

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

“Good information is the best medicine...”
Donald A.B. Lindberg



Third number

June 2016

Volume III - N° 3

1. J Pain Symptom Manage. 2016 May 21. [Epub ahead of print]

[Quality of Life in Children with Advanced Cancer: A Report from the PediQUEST Study.](#)

Rosenberg AR¹, Orellana L², Ullrich C³, Kang T⁴, Geyer JR⁵, Feudtner C⁴, Dussel V⁶, Wolfe J⁷.

Abstract

CONTEXT: Modifiable factors of health-related quality of life (HRQOL) are poorly described among children with advanced cancer. Symptom-distress may be an important factor for intervention.

OBJECTIVES: We aimed to describe patient-reported HRQOL and its relationship to symptom distress.

METHODS: Prospective, longitudinal data from the multicenter Pediatric Quality of Life and Symptoms Technology (PediQUEST) study included primarily patient-reported symptom-distress and HRQOL, measured at most weekly with the Memorial Symptoms Assessment Scale and Pediatric Quality of Life [PedsQL] inventory, respectively. Associations were evaluated using linear mixed-effects models adjusting for sex, age, cancer type, intervention arm, treatment intensity, and time since disease progression.

RESULTS: Of 104 enrolled patients, 49% were female, 89% were white, and median age was 12.6 years. Nine hundred and twenty surveys were completed over nine months of follow-up (84% by patients). The median total PedsQL score was 74 (IQR 63-87) and was "poor/fair" (e.g., <70) 38% of the time. "Poor/fair" categories were highest in physical (53%) and school (48%) compared to emotional (24%) and social (16%) subscores. Thirteen of 24 symptoms were independently associated with reductions in overall or domain-specific HRQOL. Patients commonly reported distress from two or more symptoms, corresponding to larger HRQOL score reductions. Neither cancer type, time since progression, treatment intensity, sex, nor age was associated with HRQOL scores in multivariable models. Among 25 children completing surveys during the last 12 weeks of life, 11 distressing symptoms were associated with reductions in HRQOL.

CONCLUSION: Symptom-distress is strongly associated with HRQOL. Future research should determine whether alleviating distressing symptoms improves HRQOL in children with advanced cancer.

PMID: 27220948

2. J Pain Symptom Manage. 2016 May 21. [Epub ahead of print]

[Bispectral Index \(BIS\) Monitoring in Terminally Ill Patients: A Validation Study.](#)

Masman AD¹, van Dijk M², van Rosmalen J³, Blussé van Oud-Alblas HJ⁴, Ista E⁵, Baar FP⁶, Tibboel D².

Abstract

CONTEXT: If regular therapies cannot relieve symptoms sufficiently in the last days of life, continuous palliative sedation may serve to reduce consciousness. Sedation level can be measured with EEG monitoring with the bispectral index (BIS) monitor.

OBJECTIVES: To determine the feasibility and validity of BIS monitoring in terminally ill patients.

METHODS: In this prospective study, BIS registrations were performed in unconscious end-of-life patients admitted to a palliative care center. Validated scores were used to measure level of sedation (Ramsay score), pain (Numeric Rating Scale or Rotterdam Elderly Pain Observations Scale), delirium (Delirium Observation Screening score) and overall comfort (Numeric Rating Scale). Validity and sensitivity to change of BIS values were considered and the effects of medication and the time till death on BIS values were evaluated in a linear mixed model analysis.

RESULTS: Fifty-eight patients were included for analysis. BIS monitoring was acceptable to patients, relatives and medical staff. BIS values were moderately correlated with Ramsay scores (0.46), but were highly variable for deeply sedated patients. BIS values changed significantly before and after a midazolam dose ($P < 0.001$). Midazolam treatment resulted on average in a statistically significant reduction of the BIS values (-4.5, 95% confidence interval -7.0 to -2.0) whereas morphine and haloperidol did not.

CONCLUSION: This is one of the first validation studies in which BIS monitoring in end-of-life patients is described. BIS monitoring is feasible in unconscious terminally ill patients. However, based on our results, the wide range of BIS values in deeply sedated and comfortable patients seems to hamper its use in daily clinical practice.

PMID: 27220943

3. JAMA Intern Med. 2016 May 23. [Epub ahead of print]

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

[Kirkpatrick JN¹, Hauptman PJ², Swetz KM³, Blume ED⁴, Gauvreau K⁴, Maurer M⁵, Goodlin SJ⁶.](#)

PMID: 27214624

4. Nurs Child Young People. 2016 May 9;28(4):65.

[OC13 - Parents' support needs during and following the death of their baby.](#)

[Barnard M¹.](#)

Abstract

Theme: Complex health care and chronic disease management.

