

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

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



The sixth number

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1. An Pediatr (Barc). 2015 Nov 24. [Epub ahead of print]

[\[Critically ill paediatric hemato-oncology patient: What we do is what we should do?\]](#)

[Article in Spanish]

OBJECTIVE: Primary objective, to describe the management and monitorization of critically ill pediatric hemato-oncology patient (CIPH0) in the Spanish pediatric intensive care units (PICU). Secondary objective, through a literature review, to identify possible areas of improvement. **MATERIAL AND METHODS:** Observational transversal descriptive study. An anonymous web-based survey was sent to 324 Spanish pediatric intensivists from April 2011 to May 2011. None of them were pediatric residents. **RESULTS:** The survey was answered by 105 intensivists, 59/105 always agreed their treatment with the oncologist. In case of hemodynamic instability, non-invasive blood pressure monitoring is always done by 85/105 and almost always optimized by intra-arterial measuring (85/105) and central venous pressure (70/105). If respiratory failure the use of non-invasive ventilation (NIPPV) is always (36/105) or frequently (60/105) established prior to conventional mechanical ventilation. To replace or withdraw non-invasive ventilation only 44/96 of the respondents to this question use a clinical protocol. Before the instauration of conventional mechanical ventilation the oncological prognosis is considered by 72/105. In case of acute oliguric renal failure the renal replacement techniques are widely used (74/105). The withdrawal of sustaining life support is frequently discussed (75/103) and agreed with the oncologist (91/103) and caregivers (81/103). **CONCLUSIONS:** In our study, despite there is not a defined standard-of-care, the respondents showed similar therapeutics and monitorization choices. The use of NIPPV as first respiratory assistance is extended. Prospective, observational and multicenter studies should be developed to establish the results of this management in this population.

PMID: 26619931 [PubMed - as supplied by publisher]

2. Int J Palliat Nurs. 2015 Nov 2;21(11):542-7.

['Fighting for care': parents' perspectives of children's palliative care in South Tyrol, Italy.](#)

[Darbyshire P¹, Mischo-Kelling M², Lochner L³, Messerschmidt-Grandi C⁴.](#)

BACKGROUND: Children's palliative care in Italy develops comparatively slowly. Recent legislation is enabling, but foundational research exploring parental experiences and perceptions is lacking. **AIM:** To investigate the experiences and perceptions of parents in South Tyrol, Italy regarding caring for a child with a life-threatening or life-limiting illness. **DESIGN:** A mixed qualitative design incorporated both an online survey and parent interviews. Using purposive sampling, 13 parents undertook 9 interviews and 7 parents completed the survey. **RESULTS:** The authors highlight a major parental theme describing difficult relationships with health services requiring them to 'fight the system' for services. **DISCUSSION:** The authors raise a disturbing possibility that such 'fighting the system' is now so widely recognised worldwide that it cannot be considered to be accidental. **CONCLUSION:** The authors recommend the establishment of a specialist, dedicated paediatric palliative care service in South Tyrol with the international recognised values and operating standards that would render such parental 'fighting' unnecessary.

PMID: 26619238 [PubMed - in process]

3. JAMA Pediatr. 2015 Nov 30:1-7. [Epub ahead of print]

[International and Interdisciplinary Identification of Health Care Transition Outcomes.](#)

[Fair C¹, Cuttance J², Sharma N³, Maslow G⁴, Wiener L⁵, Betz C⁶, Porter J⁷, McLaughlin S⁸, Gilleland-Marchak J⁹, Renwick A¹⁰, Naranjo D¹¹, Jan S¹², Javalkar K², Ferris M², International and Interdisciplinary Health Care Transition Research Consortium.](#)

IMPORTANCE: There is a lack of agreement on what constitutes successful outcomes for the process of health care transition (HCT) among adolescent and young adults with special health care needs. **OBJECTIVE:** To present HCT outcomes identified by a Delphi process with an interdisciplinary group of participants. **DESIGN, SETTING, AND PARTICIPANTS:** A Delphi method involving 3 stages was deployed to refine a list of HCT outcomes. This 18-month study (from January 5, 2013, of stage 1 to July 3, 2014, of stage 3) included an initial literature search, expert interviews, and then 2 waves of a web-based survey. On this survey, 93 participants from outpatient, community-based, and primary care clinics rated the importance of the top HCT outcomes identified by the Delphi process. Analyses were performed from July 5, 2014, to December 5, 2014. **EXPOSURES:** Health care transition outcomes of adolescents and young adults with special health care needs. **MAIN OUTCOMES AND MEASURES:** Importance ratings of identified HCT outcomes rated on a Likert scale from 1 (not important) to 9 (very important). **RESULTS:** The 2 waves of surveys included 117 and 93 participants as the list of outcomes was refined. Transition outcomes were refined by the 3 waves of the Delphi process, with quality of life being the highest-rated outcome with broad agreement. The 10 final outcomes identified included individual outcomes (quality of life, understanding the characteristics of conditions and complications, knowledge of medication, self-management, adherence to medication, and understanding health insurance), health services outcomes (attending medical appointments, having a medical home, and avoidance of unnecessary hospitalization), and a social outcome (having a social network). Participants indicated that different outcomes were likely needed for individuals with cognitive disabilities. **CONCLUSIONS AND RELEVANCE:** Quality of life is an important construct relevant to HCT. Future research should identify valid measures associated with each outcome and further explore the role that quality of life plays in the HCT process. Achieving consensus is a critical step toward the development of reliable and objective comparisons of HCT outcomes across clinical conditions and care delivery locations. PMID: 26619178 [PubMed - as supplied by publisher]

4. J Palliat Med. 2015 Nov 30. [Epub ahead of print]

Perceptions of the Pediatric Hospice Experience among English- and Spanish-Speaking Families.

Thienprayoon R^{1,2}, Marks E³, Funes M³, Martinez-Puente LM³, Winick N^{4,5}, Lee SC^{3,6}.

OBJECTIVE: Many children who die are eligible for hospice enrollment but little is known about parental perceptions of the hospice experience, the benefits, and disappointments. The objective of this study was to explore parental perspectives of the hospice experience in children with cancer, and to explore how race/ethnicity impacts this experience. **STUDY DESIGN:** We held 20 semistructured interviews with 34 caregivers of children who died of cancer and used hospice. Interviews were conducted in the caregivers' primary language: 12 in English and 8 in Spanish. Interviews were recorded, transcribed, and analyzed using accepted qualitative methods. **RESULTS:** Both English and Spanish speakers described the importance of honest, direct communication by medical providers, and anxieties surrounding the expectation of the moment of death. Five English-speaking families returned to the hospital because of unsatisfactory symptom management and the need for additional supportive services. Alternatively, Spanish speakers commonly stressed the importance of being at home and did not focus on symptom management. Both groups invoked themes of caregiver appraisal, but English-speaking caregivers more commonly discussed themes of financial hardship and fear of insurance loss, while Spanish-speakers focused on difficulties of bedside caregiving and geographic separation from family. **CONCLUSIONS:** The intense grief associated with the loss of a child creates shared experiences, but Spanish- and English-speaking parents describe their hospice experiences in different ways. Additional studies in pediatric hospice care are warranted to improve the care we provide to children at the end of life.

PMID: 26618809 [PubMed - as supplied by publisher]

5. Am J Hosp Palliat Care. 2015 Nov 24. [Epub ahead of print]

Barriers of Palliative Care in Neonatal Intensive Care Units: Attitude of Neonatal Nurses in Southeast Iran.

Azzizadeh Forouzi M¹, Banazadeh M², Ahmadi JS², Razban F³.

OBJECTIVE: Neonatal nurses face numerous barriers in providing end-of-life (EOL) care for neonates and their families. Addressing neonatal nurses' attitudes could provide insight into barriers that impede neonatal palliative care (NPC). This study thus conducted to examine neonatal nurses' attitude toward barriers in providing NPC in Southeast Iran. **METHOD:** In this cross-sectional study, a translated modified version of Neonatal Palliative Care Attitude Scale was used to examine attitudes of 70 nurses toward barriers of palliative care in 3 neonatal intensive care units in Southeast Iran. **RESULTS:** Findings indicated that overall 42.63% of nurses were strongly agreed or agreed with the proposed barriers in NPC. Among all categories, the highest and the lowest scores belonged to the categories of "insufficient resources" (3.42 ± 0.65) and "inappropriate personal and social attitudes" (2.33 ± 0.48), respectively. Neonatal nurses who had less education and study regarding NPC reported the presence of more barriers to NPC in the categories of "inappropriate organizational culture" and/or "inadequate nursing proficiency." Also, younger nurses had more positive attitudes toward the category of inappropriate organizational culture as being a barrier to provision of NPC (4.62). **CONCLUSION:** The findings suggest that developing a context-based instrument is required to represent the barrier more precisely. Neonatal palliative care can be improved by establishing a special environment to focus on infants' EOL care. This establishment requires standard palliative care guidelines and adequate NPC-trained nurses. © The Author(s) 2015.

PMID: 26602317 [PubMed - as supplied by publisher]

6. Am J Hosp Palliat Care. 2015 Nov 24. [Epub ahead of print]

Discussing Serious News: Teaching Communication Skills Through Role Play With Bereaved Parents.

Flint H¹, Meyer M², Hossain M³, Klein M⁴.

AIM: The ability to communicate serious news to patients and families in a caring and compassionate way is a critical skill for physicians. This study explores the impact of a novel communication skills workshop that included bereaved parents in role play on pediatric residents' confidence to communicate serious news. **METHODS:** Following the workshop, pediatric residents were surveyed to assess their perceived efficacy of the educational intervention. The survey included anchored

response and open-ended questions to yield qualitative and quantitative results. **RESULTS:** After completing the workshop, residents' confidence in discussing goals, managing emotions, and expressing empathy all increased significantly. Residents reported that the inclusion of bereaved parents was beneficial since it made the experience more realistic. In addition, they believed their ability to communicate with patients and families had improved. **CONCLUSIONS:** Including bereaved parents in this communication skills workshop improved the residents' confidence in discussing serious topics and enhanced the reality of the experience. © The Author(s) 2015.

PMID: 26602316 [PubMed - as supplied by publisher]

7. J Palliat Med. 2015 Nov 24. [Epub ahead of print]

Intensity of Medical Interventions between Diagnosis and Death in Patients with Advanced Lung and Colorectal Cancer: A CanCORS Analysis.

Brooks GA^{1,2}, Cronin AM¹, Uno H^{1,3}, Schrag D^{1,2}, Keating NL^{2,4}, Mack JW^{1,2,5}.

BACKGROUND: Medical interventions are an important component of the illness experience in advanced cancer. **OBJECTIVE:** To describe the use of medical interventions between diagnosis and death in decedents with metastatic lung and colorectal cancer. **DESIGN:** Retrospective analysis of a prospective cohort study. **SETTING/SUBJECTS:** We studied 1,840 decedents from the Cancer Care Outcomes Research and Surveillance (CanCORS) study. Subjects had been diagnosed with stage IV lung or colorectal cancer between 2003 and 2005. **MEASUREMENTS:** Hospitalizations, surgeries, radiation therapy treatments, chemotherapy treatments, and end-of-life care, reported by tertile of overall survival time. **RESULTS:** Median survival in the bottom, middle, and top tertiles of survival was 1.2, 5.3, and 15.3 months for lung cancer, and 3.0, 18.0, and 44.4 months for colorectal cancer. Hospitalizations, chemotherapy receipt, and hospice enrollment increased with increasing survival. The median duration of chemotherapy in the top survival tertile was 149 days for lung cancer and 498 days for colorectal cancer. A minority of decedents used any hospice services, and the median duration of hospice enrollment exceeded 30 days only for enrollees in the top survival tertile (lung cancer, 35 days; colorectal cancer, 66 days). **CONCLUSIONS:** For patients with metastatic lung and colorectal cancer, longer survival is associated with increased intensity of medical care, characterized by greater use of chemotherapy and acute hospital care. Hospice utilization was uniformly low, and most hospice enrollees were referred to hospice in the last 30 days of life.

