. Despite analgesic use, the frequency of pain episodes and distress were invariant over time, suggesting that treatments were not successful. Parents experienced anxiety, depression and burden; at the same time they also reported positive life change and a high degree of spirituality. The child's condition resulted in parental changes in living arrangements, work status and hours devoted to caregiving. Nearly two-thirds of families were involved with a palliative care team; the size of the community in which a family resided did not make a significant difference in such involvement. **CONCLUSIONS:** These families experience many challenges, for the patient, other individual members and the family as a whole. At least some of these challenges may be alleviated by early and organized palliative care. Effective interventions are needed to enhance symptom management for the ill child and to alleviate the various negative impacts on the family.

PMID: 25914572

48. Int J Palliat Nurs. 2015 Apr 2;21(4):162-4.

[Methylnaltrexone for opioid-induced constipation in patients at the end of life.](#)

Santucci G¹, Battista V.

PMID: 25901587

49. AACN Adv Crit Care. 2015 Apr-Jun;26(2):151-66.

[Improving End-of-Life Care Prognostic Discussions: Role of Advanced Practice Nurses.](#)

Kalowes P¹.

Abstract Research has validated the desire of patients and families for ongoing prognostic information; however, few conversations occur before patients reach the advanced stages of their disease trajectory. Physician hesitation and delay in discussing unfavorable prognoses deny patients and families optimal time to prepare for critical decision making. Advanced practice registered nurses can play a crucial, complementary role with the critical care interdisciplinary team to implement strategies to improve communication about prognosis and end of life with patients and families. Clinicians should discuss deterioration in disease-specific characteristics and changes (decline) in functional status. Functional status can serve as an accurate guide for forecasting prognosis, particularly in patients with heart failure, stroke, chronic lung disease, and end-stage renal disease. This article provides an overview of effective intensive care unit prognostic systems and discusses barriers and opportunities for nurses to use evidence-based knowledge related to disease trajectory and prognosis to improve communication and the quality of palliative and end-of-life care for patients.

PMID: 25898883

50. Lancet. 2015 Apr 4;385(9975):1261.

[Guidance for clinicians involved in end-of-life care of children.](#)

[No authors listed]

PMID: 25890892

51. J Pediatr Hematol Oncol. 2015 May;37(4):257-63.

[Ethical decision making about end-of-life care issues by pediatric oncologists in economically diverse settings.](#)

Sanchez Varela AM¹, Johnson LM, Kane JR, Kasow KA, Quintana Y, Coan A, Yuan Y, Barfield R, Church C, Hester M, Baker JN.

PURPOSE: Pediatric cancer represents 1% to 4% of all cancers worldwide, with the majority of diagnoses in developing countries where mortality remains much higher than that in high-income countries. We sought to describe differences in ethical decision-making at the end of life among an international sample of pediatric oncologists practicing in countries with a variety of income levels and resource settings. **METHODS:** Pediatric oncologists subscribing to an educational international oncology Web site were invited to complete a 38-item web-based survey investigating ethical domains related to end-of-life care: level of care, fiduciary responsibility, decision making, and justice. **RESULTS:** Responses were received from 401 physicians in 83 countries, with most respondents practicing in middle-income or high-income countries. Significant differences in attitudes toward ethical issues existed across the national developmental indices. **CONCLUSIONS:** Further education on ethical principles is warranted in pediatric oncology, particularly among oncologists practicing in low-income or middle-income countries.

PMID: 25887639

52. Nurs Child Young People. 2015 Apr;27(3):6.

[Framework on decision making about end of life care updated.](#)

Crawford D.

Abstract SITUATIONS WHERE it may not be in a child's best interests to continue treatment if it cannot prolong life are out-

lined in an updated framework for practice, which aims to minimise suffering and deal with crucial ethical issues in end of life care.

PMID: 25858390

53. Int J Clin Pharm. 2015 Apr 9. [Epub ahead of print]

[Medication use during end-of-life care in a palliative care centre.](#)

[Masman AD¹](#), [van Dijk M](#), [Tibboel D](#), [Baar FP](#), [Mathôt RA](#).

