

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

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

*Donald A.B. Lindberg*



## Quarto numero

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1. J Educ Health Promot. 2016 Jun 23;5:19.

### **Parental needs in infant's end-of-life and bereavement in NICU: A qualitative study.**

Hasanpour M<sup>1</sup>, Sadeghi N<sup>2</sup>, Heidarzadeh M<sup>3</sup>.

#### **Abstract**

**BACKGROUND AND AIMS:** Newborn death is an unexpected outcome for parents. Parents face with several needs in infant end-of-life. The health care team is responsible for meet these needs. This qualitative study aim was to explore of parental needs in infant end-of-life and bereavement.

**MATERIALS AND METHODS:** For this qualitative study, 24 single semi-structure interviews were done. A qualitative content analysis method was used. Sampling conducted on purposeful with maximum variation in five Neonatal Intensive Care Unit (NICU) environments in Isfahan city. Inclusion criteria for nurses and doctors were having at least one experience of caring for an infant and their family at end-of-life. Inclusion criteria for parents and their families were having at least one infant at end-of-life or had lost their infant for 6 months before in NICU.

**RESULTS:** Data analysis uncovered two main themes. Family's support needs with two subthemes (family's support needs before infant's death and family's support needs after infant's death) and family's preparatory needs upon infant's death with two subthemes (management of the bad news of infant's death by treatment team and management of the bad news of infant's death by family).

**DISCUSSION:** Mourning mother's need for her husband's presence by her side, getting hospitalized in a separate room, and management of infant's death news by father and family were among items rarely pointed out in other studies. Exploration of these needs cab be helpful for the health care team for providing care.

PMID: 27500172

2. Arch Pediatr. 2016 Jul 26.

### **[Perinatal palliative care in France: Who? Why? How?]**

[Article in French]

Tosello B<sup>1</sup>.

#### **Abstract**

Severe congenital or morphologic anomalies are one of the main causes of infant morbidity and mortality. Some of these prenatally-diagnosed pathologies are incompatible with postnatal survival. In this context, some women choose to continue with pregnancy. Subsequently, perinatal palliative care seems to be a constructive answer to offer in such situations. At international level, this is a new clinical practice where decision dilemmas exist (prognostic uncertainty, prolonged survival, and attachment to the infant). It might be necessary to identify the factors that can affect these ethical tensions. With no national data, we explored the perceptions and professional practices that may influence parental requests for continuing with pregnancy, despite the uncertainty corresponding to the postnatal condition of a newborn with a lethal

pathology. This exploration aims to question and debate current norms, especially in medical termination of pregnancy, discussing the dilemmas and divergences that affect decision-making and professional practices in neonatal palliative care. Reflection is also necessary on how to find an answer that can make sense within a request for continuation of pregnancy, despite the uncertainty inherent in the postnatal period in case of live birth of a newborn with a lethal abnormality.

PMID: 27472997

3. Am J Hosp Palliat Care. 2016 Jul 28.

**Palliative Care in Undergraduate Medical Education-How Far Have We Come?**

Fitzpatrick D<sup>1</sup>, Heah R<sup>2</sup>, Patten S<sup>2</sup>, Ward H<sup>3</sup>

**Abstract**

**PURPOSE:** There is an increasing demand for quality palliative care teaching within undergraduate medical education. Studies suggest that many junior doctors feel underprepared to perform end-of-life care. Previous systematic reviews on palliative care teaching within medical schools have identified significant variability and lack of consistency in teaching. This review aims to update the literature on the current status of palliative care teaching to undergraduates within medical schools.

**METHOD:** A systematic review was undertaken on articles published from December 2001 to November 2015 on palliative care teaching for undergraduate medical students. In all, 650 abstract citations were obtained, of which 126 were relevant to the research questions. Thematic analysis was performed on remaining articles according to whether they discussed content and/or methodology of palliative care education, and data collated.

**RESULTS:** There is greater consistency in the content being delivered as part of end-of-life care education within medical schools. The most frequently taught topics include attitudes to death and dying, communication skills, and pain management. Pediatric care and religious/cultural issues are less frequently addressed. Teaching institutions are also utilising a broader range of teaching modalities.

**CONCLUSION:** There is significant progress in palliative care education within medical schools. Ongoing challenges relate to correlating our current practice in medical education to professional recommendations and the expressed needs of junior doctors to practice competent end-of-life care.

PMID: 27468933

4. J Soc Work End Life Palliat Care. 2016 Jul-Sep;12(3):289-306.

**Exhaust All Measures: Ethical Issues in Pediatric End-of-Life Care.**

Thieleman KJ<sup>1</sup>, Wallace C<sup>2</sup>, Cimino AN<sup>3</sup>, Rueda HA<sup>4</sup>.

**Abstract**

The death of a child may have a profound impact on parents, family members, and health care providers who provided care for the child. Unique challenges are faced by parents of seriously ill children as they must serve as the legal authority for health care decisions of children under age 18, although the child's wishes must also be considered. Social workers must balance core social work values, bioethical values, and psychosocial issues presented by such situations. While studies have been conducted with physicians and nurses regarding ethical issues in pediatric end-of-life care settings, little is known about how social workers experience these conflicts. This article utilizes two vignettes to illustrate potential ethical issues in this setting and applies the National Association of Social Workers Standards for Palliative and End of Life Care (NASW, 2004 ) to explore options for their resolution. These vignettes provide descriptions of possible reactions in this setting and can be used as a basis for further exploration of ethics in pediatric end-of-life care from a social work perspective.

PMID: 27462957

5. J Palliat Med. 2016 Jul 25.

**Pediatric Palliative Care Program versus Usual Care and Healthcare Resource Utilization in British Columbia: A Matched-Pairs Cohort Study.**

**Abstract**

**BACKGROUND:** Evidence on the impact of pediatric palliative care programs (PPCP) on resource utilization is scarce and requires broader measures to include utilization beyond the hospital setting.

**OBJECTIVE:** This research aims to provide a Canadian comparative analysis between children in a PPCP with those under usual care, including hospice use to inpatient resource use measurement.

**METHODS:** We conducted a retrospective matched-pairs (disease and age at death) cohort comparison of children who died in hospice versus hospital (never enrolled in a PPCP), from 2008 to 2012. Utilization was retrieved from administrative databases and chart review. The main outcomes were number of admissions and length of stay (LOS).

**RESULTS:** Eleven pairs were found. PPCP users were more likely to have advanced directives (100% vs. 27%). After controlling for disease and age, we found no significant difference in number of admissions; however, PPCP users had an increase in admissions post-referral compared to pre-referral (median 3.08 admissions), driven by the need for critical care. We did not find a significant difference in LOS, but observed longer admissions among PPCP users pre- (1.91

days/month) and post-referral (3.66 days/month) compared to usual care. Over 60% of inpatient utilization shifted to the hospice post-referral.

**DISCUSSION:** The terminal pediatric population referred to PPCP may systematically differ from those under usual care even before enrollment, presenting with higher inpatient utilization in critical care nearing death. A significant portion of inpatient utilization shifted to the hospice, with implications for resource reallocation and enhancements in PPCP referrals.

PMID: 27455077

6. Am J Hosp Palliat Care. 2016 Jul 22.

**Risk Factors for Hospitalization of Home Hospice Enrollees: Development and Validation of a Predictive Tool.**

**Abstract**

**BACKGROUND:** Over 10% of hospice patients experience at least 1 care transition 6 months prior to death. Transitions at the end of life, particularly from hospice to hospital, result in burdensome and fragmented care for patients and families. Little is known about factors that predict hospitalization in this population.

**OBJECTIVES:** To develop and validate a model predictive of hospitalization after enrollment into home hospice using pre-hospice admission risk factors.

**DESIGN:** Retrospective cohort study using Medicare fee-for-service claims.

**PARTICIPANTS:** Patients enrolled into the Medicare hospice benefit were  $\geq 18$  years old in 2012.

**OUTCOME MEASURED:** Hospitalization within 2 days from a hospice discharge.

**RESULTS:** We developed a predictive model using 61 947 hospice enrollments, of which 3347 (5.4%) underwent a hospitalization. Seven variables were associated with hospitalization: age 18 to 55 years old (adjusted odds ratio [95% confidence interval]: 2.94 [2.41-3.59]), black race (2.13 [1.93-2.34]), east region (1.97 [1.73-2.24]), a noncancer diagnosis (1.32 [1.21-1.45]), 4 or more chronic conditions (8.11 [7.19-9.14]), 2 or more prior hospice enrollments (1.75 [1.35-2.26]), and enrollment in a not-for-profit hospice (2.01 [1.86-2.18]). A risk scoring tool ranging from 0 to 29 was developed, and a cutoff score of 18 identified hospitalized patients with a positive predictive value of 22%.

**CONCLUSIONS:** Reasons for hospitalization among home hospice patients are complex. Patients who are younger, belong to a minority group, and have a greater number of chronic conditions are at increased odds of hospitalization. Our newly developed predictive tool identifies patients at risk for hospitalization and can serve as a benchmark for future model development.