PMID: 26600474 [PubMed - as supplied by publisher]

8. Childs Nerv Syst. 2015 Nov 23. [Epub ahead of print]

Pediatric thalamic tumors in the MRI era: a Canadian perspective.

Steinbok P¹, Gopalakrishnan CV², Hengel AR², Vitali AM³, Poskitt K⁴, Hawkins C⁵, Drake J⁶, Lamberti-Pasculli M⁶, Ajani O⁷, Hader W⁸, Mehta V⁹, McNeely PD¹⁰, McDonald PJ¹¹, Ranger A¹², Vassilyadi M¹³, Atkinson J¹⁴, Ryall S¹⁵, Eisenstat DD¹⁶, Hukin J¹⁷.

BACKGROUND: Thalamic gliomas are rare. The natural history is unpredictable, and the optimal management of these tumors in children is poorly defined. The aim was to identify outcomes, prognostic factors, and response to various modalities of treatment in a relatively large population of pediatric thalamic tumors from many centers within a fairly homogeneous health care system. **METHODS:** We performed a Canadian multicenter retrospective review of pediatric thalamic tumors presenting during the MRI era (1989-2012). Radiology and pathology were reviewed by central independent reviewers. Paraffin shavings for RNA extraction were taken and tested for fusion events involving KIAA1549:BRF. Tumors were classified as unilateral or bithalamic based on their origin on imaging. Univariate and multivariate analyses on factors influencing survival were performed. **RESULTS:** Seventy-two thalamic tumors were identified from 11 institutions. Females represented 53 % of the study population, and the mean age at presentation was 8.9 years. Sixty-two tumors were unilateral and 10 bithalamic. Unilateral tumors had a greater propensity to grow inferiorly towards the brainstem. These tumors were predominantly low grade in comparison to bithalamic tumors which were high-grade astrocytomas. The 5-year overall survival was 61 ± 13 % for unithalamic tumors compared to 37 ± 32 % for bithalamic tumors (p = 0.097). Multivariate analysis indicated tumor grade as the only significant prognostic factor for unithalamic tumors. Six unilateral tumors, all low grade, were BRAF fusion positive. **CONCLUSION:** Unilateral and bilateral thalamic tumors behave differently. Surgical resection is an appropriate treatment option in unilateral tumors, most of which are low grade, but outcome is not related to extent of resection (EOR). Bilateral thalamic tumors have a poorer prognosis, but the occasional patient does remarkably well. The efficacy of chemotherapy and radiotherapy has not been clearly demonstrated. Novel therapeutic approaches are required to improve the prognosis for malignant unilateral thalamic tumors and bilateral thalamic tumors.

PMID: 26597682 [PubMed - as supplied by publisher]

9. J Emerg Med. 2015 Nov 17. [Epub ahead of print]

Drug Reaction with Eosinophilia and Systemic Symptoms Syndrome Induced by Levetiracetam in a Pediatric Patient.

Bayram AK¹, Canpolat M¹, Çınar SL², Tahan F³, Gumus H¹, Kumandaş S¹, Per H¹.

BACKGROUND: Drug reaction with eosinophilia and systemic symptoms (DRESS) syndrome is a rare, life-threatening hypersensitivity drug reaction. Patients present with cutaneous rash, fever, lymphadenopathy, hematologic abnormalities with eosinophilia and atypical lymphocytes, and visceral organ involvement. The prognosis of DRESS syndrome is related to the degree of end-organ damage, and the mortality rate is approximately 10%. **OBJECTIVE:** ... **CASE REPORT:** We report a 9-year-old girl treated with only levetiracetam because of intracranial space occupying mass-related seizures. The patient developed pharyngitis accompanied by exudative membrane, bilateral cervical lymphadenopathy, tender hepatomegaly, skin rash, and fever after 19 days of levetiracetam therapy. Laboratory findings revealed leukocytosis, lymphocytosis with an atypical lymphocytosis, eosinophilia, thrombocytopenia, and elevated serum transaminases. Serologic studies of viruses were negative. The patient was diagnosed with DRESS syndrome and antiepileptic therapy was ceased immediately. The systemic signs and symptoms of the patient were improved after systemic steroid and antihistamine therapy. **WHY SHOULD AN EMERGENCY PHYSICIAN BE AWARE OF THIS?:** It is important that emergency physicians be aware of the possibility of

DRESS syndrome when attending children that present with clinical viral infections. We would like to emphasize that obtaining a careful and detailed medication history is an essential part of clinical assessment for the diagnosis of DRESS syndrome. Copyright © 2015 Elsevier Inc. All rights reserved.

PMID: 26597350 [PubMed - as supplied by publisher]

10. Clin Neurophysiol. 2015 Oct 28. [Epub ahead of print]

Electroencephalography during general anaesthesia differs between term-born and premature-born children.

Poorun R¹, Hartley C², Goksan S¹, Worley A³, Boyd S³, Cornelissen L⁴, Berde C⁴, Rogers R⁵, Ali T⁵, Slater R⁶.

OBJECTIVES: Premature birth is associated with a wide range of complications in later life, including structural and functional neurological abnormalities and altered pain sensitivity. We investigated whether during anaesthesia premature-born children display different patterns of background EEG activity and exhibit increased responses to nociceptive stimuli.

METHODS: We examined background EEG and time-locked responses to clinical cannulation in 45 children (mean age (\pm SD) at study: 4.9(\pm 3.0)years) under sevoflurane monoanaesthesia maintained at a steady-state end-tidal concentration of 2.5%. 15 were born prematurely (mean gestational age at birth: 29.2 \pm 3.9weeks) and 30 were age-matched term-born children.

RESULTS: Background levels of alpha and beta power were significantly lower in the premature-born children compared to term-born controls ($p=0.048$). Clinical cannulation evoked a significant increase in delta activity ($p=0.032$), which was not significantly different between the two groups ($p=0.44$).

CONCLUSIONS: The results indicate that whilst under anaesthesia premature-born children display different patterns of background brain activity compared to term-born children.

SIGNIFICANCE: As electrophysiological techniques are increasingly used by anaesthetists to gauge anaesthetic depth, differences in background levels of electrophysiological brain activity between premature and term-born children may be relevant when considering titration of anaesthetic dose.

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PMID: 26589678 [PubMed - as supplied by publisher]

11. BMJ. 2015 Nov 19;351:h6123.

Problems with preference and place of death for children too.

Bluebond-Langner M¹, Beecham E², Candy B², Langner R¹, Jones L².

PMID: 26585650 [PubMed - in process]

12. J Perinatol. 2015 Nov 19. [Epub ahead of print]

Extremely premature birth and the choice of neonatal intensive care versus palliative comfort care: an 18-year single-center experience.

Kaempf JW¹, Tomlinson MW², Tuohey J³.

OBJECTIVE: Review all live births 22 0/7 through 26 6/7 weeks gestation born 1996 through 2013 at our institution to describe the decision process and immediate outcomes of palliative comfort care (PCC) versus neonatal intensive care (NICU) and whether any significant family complaints or quality assurance concerns arose.

STUDY DESIGN: Retrospective chart review, physician and ethicist interview process and database review focused upon our established periviability counseling guidelines that are directive of PCC at 22 weeks gestation and NICU at 26 weeks but supportive of informed family choice of either option at 23, 24 and 25 weeks.

RESULT: At 22 weeks-all 54 infants had PCC; at 23 weeks-29/78 (37%) chose NICU care, 6/29 (21%) infants survived; at 24 weeks-79/108 (73%) chose NICU care, 47/79 (59%) survived; at 25 weeks-147/153 (96%) chose NICU care, 115/147 (78%) survived; and at 26 weeks-all infants had NICU care, 176/203 (87%) survived. Over 18 years and 606 births, we identified only three significant concerns from families and/or physicians that required formal review.

CONCLUSION: Most pregnant women and families choose NICU care for their extremely premature infant, but if given the option via shared decision making, a significant proportion will choose PCC at gestational ages that some NICUs mandate resuscitation. We support a reasoned dialogue and bioethical framework that recognizes human values to be irreducibly diverse, sometimes conflicting, and ultimately incommensurable-value pluralism.

Respectful shared decision making requires thoughtful and compassionate flexibility, nuanced and individualized suggestions for PCC or NICU and the reduction of hierarchical directives from physicians to families. We continue to advocate and rely upon informed family preference between 23 and 25 weeks gestation in our updated 2015 periviability guidelines.

Journal of Perinatology advance online publication, 19 November 2015; doi:10.1038/jp.2015.171.

PMID: 26583942 [PubMed - as supplied by publisher]

13. Minerva Pediatr. 2015 Nov 19. [Epub ahead of print]

Habit Reversal Training in children and adolescents with chronic tic disorders: an Italian randomized, single blind, pilot study.

Seragni G¹, Chiappedi M, Bettinardi B, Zibordi F, Colombo T, Reina C, Angelini L.

AIM: to test the possibility to apply Habit Reversal Training (HRT) in Italy and to evaluate the effectiveness of HRT in reducing tic severity compared with the "Usual Care" (UC) in Italian children and adolescents with Tourette Syndrome.

METHODS: we performed a single blind, randomized, pilot study comparing HRT (active treatment) and UC (treatment as usual).

Out of 69 patients seen during study period, we were able to enrol 21 patients (11 randomized to HRT e 10 to UC). Assessment included in-depth neurological and psychiatric examination, K-SADS-PL, YGTSS, KIDSCREEN, GTS-QOL, CGI and C-GAS. All these evaluations but the K-SADS-PL were used for baseline assessment but also one week after the end of treatment (T1) and then 3, 6 and 9 months later (respectively T2, T3 and T4).

RESULTS: the sample was largely composed of patients of relevant clinical severity (CGI = 3 or more: 85%). OCD and ADHD were the most frequent comorbidities (30% each). Only minor differences in terms of treatment effectiveness were found, although the HRT group turned out to include patients with more tics and a more compromised general functioning despite randomization.

CONCLUSIONS: we had a high number of patients who refused to be randomized (23 out of 69) and a high number of drop outs (27% in the HRT group,

50% in the UC group). There was an improvement in terms of reduced tics and improved global functioning in both groups, without significant changes in terms of Quality of Life.
PMID: 26583455 [PubMed - as supplied by publisher]

14.

Pediatric Supportive Care (PDQ®): Patient Version [Internet].

Authors PDQ Supportive and Palliative Care Editorial Board.

PDQ Cancer Information Summaries [Internet]. Bethesda (MD): National Cancer Institute (US); 2002-. 2015 Jan 22.

Excerpt This PDQ cancer information summary has current information about supportive care issues related to treatment in children and adolescents. It is meant to inform and help patients, families, and caregivers. It does not give formal guidelines or recommendations for making decisions about health care. Editorial Boards write the PDQ cancer information summaries and keep them up to date. These Boards are made up of experts in cancer treatment and other specialties related to cancer. The summaries are reviewed regularly and changes are made when there is new information. The date on each summary ("Date Last Modified") is the date of the most recent change. The information in this patient summary was taken from the health professional version, which is reviewed regularly and updated as needed, by the PDQ Supportive and Palliative Care Editorial Board. **Free Books & Documents**

PMID: 26389483 [PubMed]

15.

Pediatric Supportive Care (PDO®): Health Professional Version [Internet].

Authors DQ Supportive and Palliative Care Editorial Board.

PDQ Cancer Information Summaries [Internet]. Bethesda (MD): National Cancer Institute (US); 2002-. 2015 Jan 15.

Excerpt This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about supportive care issues related to treatment in children and adolescents. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making health care decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive and Palliative Care Editorial Board, which is editorially independent of the National Cancer Institute (NCI). The summary reflects an independent review of the literature and does not represent a policy statement of NCI or the National Institutes of Health (NIH).