INTRODUCTION: Support for bereaved parents after the death of a baby in the neonatal period is variable in the UK.

AIM: To explore parents' experiences and perceptions of support needs during and following the death of their baby.

METHODS: An interpretative phenomenological study using unstructured interviews was undertaken. Analysis was undertaken using interpretative phenomenological analysis.

RESULTS: Parental grief journeys are complicated by events experienced at the end of their baby's life. A variety of support systems are needed to facilitate parental grief journeys.

DISCUSSION: The variation in availability of support for parents after a neonatal death needs addressing. Whilst parental need is individualised, most parents need support in some format.

CONCLUSIONS: Health professionals have a key role to play in supporting parents and signposting other supportive mechanisms after a neonatal death.

PMID: 27214428

5. BMJ Support Palliat Care. 2016 May 20. [Epub ahead of print]

['The nice thing about doctors is that you can sometimes get a day off school': an action research study to bring lived experiences from children, parents and hospice staff into medical students' preparation for practice.](#)

[Spalding J¹, Yardley S².](#)

Abstract

Patient and public involvement in healthcare is important to ensure services meet their needs and priorities. Increasingly, patient experiences are being used to educate healthcare professionals. The potential contribution to medical education of children and parents using hospice services has not yet been fully explored.

OBJECTIVES: (1) To explore perceptions of what medical students must learn to become 'good doctors' among children, parents and staff in a hospice. (2) To collaborate with children/parents and staff to develop educational materials based on their lived experiences for medical students. (3) To assess feasibility of student-led action research in a children's hospice to develop research skills.

METHODS: Prospective ethical approval received. Volunteer children (n=7), parents (n=5) and staff (n=6) were recruited from a children's hospice. Data were generated in audio-recorded semistructured focus groups, individual interviews and/or activity workshops. Participants discussed what newly qualified doctors' needed to care for children with life-limiting conditions. Audio data were transcribed and combined with visual data for thematic analysis. Findings were refined by participant feedback. This paper presents thematic findings and educational material created from the project.

RESULTS: Thematic analysis identified six learning themes: (1) treat children as individuals; (2) act as a person before being a doctor; (3) interpersonal communication; (4) appreciate the clinical environment; (5) learn from children, parents and other staff; (6) how to be a doctor as part of a team. The student researcher successfully developed qualitative research skills, coproducing materials with participants for sharing learning derived from lived experiences.

CONCLUSIONS: All participants were willing and able to make valuable contributions, and believed that this was a worthwhile use of time and effort. Further work is required to understand how best to integrate the experiences of children in hospices into medical education.

PMID: 27208813

6. J Palliat Med. 2016 May 20. [Epub ahead of print]

[Assessing the Presence and Severity of Constipation with Plain Radiographs in Constipated Palliative Care Patients.](#)

[Clark K^{1,2}, Lam LT^{3,4}, Talley NJ^{2,5}, Quinn J⁶, Blight A¹, Byfieldt N¹, Currow DC⁷.](#)

Abstract

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

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

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

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

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

PMID: 27203628

7. Ann Palliat Med. 2016 May 9. [Epub ahead of print]

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

Olagunju AT¹, Sarimiye FO², Olagunju TO³, Habeebu MY⁴, Aina OF⁵.

Abstract

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

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

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

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

Free Article

PMID: 27199271

9. Am J Hosp Palliat Care. 2016 May 17. [Epub ahead of print]

Nurse Knowledge, Work Environment, and Turnover in Highly Specialized Pediatric End-of-Life Care.

Lindley LC¹, Cozad MJ².

Abstract

OBJECTIVE: To examine the relationship between nurse knowledge, work environment, and registered nurse (RN) turnover in perinatal hospice and palliative care organizations.

METHODS: Using nurse intellectual capital theory, a multivariate analysis was conducted with 2007 National Home and Hospice Care Survey data.

RESULTS: Perinatal hospice and palliative care organizations experienced a 5% turnover rate. The professional experience of advanced practice nurses (APNs) was significantly related to turnover among RNs ($\beta = -.032, P < .05$). Compared to organizations with no APNs professional experience, clinical nurse specialists and nurse practitioners significantly reduced RN turnover by 3 percentage points. No other nurse knowledge or work environment variables were associated with RN turnover. Several of the control variables were also associated with RN turnover in the study; Organizations serving micropolitan ($\beta = -.041, P < .05$) and rural areas ($\beta = -.037, P < .05$) had lower RN turnover compared to urban areas. Organizations with a technology climate where nurses used electronic medical records had a higher turnover rate than those without ($\beta = .036, P < .05$).