PMID: 27448668

7. Int J Palliat Nurs. 2016 Jul 2;22(7):317-23.

**End-of-life care in the neonatal intensive care unit: applying comfort theory.**

Marchuk A<sup>1</sup>.

**Abstract**

The provision of quality end-of-life care is essential when a neonate is dying. End-of-life care delivered in a neonatal intensive care unit (NICU) must consider the needs of both the newborn and their family. The purpose of this paper is to demonstrate how comfort theory and its associated taxonomic structure can be used as a conceptual framework for nurses and midwives providing end-of-life care to neonates and their families. Comfort theory and its taxonomic structure are presented and issues related to end-of-life care in the NICU are highlighted. A case study is used to illustrate the application of comfort theory and issues related to implementation are discussed. The delivery of end-of-life care in the NICU can be improved through the application of comfort.

PMID: 27444160

8. Am J Hosp Palliat Care. 2016 Jul 21.

**A Multimodal Mindfulness Training to Address Mental Health Symptoms in Providers Who Care for and Interact With Children in Relation to End-of-Life Care.**

**Abstract**

**AIM:** Medical providers may face unique emotional challenges when confronted with the suffering of chronically ill, dying, and bereaved children. This study assessed the preliminary outcomes of participation in a group-based multimodal mindfulness training pilot designed to reduce symptoms of burnout and mental health symptoms in providers who interact with children in the context of end-of-life care.

**METHODS:** A total of 13 medical providers who care for children facing life-threatening illness or bereaved children participated in a 9-session multimodal mindfulness session. Mental health symptoms and burnout were assessed prior to the program, at the program midpoint, and at the conclusion of the program.

**RESULTS:** Participation in the pilot was associated with significant reductions in depressive and posttraumatic stress disorder (PTSD) symptoms among providers ( $P < .05$ ).

**CONCLUSION:** Mindfulness-based programs may help providers recognize and address symptoms of depression and PTSD. Additional research is needed to enhance access and uptake of programming among larger groups of participants.

PMID: 27443283

9. Health Commun. 2016 Jul 19:1-7.

**A Qualitative Examination of Physician Gender and Parental Status in Pediatric End-of-Life Communication.**

Bateman LB<sup>1</sup>, White ML<sup>2</sup>, Tofil NM<sup>2</sup>, Clair JM<sup>3</sup>, Needham BL<sup>4</sup>.

**Abstract**

In this study we utilized the framework of patient-centered communication to explore the influence of physician gender and physician parental status on (1) physician-parent communication and (2) care of pediatric patients at the end of life (EOL). The findings presented here emerged from a larger qualitative study that explored physician narratives surrounding pediatric EOL communication. The current study includes 17 pediatric critical care and pediatric emergency medicine physician participants who completed narrative interviews between March and October 2012 to discuss how their backgrounds influenced their approaches to pediatric EOL communication. Between April and June of 2013, participants completed a second round of narrative interviews to discuss topics generated out of the first round of interviews. We used grounded theory to inform the design and analysis of the study. Findings indicated that physician gender is related to pediatric EOL communication and care in two primary ways: (1) the level of physician emotional distress and (2) the way physicians perceive the influence of gender on communication. Additionally, parental status emerged as an important theme as it related to EOL decision-making and communication, emotional distress, and empathy. Although physicians reported experiencing more emotional distress related to interacting with patients at the EOL after they became parents, they also felt that they were better able to show empathy to parents of their patients.

PMID: 27436067

10. Pain. 2016 Jul 15.

**Young children's ability to report on past, future and hypothetical pain states: a cognitive developmental perspective.**

Jaaniste T<sup>1</sup>, Noel M, von Baeyer CL.

**Abstract**

Children are at times asked by clinicians or researchers to rate their pain associated with past, future or hypothetical experiences. However, little consideration is typically given to the cognitive-developmental requirements of such pain reports. Consequently, these pain assessment tasks may exceed the abilities of some children, potentially resulting in biased or random responses. This could lead to the over- or under-treatment of children's pain. This review provides an overview of factors, and specifically the cognitive-developmental pre-requisites, that may affect a child's ability to report on non-present pain states, such as past, future or hypothetical pain experiences. Children's ability to report on past pains may be influenced by developmental (age, cognitive ability), contextual (mood state, language used by significant others), affective and pain-related factors. The ability to mentally construct and report on future painful experiences may be shaped by memory of past experiences, information provision and learning, contextual factors, knowledge about oneself, cognitive coping style, and cognitive development. Hypothetical pain reports are sometimes used in the development and validation of pain assessment scales, as a tool in assessing cognitive-developmental and social-developmental aspects of children's reports of pain, and for the purposes of training children to use self-report scales. Rating pain associated with hypothetical pain scenarios requires the ability to recognize pain in another person and depends on the child's experience with pain. Enhanced understanding of cognitive-developmental requirements of young children's pain reports could lead to improved understanding, assessment, and treatment of pediatric pain.

PMID: 27429175

11. Am J Hosp Palliat Care. 2016 Jul 12

**Can Playing an End-of-Life Conversation Game Motivate People to Engage in Advance Care Planning?**

Van Scoy LJ<sup>1</sup>, Green MJ<sup>2</sup>, Reading JM<sup>3</sup>, Scott AM<sup>4</sup>, Chuang CH<sup>5</sup>, Levi BH<sup>6</sup>.

**Abstract**

**BACKGROUND:** Advance care planning (ACP) involves several behaviors that individuals undertake to prepare for future medical care should they lose decision-making capacity. The goal of this study was to assess whether playing a conversation game could motivate participants to engage in ACP.

**METHODS:** Sixty-eight English-speaking, adult volunteers (n = 17 games) from communities around Hershey, Pennsylvania, and Lexington, Kentucky, played a conversation card game about end-of-life issues. Readiness to engage in 4 ACP behaviors was measured by a validated questionnaire (based on the transtheoretical model) immediately before and 3 months postgame and a semistructured phone interview. These behaviors were (1) completing a living will; (2) completing a health-care proxy; (3) discussing end-of-life wishes with loved ones; and (4) discussing quality versus quantity of life with loved ones.

**RESULTS:** Participants' (n = 68) mean age was 51.3 years (standard deviation = 0.7, range: 22-88); 94% of the participants were caucasian and 67% were female. Seventy-eight percent of the participants engaged in ACP behaviors within 3 months of playing the game (eg, updating documents, discussing end-of-life issues). Furthermore, 73% of the participants progressed in stage of change (ie, readiness) to perform at least 1 of the 4 behaviors. Scores on measures of decisional balance and processes of change increased significantly by 3 months postintervention.

**CONCLUSION:** This pilot study found that individuals who played a conversation game had high rates of performing ACP behaviors within 3 months. These findings suggest that using a game format may be a useful way to motivate people to perform important ACP behaviors.

PMID: 27406696

12. Home Health Care Serv Q. 2016 Jul 6:1-11.

**Home care for children with multiple complex chronic conditions at the end of life: The choice of hospice versus home health.**

**Abstract**

Families desire to bring their children home at end of life, and this creates a variety of unique care needs at home. This study analyzed the child and family factors associated with hospice versus home health care use in the last year of life among children with multiple complex chronic conditions. Using the Andersen Behavioral Healthcare Utilization Model, the predisposing, enabling, and need factors of the child and family were shown to be significant predictors of hospice and home health care use. Hospice and home health care have advantages, and families may wish to use the service that best fits their needs.

PMID: 27383451

13. Int J Palliat Nurs. 2016 Jun 2;22(6):278-85.

**Development of a logic model to support a network approach in delivering 24/7 children's palliative care: part two.**  
Maynard L<sup>1</sup>, Lynn D<sup>2</sup>.

**Abstract**

**BACKGROUND:** This is the second of a two-part article that discusses a research project that aimed to develop and evaluate a 24/7 symptom-management service for children with palliative care needs and a nursing logic model to enable a novel service approach to be generalised and replicated.

**RESULTS:** Findings demonstrated that the service standards were met and exceeded expectations. Families valued the role, which enabled choice in location of care and perceived the service as a 'lifeline'.

**DISCUSSION:** Team composition with the right level of specialist and advanced nursing skills, anticipating symptom-management planning, clinical supervision and funded on-call processes were key success criteria. The nursing logic model demonstrated relationships between context investments into the service and outcomes for children and families.

PMID: 27349846

14. BMJ Support Palliat Care. 2016 Jun 17.

**Educational impact of paediatric palliative simulation study days.**

Renton K<sup>1</sup>, Quinton H<sup>2</sup>, Mayer AT<sup>3</sup>.

**Abstract**

**BACKGROUND:** The use of simulation-based medical/nursing teaching is increasingly widespread. Simulation-based teaching offers an immersive learning experience where professionals can practice communication and practical skills in a safe, authentic environment. We designed a paediatric palliative simulation study day primarily aimed at nursing staff who manage these patients in the community/hospice. We believe this is the first of its kind in the UK.