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PMID: 26389208 [PubMed]

16. *Pediatr Blood Cancer*. 2015 Nov 18. [Epub ahead of print]

Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families.

Kaye EC¹, Friebert S², Baker JN¹.

Abstract Despite increasing data to support pediatric palliative care (PPC) as an integral component of high-quality care for children with life-threatening conditions and their families, timely integration of PPC is offered inconsistently to children with high-risk cancer. In this review, we summarize the growing body of literature in support of early integration of PPC for children with high-risk cancer and their families, advocating that PPC principles and resources are imperative to holistic cancer-directed care and rooted in evidence-based medicine. Finally, we offer possible strategies for optimizing integration of PPC into holistic cancer care for children and families. © 2015 Wiley Periodicals, Inc.

PMID: 26579997 [PubMed - as supplied by publisher]

17. *J Clin Oncol*. 2015 Nov 17. [Epub ahead of print]

Provision of Palliative Care in Low- and Middle-Income Countries: Overcoming Obstacles For Effective Treatment Delivery.

Hannon B¹, Zimmermann C¹, Knaul FM¹, Powell RA¹, Mwangi-Powell FN¹, Rodin G².

Abstract Despite being declared a basic human right, access to adult and pediatric palliative care for millions of individuals in need in low- and middle-income countries (LMICs) continues to be limited or absent. The requirement to make palliative care available to patients with cancer is increasingly urgent because global cancer case prevalence is anticipated to double over the next two decades. Fifty percent of these cancers are expected to occur in LMICs, where mortality figures are disproportionately greater as a result of late detection of disease and insufficient access to appropriate treatment options. Notable initiatives in many LMICs have greatly improved access to palliative care. These can serve as development models for service scale-up in these regions, based on rigorous evaluation in the context of specific health systems. However, a multi-pronged public health approach is needed to fulfill the humane and ethical obligation to make palliative care universally available. This includes health policy that supports the integration of palliative care and investment in systems of health care delivery; changes in legislation and regulation that inappropriately restrict access to opioid medications for individuals with life-limiting illnesses; education and training of health professionals; development of a methodologically rigorous data and research base specific to LMICs that encompasses health systems and clinical care; and shifts in societal and health professional attitudes to palliative and end-of-life care. International partnerships are valuable to achieve these goals, particularly in education and research, but leadership and health systems stewardship within LMICs are critical factors that will drive and implement change. © 2015 by American Society of Clinical Oncology.

PMID: 26578612 [PubMed - as supplied by publisher]

18. Palliat Med. 2015 Nov 17. [Epub ahead of print]

[A systematic review of reasons for gatekeeping in palliative care research.](#)

[Kars MC¹](#), [van Thiel GJ²](#), [van der Graaf R²](#), [Moors M²](#), [de Graeff A³](#), [van Delden JJ²](#).

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. © The Author(s) 2015.

PMID: 26577927 [PubMed - as supplied by publisher]

19. Patient Educ Couns. 2015 Nov 2. [Epub ahead of print]

[Death talk: Basic linguistic rules and communication in perinatal and paediatric end-of-life discussions.](#)

[Xafis V¹](#), [Watkins A²](#), [Wilkinson D³](#).

OBJECTIVE: This paper considers clinician/parent communication difficulties noted by parents involved in end-of-life decision-making in the light of linguistic theory. **METHODS:** Grice's Cooperative Principle and associated maxims, which enable effective communication, are examined in relation to communication deficiencies that parents have identified when making end-of-life decisions for the child. Examples from the literature are provided to clarify the impact of failing to observe the maxims on parents and on clinician/parent communication. **RESULTS:** Linguistic theory applied to the literature on parental concerns about clinician/parent communication shows that the violation of the maxims of quantity, quality, relation, and manner as well as the stance that some clinicians adopt during discussions with parents impact on clinician/parent communication and lead to distrust, anger, sadness, and long-term difficulties coping with the experience of losing one's child. **CONCLUSION:** Parents have identified communication deficiencies in end-of-life discussions. Relating these communication deficiencies to linguistic theory provides insight into communication difficulties but also solutions. **PRACTICE IMPLICATIONS:** Gaining an understanding of basic linguistic theory that underlies human interactions, gaining insight into the communication deficiencies that parents have identified, and modifying some communication behaviours in light of these with the suggestions made in this article may lead to improved clinician/parent communication.

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PMID: 26561310 [PubMed - as supplied by publisher]

20. Qual Life Res. 2015 Nov 13. [Epub ahead of print]

[Patient-reported outcomes: pathways to better health, better services, and better societies.](#)

[Black N¹](#), [Burke L²](#), [Forrest CB³](#), [Ravens Sieberer UH⁴](#), [Ahmed S^{5,6,7}](#), [Valderas JM⁸](#), [Bartlett SJ⁹](#), [Alonso J^{10,11,12}](#).

Abstract While the use of PROs in research is well established, many challenges lie ahead as their use is extended to other applications. There is consensus that health outcome evaluations that include PROs along with clinician-reported outcomes and administrative data are necessary to inform clinical and policy decisions. The initiatives presented in this paper underline evolving recognition that PROs play a unique role in adding the patient perspective alongside clinical (e.g., blood pressure) and organizational (e.g., admission rates) indicators for evaluating the effects of new products, selecting treatments, evaluating quality of care, and monitoring the health of the population. In this paper, we first explore the use of PRO measures to support drug approval and labeling claims. We critically evaluate the evidence and challenges associated with using PRO measures to improve healthcare delivery at individual and population levels. We further discuss the challenges associated with selecting from the abundance of measures available, opportunities afforded by agreeing on common metrics for constructs of interest, and the importance of establishing an evidence base that supports integrating PRO measures across the healthcare system to improve outcomes. We conclude that the integration of PROs as a key end point within individual patient care, healthcare organization and program performance evaluations, and population surveillance will be essential for evaluating whether increased healthcare expenditure is translating into better health outcomes.

PMID: 26563251 [PubMed - as supplied by publisher]

21. Med J Malaysia. 2015 Oct;70(5):295-9.

[Parents' perspectives on the important aspects of care in children dying from life limiting conditions: A qualitative study.](#)

[Kuan GL¹](#), [Low WY²](#).

INTRODUCTION: The importance of Paediatric Palliative Care (PPC) is increasingly recognised worldwide, with the World Health Organization (WHO) and the American Academy of Pediatrics (AAP) endorsing the development and wide availability of PPC. When these children are in the terminal phase of their illness, PPC should be tailored to the different needs and desires of the child and the family, with the goal of providing the best possible quality of life (QOL) for the days that remain.

METHOD: Malaysia has yet to develop a national PPC policy. In anticipation of this, as part of a needs based qualitative

study, parents' views were solicited, as to the unmet needs of their children during the terminal phases of their illness. A purposive sampling was conducted amongst fifteen parents of nine deceased children (ages 2-14 years, eight cancer, one Prader Willi Syndrome) who had received care in the Paediatric Department, Malacca General Hospital, a Malaysian government hospital. Two focus group discussions and three in-depth interviews were conducted, based on a semi-structured interview guideline. The interviews were audiotaped with permission and the tape recordings were transcribed verbatim. The data were managed and analysed by NVivo 9 software using a thematic analysis approach. **RESULTS:** The frequently emerging themes were the strengths and weaknesses pertaining to the healthcare system, processes within palliative care. These were symptom control, closed communication and lack of support and anticipatory guidance as death approached. **CONCLUSION:** Dying Malaysian children and their families deserve to receive care that is more consistent with optimal palliative care. **Free Article**
PMID: 26556118 [PubMed - in process]

22. J Pain Symptom Manage. 2015 Nov 6. [Epub ahead of print]

Advance Care Discussions: Pediatric Clinician Preparedness and Practices.

Sanderson A¹, Hall AM², Wolfe J³.

CONTEXT: Few data exist regarding clinician preparedness to participate in advance care discussions (ACD) and the practices surrounding these discussions for children with life-threatening conditions. **OBJECTIVES:** We sought to understand pediatric clinician preparedness to participate in ACD and the practices surrounding these discussions. **METHODS:** A survey was administered to assess clinician attitudes and behaviors regarding ACD. **RESULTS:** Two hundred sixty-six clinicians (107 physicians and 159 nurses) responded to the survey (response rate 53.6%). Seventy-five percent of clinicians felt prepared to participate in ACD. Most clinicians believed they were prepared to express empathy (98.8%), discuss goals of care for an adolescent patient (90.3%) and elicit a parent's hopes (90.3%). Conversely, several felt unprepared to discuss resuscitation status with school-aged (59.7%) and adolescent (48.5%) patients and to conduct a family conference (39.5%). The most frequent topics addressed were: parents' understanding of the patient's illness (75.5%), primary goals of the parent (75.1%) and the parents' understanding of prognosis (71.1%). Conversely, the topics least commonly discussed were: belief system of the patient/family (22.0%), patient's hopes (21.2%) and the patient's perceptions of his/her quality of life (19.8%). Notably, 40% of clinicians believe that caring for patients with poor prognoses is depressing and this was more common among less experienced clinicians (P =0.048). **CONCLUSION:** Many clinicians believe they are prepared to participate in ACD but practices are not consistent with expert recommendations for optimal ACD. Educational interventions aimed at improving clinician knowledge, attitudes, and behavior and greater clinician support may enhance health care provider ACD preparedness and skills. Copyright © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

PMID: 26550935 [PubMed - as supplied by publisher]

23. Child Care Health Dev. 2015 Nov 7. [Epub ahead of print]

Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model.

Ling J¹, Payne S², Connaire K³, McCarron M⁴.

BACKGROUND: Respite in children's palliative care aims to provide a break for family's from the routine of caring. Parental decision-making regarding the utilisation of out-of-home respite is dependent on many interlinking factors including the child's age, diagnosis, geographical location and the family's capacity to meet their child's care needs. A proposed model for out-of-home respite has been developed based on the findings of qualitative case study research. **METHODS:** Utilising multiple, longitudinal, qualitative case study design, the respite needs and experiences of parents caring for a child with a life-limiting condition were explored. Multiple, in-depth interviews were undertaken with the parents identified by a hospital-based children's palliative care team. Data were analysed using thematic analysis. Each individual case consists of a whole study. Cross-case comparison was also conducted. **RESULTS:** Nine families were recruited and followed for two years. A total of 19 in-depth interviews were conducted with mothers and fathers (one or both) caring for a child with a life-limiting condition in Ireland. Each family reported vastly different needs and experiences of respite from their own unique perspective. Cross-case comparison showed that for all parents utilising respite care, regardless of their child's age and condition, home was the location of choice. Many interlinking factors influencing these decisions included: past experience of in-patient care, and trust and confidence in care providers. Issues were raised regarding the impact of care provision in the home on family life, siblings and the concept of home. **CONCLUSION:** Respite is an essential element of children's palliative care. Utilisation of out-of-home respite is heavily dependent on a number of interlinked and intertwined factors. The proposed model of care offers an opportunity to identify how these decisions are made and may ultimately assist in identifying the elements of responsive and family-focused respite that are important to families of children with life-limiting conditions. © 2015 John Wiley & Sons Ltd.

PMID: 26547275 [PubMed - as supplied by publisher]

24. Arch Dis Child Fetal Neonatal Ed. 2015 Nov 5. [Epub ahead of print]

End of life decisions for newborns: an ethical and compassionate process?

Carter BS.

PMID: 26542878 [PubMed - as supplied by publisher]

25. BMC Palliat Care. 2015 Nov 5;14:57.

Paediatric palliative care: recommendations for treatment of symptoms in the Netherlands.

Knops RR¹, Kremer LC², Verhagen AA³, Dutch Paediatric Palliative Care Guideline Group for Symptoms.

Collaborators: (12)

Beek L, Fock JM, Hartvelt-Faber G, Knops RR, Kremer LC, Mensink MO, Michiels EC, Schouten-van Meeteren AY, Uitdehaag MJ, Venmans LM, Verhagen AA, de Weerd W.