CONCLUSION: The findings revealed that advanced professional experience in the form of APNs was associated with reductions in RN turnover. This suggests that having a clinical nurse specialist or nurse practitioner on staff may provide knowledge and experience to other RNs, creating stability within the organization.

PMID: 27188758

10. Palliat Med. 2016 May 13. [Epub ahead of print]

A call for increased paediatric palliative care research: Identifying barriers.

[Beecham E¹](#), [Hudson BF¹](#), [Oostendorp L²](#), [Candy B³](#), [Jones L³](#), [Vickerstaff V³](#), [Lakhanpaul M⁴](#), [Stone P³](#), [Chambers L⁵](#), [Hall D](#), [Hall K](#), [Ganeshamoorthy T](#), [Comac M⁶](#), [Bluebond-Langner M⁷](#).

PMID: 27178539

11. J Palliat Care Pharmacother. 2016 May 12:1-3.

[A Tragedy of Errors.](#)

[Srikanth L¹](#).

Abstract

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

PMID: 27171792

12. J Palliat Med. 2016 May 11. [Epub ahead of print]

[Identifying the Deliberate Prevention and Intervention Strategies of Pediatric Palliative Care Teams Supporting Providers During Times of Staff Distress.](#)

[Jonas DF¹](#), [Bogetz JF²](#).

Abstract

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

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

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

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

PMID: 27167894

13. J Palliat Med. 2016 May 11. [Epub ahead of print]

[Starting and Sustaining Palliative Care in Public Hospitals: Lessons Learned from a Statewide Initiative.](#)

[Kinderman AL^{1,2}](#), [Harris HA^{1,2}](#), [Brousseau RT³](#), [Close P^{4,5}](#), [Pantilat SZ²](#).

Abstract

BACKGROUND: Compared with private, not-for-profit hospitals, significantly fewer public hospitals report that they provide palliative care services for their patients. Because uninsured and underinsured patients largely depend on public hospitals for acute medical care, they therefore experience disparities in access to inpatient palliative care services. To address this disparity, the statewide Spreading Palliative Care in Public Hospitals Initiative (SPCPHI) was established to help implement or expand inpatient palliative care services in all 17 of California's public acute care hospitals.

AIM: The aim of this article is to use the experiences from the SPCPHI to describe the unique challenges to providing palliative care in public hospitals; the major barriers to initiating, growing, and sustaining palliative care programs in public hospitals; and the common solutions to overcoming those barriers.

CONCLUSIONS: Palliative care programs in public hospitals must develop the necessary skills and staffing to meet the complex needs of vulnerable patients and their families. These programs face a variety of unique organizational and operational challenges such as limited and uncertain funding, limited access to hospital data and analytic support, and complex regulatory structures, which may hinder growth of palliative care in these systems. Experiences from the SPCPHI suggest that networking, technical assistance, and startup funding are helpful to overcome these barriers and to develop high-quality, sustainable palliative care programs in public hospitals.

PMID: 27167527

14. Zhongguo Dang Dai Er Ke Za Zhi. 2016 May;18(5):379-85.

[Neonatal end of life care in a tertiary care centre in Canada: a brief report.](#)

[Sankaran K¹](#), [Hedin E](#), [Hodgson-Viden H](#).

Abstract

OBJECTIVE: To describe the processes followed by a neonatal team engaging parents with respect to end of life care of babies in whom long term survival was negligible or impossible; and to describe feedback from these parents after death of their child.

METHODS: A retrospective review was conducted of health records of neonates who had died receiving palliative care over a period of 5 years at a tertiary neonatal centre. Specific inclusion criteria were determined in advance that identified care given by a dedicated group of caregivers.

RESULTS: Thirty infants met eligibility criteria. After excluding one outlier an average of 4 discussions occurred with families before an end of life decision was arrived at. Switching from aggressive care to comfort care was a more common decision-making route than having palliative care from the outset. Ninety per cent of families indicated satisfaction with

the decision making process at follow-up and more than half of them returned later to meet with the NICU team. Some concerns were expressed about the availability of neonatologists at weekends.