**AIMS:** To establish whether attendance at a paediatric palliative simulation study day improved confidence and knowledge in management of common and/or difficult situations in palliative care.

**METHOD:** Health professionals working at local paediatric hospices or in associated specialties to palliative care were invited to attend the free 1-day course. 5 scenarios were developed by experienced health professionals working in paediatric palliative care. On the day, participants were asked to complete a questionnaire to check basic demographic data, confidence levels and knowledge (50 true/false questions). Following participation/observation of 5 scenarios, they again completed the same questionnaire regarding confidence levels and knowledge. Results were analysed with Excel and XLStat using basic demographic data and Wilcoxon signed rank two-tailed test.

**RESULTS:** 57 healthcare workers participated in 5 study days. 81% (n=47) professionals described themselves as working primarily in palliative care. Only 35% (n=20) had previously experienced simulation. Based on confidence questions, attendees felt more confident in managing specific palliative scenarios (p<0.0001). Based on true/false questions prestudy and poststudy day, 86% (n=49) of participants improved their knowledge. The median improvement score for the cohort was 3 (p<0.0001).

**CONCLUSIONS:** The study demonstrated a significant improvement in confidence and knowledge following the simulation course. This supports further time/financial investment in developing this type of study day. Simulation is a useful teaching adjunct in paediatric palliative care. The course also provides a valuable opportunity for professionals to network and discuss/share experiences.

<http://www.bmj.com/company/products-services/rights-and-licensing/>

PMID: 27316635

15. J Natl Compr Canc Netw. 2016 Jun;14(6):741-8.

**Integrating Palliative Care in Pediatric Oncology: Evidence for an Evolving Paradigm for Comprehensive Cancer Care.**

Levine DR<sup>1</sup>, Johnson LM<sup>1</sup>, Snyder A<sup>1</sup>, Wiser RK<sup>1</sup>, Gibson D<sup>1</sup>, Kane JR<sup>1</sup>, Baker JN<sup>1</sup>.

**Abstract**

**BACKGROUND:** The demonstrated benefit of integrating palliative care (PC) into cancer treatment has triggered an increased need for PC services. The trajectory of integrating PC in comprehensive cancer centers, particularly pediatric centers, is unknown. We describe our 8-year experience of initiating and establishing PC with the Quality of Life Service (QoLS) at St. Jude Children's Research Hospital.

**METHODS:** We retrospectively reviewed records of patients seen by the QoLS (n=615) from March 2007 to December 2014. Variables analyzed for each year, using descriptive statistics, included diagnostic groups, QoLS encounters, goals of care, duration of survival, and location of death.

**RESULTS:** Total QoLS patient encounters increased from 58 (2007) to 1,297 (2014), new consults increased from 17 (2007) to 115 (2014), and mean encounters per patient increased from 5.06 (2007) to 16.11 (2014). Goal of care at initial consultation shifted from primarily comfort to an increasing goal of cure. The median number of days from initial consult to death increased from 52 days (2008) to 223 days (2014). A trend toward increased outpatient location of death was noted with 42% outpatient deaths in 2007, increasing to a majority in each subsequent year (range, 51%-74%). Hospital-wide, patients receiving PC services before death increased from approximately 50% to nearly 100%.

**CONCLUSIONS:** Since its inception, the QoLS experienced a dramatic increase in referrals and encounters per patient, increased use by all clinical services, a trend toward earlier consultation and longer term follow-up, increasing outpatient location of death, and near-universal PC involvement at the end-of-life. The successful integration of PC in a comprehensive cancer center, and the resulting potential for improved care provision over time, can serve as a model for other programs on a broad scale.

PMID: 27283167

16. JAMA Oncol. 2016 Jun 1;2(6):832.

**Against "Healthy Paternalism" at the End of Life.**

Marron JM<sup>1</sup>, Truog RD<sup>2</sup>.

PMID: 27281629 [PubMed - in process]

17. Acta Paediatr. 2016 Jun 8.

**Delivery room hospice.**

Garbi LR<sup>1</sup>, Shah S<sup>1</sup>, La Gamma EF<sup>1</sup>.

**Abstract**

Advances in perinatal science over the past five decades have reduced the practical 'threshold of viability' by approximately one week every 10 years such that survivors are expected as early as 22 weeks. Ethical standards regarding treatment of this periviable patient population remain enigmatic.

**CONCLUSION:** We review limitations in the current ethical rationale for caring for these infants in the delivery room and introduce an alternative utilising a delivery room hospice care approach involving the administration of opioids.

PMID: 27275634

18. Pediatr Int. 2016 Jun 8.

**Effectiveness of subarachnoid drug infusion for pediatric tumor-related pain.**

Higuchi T<sup>1</sup>, Shimada K<sup>1</sup>, Cho Y<sup>1</sup>, Minami K<sup>1</sup>, Takeuchi K<sup>1</sup>, Sakamoto A<sup>2</sup>.

**Abstract**

Although the effectiveness of subarachnoid continuous drug infusion has been established in cancer pain management, its clinical use in children is rare. A 14-year-old girl with neurofibromatosis type I complained of right leg pain stemming from a growing tumor on her right buttock. Continuous and breakthrough right leg pain were unbearable, even at high doses of systemic opioids that caused severe constipation and deep sedation. Subsequent continuous infusion of bupivacaine and morphine through a subarachnoid catheter effectively relieved the girl's pain. The corresponding decrease in systemic opioid also improved her activities of daily living. The patient eventually died of cachexia due to the rapidly growing buttock lesion that was pathologically confirmed post-mortem as a malignant peripheral nerve sheath tumor. Subarachnoid continuous drug infusion may be very useful in controlling severe pain with few side-effects, even in the field of pediatric palliative care.

PMID: 27273434

19. Acta Paediatr. 2016 Jun 7.

**Children with cancer share their views: tell the truth but leave room for hope.**

Jalmsell L<sup>1,2</sup>, Lövgren M<sup>3,4</sup>, Kreicbergs U<sup>3,4</sup>, Henter JI<sup>3</sup>, Frost BM<sup>5</sup>.

**Abstract**

**AIM:** One in five children diagnosed with cancer will die from the disease. The aim of the study was to explore how children with cancer want to receive bad news about their disease, such as when no more treatment options are available.

**METHODS:** We conducted individual interviews with ten children with cancer, aged seven to 17 years, at a single paediatric oncology unit in central Sweden. Interviews were audio-taped and analysed with systematic text condensation. Bad news was defined as information about a potentially fatal outcome, such as a disease relapse, or information that the treatment administered was no longer working and that there was no more treatment possible.

**RESULTS:** All children expressed that they wanted truthful information and they did not want to be excluded from bad news regarding their illness. They wanted to be informed as positively as possible, allowing them to maintain hope, and in words that they could understand. They also wanted to receive any bad news at the same time as their parents.

**CONCLUSION:** Children with cancer want to be fully informed about their disease, but they also wanted it to be relayed as positively as possible so that they could stay hopeful.

PMID: 27272911

20. J Pain Symptom Manage. 2016 Jun 3.

**Trend in and Correlates of Undergoing Radiotherapy in Taiwanese Cancer Patients' Last Month of Life.**

Hung YN<sup>1</sup>, Cheng SH<sup>2</sup>, Liu TW<sup>3</sup>, Chang WC<sup>4</sup>, Chen JS<sup>4</sup>, Tang ST<sup>5</sup>.

**Abstract**

**CONTEXT:** A significant proportion of cancer patients at end of life (EOL) undergo radiotherapy, but this evidence is not from nationwide population-based studies.

**OBJECTIVES:** The aims of this population-based study were to investigate the trend in undergoing radiotherapy among Taiwanese cancer patients' last month of life (EOL radiotherapy) in 2001-2010 and to identify factors associated with EOL radiotherapy.

**METHODS:** This was a population-based retrospective cohort study analyzing data from Taiwan's national death registry, cancer registry, and National Health Insurance claims for EOL radiotherapy using multilevel generalized linear mixed modeling. Participants were Taiwanese cancer patients (N = 339,546) who died in 2001-2010.

**RESULTS:** Overall, 8.59% (7.97%-9.85%) of patients underwent EOL radiotherapy with a decreasing trend over time. Correlates of EOL radiotherapy included male gender, younger age, residing in less urbanized areas, diagnosis of lung cancer, metastatic disease, death within two years of diagnosis, and without comorbidities. Cancer patients were more likely to undergo EOL radiotherapy if they received primary care from medical oncologists and pediatricians, in a nonprofit, teaching hospital with a larger case volume of terminally ill cancer patients, and greater EOL care intensity.

**CONCLUSION:** Approximately one-tenth of Taiwanese cancer patients underwent EOL radiotherapy with a decreasing trend over time. Undergoing EOL radiotherapy was associated with demographics, disease characteristics, physician specialty, and primary hospital's characteristics and EOL care practice patterns. Clinical and financial interventions should target hospitals/physicians that tend to aggressively treat at-risk cancer patients at EOL to carefully evaluate the appropriateness and effectiveness of using EOL radiotherapy.