BACKGROUND: Children dying of a life threatening disease suffer a great deal at the end of life. Symptom control is often unsatisfactory, partly because many caregivers are simply not familiar with paediatric palliative care. To ensure that a child with a life-threatening condition receives high quality palliative care, clinical practice guidelines are needed. The aim of this study is to improve palliative care for children by making high quality care recommendations to recognize and relieve symptoms in paediatric palliative care. **METHODS:** An extensive search was performed for guidelines and systematic reviews on paediatric palliative care up to year 2011. An expert panel combined the evidence with consensus to form recommendations on the treatment of symptoms in paediatric palliative care. **RESULTS:** We appraised 21 guidelines and identified 693 potentially eligible articles of which four met our inclusion criteria. None gave recommendations on the treatment of symptoms in paediatric palliative care. Two textbooks and an adult palliative care website were eventually our main sources of evidence. **CONCLUSION:** Hardly any evidence is available for the treatment of symptoms in paediatric palliative care. By combining evidence for adult palliative care and the sparse evidence for paediatric palliative care with expert opinion we defined a unique set of high quality care recommendations to relieve symptoms and lessen the suffering of children in palliative care. These results are an important tool to educate caregivers on how to relieve symptoms in children in paediatric palliative care.

PMCID: PMC4634793 **Free PMC Article**

PMID: 26542477 [PubMed - in process]

26. J Palliat Med. 2015 Dec;18(12):1026-1032. Epub 2015 Nov 5.

Exploring the Relationship of Patient and Informal Caregiver Characteristics with Heart Failure Self-Care Using the Actor-Partner Interdependence Model: Implications for Outpatient Palliative Care.

Buck HG¹, Mogle J¹, Riegel B², McMillan S³, Bakitas M⁴.

BACKGROUND: The convergence of prevalence, cost, symptom experience, community setting, and informal caregiving in heart failure (HF) has profound implications for outpatient palliative care. The majority of HF patients depend on informal caregiver's assistance. Dyadic (patients and caregiver) characteristics can complicate this assistance. Yet relatively little is known concerning dyadic characteristics' impact on self-care. HF self-care involves routine, daily treatment adherence and symptom monitoring (self-care maintenance), and symptom response (self-care management). **OBJECTIVE:** Describe the dyadic characteristics of mood and perception of the relationship in HF patients and caregivers, then explore the relationship of the characteristics with self-care. **DESIGN:** Prospective, cross sectional study of hospitalized HF patients in mixed dyads (spousal/adult child/relative) analyzed using Actor-Partner Interdependence Model (APIM) techniques. **MEASUREMENTS:** Mood was measured by the Brief Symptom Inventory and Patient Health Questionnaire, perception of the relationship by the Dyadic Adjustment Scale, and self-care by the Self-care in Heart Failure Index. **RESULTS:** In 40 dyads the average patient was a 71 year old male (n = 30); caregiver was a 59 years old female (n = 26). Overall self-care scores were consistently low. Patient depression scores were significantly greater than caregivers (p = .0055). Greater caregiver anxiety were associated with lower caregiver maintenance scores (p < .0001) but greater caregiver depression were associated with lower patient maintenance scores (p < .0001). While patient and caregiver's perception of the relationship was associated with their self-care, more importantly, caregiver's perception of the relationship was associated with their confidence to engage in the patient's self-care (p = .003). **DISCUSSION/CONCLUSION:** This study suggests that caregivers, often unacknowledged or unmeasured, impact patient's day to day HF self-care. Palliative care clinicians need to talk to dyads with a history of poor self-care about their relationship.

PMID: 26540092 [PubMed - as supplied by publisher]

27. Child Care Health Dev. 2015 Nov 4. [Epub ahead of print]

The influence of mothers' and fathers' sensitivity in the first year of life on children's cognitive outcomes at 18 and 36 months.

Malmberg LE¹, Lewis S², West A³, Murray E⁴, Sylva K¹, Stein A⁴.

BACKGROUND: There has been increasing interest in the relative effects of mothers' and fathers' interactions with their infants on later development. However to date there has been little work on children's cognitive outcomes. **METHODS:** We examined the relative influence of fathers' and mothers' sensitivity during interactions with their children at the end of the child's first year (10-12 months, n = 97), on child general cognitive development at 18 months and language at 36 months. **RESULTS:** Both parents' sensitivity was associated with cognitive and language outcomes in univariate analyses. Mothers' sensitivity, however, appeared to be associated with family socio-demographic factors to a greater extent than fathers' sensitivity. Using path modelling the effect of paternal sensitivity on general cognitive development at 18 months and language at 36 months was significantly greater than the effect of maternal sensitivity, when controlling for socio-demographic background. In relation to language at 36 months, there was some evidence that sensitivity of one parent buffered the effect of lower sensitivity of the other parent. **CONCLUSIONS:** These findings suggest that parental sensitivity can play an important role in children's cognitive and language development, and that higher sensitivity of one parent can compensate for the lower sensitivity of the other parent. Replication of these findings, however, is required in larger samples. © 2015 John Wiley & Sons Ltd.

PMID: 26538379 [PubMed - as supplied by publisher]

28. BMC Med Educ. 2015 Nov 2;15(1):194.

Impact of a multifaceted education program on implementing a pediatric palliative care guideline: a pilot study.

Jagt-van Kampen CT¹, Kremer LC², Verhagen AA³, Schouten-van Meeteren AY².

BACKGROUND: A national clinical practice guideline for pediatric palliative care was published in 2013. So far there are only few reports available on whether an educational program fosters compliance with such a guideline implementation. We aimed to test the effect of the education program on actual compliance as well as documentation of compliance to the guideline. **METHODS:** We performed a prospective study with pre- and post-intervention evaluation on compliance to the guideline of the nurse specialists of a pediatric palliative care team for case management at a children's university hospital. Eleven

quality indicators were selected from 192 recommendations from the pediatric palliative care guideline, based on frequency, measurability and relevance. The multifaceted education program included e-learning and an interactive educational meeting. Four e-learning modules addressed 19 patient cases on symptoms, diagnostics and treatment, and a chart-documentation exercise. During the interactive educational meeting patient cases were discussed on how to use the guideline. Documentation of compliance to the guideline in the web-based patient-charts as well as actual compliance to the guideline through weekly web-based parent reports was measured before and after completion of the e-learning. **RESULTS:** Eleven quality indicators were selected. The educational program did not result in significant improvement in compliance for any of these indicators. The indicators "treatment of nausea", "pain medications two steps ahead" and "pain medication for 48 h present", measured through parent reports, scored a compliance beyond 80 % before and after e-learning. The remaining indicators measuring compliance, as well as six indicators measuring documentation by chart review, showed a compliance below 80 % before and after e-learning. **CONCLUSIONS:** The multifaceted education program did not lead to improvement in documentation of compliance to the guideline. Parent reported outcome revealed better performance and might be the more adequate assessment tool for future studies.

PMCID: PMC4631052 **Free PMC Article**

PMID: 26525299 [PubMed - in process]

29. J Paediatr Child Health. 2015 Oct 29. [Epub ahead of print]

Attitudes of Slovene paediatricians to end-of-life care.

Grosek S^{1,2}, Orazem M³, Kanic M⁴, Vidmar G^{5,6}, Groselj U⁷.

AIMS: The aims of this study were to assess the attitudes of Slovene paediatricians to aspects of end-of-life (EOL) care and compare these attitudes between paediatric intensivists, paediatric specialists and paediatric residents. **METHODS:** We performed a cross-sectional survey, using a specifically designed 43-item anonymous questionnaire. **RESULTS:** We included 323 out of 586 Slovene paediatricians and residents, while 46.7% (151 of 323) of them responded to our questionnaire. More than half of intensivists (54.2%) had sought counsel from the Committee for Medical Ethics in the past as compared with 12.0% and 12.1% of specialists and residents, respectively ($P < 0.001$). The decision to limit life-sustaining treatment (LST) was found to be ethically acceptable in all groups of respondents. The highest level of agreement was found in residents (90.2%), followed by 83.3% among intensivists and 73.8% among specialists ($P =$ not statistically significant (NS)). Disagreement with termination of hydration was highest among residents (85%) and intensivists (79.2%) while it was lower among specialists (66.7%) ($P =$ NS). Patient's best interest, good clinical practice and patient's autonomous decision were graded as the top three aspects of the EOL care, while cost effectiveness and availability of patient's bed in intensive care were the least important. **CONCLUSIONS:** The decision to limit LST measures was found to be ethically acceptable for Slovene paediatricians. No major differences were found among paediatric intensivists, specialist paediatricians and paediatric residents in the attitudes towards the EOL care.

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PMID: 26515146 [PubMed - as supplied by publisher]

30. Pediatr Blood Cancer. 2015 Oct 29. [Epub ahead of print]

Trends in End-of-Life Care in Pediatric Hematology, Oncology, and Stem Cell Transplant Patients.

Brock KE¹, Steineck A², Twist CJ¹.

BACKGROUND: Decisions about end-of-life care may be influenced by cultural and disease-specific features. We evaluated associations of demographic variables (race, ethnicity, language, religion, and diagnosis) with end-of-life characteristics (Phase I enrollment, do-not-resuscitate (DNR) orders, hospice utilization, location of death), and trends in palliative care services delivered to pediatric hematology, oncology, and stem cell transplant (SCT) patients. **PROCEDURE:** In this single-center retrospective cohort study, inclusion criteria were as follows: patients aged 0-35 who died between January 1, 2002 and March 1, 2014, and had been cared for in the pediatric hematology, oncology, and SCT divisions. The era of 2002-2014 was divided into quartiles to assess trends over time. **RESULTS:** Of the 445 included patients, 64% of patients had relapsed disease, 45% were enrolled in hospice, and 16% had received palliative care consultation. Patients with brain or solid tumors enrolled in hospice ($P < 0.0001$) and died at home more frequently than patients with leukemia/lymphoma ($P < 0.0001$). Patients who received Phase I therapy or identified as Christian/Catholic religion enrolled in hospice more frequently ($P < 0.0001$ and $P = 0.03$, respectively). When patient deaths were analyzed over quartiles, the frequency of DNR orders ($P = 0.02$) and palliative care consultation ($P = 0.04$) increased over time. Hospice enrollment, location of death, and Phase I trial enrollment did not change significantly. **CONCLUSIONS:** Despite increases in palliative care consultation and DNR orders over time, utilization remains suboptimal. No increase in hospice enrollment or shift in death location was observed. These data will help target future initiatives to achieve earlier discussions of goals of care and improved palliative care for all patients. © 2015 Wiley Periodicals, Inc.

PMID: 26513237 [PubMed - as supplied by publisher]

31. J Perinatol. 2015 Dec;35(12):1000-5. Epub 2015 Oct 22.

Primary palliative care in the delivery room: patients' and medical personnel's perspectives.

Garten L¹, Glöckner S¹, Siedentopf JP², Bühner C¹.

OBJECTIVE: To investigate circumstances of primary palliative care (PPC) in the delivery room (DR), medical personnel's experience with neonates who died under PPC in the DR and perceived sources of care-related distress in DR staff. **STUDY DESIGN:** Retrospective chart review of all neonates who were cared for under PPC in the DR during the years 2000-2010 at Charité University Medical Center Berlin, and structured face-to-face interviews with DR nursing staff and physicians. **RESULT:** Neonates undergoing PPC could be grouped as preterm infants at the limits of viability with a gestational age between 22 (0)/7 and 23 (6)/7 weeks ($n=86$, 76%) and newborn infants with complex chronic conditions ($n=27$, 24%). The median age of neonates at death was 59 min (interquartile range [IQR] 28-105 min). Most of DR staff did not report relevant signs of distress in dying neonates, and providing palliative care was not named as a relevant care-related source of distress

by medical personnel. However, half of the participants reported on high degrees of caregiver's emotional distress in PPC situations, identifying insecurity of how to communicate with parents and to provide emotional support as the most common source of distress. **CONCLUSION:** Caregiver's emotional distress primarily originates from providing support to parents and not from providing medical care to the dying newborn. Implications for future practice include the need for structured education to improve DR staff's communication and counselling skills related to parents in PPC situations.