Abstract Background In end-of-life care, symptoms of discomfort are mainly managed by drug therapy, the guidelines for which are mainly based on expert opinions. A few papers have inventoried drug prescriptions in palliative care settings, but none has reported the frequency of use in combination with doses and route of administration. Objective To describe doses and routes of administration of the most frequently used drugs at admission and at day of death. Setting Palliative care centre in the Netherlands. Method In this retrospective cohort study, prescription data of deceased patients were extracted from the electronic medical records. Main outcome measure Doses, frequency and route of administration of prescribed drugs Results All regular medication prescriptions of 208 patients, 89 % of whom had advanced cancer, were reviewed. The three most prescribed drugs were morphine, midazolam and haloperidol, to 21, 11 and 23 % of patients at admission, respectively. At the day of death these percentages had increased to 87, 58 and 50 %, respectively. Doses of these three drugs at the day of death were statistically significantly higher than at admission. The oral route of administration was used in 89 % of patients at admission versus subcutaneous in 94 % at the day of death. Conclusions Nearing the end of life, patients in this palliative care centre receive discomfort-relieving drugs mainly via the subcutaneous route. However, most of these drugs are unlicensed for this specific application and guidelines are based on low level of evidence. Thus, there is every reason for more clinical research on drug use in palliative care.

PMID: 25854310

54. Klin Padiatr. 2015 May;227(3):137-143.

[Critical Situations in Children, Adolescents and Young Adults with Terminal Cancer within the Home Setting.](#)

[Kuhlen M¹](#), [Balzer S¹](#), [Friedland C¹](#), [Borkhardt A¹](#), [Janßen G¹](#).

Background: Over the course of terminal cancer towards the end-of-life, children may experience symptoms that lead to distressing critical situations (CS) for the child and caregivers. **Methods:** We analysed the records of 133 children cared for by our paediatric palliative care team (PPCT) from 01/98-12/09. A CS was defined as deterioration of a condition caused by a symptom, which was life-threatening or acutely scaring the patient (pt) or caregivers. **Results:** The majority of pts who died sustained no CS. In 38 (28.6%) pts 45 CS occurred. These accumulated towards the end-of-life (62.2% within the last week). About two-thirds were anticipated. There was no clustering of CS during the night/weekend. Leading symptoms were neurological. In 4 CS a pre-hospital emergency physician was alerted. 5 pts were readmitted to hospital. Most CS (88.9%) could be controlled in the home setting. **Discussion:** Despite anticipation, a relevant number of pts developed CS, which needed either additional medical intervention or other support by the PPCT. Considering the distressing and suffering character of status epilepticus and dyspnoea, it is important to thoroughly address these conditions in palliative care. **Conclusion:** Advanced planning, close contact, good communication, detailed parental information, and a 24-h on-call service can reduce CS in children with terminal cancer. CS are mainly manageable within the home setting. Treatment of CS should focus on the child's symptoms and wishes, and the needs of the whole family.

PMID: 25811741

55. Acta Paediatr. 2015 May;104(5):529-34.

[Not just little adults: a review of 102 paediatric ethics consultations.](#)

[Thomas SM¹](#), [Ford PJ](#), [Weise KL](#), [Worley S](#), [Kodish E](#).

AIM: The American Academy of Pediatrics statement on institutional ethics committees highlights the importance of paediatric ethics consultation. However, little has been published on actual experience with ethics consultation in paediatrics. The objective of this study was to review and describe topics covered by a large retrospective sample of clinical ethics consultations in paediatric medicine. **METHODS:** We reviewed ethics consultations involving patients of <18 years of age from January 2005 to July 2013 at one institution. Descriptive statistics of the patient population, the reason for the ethics consultation and the consultant's perceived contribution to the case were generated. Subgroups of patients were compared based on demographic and clinical characteristics using Wilcoxon's rank sum tests, chi-square tests and logistic regression models. **RESULTS:** Most of the 102 eligible consultations originated from intensive care units and were requested by attending physicians. The most frequent topic leading to consultation was end-of-life issues. Both younger age and male sex were associated with consults for end-of-life issues ($p < 0.001$ and $p = 0.010$). **CONCLUSION:** This analysis provides important information describing the type of consults requested in paediatric medicine, which is necessary given the movement towards professionalising clinical ethics consultation. Further empirical research is needed on ethics consultation in paediatrics.