PMID: 27265817

21. Contemp Clin Trials. 2016 Jul;49:15-20.

**The Family Communication Study: A randomized trial of prospective pediatric palliative care consultation, study methodology and perceptions of participation burden.**

Starks H<sup>1</sup>, Doorenbos A<sup>2</sup>, Lindhorst T<sup>3</sup>, Bourget E<sup>4</sup>, Aisenberg E<sup>5</sup>, Oman N<sup>4</sup>, Rue T<sup>6</sup>, Curtis JR<sup>7</sup>, Hays R<sup>8</sup>.

**Abstract**

**BACKGROUND:** To describe the study methods, baseline characteristics and burden of study procedures of an intervention designed to reduce family stress symptoms through early support from the palliative care team. Length of stay of ≥8 days was the trigger for early palliative care involvement.

**METHODS:** Cluster-randomized trial with children as the unit of randomization. Up to 3 family members per child were recruited. Family stress symptoms were recorded at baseline, discharge from the ICU, and 3 months post-enrollment. Questionnaire burden was assessed on a 1-10 point scale at each time point and open-ended comments were analyzed to describe the participants' experience in the study.

**RESULTS:** 380 family members of 220 children (control=115 children and 204 family members; intervention=105 children and 176 family members) were recruited, which represented 50% of all eligible families. Most family participants were parents (86% control; 92% intervention) and female (66% both groups). Retention rates were high through the 3-month follow-up: 93% and 90% for the control and intervention groups respectively. Questionnaire burden was very low: mean (sd) scores were 1.1 (1.6), 0.7 (1.5), and 0.9 (1.6) for the baseline, discharge and follow-up questionnaires, respectively. Comments suggest that participation was beneficial by promoting reflection and self-awareness about stress, coping and resilience, and feeling cared for because the intervention and questionnaires focused on their own well-being.

**CONCLUSIONS:** The participants' comments regarding the focus on them as the point of intervention reflects the value of conducting research with family members of seriously ill children during ICU stays.

PMID: 27263074

22. J Pain Symptom Manage. 2016 Jun 1.

**Milestones for the Final Mile: Interspecialty Distinctions in Primary Palliative Care Skills Training.**

Harris JA<sup>1</sup>, Herrel LA<sup>2</sup>, Healy MA<sup>3</sup>, Wancata LM<sup>4</sup>, Perumalswami CR<sup>5</sup>.

**Abstract**

**CONTEXT:** Primary palliative care (PPC) skills are useful in a wide variety of medical and surgical specialties, and the expectations of PPC skill training are unknown across graduate medical education.

**OBJECTIVES:** We characterized the variation and quality of PPC skills in residency outcomes-based Accreditation Council for Graduate Medical Education (ACGME) milestones.

**METHODS:** We performed a content analysis with structured implicit review of 2015 ACGME milestone documents from 14 medical and surgical specialties chosen for their exposure to clinical situations requiring PPC. For each specialty milestone document, we characterized the variation and quality of PPC skills in residency outcomes-based ACGME milestones.

**RESULTS:** We identified 959 occurrences of 29 palliative search terms within 14 specialty milestone documents. Within these milestone documents, implicit review characterized 104 milestones with direct saliency to PPC skills and 196 milestones with indirect saliency. Initial interrater agreement of the saliency rating among the primary reviewers was 89%. Specialty milestone documents varied widely in their incorporation of PPC skills within milestone documents. PPC milestones were most commonly found in milestone documents for Anesthesiology, Pediatrics, Urology, and Physical Medicine and Rehabilitation. PPC-relevant milestones were most commonly found in the Interpersonal and Communication Skills core competency with 108 (36%) relevant milestones classified under this core competency.

**CONCLUSIONS:** Future revisions of specialty-specific ACGME milestone documents should focus on currently underrepresented, but important PPC skills.

**Free Article**

PMID: 27260828

23. Cancer. 2016 Jun 3.

**Genetic testing for the risk of developing late effects among survivors of childhood cancer: Consumer understanding, acceptance, and willingness to pay.**

Georgiou G<sup>1,2</sup>, Wakefield CE<sup>1,2</sup>, McGill BC<sup>1,2</sup>, Fardell JE<sup>1,2</sup>, Signorelli C<sup>1,2</sup>, Hanlon L<sup>1,2</sup>, Tucker K<sup>3,4</sup>, Patenaude AF<sup>5,6</sup>, Cohn RJ<sup>1,2</sup>.

**Abstract**

**BACKGROUND:** Genetic testing to determine cancer survivors' risk of developing late effects from their cancer treatment will be increasingly used in survivorship care. This 2-stage study with 64 survivors of childhood cancer and their parents investigated the preferences and acceptability of testing among those who may be at risk of developing late effects.

**METHODS:** The first stage (Stage 1) identified the most commonly perceived benefits and concerns regarding genetic testing for the risk of late effects among 24 participants. In Stage 2, during interviews, 20 survivors (55% of whom were female; mean age, 26.0 years [range, 18-39 years]; standard deviation [SD], 0.80) and 20 parents (55% of whom were male; mean age of child survivor, 14.2 years [range, 10-19 years]; SD, 0.79) rated the 7 most common benefits and concerns from those identified in Stage 1. Interviews were transcribed verbatim and analyzed. Decisional balance ratios were calculated by dividing the participants' average concerns scores with the average benefits scores.

**RESULTS:** Genetic testing for late effects was highly acceptable: 95% of participants leaned toward testing, and the majority (65.9%) would pay up to Australian \$5000. The majority (97.2%) reported it was acceptable to wait for up to 6 months to receive results, and to be offered testing immediately after treatment or when the survivor reached adulthood (62.9%). Survivors and parents had a highly positive decisional balance (Mean (M), 0.5 [SD, 0.38] and M, 0.5 [SD, 0.39], respectively), indicating that perceived benefits outweighed concerns.

**CONCLUSIONS:** Although to our knowledge clinical efficacy has yet to be clearly demonstrated, survivors and parents described positive interest in genetic testing for the risk of developing late effects. Perceived benefits outweighed harms, and the majority of participants would be willing to pay, and wait, for testing.

PMID: 27258553

24. J Palliat Med. 2016 Jul;19(7):698-705.

**The Spectrum of Caregiving in Palliative Care for Serious, Advanced, Rare Diseases: Key Issues and Research Directions.**

Adams LS<sup>1</sup>, Miller JL<sup>1</sup>, Grady PA<sup>1</sup>.

**Abstract**

Rare diseases are often life-limiting conditions, the majority of which require constant caregiving needs. The realization of a spectrum of palliative care throughout the trajectory of rare diseases could ensure individualized and caregiver-focused approaches to the care of patients and families. In June 2015, the National Institute of Nursing Research (NINR), the lead institute at the National Institutes of Health for end-of-life research, in conjunction with the National Center for Advancing Translational Sciences, Office of Rare Diseases Research (ORDR) held an interdisciplinary workshop on the unique challenges of caregiving and palliative care in adult and pediatric rare diseases. The panel identified gaps in current

knowledge, and afforded suggestions for research opportunities in palliative care science to improve the care of individuals with serious, advanced, rare diseases and their caregivers. This meeting provided an in-depth opportunity to incorporate new concepts into palliative and end-of-life care for individuals with a range of rare diseases and their caregivers. This report presents a summary of the workshop.

PMID: 27249541

25. J Pain Symptom Manage. 2016 Jul;52(1):35-42.

**Spiritual Needs of Families With Bereavement and Loss of an Infant in the Neonatal Intensive Care Unit: A Qualitative Study.**

Sadeghi N<sup>1</sup>, Hasanpour M<sup>2</sup>, Heidarzadeh M<sup>3</sup>, Alamolhoda A<sup>4</sup>, Waldman E<sup>5</sup>.

**Abstract**

**CONTEXT:** The hospital is a place full of distress and questions about the meaning of life. The death of a child can cause a spiritual struggle and crisis. Therefore, it is necessary for health care providers in the neonatal intensive care unit (NICU) to assess the spiritual needs of families that have lost a child.

**OBJECTIVES:** The purpose of this study was to explore the spiritual needs of families in Iran at the end of their baby's life and through bereavement in the NICU.

**METHODS:** This study was an exploratory qualitative study performed using purposeful sampling and semi-structured interviews with 24 participants. Inclusion criteria for families, nurses, and physicians included having experienced at least one newborn death in the last six months in the NICU. The research environment was the NICU in Isfahan, one of the largest cities in Iran.

**RESULTS:** Data analysis revealed three main themes: spiritual belief in a supernatural power, the need for comfort of the soul, and human dignity for the newborn.

**CONCLUSION:** The results of this study created a new vision in addressing spiritual needs of Iranian families who experience the death of a newborn.