PMID: 26491848 [PubMed - in process]

32. J Pediatr Oncol Nurs. 2015 Oct 19. [Epub ahead of print]

"It's Back! My Remission Is Over": Online Communication of Disease Progression Among Adolescents With Cancer.

Keim-Malpass J¹, Stegenga K², Loudin B³, Kennedy C³, Kools S³.

Abstract Cancer in adolescence presents unique challenges to patients and families due to the dramatic physical and psychological vulnerabilities that occur during a time of identity development. Additionally, adolescents who experience progression of their cancer, or failure of first-line therapies, represent an understudied group within pediatric oncology. Illness blogs offer a unique opportunity to understand the experience of a chronic or serious illness through a naturalistic and longitudinal perspective that is inherently patient centered. The purpose of this exploratory qualitative study was to describe the experiences of adolescents with cancer who experienced disease progression through analysis of their online illness blogs. Seven illness blogs written by adolescents with cancer diagnosed between the ages of 13 and 18 years were analyzed using thematic analysis. Several key themes were described among the adolescents, including normalizing the news, facing treatment failure, and reconciling chronos-the finite concept of time. These findings provide vital descriptive evidence for the experience of disease progression as described by adolescents, as well as identifying key points of further study and intervention development for nurse researchers and nurses who care for this vulnerable patient population.

PMID: 26483425 [PubMed - as supplied by publisher]

33. J Pain Symptom Manage. 2015 Oct 23. [Epub ahead of print]

Unexpected Death on an Acute Palliative Care Unit.

Mercadante S¹, Ferrera P², Casuccio A³.

PMID: 26476392 [PubMed - as supplied by publisher]

34. J Med Ethics. 2015 Oct 16. [Epub ahead of print]

Against euthanasia for children: a response to Bovens.

Kaczor C.

Abstract If we accept euthanasia for adults, should we also accept voluntary euthanasia for children? In 'Child Euthanasia: Should We Just Not Talk about It?', Luc Bovens answers this question affirmatively. Bovens examines five arguments against extending euthanasia to minors, the arguments being weightiness, capability of discernment, pressure, sensitivity and sufficient palliative care. He rejects each of these arguments. In this paper, I provide a rejoinder for each of his responses. I also critique his view that opponents of euthanasia have extra responsibility to promote palliative care. On the contrary, if euthanasia is legalised, advocates of euthanasia have a special obligation to promote improvements in palliative care.

PMID: 26474602 [PubMed - as supplied by publisher]

35. Am J Hosp Palliat Care. 2015 Oct 16. [Epub ahead of print]

Ethics Roundtable: Parental Autonomy and the Minor Patient.

Baumrucker SJ¹, Easterday J², Stolic M³, McCall-Burton M⁴, Adkins RW⁵, Winiger D⁶, Cook C⁷.

PMID: 26475460 [PubMed - as supplied by publisher]

36. BMC Palliat Care. 2015 Oct 16;14:50.

Promoting an ethic of engagement in pediatric palliative care research.

Rahimzadeh V¹, Bartlett C², Longo C², Crimi L², Macdonald ME³, Jabado N⁴, Ells C⁵.

BACKGROUND: This paper defends the ethical and empirical significance of direct engagement with terminally ill children and adolescents in PPC research on health-related quality of life. Clinical trials and other forms of health research have resulted in tremendous progress for improving clinical outcomes among children and adolescents diagnosed with a life-threatening illness. Less attention has been paid, however, to engaging this patient population directly in studies aimed at optimizing health-related quality of life in PPC. Though not restricted to care at the end of life, PPC--and by extension PPC research--is in part dependent on recognizing the social complexities of death and dying and where health-related quality of life is a fundamental element. To explore these complexities in depth requires partnership with terminally ill children and adolescents, and acknowledgement of their active social and moral agency in research. **DISCUSSION:** Principles of pediatric research ethics, theoretical tenets of the "new sociology of the child(hood)," and human rights codified in the United Nations Convention on the Rights of the Child (UNCRC) underpin the position that a more engagement-centered approach is needed in PPC research. The ethics, sociologies and human rights of engagement will each be discussed as they relate to research with terminally ill children and adolescents in PPC. Qualitative method(ologies) presented in this paper, such as deliberative stakeholder consultations and phenomenology of practice can serve as meaningful vehicles for achieving i) participation among terminally ill children and adolescents; ii) evidence-bases for PPC best practices; and iii) fulfillment of research ethics principles. **CONCLUSION:** PPC research based on direct engagement with PPC patients better reflects their unique expertise and social epistemologies of terminal illness. Such an approach to research would strengthen both the ethical and methodological soundness of HRQoL inquiry in PPC.

PMCID: PMC4608148 **Free PMC Article**

PMID: 26474573 [PubMed - in process]

37. BMJ Support Palliat Care. 2015 Oct 15. [Epub ahead of print]

Cost trajectories from the final life year reveal intensity of end-of-life care and can help to guide palliative care interventions.

von Wyl V¹, Telser H², Weber A³, Fischer B⁴, Beck K⁵.

OBJECTIVE: Exploration of healthcare utilisation patterns in the final life year to assess palliative care potential. **METHODS:** Retrospective cluster analyses (k-means) of anonymised healthcare expenditure (HCE) trajectories, derived from health insurance claims of a representative sample of Swiss decedents who died between 2008 and 2010 (2 age classes: 4818 <66 years, 22 691 elderly). **RESULTS:** 3 (<66 years) and 5 (elderly) trajectory groups were identified, whose shapes were dominated by HCE from inpatient care in hospitals and at nursing homes. In each age class, the most expensive group (average cumulative HCE for <66 years: SFr 84 295; elderly: SFr 84 941) also had the largest abundance of cancers (<66 years: 55%; elderly: 32%) and showed signs of continued treatment intensification until shortly before death. Although sizes of these high-cost groups were comparatively small (26% in younger; 6% in elderly), they contributed substantially to the end-of-life HCE in each age class (62% and 18%, respectively). As age increased, these potential target groups for palliative care gained in share among <66-year olds (from 9% in children to 28% in 60-65-year olds), but decreased from 17% (66-70-year olds) to 1% (>90-year olds) among elderly. **CONCLUSIONS:** Cost trajectory clustering is well suited for first-pass population screenings of groups that warrant closer inspection to improve end-of-life healthcare allocation. The Swiss data suggest that many decedents undergo intensive medical treatment until shortly before death. Investigations into the clinical circumstances and motives of patients and physicians may help to guide palliative care. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>.

PMID: 26470876 [PubMed - as supplied by publisher]

38. Palliat Support Care. 2015 Oct 14:1-9. [Epub ahead of print]

Teenagers' reasoning about a parent's recent death in cancer.

Sveen J¹, Kreicbergs U¹, Melcher U², Alvariza A³.

OBJECTIVE: The aim of the study was to explore how teenagers reason about a parent's recent death and about their life without that parent. **METHOD:** A total of 10 teenagers (aged 14-19 years, 7 boys and 3 girls) were interviewed twice, 3-12 months after their parent's death. The interviews were carried out individually and as free-ranging conversations. A content analysis with a descriptive and interpretive design was conducted. **RESULTS:** Importantly, all teenagers appreciated participating in the interviews. Some had not previously talked in such depth about this with anyone, while others had more open communications within their families and with others. Their parent's death was the worst thing that could happen, but they still expressed the feeling that it had been a relief for both the ill parent and themselves. The death had relieved the parent from suffering and a life with severe illness. Many of the teenagers empathized with the surviving parent's grief and worried about him or her as well as the entire home situation. As a consequence, the teenagers did not show their grief, as they did not want to burden the grieving parent. Seeing the parent grieving could lead to feelings of loneliness and hopelessness and that the support they needed was not there for them. Nevertheless, some teenagers could grieve together with the surviving parent in common understanding and with openness. **SIGNIFICANCE OF RESULTS:** A tentative conclusion is that the teenagers who were more likely to talk and grieve together with their surviving parent coped better with their situation than teenagers who did not. Parentally bereaved teenagers tend to take on a responsibility to support the grieving parent, when it is they themselves who need and should receive support.

PMID: 26462758 [PubMed - as supplied by publisher]

39. Neuro Oncol. 2015 Oct 11. [Epub ahead of print]

Palliative and end-of-life care for children with diffuse intrinsic pontine glioma: results from a London cohort study and international survey.

Veldhuijzen van Zanten SE¹, van Meerwijk CL¹, Jansen MH¹, Twisk JW¹, Anderson AK¹, Coombes L¹, Breen M¹, Hargrave OJ¹, Hemsley J¹, Craig F¹, Cruz O¹, Kaspers GJ¹, van Vuurden DG¹, Hargrave DR; SIOPE DIPG Network.

BACKGROUND: More than 90% of patients with diffuse intrinsic pontine glioma (DIPG) will die within 2 years of diagnosis. Patients deteriorate rapidly during the disease course, which severely impairs their quality of life. To date, no specific research on this clinically important subject has been conducted. This study aimed to compile an inventory of symptoms experienced, interventions applied, and current service provision in end-of-life care for DIPG. **METHODS:** We performed a retrospective cohort study of children with DIPG, aged 0-18 years, who received treatment under the care of 2 London hospitals. Symptoms, interventions, and services applied during the 12 weeks before death were analyzed. In addition, we conducted a global questionnaire-study among health care professionals. **RESULTS:** In more than 78% of DIPG patients, problems concerning mobility, swallowing, communication, consciousness, and breathing arose during end-stage disease. Supportive drugs were widely prescribed. The use of medical aids was only documented in <15% of patients. Palliative and end-of-life care was mostly based on the health care professional's experience; only 21% of the questionnaire respondents reported to have a disease-specific palliative care guideline available. **CONCLUSIONS:** This research assessed the current state of palliative and end-of-life care for children with DIPG. Our results show the variability and complexity of symptoms at end-stage disease and the current lack of disease-specific guidelines for this vulnerable group of patients. This first descriptive paper is intended to act as a solid basis for developing an international clinical trial and subsequent guideline to support high-quality palliative and end-of-life care. © The Author(s) 2015. Published by Oxford University Press on behalf of the Society for Neuro-Oncology. All rights reserved. For permissions, please e-mail: journals.permissions@oup.com.

PMID: 26459800 [PubMed - as supplied by publisher]

40. Palliat Support Care. 2015 Oct 14:1-12. [Epub ahead of print]

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

Mooney-Doyle K¹, Deatrack JA².

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 [PubMed - as supplied by publisher]

41. J Pediatr Oncol Nurs. 2015 Oct 12. [Epub ahead of print]

Geographic Variation in Mortality Among Children and Adolescents Diagnosed With Cancer in Tennessee: Does Race Matter?

Lindley LC¹, Oyana TJ².

Abstract Cancer is one of the leading causes of death among children in the United States. Previous research has examined geographic variation in cancer incidence and survival, but the geographic variation in mortality among children and adolescents is not as well understood. The purpose of this study was to investigate geographic variation by race in mortality among children and adolescents diagnosed with cancer in Tennessee. Using an innovative combination of spatial and nonspatial analysis techniques with data from the 2004-2011 Tennessee Cancer Registry, pediatric deaths were mapped and the effect of race on the proximity to rural areas and clusters of mortality were explored with multivariate regressions. The findings revealed that African American children and adolescents in Tennessee were more likely than their counterparts of other races to reside in rural areas with close proximity to mortality clusters of children and adolescents with a cancer. Findings have clinical implications for pediatric oncology nurses regarding the delivery of supportive care at end of life for rural African American children and adolescents. © 2015 by Association of Pediatric Hematology/Oncology Nurses.