PMID: 25611088

56. Pediatr Blood Cancer. 2015 Apr;62(4):710-4.

[Adolescent end of life preferences and congruence with their parents' preferences: results of a survey of adolescents with cancer.](#)

[Jacobs S¹](#), [Perez J](#), [Cheng YI](#), [Sill A](#), [Wang J](#), [Lyon ME](#).

BACKGROUND: Little is known about how well family members accurately represent adolescents when making EOL decisions on their behalf. This study reports on surveys given to adolescents with cancer and their parents as part of a larger study facilitating advanced care discussions, as well as the results of a survey for health care providers. **PROCEDURE:** Trained facilitators administered surveys orally to adolescents and families in the intervention arm of the FAmily CEntered Advance Care Planning (ACP) for Teens with Cancer (FACE-TC) study. In addition, a post-hoc survey was sent to oncology providers. **RESULTS:** Seventeen adolescent/family dyads completed this survey. Seventy five percent of adolescents be-

lieved it was appropriate to discuss EOL decisions early and only 12% were not comfortable discussing death. Most preferred to be at home if dying. There were substantial areas of congruence between adolescents and their surrogates, but lower agreement on the importance of dying a natural death, dying at home and "wanting to know if I were dying." Among providers, 83% felt their patients' participation in the study was helpful to the patients and 78% felt it was helpful to them as providers. **CONCLUSIONS:** Adolescents with cancer were comfortable discussing EOL, and the majority preferred to talk about EOL issues before they are facing EOL. There were substantive areas of agreement between adolescents and their surrogates, but important facets of adolescents' EOL wishes were not known by their families, reinforcing the importance of eliciting individual preferences and engaging dyads so parents can understand their children's wishes.
PMID: 25545105

57. J Clin Nurs. 2015 Apr;24(7-8):927-36.

The challenge to health professionals when carers resist truth telling at the end of life: a qualitative secondary analysis.

Noble H¹, Price JE, Porter S.

AIMS AND OBJECTIVES: To draw out the similar complexities faced by staff around truth-telling in a children's and adult population and to interrogate the dilemmas faced by staff when informal carers act to block truth-telling. **BACKGROUND:** Policy encourages normalisation of death, but carers may act to protect or prevent the patient from being told the truth. Little is known about the impact on staff. **DESIGN:** Secondary analysis of data using a supra-analysis design to identify commonality of experiences. **METHODS:** Secondary 'supra-analysis' was used to transcend the focus of two primary studies in the UK, which examined staff perspectives in a palliative children's and a palliative adult setting, respectively. The analysis examined new theoretical questions relating to the commonality of issues independently derived in each primary study. Both primary studies used focus groups. Existing empirical data were analysed thematically and compared across the studies. **RESULTS:** Staff reported a hiding of the truth by carers and sustained use of activities aimed at prolonging life. Carers frequently ignored the advance of end of life, and divergence between staff and carer approaches to truth-telling challenged professionals. Not being truthful with patients had a deleterious effect on staff, causing anger and feelings of incompetence. **CONCLUSIONS:** Both children's and adult specialist palliative care staff found themselves caught in a dilemma, subject to policies that promoted openness in planning for death and informal carers who often prevented them from being truthful with patients about terminal prognosis. This dilemma had adverse psychological effects upon many staff. **RELEVANCE TO CLINICAL PRACTICE:** There remains a powerful death-denying culture in many societies, and carers of dying patients may prevent staff from being truthful with their patients. The current situation is not ideal, and open discussion of this problem is the essential first step in finding a solution.
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