PMID: 27233143

26. JAMA Intern Med. 2016 Jul 1;176(7):1017-9.

**Palliative Care for Patients With End-Stage Cardiovascular Disease and Devices: A Report From the Palliative Care Working Group of the Geriatrics Section of the American College of Cardiology.**

Kirkpatrick JN<sup>1</sup>, Hauptman PJ<sup>2</sup>, Swetz KM<sup>3</sup>, Blume ED<sup>4</sup>, Gauvreau K<sup>4</sup>, Maurer M<sup>5</sup>, Goodlin SJ<sup>6</sup>.

PMID: 27214624 [PubMed - in process]

27. J Palliat Med. 2016 Jun;19(6):617-21.

**Assessing the Presence and Severity of Constipation with Plain Radiographs in Constipated Palliative Care Patients.**

Clark K<sup>1,2</sup>, Lam LT<sup>3,4</sup>, Talley NJ<sup>2,5</sup>, Quinn J<sup>6</sup>, Blight A<sup>1</sup>, Byfieldt N<sup>1</sup>, Currow DC<sup>7</sup>.

**Abstract**

**BACKGROUND:** Palliative care guidelines recommend plain radiographs to assess constipation based on the presumption that visible fecal shadowing represents stool retention. Despite this, using plain radiographs in this way is not well validated.

**OBJECTIVES:** This work's main aim was to compare clinicians' reports of fecal loading on radiographs. This study also compares clinicians' assessments with radio-opaque marker transit studies and patients' self-reported constipation symptoms.

**METHODS:** This study was conducted in a sample of 30 constipated palliative care patients taking laxatives who had all undergone colon transit studies and contemporaneous assessment of constipation symptoms with the Patient Assessment of Constipation Symptom (PAC-SYM) questionnaire. Four separate clinicians independently reported their opinions of fecal loading using a previously developed fecal loading scale. Participant details were summarized and pair-wise inter-rater agreement among all four raters were examined using the Bland-Altman approach. For the comparisons of the clinician-assigned fecal loading score between the radiographic assessment of the normal and slow colon transit time, the nonparametric approach of Mann-Whitney U tests were applied. Spearman's correlation analyses were employed to investigate the association between the clinician-assigned fecal loading score and the patient self-reported PAC-SYM score.

**RESULTS:** The results of this study are very similar to other studies conducted in functional constipation, highlighting systematic disagreement between observers. Further poor correlations were noted between fecal loading scores and colon transit times and with patient self-reported symptoms.

**CONCLUSION:** These results, when considered with other work in chronic constipation, question the ongoing use of radiographs in the diagnosis of constipation.

PMID: 27203628

28. Ann Palliat Med. 2016 Jul;5(3):157-65.

**Child's symptom burden and depressive symptoms among caregivers of children with cancers: an argument for early integration of pediatric palliative care.**

Olagunju AT<sup>1</sup>, Sarimiye FO<sup>2</sup>, Olagunju TO<sup>3</sup>, Habeebu MY<sup>4</sup>, Aina OF<sup>5</sup>.

**Abstract**

**BACKGROUND:** Childhood cancers evoke various emotional reactions in caregivers which can impair their well-being and roles. Little is known about caregiving and which cancer-associated factors are related to caregiver's depression in resource-restricted settings. We sought to investigate if child's symptom burden is related to depressive symptoms in caregivers.

**METHODS:** Seventy-two caregivers and children with cancers were administered questionnaires to elicit socio-demographic and disease-related data. Subsequently, the child's symptoms were profiled with Memorial Symptom Assessment Scale (MSAS 7-12); while screening for depressive symptoms in caregivers was done using the Center for Epidemiologic Studies Depression Scale-Revised (CES-DR).

**RESULTS:** All the caregivers were parents, and largely mothers (83.7%). The mean ages of caregivers and children were 39±2 and 10±2 years respectively. Majority of caregivers (90.3%) were either ignorant or attributed spiritual causation to the cancers. The common symptoms with prevalence >50% in the children included pain, nausea, worry, and lack of energy (LE); symptoms' prevalence ranged from LE (68%) to itching (32%). Approximately, one-third each of the children reported hair and weight loss which were considered 'unusual' in the design of MSAS 7-12. The symptoms showed variability in distress, frequency and intensity. In particular, pain, lack of appetite (LA) and feeling sad (FS) were reported as most burdensome in >50% of the children. More than one-third of caregivers (38.2%) screened positive for significant depressive symptoms. The global symptom burden ( $r=0.58$ ) and individual symptom correlated positively with depressive symptoms in caregivers ( $P<0.05$ ).

**CONCLUSIONS:** Our findings suggest the need for improved awareness creation on childhood cancers to obviate late presentations and poor access to care. Again, early integration of pediatric palliative care in childhood cancer care to ensure symptom management as well as its extended benefits on caregivers' wellbeing is desirable. The pattern of certain "unusual" symptoms in children with cancer in our work suggests the need to put into consideration 'novel' symptoms which were not captured in existing instruments. Future research on supportive care in pediatric cancers is indicated.

**Free Article**

PMID: 27199271

29. J Pain Palliat Care Pharmacother. 2016 Jun;30(2):131-3.

**A Tragedy of Errors.**

Srikanth L<sup>1</sup>.

**Abstract:** In a village, a small boy is bitten by a snake. A tragedy of errors ensues, arising from a fatal combination of neglect, bad advice, wrong choices, and ignorance. The child and family end up running from this treatment to that until it is too late to save the boy. This is an example of how treatable and curable problems are (mis)handled by the society (parents, public, neighbors, traditional healers, village leaders, and even the so-called medical industry).

PMID: 27171792

30. J Palliat Med. 2016 Jun;19(6):679-83.

**Identifying the Deliberate Prevention and Intervention Strategies of Pediatric Palliative Care Teams Supporting Providers during Times of Staff Distress.**

Jonas DF<sup>1</sup>, Bogetz JF<sup>2</sup>.

**Abstract**

**BACKGROUND:** Pediatric palliative care focuses on caring for children who are seriously ill and their families. These children are often attended to by many other providers who face various challenges as they support these families. Issues involving staff distress are common. Although involving pediatric palliative care teams is recommended, little has been discussed in the literature about the roles and deliberate strategies that pediatric palliative care providers deploy when supporting staff.

**OBJECTIVE:** This case description focuses on staff distress experienced by pediatric providers and aims to make specific recommendations regarding the ways in which pediatric palliative care teams can be helpful in supporting the needs of providers in these challenging care situations.

**DESIGN:** Study and analysis of four pediatric palliative care cases from multidisciplinary perspectives.

**CONCLUSIONS:** In challenging pediatric patient care situations, pediatric palliative care teams may be utilized to support providers when they experience staff distress. Techniques also used with patients, such as active listening and nonjudgmental validation, can be useful. Respecting each person's opinion, establishing goals of care and fostering open communication about the complexities of each child's case can be helpful to prevent burnout and job loss. By promoting understanding and open communication, providers can feel supported in caring for children with serious illnesses and their families.

PMID: 27167894

31. Cancer. 2016 Jul 15;122(14):2224-33.

**"Being a good patient" during times of illness as defined by adolescent patients with cancer.**Weaver MS<sup>1,2</sup>, Baker JN<sup>3</sup>, Gattuso JS<sup>4</sup>, Gibson DV<sup>3</sup>, Hinds PS<sup>5,6</sup>.**Abstract**

**BACKGROUND:** Adolescents with cancer cite the opinions of others and expected impact on others as formative for their care preferences and decisions. The current study first explores how the concepts of being a good child and being a good patient may exist for adolescents with cancer and determines how adolescents describe and apply these concepts. The study then investigates parental actions and clinician behaviors perceived by adolescents with cancer as supportive in helping them to achieve their defined good child and good patient roles.

**METHODS:** In a prospective study conducted at 2 cancer treatment centers over the course of 10 months, 40 adolescents with cancer responded to 10 open-ended questions. Semantic content analysis was used. An adolescent focus group validated the findings.

**RESULTS:** Of the 40 participants in the current study, 39 confirmed 1 or both concepts; the good patient responses yielded 112 codes and 5 themes: cooperation, adherence, communication, self-care, and care for others. The good child responses revealed 88 codes and 7 themes: cooperation and respect, positivity, lightening others' burdens, taking treatment seriously, recognizing mutual impact, communication, and acknowledging mortality. Of 589 interview phrases, 184 (31%) depicted themes of care for others and 58 (10%) spoke of tolerating treatment in the hope of a better future for one's self or others. The benefits and challenges of living up to these definitions were discussed.

**CONCLUSIONS:** Clinicians may consider asking adolescents about their "good child" and "good patient" descriptions to learn more about the perceived roles carried by adolescents with cancer and how these roles may impact their decision making, medication adherence, and social interactions.