PMID: 26458417 [PubMed - as supplied by publisher]

42. Nurs Child Young People. 2015 Oct;27(8):20-4.

Parents' experiences of care decisions about children with life-limiting illnesses.

Popejoy E^{1,2}.

AIM: To understand the 'lived experience' of parents throughout the process of making and revising end of life care decisions for their child. **METHOD:** Three mothers who had been bereaved participated in semi-structured interviews. These were recorded, transcribed and analysed using interpretative phenomenological analysis. **FINDINGS:** Two overarching themes were identified: making decisions and revising and implementing end of life care plans. Sub-themes included: who should be the decision maker; when discussions should be initiated; the values underpinning the plans; revisiting the plans; and barriers and facilitators to their implementation. **CONCLUSION:** Parents understand the importance of planning for the end of their child's life but find the process difficult. They also find it a challenge to verbalise their decisions at the end of their child's life and value having the decision partly taken away from them. Professionals can assist parents by using a non-dissent model of decision making. The parents' values are important in these decisions and should be elicited by professionals during the initial stages of decision making.

PMID: 26448125 [PubMed - in process]

43. Nurs Child Young People. 2015 Oct;27(8):6.

Charity calls on Wales to focus on palliative care.

[No authors listed]

PMID: 26448105 [PubMed - in process]

44. Mult Scler. 2015 Nov;21(13):1618-25. Epub 2015 Oct 7.

Physical activity and pediatric multiple sclerosis: Developing a research agenda.

Yeh EA¹, Kinnett-Hopkins D², Grover SA³, Motl RW².

Abstract Three-quarters of children with multiple sclerosis (MS) experience fatigue or depression, and progressive neurocognitive decline may be seen as early as two years after MS diagnosis. Furthermore, a higher magnetic resonance imaging disease burden is seen in pediatric-onset MS compared with adult-onset MS. To date, limited knowledge exists regarding behavioral methods for managing symptoms and disease progression in pediatric MS. To that end, this paper builds an evidence-based argument for the possible symptomatic and disease-modifying effects of exercise and physical activity in pediatric MS. This will be accomplished through: (a) a review of pediatric MS and its consequences; (b) a brief overview of physical activity and its consequences in children and adults with MS; and (c) a selective review of research on the neurological benefits of physical activity in pediatric populations. This topical review concludes with a list of 10 questions to guide future research on physical activity and pediatric MS. The objective of this paper is the provision of a research interest, focus and agenda involving pediatric MS and its lifelong management through exercise and physical activity behavior. Such an agenda is critical as the effects and maintenance of physical activity and exercise track across the lifespan, particularly when developed in the early stages of life.

PMID: 26447061 [PubMed - in process]

45. Am J Hosp Palliat Care. 2015 Oct 5. [Epub ahead of print]

Pediatrician Ambiguity in Understanding Palliative Sedation at the End of Life.

Henderson CM¹, FitzGerald M², Hoehn KS³, Weidner N².

CONTEXT: Palliative sedation is a means of relieving intractable symptoms at the end of life, however, guidelines about its use lack consistency. In addition, ethical concerns persist around the practice. There are reports of palliative sedation in the

pediatric literature, which highlight various institutional perspectives. **OBJECTIVES:** This survey of 4786 pediatric providers sought to describe their knowledge of and current practices around pediatric palliative sedation. **METHODS:** Our survey was administered to pediatricians who care for children at the end of life. The survey assessed agreement with a definition of palliative sedation, as well as thoughts about its alignment with aggressive symptom management. Bivariate analyses using χ^2 and analysis of variance were calculated to determine the relationship between responses to closed-ended questions. Open-ended responses were thematically coded by the investigators and reviewed for agreement. **RESULTS:** Nearly half (48.6%) of the respondents indicated that the stated definition of palliative sedation "completely" reflected their own views. Respondents were split when asked if they viewed any difference between palliative sedation and aggressive symptom management: Yes (46%) versus No (54%). Open-ended responses revealed specifics about the nature of variation in interpretation. **CONCLUSIONS:** Responses point to ambiguity surrounding the concept of palliative sedation. Pediatricians were concerned with a decreased level of consciousness as the goal of palliative sedation. Respondents were split on whether they view palliative sedation as a distinct entity or as one broad continuum of care, equivalent to aggressive symptom management. Institutional-based policies are essential to clarify acceptable practice, enable open communication, and promote further research.

PMID: 26443718 [PubMed - as supplied by publisher]

46. Pediatrics. 2015 Nov;136(5):938-46. Epub 2015 Oct 5.

Hospital Use in the Last Year of Life for Children With Life-Threatening Complex Chronic Conditions.

Ananth P¹, Melvin P², Feudtner C³, Wolfe J⁴, Berry JG⁵.

BACKGROUND AND OBJECTIVES: Although many adults experience resource-intensive and costly health care in the last year of life, less is known about these health care experiences in children with life-threatening complex chronic conditions (LT-CCCs). We assessed hospital resource use in children by type and number of LT-CCCs. **METHODS:** A retrospective analysis of 1252 children with LT-CCCs, ages 1 to 18 years, who died in 2012 within 40 US children's hospitals of the Pediatric Health Information System database. LT-CCCs were identified with International Classification of Diseases, 9th Revision, Clinical Modification codes. Using generalized linear models, we assessed hospital admissions, days, costs, and interventions (mechanical ventilation and surgeries) in the last year of life by type and number of LT-CCCs. **RESULTS:** In the last year of life, children with LT-CCCs experienced a median of 2 admissions (interquartile range [IQR] 1-5), 27 hospital days (IQR 7-84), and \$142 562 (IQR \$45 270-\$410 087) in hospital costs. During the terminal admission, 76% (n = 946) were mechanically ventilated; 36% (n = 453) underwent surgery. Hospital use was greatest (P < .001) among children with hematologic/immunologic conditions (99 hospital days [IQR 51-146]; cost = \$504 145 [IQR \$250 147-\$879 331]) and children with ≥ 3 LT-CCCs (75 hospital days [IQR 28-132]; cost = \$341 222 [IQR \$146 698-\$686 585]). **CONCLUSIONS:** Hospital use for children with LT-CCCs in the last year of life varies significantly across the type and number of conditions. Children with hematologic/immunologic or multiple conditions have the greatest hospital use. This information may be useful for clinicians striving to improve care for children with LT-CCCs nearing the end of life.

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PMCID: PMC4621793 [Available on 2016-11-01]

PMID: 26438707 [PubMed - in process]

47. Breast Cancer. 2015 Oct 6. [Epub ahead of print]

The influence of familial factors on the choice of the place of death for terminally ill breast cancer patients: a retrospective single-center study.

Harano K^{1,2}, Yonemori K³, Hirakawa A⁴, Shimizu C³, Katsumata N⁵, Gemma A⁶, Fujiwara Y³, Tamura K³.

BACKGROUND: The social or familial factors influencing the location chosen for end-of-life (EOL) care for terminally ill breast cancer patients are unknown. **METHODS:** We retrospectively analyzed 195 patients with recurrent or progressive breast cancer who received anticancer treatment at the National Cancer Center Hospital between January 2008 and May 2012. Detailed data concerning the patients' demographic, familial, and clinical characteristics were collected, and multivariate and Cox logistic regression analyses were performed to evaluate the impact of these characteristics on the place of EOL care and on survival, respectively. **RESULTS:** Sixty-eight patients (34.9%) died in a hospital, 26 patients (13.3%) at home, and 101 patients (51.8%) in hospice. Most of the patients having caregivers received EOL care at palliative care facilities (hospice or home) [odds ratio (OR) 2.57; 95% confidence interval (CI) 1-6.6; p = 0.05]. In contrast, patients with factors suggesting a clinically severe status (performance status ≥ 2 , use of opioids, delirium, and ascites) more often received EOL care in a hospital. Among patients who received EOL care at hospice or home, patients with minor children received EOL care at home (OR 0.08; 95% CI 0.02-0.38; p = 0.001). Patients with brain metastases chose hospice (OR 12.37; 95% CI 2.25-68.13; p = 0.004). Furthermore, having a caregiver was associated with prolonged survival (hazard ratio 0.62; 95% CI 0.39-0.97; p = 0.035). **CONCLUSION:** Familial factors such as having children and caregivers significantly influenced the place of EOL care for terminally ill breast cancer patients.

PMID: 26439379 [PubMed - as supplied by publisher]

48. Arch Pediatr. 2015 Nov;22(11):1119-28. Epub 2015 Oct 1.

[Organization of collaborative deliberation for limiting or withholding treatments in children].

[Article in French]

Cremer R¹, Lervat C², Laffargue A³, Le Cunff J⁴, Joriot S⁴, Minnaert C⁵, Cuisset JM⁴, Mention K⁶, Thomas D⁷, Guimber D⁸, Matthews A⁹, Fayoux P¹⁰, Storme L¹¹, Vandoolaege S¹²; pour le groupe de travail de l'EEHU de Lille.

Abstract In 2005, the French law on patients' rights at the end of life required that decisions to withdraw or withhold life-sustaining treatments be made and carried out by the physician in charge of the patient, after obtaining advice from an independent consulting colleague and the caregiving team. The purpose of this study was to identify theoretical and practical obstacles to this collaborative deliberation and propose practical guidelines to organize it.

PMID: 26428736 [PubMed - in process]

49. J Pediatr. 2015 Dec;167(6):1320-6. Epub 2015 Oct 1.

Talking about Death with Children with Incurable Cancer: Perspectives from Parents.

van der Geest IM¹, van den Heuvel-Eibrink MM², van Vliet LM³, Pluijms SM⁴, Streng IC⁴, Michiels EM⁴, Pieters R², Darlington AS⁵.

OBJECTIVE: To investigate the rationale and consequences associated with a parent's decision to discuss death with a child with incurable cancer. **STUDY DESIGN:** We present data from a larger retrospective study involving bereaved parents of a child who died of cancer. Parents were asked whether they had discussed the impending death with their child, whether they reflected on this discussion positively, their reasons for not discussing death with their child, and the manner in which the conversation regarding death occurred. The data were analyzed qualitatively using a framework approach. **RESULTS:** Of the 86 parents of 56 children who answered the questions regarding discussing death with their child, 55 parents of 35 children did not discuss the impending death with their child. The following themes were identified: the parents' inability to discuss the impending death; the parents' desire to protect their child; views regarding talking with children; parents' views of child characteristics; the child's unwillingness to discuss the subject; lack of opportunity to talk; and the child's disability. The parents who did discuss death with their child generally used symbolic and/or religious narratives, or they had brief, direct conversations regarding death. The majority of parents felt positive regarding their decision about whether to talk with their child about his/her impending death. **CONCLUSION:** Most parents in this study cited several reasons for not discussing death with their child. Our findings highlight the sensitive and complex issues surrounding these conversations, indicating that there may be a role for clinicians in supporting parents.

PMID: 26427964 [PubMed - in process]

50. J Palliat Med. 2015 Nov;18(11):945-55. Epub 2015 Sep 29.

Caring Decisions: The Development of a Written Resource for Parents Facing End-of-Life Decisions.

Xafis V^{1,2}, Gillam I^{3,4}, Hynson J⁵, Sullivan J^{3,4}, Cossich M⁶, Wilkinson D^{1,7,8}.