CONCLUSIONS: A compassionate and humane approach to the family with honesty and empathy creates a positive environment for decision-making. An available, experienced team willing to engage families repeatedly is beneficial. Initiating intensive care with subsequent palliative care is acceptable to families and caregivers.

Free Article

PMID: 27165583

15. Nurs Child Young People. 2016 May 9;28(4):13.

Research and commentary.

[No authors listed]

Abstract

Aim To gain an understanding of paediatric palliative care from healthcare workers and the parents of children who have received or provided palliative care with the aim of developing services through identifying priorities for research.

PMID: 27156415

16. J Matern Fetal Neonatal Med. 2016 May 26:1-4. [Epub ahead of print]

Lethal fetal abnormalities: how to approach perinatal palliative care?

Tosello B^{1,2}, Haddad G², Gire C², Einaudi MA¹.

Abstract

OBJECTIVE: Some of the antenatally diagnosed fetal pathologies are unlikely to get compatible with life. Still some women choose to continue with pregnancy. Subsequently, perinatal palliative care (PPC) has become a constructive demarche in such situations. Our study, based on a multicentric survey, reports some cases of fetal pathologies considered as lethal according to perinatal professionals and reveals the decisional process in each case.

METHODS: We sent by emails a questionnaire to 434 maternal-fetal medicine specialists and fetal care pediatric specialists at 48 multidisciplinary centers for prenatal diagnosis.

RESULTS: The participation rate was 49.3%. In total, 61 obstetric-gynecologists and 68 neonatologists completed the survey. The results showed that 35.4% of the pregnant women asked for the continuation of pregnancy and 24.7% asked for the termination of pregnancy. More than half of professionals (52.9%) took the initiative of informing women about the options for birth support (including PPC), while 32.7% of obstetric gynecologists did not take this initiative versus 10.2% of neonatologists ($p < 0.01$).

CONCLUSION: This study demonstrates the absolute need to provide PPC training for professionals and to standardize its practices.

PMID: 27150239

17. Pediatr Blood Cancer. 2016 May 3. [Epub ahead of print]

Feasibility of Early Palliative Care Consultation for Children With High-Risk Malignancies.

Mahmood LA¹, Casey D², Dolan JC³, Dozier AM³, Korones DN¹.

Abstract

BACKGROUND: Children with cancer suffer significant morbidity throughout therapy and often face an uncertain prognosis. Because palliative care teams can provide an additional layer of support with symptom management and communication, we conducted a prospective study assessing the feasibility of early palliative care consultation for children with high-risk malignancies.

PROCEDURE: This study was part of a larger prospective study examining the impact of early palliative care consultation. Children were eligible if they were <22 years old and had a high-risk malignancy, recurrence, or required hematopoietic stem cell transplantation (HSCT). Data were collected from the medical record on diagnosis, days to consultation, acceptability of consultation to family/staff, and overall survival. Feasibility was defined as enrollment of >75% of eligible patients, palliative care consultation within 1 month of eligibility, and patient/family satisfaction.

RESULTS: Twenty of 25 (80%) eligible patients were approached and received a palliative care consultation at initial diagnosis (7), recurrence (12), or time of HSCT (1). Median age of the children was 5 years (0.1-20 years). Median time from new diagnosis/recurrence to consultation was 12 days (2-180 days); 17 (85%) received the consultation within 30 days. Eleven (55%) of the 20 children died. Median time of consultation prior to death was 128 days (10-648 days). Ten of the 11 (91%) received their consultation >30 days prior to death. No families or oncologists declined an early consultation.

CONCLUSIONS: Early palliative care consultation is feasible for children with high-risk cancer and is acceptable to children, families, and pediatric oncologists.

PMID: 27148856

18. CA Cancer J Clin. 2016 May 4. [Epub ahead of print]

Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps.

Kirch R^{1,2}, Reaman G³, Feudtner C^{4,5}, Wiener L⁶, Schwartz LA^{7,8}, Sung L⁹, Wolfe J^{10,11}.