PMID: 27141846

32. Adv Neonatal Care. 2016 Jun;16(3):191-200.

**Perceptions of Palliative Care in the NICU.**Falck AJ<sup>1</sup>, Moorthy S, Hussey-Gardner B.**Abstract**

**BACKGROUND AND PURPOSE:**The American Academy of Pediatrics supports palliative care (PC) for all children with life-threatening illnesses. Thus, many neonatal intensive care unit (NICU) patients and their families could benefit from PC. Our study objective was to examine provision of PC as experienced by mothers and healthcare providers (HCPs) of NICU patients with life-threatening illnesses. Palliative care components explored included communication, choices, comfort, psychosocial and spiritual needs, and coordination of care.

**METHODS:** In this qualitative, descriptive study, we conducted semistructured interviews with mothers of infants with life-threatening illnesses and NICU HCPs who cared for these infants. Mothers selected HCPs who were key figures during their infant's NICU stay to participate. Interviews were transcribed and manually coded until themes emerged and theoretical saturation was achieved. Researchers reviewed charts for demographics and notes pertaining to PC. Triangulation of maternal interviews, HCP interviews, and chart notes was performed.

**RESULTS:** Theoretical saturation was achieved after 12 interviews. Mothers identified 5 nurses and 1 physician to be interviewed. Five themes were identified following data analysis and triangulation: (1) communication, (2) privacy, (3) continuity of care and relationship building, (4) maternal knowledge seeking, and (5) emotional turmoil.

**IMPLICATIONS FOR PRACTICE AND RESEARCH:** Of domains of pediatric PC explored, participants emphasized transparent communication, family meetings as a venue for collaboration and shared decision making, the significance of psychosocial support for maternal emotional distress, and the importance of continuity of care across an often long and stressful hospitalization. Although mothers desired privacy, participants valued the security of the open-room NICU design. Future research should address components of PC that predominate in this specialized population.

PMID: 27140033

33. J Palliat Med. 2016 Jul;19(7):763-6.

**Assessment of the Spiritual Needs of Primary Caregivers of Children with Life-Limiting Illnesses Is Valuable Yet Inconsistently Performed in the Hospital.**Kelly JA<sup>1</sup>, May CS<sup>2</sup>, Maurer SH<sup>2,3</sup>.**Abstract**

**BACKGROUND:** Religion and spirituality influence how many patients and families experience illness, but knowledge of the level of spiritual care provided to caregivers of pediatric patients within the hospital is limited.

**OBJECTIVE:** We evaluated patient caregivers' perceptions of the extent to which their religious and spiritual (R/S) needs were assessed and addressed in the hospital.

**METHODS:** We surveyed primary caregivers of children referred to palliative care <1 year prior at an urban, pediatric academic medical center. Participants completed a structured questionnaire with quantitative and qualitative measures of the provision of spiritual care in the hospital. Nonparametric tests were used to compare various measures of perceived and desired R/S support.

**RESULTS:** The majority (16/24) of caregivers desired inquiry about R/S needs by the medical team. Fewer than half (12/25) had these needs assessed. No subjects were uncomfortable with questions regarding R/S needs. Only 35% (8/23) specifically wanted a physician to inquire about R/S needs. Subjects whose R/S needs were assessed perceived higher levels of support from the medical team (4.40 versus 3.08,  $p = 0.02$ ). A significant correlation existed between number of hospital-based R/S resources used and reported R/S-related comfort ( $r_s = 0.438$ ,  $p = 0.043$ ).

**CONCLUSIONS:** Assessment of R/S needs of caregivers of pediatric palliative care patients is performed less often than desired, even though it can improve perceptions of support from medical teams. Use of hospital-based R/S resources can increase spiritual comfort. Standardizing assessment of caregivers' R/S needs and referral to appropriate resources is a target for quality improvement in pediatric palliative medicine.

PMID: 27136401

34. Arch Pediatr. 2016 Jun;23(6):577-83.

**[Comparison of palliative care representations between pediatrician residents and oncologist residents: A qualitative study].**

[Article in French]

Toulouse J<sup>1</sup>, Leneveu MC<sup>2</sup>, Brouard J<sup>3</sup>, Alexandre M<sup>4</sup>.

**Abstract**

**BACKGROUND:** Pediatrics residents treat patients who are particularly vulnerable and they care for many patients in palliative situations. The purpose of this study was to build a typology detailing the representations of pediatrics and oncology residents on palliative care and how these transfer to their practice, and to determine their knowledge of euthanasia and end-of-life legislation.

**METHODS:** To draw up this typology, we used a semidirective interview method. The topics treated were their definition of palliative care, end of life, the emotions involved in these situations, and their daily practice. Then we asked them to speak about their opinions and knowledge of euthanasia and end-of-life legislation.

**RESULTS:** Thirteen residents were interviewed: eight pediatrics residents, two oncologists, and three hemato-oncologists. Interviews lasted around 45min. Pediatrics and oncology residents had common representations based on "care giving." Nevertheless, pediatrics residents remained within the technical aspects to protect themselves from their negative emotions and stayed away from their patients. Oncology residents set their emotions aside to be able to carry on taking care of their patients.

**CONCLUSION:** It seems necessary to disseminate a palliative culture, particularly in pediatrics, to improve management of children in palliative situations and to improve resident's feelings.

PMID: 27133365

35. Pediatr Blood Cancer. 2016 Jul;63(7):1315.

**Response: A Call for Psychosocial and Palliative Care Training Standards for Pediatric Hematology-Oncology Physicians, A Reply To: Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology.**

Patenaude AF<sup>1</sup>, Pelletier W<sup>2</sup>, Bingen K<sup>3</sup>.

PMID: 27082206

36. Expert Opin Drug Metab Toxicol. 2016 Jun;12(6):669-80.

**Pharmacokinetic considerations and recommendations in palliative care, with focus on morphine, midazolam and haloperidol.**

Franken LG<sup>1</sup>, de Winter BC<sup>1</sup>, van Esch HJ<sup>2</sup>, van Zuylen L<sup>3</sup>, Baar FP<sup>2</sup>, Tibboel D<sup>4,5</sup>, Mathôt RA<sup>6</sup>, van Gelder T<sup>1</sup>, Koch BC<sup>1</sup>.

**Abstract**

**INTRODUCTION:** A variety of medications are used for symptom control in palliative care, such as morphine, midazolam and haloperidol. The pharmacokinetics of these drugs may be altered in these patients as a result of physiological changes that occur at the end stage of life.

**AREAS COVERED:** This review gives an overview of how the pharmacokinetics in terminally ill patients may differ from the average population and discusses the effect of terminal illness on each of the four pharmacokinetic processes absorption, distribution, metabolism, and elimination. Specific considerations are also given for three commonly prescribed drugs in palliative care: morphine, midazolam and haloperidol).

**EXPERT OPINION:** The pharmacokinetics of drugs in terminally ill patients can be complex and limited evidence exists on guided drug use in this population. To improve the quality of life of these patients, more knowledge and more pharmacokinetic/pharmacodynamics studies in terminally ill patients are needed to develop individualised dosing guidelines. Until then knowledge of pharmacokinetics and the physiological changes that occur in the final days of life can provide a base for dosing adjustments that will improve the quality of life of terminally ill patients. As the interaction of drugs with the physiology of dying is complex, pharmacological treatment is probably best assessed in a multi-disciplinary setting and the advice of a pharmacist, or clinical pharmacologist, is highly recommended. PMID: 27081769

37. J Psychosoc Oncol. 2016 Jul-Aug;34(4):274-90.

**Health-related quality of life in parents of pediatric brain tumor survivors at the end of tumor-directed therapy.**

Quast LF<sup>1</sup>, Turner EM<sup>2</sup>, McCurdy MD<sup>2</sup>, Hocking MC<sup>1</sup>

**Abstract**

**OBJECTIVE:** This study examines theoretical covariates of health-related quality of life (HRQL) in parents of pediatric brain tumor survivors (PBTs) following completion of tumor-directed therapy.

**METHODS:** Fifty PBTs (ages 6-16) completed measures of neurocognitive functioning and their parents completed measures of family, survivor, and parent functioning.

**RESULTS:** Caregiving demand, caregiver competence, and coping/supportive factors were associated with parental physical and psychosocial HRQL, when controlling for significant background and child characteristics.

**CONCLUSION:** Study findings can inform interventions to strengthen caregiver competence and family functioning following the completion of treatment, which may improve both parent and survivor outcomes.

PMID: 27070180

38. Pediatr Blood Cancer. 2016 Jul;63(7):1314.

**A Call for Psychosocial and Palliative Care Training Standards for Pediatric Hematology-Oncology Physicians, A Reply to: Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology.**

Force LM<sup>1,2</sup>, Rosenberg AR<sup>3,4,5,6</sup>

PMID: 27015275

39. J Palliat Med. 2016 Jul;19(7):760-2.

**The Role of Psychology in Pediatric Palliative Care.**

Edlynn E<sup>1,2</sup>, Kaur H<sup>3</sup>

**Abstract**

Pediatric medicine increasingly has recognized the value of integrating behavioral health in medical care, but this trend has not yet extended to pediatric palliative care. Results from a recent survey of pediatric palliative care programs across the United States indicate that team composition almost never included a psychologist. This article presents a model of collaborative care to optimize the integration of psychosocial and medical aspects of treatment in pediatric palliative care, delineating how a psychologist adds to this model. This article argues that psychology brings specialized skills in assessment, intervention, and research that fit with the premise of palliative care as a holistic approach that relieves symptoms. Systematic inclusion of psychologists on pediatric palliative care teams may help to improve effectiveness of services as well as extend the knowledge base of mental health in pediatric palliative care.