BACKGROUND: Written resources in adult intensive care have been shown to benefit families facing end of life (EoL) decisions. There are few resources for parents making EoL decisions for their child and no existing resources addressing ethical issues. The Caring Decisions handbook and website were developed to fill these gaps. **AIM:** We discuss the development of the resources, modification after reviewer feedback and findings from initial pilot implementation. **DESIGN:** A targeted literature review-to identify resources and factors that impact on parental EoL decision-making; development phase-guided by the literature and the researchers' expertise; consultation process-comprised a multi-disciplinary panel of experts and parents; pilot evaluation study-hard-copy handbook was distributed as part of routine care at an Australian Children's Hospital. **SETTING/PARTICIPANTS:** Twelve experts and parents formed the consultation panel. Eight parents of children with life-limiting conditions and clinicians were interviewed in the pilot study. **RESULTS:** Numerous factors supporting/impeding EoL decisions were identified. Caring Decisions addressed issues identified in the literature and by the multidisciplinary research team. The consultation panel provided overwhelmingly positive feedback. Pilot study parents found the resources helpful and comforting. Most clinicians viewed the resources as very beneficial to parents and identified them as ideal for training purposes. **CONCLUSIONS:** The development of the resources addressed many of the gaps in existing resources. The consultation process and the pilot study suggest these resources could be of significant benefit to parents and clinicians.

PMCID: PMC4638203 **Free PMC Article**

PMID: 26418215 [PubMed - in process]

51. J Am Acad Child Adolesc Psychiatry. 2015 Oct;54(10):791-2.

Child and Adolescent Psychiatry and Palliative Care.

Buxton D¹.

PMID: 26407485 [PubMed - in process]

52. J Palliat Med. 2015 Nov;18(11):981-4. Epub 2015 Sep 22.

Psychological Well-Being and Family Environment of Siblings of Children with Life Threatening Illness.

Humphrey LM¹, Hill DL², Carroll KW², Rourke M³, Kang TI², Feudtner C².

BACKGROUND: The psychological well-being of siblings of children with life threatening illness remains largely uncharted. Pediatric cancer research suggests that a supportive family environment may protect the psychological well-being of siblings. **OBJECTIVE:** We hypothesized that (1) siblings of pediatric palliative care patients would show clinical/behavioral scores that were elevated but that rates of serious psychopathology would be comparable to the general population of children their age; and (2) higher family functioning scores would be associated with lower clinical scores and higher adaptive scores for these siblings. **METHODS:** We conducted an observational study with families in which a patient receiving palliative care had one or more siblings between the ages of 6 and 11. Parents completed the Behavioral Assessment System for Children, Second Edition (BASC-2) to assess the siblings' psychological well-being and the Family Assessment Device (FAD) to assess the family environment. **RESULTS:** Twenty-four parents reported data for 30 siblings. Only three siblings scored in the clinical range on a BASC-2 composite clinical scale, and 11 siblings scored in the at-risk range on one or more composite scales. Higher FAD scores predicted significantly higher externalization composite clinical scores (7.54, 95% CI: 1.12, 13.97, $p < 0.05$) and significantly higher behavioral composite scores (7.88, 95% CI: 1.55, 14.21, $p < 0.05$). **DISCUSSION:** Siblings of pediatric palliative care patients are not experiencing lower psychological well-being than the general population. The prediction that a positive family environment would be associated with higher levels of psychological health was supported.

PMID: 26393493 [PubMed - in process]

53. Nursing. 2015 Oct;45(10):14-5.

Best practices for perinatal palliative care.

Ryan A¹, Bernhard H, Fahlberg B.

University of Wisconsin-Madison School of Nursing. Alli Ryan is a certified birth and bereavement doula, a certified child-birth educator, and the owner of The Rainbow Sisters LLC. Heather Bernhard is a doula and a nursing student at the University of Wisconsin-Madison School of Nursing.

PMID: 26372234 [PubMed - in process]

54. J Pediatr (Rio J). 2015 Nov-Dec;91(6 Suppl 1):S44-51. Epub 2015 Sep 6.

[The pediatrician's role in the first thousand days of the child: the pursuit of healthy nutrition and development.](#)

da Cunha AJ¹, Leite AJ², de Almeida IS³.

OBJECTIVES: To describe the concept of the first 1000 days, its importance for health, and actions to be implemented, particularly by pediatricians, in order to attain healthy nutrition and development. **SOURCES:** A nonsystematic review was carried out in the SciELO, LILACS, MEDLINE, Scopus, and Web of Science databases, encompassing the last decade, using the terms 1000 days, child nutrition, child development, childhood, and child. A non-systematic search was performed online for organizations that use the 1000-day concept and give recommendations on children's health. **SUMMARY OF THE FINDINGS:** The first 1000 days range from conception to the end of the second year of life. It represents an important period to implement interventions to ensure healthy nutrition and development, which will bring benefits throughout life. Children should receive adequate nutrition, through proper prenatal diet, exclusive breastfeeding for the first 6 months, addition of adequate complementary foods, and continued breastfeeding up to 2 years of life. Given the condition of absolute dependence on an adult's care, it is crucial to establish an enabling and friendly environment, necessary for the development of strong bonds with caregivers, laying the groundwork for a full and healthy development. **CONCLUSIONS:** The pediatrician, together with other professionals, can act by promoting actions emphasizing the concept of the first 1000 days to ensure healthy nutrition and development. Focusing on actions in this period may increase the child's chance of having a healthy and productive life in the future, strengthening family and community ties, helping to break the intergenerational cycle of poverty.

PMID: 26351769 [PubMed - in process] **Free Article**

55. Pediatr Int. 2015 Oct;57(5):1015-6. Epub 2015 Aug 19.

[Full circle: Resolving an adolescent's end-of-life issues.](#)

Abd Rahman FN¹, Lee VY¹, Shamsuddin AF¹, Yaakup H².

Abstract We report the challenges in managing a troubled, medically ill adolescent with end-of-life issues. Our role as multi-professional service providers complemented the family's efforts to help him reconcile with himself before death. The present experience enhances understanding of the biopsychosocial aspects of care. Every child has the right to optimal care.

PMID: 26286660 [PubMed - in process]

56. J Med Ethics. 2015 Oct;41(10):795-8. Epub 2015 Aug 13.

[End-of-life decisions for children under 1 year of age in the Netherlands: decreased frequency of administration of drugs to deliberately hasten death.](#)

Ten Cate K¹, van de Vathorst S², Onwuteaka-Philipsen BD³, van der Heide A⁴.

OBJECTIVE: To assess whether the frequency of end-of-life decisions for children under 1 year of age in the Netherlands has changed since ultrasound examination around 20 weeks of gestation became routine in 2007 and after a legal provision for deliberately ending the life of a newborn was set up that same year. **METHODOLOGY:** This was a recurrent nationwide cross-sectional study in the Netherlands. In 2010, a sample of death certificates from children under 1 year of age was derived from the central death registry. All 223 deaths that occurred in a 4-month study period were included. Physicians who had reported a non-sudden death (n=206) were sent a questionnaire on the end-of-life decisions made. 160 questionnaires were returned (response 78%). **FINDINGS:** In 2010, 63% of all deaths of children under 1 year of age were preceded by an end-of-life decision—a percentage comparable to other times when this study was conducted (1995, 2001, 2005). These end-of-life decisions were mainly decisions to withdraw or withhold potentially life-sustaining treatment. In 2010, the percentage of cases in which drugs were administered with the explicit intention to hasten death was 1%, while in 1995 and 2001, this was 9% and in 2005, this was 8%. **DISCUSSION AND CONCLUSION:** There has been a reduction of infant deaths that followed administration of drugs with the explicit intention to hasten death. One explanation for this reduction relates to the introduction of routine ultrasound examination around 20 weeks of gestation. In addition, the introduction of legal criteria and a review process for deliberately ending the life of a newborn may have left Dutch physicians with less room to hasten death.

PMID: 26272986 [PubMed - in process]

57. Cancer. 2015 Nov 15;121(22):4080-7. Epub 2015 Jul 28.

[Symptom profiles in children with advanced cancer: Patient, family caregiver, and oncologist ratings.](#)

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

BACKGROUND: Systematic symptom assessment is not routinely performed in pediatric oncology. The objectives of the current study were to characterize the symptoms of pediatric oncology outpatients and evaluate agreement between patient and proxy reports and the association between children's ratings and oncologists' treatment recommendations. **METHODS:** Two versions of the pediatric Memorial Symptom Assessment Scale (pMSAS) were translated into Spanish. An age-appropriate and language-appropriate pMSAS was administered independently before visits to the oncologist to patients and family caregivers (caregivers) and after visits to consenting oncologists. Statistical analysis included Spearman correlation coefficients and weighted kappa values. **RESULTS:** English and Spanish results were similar and were combined. A total of 60 children and their caregivers completed the pMSAS. The children had a median age of 10 years (range, 7-18 years); approximately 62% were male and 33% were Spanish-speaking. Fourteen oncologists completed the pMSAS for 25 patients. Nine patients (15%) had no symptoms and 38 patients (63%) reported ≥ 2 symptoms. The most common symptoms were fatigue (12 patients; 40%) and itch (9 patients; 30%) for the younger children and pain (15 patients; 50%) and lack of energy

(13 patients; 45%) among the older children. Total and subscale score agreement varied by proxy type and subscale, ranging from fair to good for most comparisons. Agreement for individual symptoms between the patient and proxy ranged from a kappa of -0.30 (95% confidence interval, -0.43 to -0.01) to 0.91 (95% confidence interval, 0.75 to 1.00). Three of 51 symptomatic patients (6%) had treatment recommendations documented in the electronic health record. **CONCLUSIONS:** Symptoms are common and cross several functional domains. Proxy and child reports are often not congruent, possibly explaining apparent undertreatment among this group of patients. Cancer 2015;121:4080-4087. © 2015 American Cancer Society. PMID: 26218240 [PubMed - in process]

58. J Pediatr. 2015 Oct;167(4):919-924.e1. Epub 2015 Jul 23.

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

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

OBJECTIVE: To conduct a national survey of pediatricians' access to and experience with clinical ethics consultation.

STUDY DESIGN: We surveyed a randomly selected sample of 3687 physician members of the American Academy of Pediatrics. We asked about their experiences with ethics consultation, the helpfulness of and barriers to consultation, and ethics education. Using a discrete choice experiment with maximum difference scaling, we evaluated which traits of ethics consultants were most valuable. **RESULTS:** Of the total sample of 3687 physicians, 659 (18%) responded to the survey. One-third of the respondents had no experience with clinical ethics consultation, and 16% reported no access to consultation. General pediatricians were less likely to have access. The vast majority (90%) who had experience with consultation had found it helpful. Those with fewer years in practice were more likely to have training in ethics. The most frequently reported issues leading to consultation concerned end-of-life care and conflicts with patients/families or among the team. Intensive care unit physicians were more likely to have requested consultation. Mediation skills and ethics knowledge were the most highly valued consultant characteristics, and representing the official position of the hospital was the least-valued characteristic.

CONCLUSION: There is variability in pediatricians' access to ethics consultation. Most respondents reported that consultation had been helpful in the past. Determining ethically appropriate end-of-life care and mediation of disagreements are common reasons that pediatricians request consultation. Copyright © 2015 Elsevier Inc. All rights reserved.

PMID: 26210945 [PubMed - in process]

59. J Palliat Med. 2015 Oct;18(10):842-8. Epub 2015 Jul 17.

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

Brock KE^{1,2}, Cohen HJ¹, Popat RA³, Halamek LP^{1,4,5}.

BACKGROUND: Interventions to improve pediatric trainee education in palliative care have been limited by a lack of reliable and valid tools for measuring effectiveness. **OBJECTIVE:** We developed a questionnaire to measure pediatric fellows' self-efficacy (comfort), knowledge, and perceived adequacy of prior medical education. We measured the questionnaire's reliability and validity. **METHODS:** The questionnaire contains questions regarding self-efficacy (23), knowledge (10), fellow's perceived adequacy of prior medical education (6), and demographics. The survey was developed with palliative care experts, and sent to fellows in U.S. pediatric cardiology, critical care, hematology/ oncology, and neonatal-perinatal medicine programs. Measures of reliability, internal consistency, and validity were calculated. **RESULTS:** One hundred forty-seven fellows completed the survey at test and retest. The self-efficacy and medical education questionnaires showed high internal consistency of 0.95 and 0.84. The test-retest reliability for the Self-Efficacy Summary Score, measured by intraclass correlation coefficient (ICC) and weighted kappa, was 0.78 (item range 0.44-0.81) and 0.61 (item range 0.36-0.70), respectively. For the Adequacy of Medical Education Summary Score, ICC was 0.85 (item range 0.6-0.78) and weighted kappa was 0.63 (item range 0.47-0.62). Validity coefficients for these two questionnaires were 0.88 and 0.92. Fellows answered a mean of 8.8/10 knowledge questions correctly; percentage agreement ranged from 65% to 99%. **CONCLUSIONS:** This questionnaire is capable of assessing self-efficacy and fellow-perceived adequacy of their prior palliative care training. We recommend use of this tool for fellowship programs seeking to evaluate fellow education in palliative care, or for research studies assessing the effectiveness of a palliative care educational intervention.

PMCID: PMC4598892 [Available on 2016-10-01]

PMID: 26185912 [PubMed - in process]

60. J Pain Symptom Manage. 2015 Nov;50(5):685-92. Epub 2015 Jul 8.

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

Hung YN¹, Liu TW², Tang ST³.

CONTEXT: Factors influencing pediatric cancer patients' place of death may have evolved with advances in medical and hospice care since earlier studies were done. **OBJECTIVES:** To comprehensively analyze factors associated with hospital death in an unbiased population of pediatric cancer patients in Taiwan. **METHODS:** This was a retrospective cohort study using administrative data for 1603 Taiwanese pediatric cancer patients who died in 2001-2010. Place of death was hypothesized to be associated with 1) patient sociodemographics and disease characteristics, 2) primary physician's specialty, 3) characteristics and health care resources at both the hospital and regional levels, and 4) historical trends. **RESULTS:** Most Taiwanese pediatric cancer patients (87.4%) died in an acute care hospital. The probability of dying in hospital increased slightly over time, reaching significance only in 2009 (adjusted odds ratio [AOR], 95% CI: 2.84 [1.32-6.11]). Children were more likely to die in an acute care hospital if they resided in the most urbanized area, were diagnosed with leukemia or lymphoma (2.32 [1.39-3.87]), and received care from a pediatrician (1.58 [1.01-2.47]) in a nonprofit proprietary hospital (1.50 [1.01-2.24]) or large hospital, reaching significance for the third quartile (2.57 [1.28-5.18]) of acute care hospital beds. **CONCLUSION:** Taiwanese pediatric cancer patients predominantly died in an acute care hospital with a slightly increasing trend of shifting place of death from home to hospital. Propensity for hospital death was determined by residential urbanization level, diagnosis, primary physician's specialty, and the primary hospital's characteristics and health care resources. Clinical interventions and health policies should ensure that resources are allocated to allow pediatric cancer patients to die in the

place they and their parents prefer to achieve a good death and promote their parents' bereavement adjustment.

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PMID: 26162507 [PubMed - in process]

61. Lancet. 2015 Oct 31;386(10005):1776-85. Epub 2015 Jul 6.

Controversies in faith and health care.

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

Erratum in: Department of Error. [Lancet. 2015]

Abstract Differences in religious faith-based viewpoints (controversies) on the sanctity of human life, acceptable behaviour, health-care technologies and health-care services contribute to the widespread variations in health care worldwide. Faith-linked controversies include family planning, child protection (especially child marriage, female genital mutilation, and immunisation), stigma and harm reduction, violence against women, sexual and reproductive health and HIV, gender, end-of-life issues, and faith activities including prayer. Buddhism, Christianity, Hinduism, Islam, Judaism, and traditional beliefs have similarities and differences in their viewpoints. Improved understanding by health-care providers of the heterogeneity of viewpoints, both within and between faiths, and their effect on health care is important for clinical medicine, public-health programmes, and health-care policy. Increased appreciation in faith leaders of the effect of their teachings on health care is also crucial. This Series paper outlines some faith-related controversies, describes how they influence health-care provision and uptake, and identifies opportunities for research and increased interaction between faith leaders and health-care providers to improve health care. Copyright © 2015 Elsevier Ltd. All rights reserved.

PMID: 26159392 [PubMed - in process]

62. Int J Clin Pharm. 2015 Oct;37(5):767-75. Epub 2015 Apr 9.

Medication use during end-of-life care in a palliative care centre.

Masman AD^{1,2,3}, van Dijk M^{4,5}, Tibboel D^{4,5}, Baar FP^{4,6}, Mathôt RA^{4,7}.

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.

PMCID: PMC4594093 **Free PMC Article**

PMID: 25854310 [PubMed - in process]

63. J Pediatr Nurs. 2015 Nov-Dec;30(6):e11-7. Epub 2015 Mar 21.

Compassion Fatigue in Pediatric Nurses.

Berger J¹, Polivka B², Smoot EA³, Owens H².

Abstract Compassion fatigue in nursing has been shown to impact the quality of patient care and employee satisfaction and engagement. The aims of this study were to determine the prevalence and severity of compassion fatigue among pediatric nurses and variations in prevalence based on respondent demographics using a cross-sectional survey design. Nurses under 40 years of age, with 6-10 years of experience and/or working in a medical-surgical unit had significantly lower compassion satisfaction and higher levels of burnout. Secondary traumatic stress from caring for children with severe illness or injury or end of life was a key contributor to compassion fatigue. Copyright © 2015 Elsevier Inc. All rights reserved.

PMID: 25800590 [PubMed - in process]

64. Psychooncology. 2015 Nov;24(11):1471-6. Epub 2015 Feb 6.

An exploratory study of end-of-life prognostic communication needs as reported by widowed fathers due to cancer.

Park EM¹, Check DK², Yopp JM¹, Deal AM³, Edwards TP⁴, Rosenstein DL^{1,5}.

OBJECTIVE: Effective physician communication about prognosis is a critical aspect of quality care for families affected by terminal illness. This is particularly important for spousal caregivers of terminally ill parents of dependent children, who may have unique needs for communication about anticipated death. The objective of this study was to explore end-of-life prognostic communication experiences reported by bereaved fathers whose wives died from cancer. **METHODS:** From October 2012 to November 2013 we surveyed widowed fathers whose wives died from cancer through an open-access educational website. The survey included the following open-ended questions regarding prognostic communication: 'What is the most important thing you would like us to know about whether/how your wife's doctors communicated with you about her anticipated death? What do you wish had been different, if anything?' We performed traditional content analysis of responses. Two researchers coded and categorized the data. **RESULTS:** Two hundred forty-four men responded to the survey questions on prognostic communication. Major themes addressed by respondents were the importance of clear and honest communication and physician bedside manner. They also identified unmet information needs, including wanting to know prognosis sooner. Relevant sub-themes included death coming as a surprise, avoidance, and caregiver regret. **CONCLUSIONS:** Surviving spouses due to cancer can provide important insights for health care providers about optimum prognostic

communication at the end of life. Increased physician attention to the communication preferences of both patients and their partners may improve bereavement outcomes for family members. Copyright © 2015 John Wiley & Sons.
PMID: 25655038 [PubMed - in process]

65. *Pediatr Nephrol.* 2015 Oct;30(10):1761-9. Epub 2014 Oct 21.

Sustaining life or prolonging dying? Appropriate choice of conservative care for children in end-stage renal disease: an ethical framework.

Dionne JM¹, d'Agincourt-Canning L.

Abstract Due to technological advances, an increasing number of infants and children are surviving with multi-organ system dysfunction, and some are reaching end-stage renal disease (ESRD). Many have quite limited life expectancies and may not be eligible for kidney transplantation but families request dialysis as alternative. In developed countries where resources are available there is often uncertainty by the medical team as to what should be done. After encountering several of these scenarios, we developed an ethical decision-making framework for the appropriate choice of conservative care or renal replacement therapy in infants and children with ESRD. The framework is a practical tool to help determine if the burdens of dialysis would outweigh the benefits for a particular patient and family. It is based on the four topics approach of medical considerations, quality-of-life determinants, patient and family preferences and contextual features tailored to pediatric ESRD. In this article we discuss the basis of the criteria, provide a practical framework to guide these difficult conversations, and illustrate use of the framework with a case example. While further research is needed, through this approach we hope to reduce the moral distress of care providers and staff as well as potential conflict with the family in these complex decision-making situations.

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66. *Health Expect.* 2015 Oct;18(5):1052-65. Epub 2013 May 20.

Problems and hopes perceived by mothers, fathers and physicians of children receiving palliative care.

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BACKGROUND: The quality of shared decision making for children with serious illness may depend on whether parents and physicians share similar perceptions of problems and hopes for the child. **OBJECTIVE:** (i) Describe the problems and hopes reported by mothers, fathers and physicians of children receiving palliative care; (ii) examine the observed concordance between participants; (iii) examine parental perceived agreement; and (iv) examine whether parents who identified specific problems also specified corresponding hopes, or whether the problems were left 'hopeless'. **METHOD:** Seventy-one parents and 43 physicians were asked to report problems and hopes and perceived agreement for 50 children receiving palliative care. Problems and hopes were classified into eight domains. Observed concordance was calculated between parents and between each parent and the physicians. **RESULTS:** The most common problem domains were physical body (88%), quality of life (74%) and medical knowledge (48%). The most common hope domains were quality of life (88%), suffering (76%) and physical body (39%). Overall parental dyads demonstrated a high percentage of concordance (82%) regarding reported problem domains and a lower percentage of concordance on hopes (65%). Concordance between parents and physicians regarding specific children was lower on problem (65-66%) and hope domains (59-63%). Respondents who identified problems regarding a child's quality of life or suffering were likely to also report corresponding hopes in these domains (93 and 82%, respectively). **CONCLUSION:** Asking parents and physicians to talk about problems and hopes may provide a straightforward means to improve the quality of shared decision making for critically ill children.

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67. *Palliat Support Care.* 2015 Oct 29:1-12. [Epub ahead of print]

The feasibility and acceptability of a chaplain-led intervention for caregivers of seriously ill patients: A Caregiver Outlook pilot study.

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OBJECTIVE: When caring for a loved one with a life-limiting illness, a caregiver's own physical, emotional, and spiritual suffering can be profound. While many interventions focus on physical and emotional well-being, few caregiver interventions address existential and spiritual needs and the meaning that caregivers ascribe to their role. To evaluate the feasibility and acceptability of the process and content of Caregiver Outlook, we employed a manualized chaplain-led intervention to improve well-being by exploring role-related meaning among caregivers of patients with a life-limiting illness. **METHOD:** We conducted a single-arm pre-post pilot evaluation among caregivers of patients with advanced cancer or amyotrophic lateral sclerosis (ALS). Caregivers completed three chaplain-led intervention sessions focusing on (1) a relationship review, (2) forgiveness, and (3) legacy. Outcomes administered at baseline and at 1 and 2 weeks after the intervention included quality of life, anxiety, depression, spiritual well-being, religious coping, caregiver burden, and grief. **RESULTS:** The sample (N = 31) included a range of socioeconomic status groups, and the average age was approximately 60 years. A third of them worked full-time. Some 74% of our participants cared for a spouse or partner, and the other quarter of the sample cared for a parent (13%), child (10%), or other close family member (3%). At baseline, participants did not demonstrate clinical threshold levels of anxiety, depression, or other indicators of distress. Outcomes were stable over time. The qualitative results showed the ways in which Caregiver Outlook was assistive: stepping back from day-to-day tasks, the opportunity to process emotions, reflecting on support received, provoking thoughts and emotions between sessions, discussing role changes, stimulating communication with others, and the anonymity of a phone conversation. Both religious and nonreligious participants were pleased with administration of the chaplain intervention. **SIGNIFICANCE OF RESULTS:** The acceptability and feasibility of Caregiver Outlook were demonstrated among caregivers of patients with an advanced illness. Our pilot findings suggest minor modifications to study participant screening, interventionist guidance, and the study measures.

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