PMID: 27008276

40. Paediatr Drugs. 2016 Jun;18(3):161-80.

**Pediatric Oncology: Managing Pain at the End of Life.**

Snaman JM<sup>1</sup>, Baker JN<sup>1</sup>, Ehrentraut JH<sup>2</sup>, Anghelescu DL<sup>3</sup>

**Abstract**

Pain is a common and highly distressing symptom in pediatric patients with advanced malignancies. Prompt recognition, assessment, and treatment of pain are necessary, especially at the end of life. Opioid medications remain the mainstay of treatment of malignant pain in children at the end of life and the amount of opioids required for adequate pain control in patients is highly variable. Nonpharmacological approaches including behavioral and physical approaches in addition to non-opioid pain medications should be used when possible to augment pain control. Identification and treatment of any underlying pathology is important and use of adjuvant medications based on pathophysiology and source of pain should be considered. In cases where adequate pain control is not achieved through these multiple modalities, an interdisciplinary approach including potential interventional techniques and alternative treatments is required. This multimodal approach to pain management is best provided by interdisciplinary teams, as these teams can best address the complex causes of pain and associated distress that occurs in patients and within families.

PMID: 26951239

41. Biol Blood Marrow Transplant. 2016 Jun;22(6):1049-55.

**End-of-Life Care Patterns Associated with Pediatric Palliative Care among Children Who Underwent Hematopoietic Stem Cell Transplant.**

Ullrich CK<sup>1</sup>, Lehmann L<sup>2</sup>, London WB<sup>2</sup>, Guo D<sup>2</sup>, Sridharan M<sup>2</sup>, Koch R<sup>3</sup>, Wolfe J<sup>4</sup>

**Abstract**

Stem cell transplantation (SCT) is an intensive therapy offering the possibility of cure for life-threatening conditions but with risk of serious complications and death. Outcomes associated with pediatric palliative care (PPC) for children who undergo SCT are unknown. Therefore, we evaluated whether PPC consultation is associated with differences in end-of-life (EOL) care patterns for children who underwent SCT and did not survive. Medical records of children who underwent SCT at Boston Children's Hospital/Dana-Farber Cancer Institute for any indication from September 2004 to December 2012 and

did not survive were reviewed. Child demographic and clinical characteristics and PPC consultation and EOL care patterns were abstracted. Children who received PPC (PPC group) were compared with those who did not (non-PPC group). Children who received PPC consultation (n = 37) did not differ from the non-PPC group (n = 110) with respect to demographic or clinical characteristics, except they were more likely to have undergone unrelated allogeneic SCT (PPC, 68%; non-PPC, 39%; P = .02) or to have died from treatment-related toxicity (PPC, 76%; non-PPC, 54%; P = .03). PPC consultation occurred at a median of .7 months (interquartile range [IQR], .4 to 4.2) before death. PPC consultations most commonly addressed goals of care/decision-making (92%), psychosocial support (84%), pain management (65%), and non-pain symptom management (70%). Prognosis discussions (ie, the likelihood of survival) occurred more commonly in the PPC group (PPC, 97%; non-PPC, 83%; P = .04), as did resuscitation status discussions (PPC, 88%; non-PPC, 58%; P = .002). These discussions also occurred earlier in the PPC group, for prognosis a median of 8 days (IQR, 4 to 26) before death compared with 2 days (IQR, 1 to 13) in the non-PPC group and for resuscitation status a median of 7 days (IQR, 3 to 18) compared with 2 days (IQR, 1 to 5) in the non-PPC group (P < .001 for both of the timing of prognosis and resuscitation status discussions). The PPC group was also more likely to have resuscitation status documented (PPC, 97%; non-PPC, 68%; P = .002). With respect to patterns of care, compared with non-PPC, the PPC group was as likely to die in a medicalized setting (ie, the hospital) (PPC, 84%; non-PPC, 77%; P = .06) or have hospice care (PPC, 22%; non-PPC, 18%; P = .6). However, among children who died in the hospital, those who received PPC were more likely to die outside the intensive care unit (PPC, 80%; non-PPC, 58%; P = .03). In addition, the PPC group was less likely to receive intervention-focused care such as intubation in the 24 hours before death (PPC, 42%; non-PPC, 66%; P = .02) or cardiopulmonary resuscitation (PPC, 3%; non-PPC, 20%; P = .03) at EOL. Children who received PPC for at least a month were more likely to receive hospice care (PPC, 41%; non-PPC, 5%; P = .01). Children who underwent SCT and did not survive were likely to die in a medicalized setting, irrespective of PPC. However, PPC was associated with less intervention-focused care and greater opportunity for EOL communication and advance preparation. In the intense, cure-oriented SCT setting, PPC may facilitate advance care planning in this high-risk population.

PMID: 26903381

42. Nutr Clin Pract. 2016 Jun;31(3):305-15.

**Incorporating Palliative Care Concepts Into Nutrition Practice: Across the Age Spectrum.**

Schwartz DB<sup>1</sup>, Olsson K<sup>2</sup>, Goldman B<sup>3</sup>, Barrocas A<sup>4</sup>, Wesley JR<sup>5</sup>.

**Abstract**

A practice gap exists between published guidelines and recommendations and actual clinical practice with life-sustaining treatments not always being based on the patient's wishes, including the provision of nutrition support therapies. Closing this gap requires an interdisciplinary approach that can be enhanced by incorporating basic palliative care concepts into nutrition support practice. In the fast-paced process of providing timely and effective medical treatments, communication often suffers and decision making is not always reflective of the patient's quality-of-life goals. The current healthcare clinical ethics model does not yet include optimum use of advance directives and early communication between patients and family members and their healthcare providers about treatment choices, including nutrition support. A collaborative, proactive, integrated process in all healthcare facilities and across levels of care and age groups, together with measurable sustained outcomes, shared best practices, and preventive ethics, will be needed to change the culture of care. Implementation of a better process, including basic palliative care concepts, requires improved communication skills by healthcare professionals. Formalized palliative care consults are warranted early in complex cases. An education technique, as presented in this article, of how clinicians can engage in critical and crucial conversations early with patients and family members, by incorporating the patient's values and cultural and religious diversity in easily understood language, is identified as an innovative tool.

PMID: 26888858

43. Support Care Cancer. 2016 Jul;24(7):3057-67.

**Psychological distress, health, and socio-economic factors in caregivers of terminally ill patients: a nationwide population-based cohort study.**

Nielsen MK<sup>1</sup>, Neergaard MA<sup>2</sup>, Jensen AB<sup>3</sup>, Bro F<sup>4</sup>, Guldin MB<sup>4,2</sup>.

**Abstract**

**PURPOSE:** At some point in life, most people become caregivers to a terminally ill relative. Previous studies have shown that many caregivers experience psychological distress and declining physical health, but these studies have predominantly been conducted in specialized palliative care settings. Therefore, caregiver studies with a population-based approach are needed. We aimed to describe socio-economic characteristics, situational factors, pre-loss grief symptoms, depressive symptoms, caregiver burden, and health status in a general population of caregivers to terminally ill patients.

**METHOD:** We conducted a nationwide population-based cohort study. Caregivers were systematically recruited through patients registered with drug reimbursement for terminal illness in 2012. Data on socio-economic characteristics was mainly obtained from Danish registries, whereas data on situational factors, distress, and health was measured in questionnaires.

**RESULTS:** Of patients to responding caregivers (n = 3635), 89 % suffered from cancer, predominantly lung cancer (23 %). Of responding caregivers, 62 % were partners and 29 % were adult children. In total, one third of caregivers reported severe outcome, 15 % reported severe pre-loss grief symptoms, 16.1 % had moderate to severe depressive symptoms, and 12 % experienced high caregiver burden. Partners had the highest levels of pre-loss grief and depressive symptoms, while adult children reported the highest levels of caregiver burden.

**CONCLUSIONS:** From this cohort, which was estimated to be representative of caregivers to terminally ill relatives in the general population, we found high levels of pre-loss grief, depressive symptoms, and/or caregiver burden in one third of all caregivers. These findings call for increased focus on caregivers' need of support.

PMID: 26887588

44. Support Care Cancer. 2016 Jul;24(7):2869-75.

**Use of complementary and alternative medicine by pediatric oncology patients during palliative care.**

Schütze T<sup>1</sup>, Längler A<sup>1</sup>, Zuzak TJ<sup>2,3,4</sup>, Schmidt P<sup>5</sup>, Zernikow B<sup>5</sup>.

**Abstract**

**PURPOSE:** Although the popularity of complementary and alternative medicine (CAM) has risen in the last decade, information about its use by pediatric patients in palliative care is still scarce. The purpose of the study was to assess the frequency and types of CAM administered by parents with children suffering from cancer during the palliative phase.

**METHODS:** All parents who lost their child due to cancer in the federal state North Rhine Westfalia/Germany were eligible for the study. The first group of eligible parents was contacted in 1999-2000 and a second group of parents in 2005-2006. Upon agreement, parents were asked to complete a semi-structured questionnaire about the frequency of CAM use and the specific treatments that had been used. The types of CAM were categorized according to the National Center for Complementary and Alternative Medicine (NCCAM).

**RESULTS:** A total of 96 parents participated in the study (48 in each cohort). Forty-three percent of all parents in both groups reported CAM use. The results show an increase of CAM use from 38 % in the first group to 49 % in the second cohort of pediatric patients during palliative care. The most common types of CAM used in both groups were homeopathy and treatment with mistletoe preparations.

**CONCLUSIONS:** The study provides information about usage of CAM in children suffering from cancer during the palliative phase of the disease. Further research is required to investigate benefits, potential adverse effects, and the potential efficacy of CAM in this population.

PMID: 26838025

45. J Pediatr Oncol Nurs. 2016 Jul;33(4):297-305.

**Bereaved Siblings' Advice to Health Care Professionals Working With Children With Cancer and Their Families.**

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**Abstract**

**INTRODUCTION:** Siblings of children with cancer experience psychosocial distress during the illness and after bereavement, but often stand outside the spotlight of attention and care. This study explored bereaved siblings' advice to health care professionals (HCPs) working with children with cancer and their families.

**MATERIALS AND METHODS:** In a nationwide Swedish survey of bereaved siblings, 174/240 (73%) participated. Of these, 108 answered an open-ended question about what advice they would give to HCPs working with children with cancer and their families. In this study, responses to this single question were analyzed using content analysis.

**RESULTS:** The most common advice, suggested by 56% of siblings, related to their own support. One third suggested giving better medical information to siblings. Some siblings wanted to be more practically involved in their brother's/sister's care and suggested that HCPs should give parents guidance on how to involve siblings. Other common advice related to psychosocial aspects, such as the siblings' wish for HCPs to mediate hope, yet also realism, and the importance of asking the ill child about what care they wanted.

**CONCLUSION:** Information, communication, and involvement should be emphasized by HCPs to support siblings' psychosocial needs in both the health care setting and within the family.

PMID: 26669875

46. Palliat Support Care. 2016 Jun;14(3):187-98.

**Parenting in the face of childhood life-threatening conditions: The ordinary in the context of the extraordinary.**

Mooney-Doyle K<sup>1</sup>, Deatrick JA<sup>2</sup>.

**Abstract**

**OBJECTIVE:** Uncovering what it means to be a parent during the extraordinary time of a child's life-threatening condition (LTC) is important for understanding family goals, decision making, and the work of parenting within this context.

**METHOD:** Qualitative descriptive methods were employed to describe the everyday experience of parenting both children who have an LTC and their healthy siblings.

**RESULTS:** Some 31 parents of 28 children with an LTC who have healthy siblings participated in our study. Four themes emerged from the data that describe a parental desire to maintain emotional connection with all of their children, how

parents use cues from their children to know them better and develop parenting strategies, how parents change as a result of caring for a child with an LTC, and how they strive to decrease suffering for all of their children.

**SIGNIFICANCE OF RESULTS:** The findings of our study have implications for clinical practice, family-focused research, and health policy pertaining to families of children with life-threatening conditions.

PMID: 26462446

47. Palliat Med. 2016 Jun;30(6):533-48.

**A systematic review of reasons for gatekeeping in palliative care research.**

Kars MC<sup>1</sup>, van Thiel GJ<sup>2</sup>, van der Graaf R<sup>2</sup>, Moors M<sup>2</sup>, de Graeff A<sup>3</sup>, van Delden JJ<sup>2</sup>.

**Abstract**

**BACKGROUND:** When healthcare professionals or other involved parties prevent eligible patients from entering a trial as a research subject, they are gatekeeping. This phenomenon is a persistent problem in palliative care research and thought to be responsible for the failure of many studies.

**AIM:** To identify potential gatekeepers and explore their reasons for gatekeeping in palliative care research.

**DESIGN:** A 'Review of Reasons' based on the systematic Preferred Reporting Items for Systematic Reviews and Meta-Analyses approach and a thematic synthesis.

**DATA SOURCE:** PubMed, Embase, Cumulative Index to Nursing and Allied Health Literature and PsycINFO from 2000 to May 20 2015 were searched. Studies in children (aged <18 years) and patients with dementia were excluded.

**RESULTS:** Thirty papers on gatekeeping in palliative care research were included. Five groups of potential gatekeepers were identified: healthcare professionals, research ethics committees, management, relatives and researchers. The fear of burdening vulnerable patients was the most reported reason for gatekeeping. Other reasons included 'difficulty with disclosure of health status', 'fear of burdening the patient's relatives', 'doubts about the importance or quality of the study', 'reticent attitude towards research and (research) expertise' and 'logistics'. In hospice and homecare settings, the pursuit of comfort care may trigger a protective attitude. Gatekeeping is also rooted in a (perceived) lack of skills to recruit patients with advanced illness.

**CONCLUSION:** Gatekeeping is motivated by the general assumption of vulnerability of patients, coupled with an emphasis on the duty to protect patients. Research is easily perceived as a threat to patient well-being, and the benefits appear to be overlooked. The patients' perspective concerning study participation is needed to gain a full understanding and to address gatekeeping in palliative care research.

PMID: 26577927

48. Palliat Support Care. 2016 Jun;14(3):177-86.

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

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**Abstract**

**OBJECTIVE:** This study aimed to generate an explanatory model of the coping strategies that adolescents employ to manage the stressors they experience in the final months of their ill parent's life and shortly after their death.

**METHOD:** The sample included 26 families of adolescents with a parent receiving care in a large hospice program in northeastern Ohio. A semistructured interview was conducted with 14 ill parents, 17 well parents/guardians, and 30 of their adolescent children before the parent's death and, additionally, with 6 of these families after the death. The interviews were audiotaped, transcribed verbatim, and analyzed using a grounded-theory approach.

**RESULTS:** The participants described two worlds that constituted the lives of the adolescents: the well world of normal adolescence and the ill world of having a parent near the end of life. The adolescents experienced a common challenge of living in two worlds and responded to the challenge with a process we labeled "managing two worlds." Five stages through which adolescents manage their worlds were identified: keeping the ill world and the well world separate; having the ill world intrude into the well world; moving between the ill world and the well world; being immersed in the ill world; and returning to the well world having been changed by the ill world.

**SIGNIFICANCE OF RESULTS:** The explanatory model of "managing two worlds" outlines a complex and nuanced process that changes over time. The model can be used by health professionals who seek to help adolescents navigate this critical time when their parents are dying or have recently died. These results can also be used to inform the development of interventions that assist families with strategies tailored to an adolescent's specific needs. Future research should investigate associations among the process of "managing two worlds" and outcomes related to adolescent bereavement.

PMID: 26126748

49. Am J Hosp Palliat Care. 2016 Jun;33(5):421-4.

**Pediatric Euthanasia and Palliative Care Can Work Together.**

Hanson SS<sup>1</sup>.

**Abstract**

Since the Netherlands produced the Groningen protocol describing the methods to be used for pediatric euthanasia and Belgium passed laws authorizing euthanasia for children who consent to it, the issue of pediatric euthanasia has become a relevant topic to discuss. Most rejections of pediatric euthanasia fall into 1 or more of 3 categories, each of which has problems. This article shows how several recent arguments against pediatric euthanasia fail to prove that pediatric euthanasia is unacceptable. It does not follow from this that the practice is permissible but rather that if one is to reject such a practice, stronger arguments will need to be made, especially in countries where adult euthanasia or assisted suicide is already permitted.

PMID: 25667147

50. J Child Health Care. 2016 Jun;20(2):145-52.

**Improving and validating children's nurses communication skills with standardized patients in end of life care.**

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**Abstract**

Children's nurse education is experiencing increases in recruitment targets at the same time that clinical placements are decreasing. With regard to end-of-life care, it has become a challenge to ensure that all students come into contact with a satisfactory range of experience as part of the requirement for competency at the point of registration. The aim of our study was to find out if students at the end of their course were able to use communication skills acquired in their three years of training and adapt and transfer them to a specific palliative care context even if they had never worked in that area of care. Focus groups were conducted after the simulations which explored the students' experiences of being involved in the scenarios. Four themes emerged that students identified either inhibited or enabled their communication skills, which included anxiety and fear, the need for professional props, the experience of it being real and feeling empowered.

PMID: 25395598