Abstract

This article highlights key findings from the "Comprehensive Cancer Care for Children and Their Families" March 2015 joint workshop by the Institute of Medicine (IOM) and the American Cancer Society. This initiative convened more than 100 family members, clinician investigators, advocates, and members of the public to discuss emerging evidence and care models and to determine the next steps for optimizing quality-of-life outcomes and well-being for children and families during pediatric cancer treatment, after treatment completion, and across the life spectrum. Participants affirmed the triple aim of pediatric oncology that strives for every child with cancer to be cured; provides high-quality palliative

and psychosocial supportive, restorative, and rehabilitative care to children and families throughout the illness course and survivorship; and assures receipt of high-quality end-of-life care for patients with advancing disease. Workshop outcomes emphasized the need for new pediatric cancer drug development and identified critical opportunities to prioritize palliative care and psychosocial support as an integral part of pediatric cancer research and treatment, including the necessity for adequately resourcing these supportive services to minimize suffering and distress, effectively address quality-of-life needs for children and families at all stages of illness, and mitigate the long-term health risks associated with childhood cancer and its treatment. Next steps include dismantling existing silos and enhancing collaboration between clinical investigators, disease-directed specialists, and supportive care services; expanding the use of patient-reported and parent-reported outcomes; effectively integrating palliative and psychosocial care; and clinical communication skills development.

Free Article

PMID: 27145249

19. Semin Oncol Nurs. 2016 May;32(2):144-53.

Vulnerable Population Challenges in the Transformation of Cancer Care.

Meneses K, Landier W, Dionne-Odom JN.

Abstract

OBJECTIVES: To consider current trends and future strategies that will bring about change in cancer care delivery for vulnerable populations.

DATA SOURCES: Institute of Medicine reports, literature review, clinical practice observations and experiences.

CONCLUSION: Vulnerable populations are older adults, both minorities and the underserved, children, and individuals at end of life. These groups pose unique challenges that require health system changes and innovative nursing models to assure access to patient-centered care in the future.

IMPLICATIONS FOR NURSING PRACTICE: In the future, attention to the needs of vulnerable populations, the growing aging cancer population and the improved outcomes in the pediatric and adolescent cancer population will all require new nursing services and models of care. System changes where nursing roles are critical to support the transition to earlier palliative care are projected.

PMID: 27137471

20. J Palliat Med. 2016 May 2. [Epub ahead of print]

Assessment of the Spiritual Needs of Primary Caregivers of Children with Life-Limiting Illnesses Is Valuable Yet Inconsistently Performed in the Hospital.

Kelly JA¹, May CS², Maurer SH^{2,3}.

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

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

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

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

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

PMID: 27136401

21. JAMA Pediatr. 2016 May 2. [Epub ahead of print]

Effect of Donor Milk on Severe Infections and Mortality in Very Low-Birth-Weight Infants: The Early Nutrition Study Randomized Clinical Trial.

Corpeleijn WE¹, de Waard M², Christmann V³, van Goudoever JB¹, Jansen-van der Weide MC⁴, Kooi EM⁵, Koper JF⁵, Kouwenhoven SM², Lafeber HN², Mank E⁶, van Toledo L⁶, Vermeulen MJ⁷, van Vliet I⁶, van Zoeren-Grobbe D⁹.

Abstract

Importance: Infections and necrotizing enterocolitis, major causes of mortality and morbidity in preterm infants, are reduced in infants fed their own mother's milk when compared with formula. When own mother's milk is not available, human donor milk is considered a good alternative, albeit an expensive one. However, most infants at modern neonatal intensive care units are predominantly fed with own mother's milk. The benefits of add-on donor milk over formula are not clear.

Objective: To determine whether providing donor milk instead of formula as supplemental feeding whenever own mother's milk is insufficiently available during the first 10 days of life reduces the incidence of serious infection, necrotizing enterocolitis, and mortality.

Design, Settings, and Participants: The Early Nutrition Study was a multicenter, double-blind randomized clinical trial in very low-birth-weight infants (birth weight <1500 g) admitted to 1 of 6 neonatal intensive care units in the Netherlands from March 30, 2012, through August 17, 2014. Intent-to-treat analysis was performed.

Interventions: Infants received pasteurized donor milk or preterm formula during the first 10 days of life if own mother's milk was not (sufficiently) available.

Main Outcomes and Measures: The primary end point was cumulative occurrence of serious infection (sepsis or meningitis), necrotizing enterocolitis, or mortality during the first 60 days of life.

Results: A total of 930 infants were screened for inclusion; 557 were excluded, resulting in 373 infants (183 receiving donor milk and 190 receiving formula) who were evaluated by intent-to-treat analysis (median birth weight, 1066 g; mean gestational age, 28.4 weeks). Own mother's milk comprised 89.1% and 84.5% of total mean intake during the intervention period for the donor milk and formula groups, respectively. The incidence of the combined outcome was not different (85 [44.7%] [formula] vs 77 [42.1%] [donor milk]; mean difference, 2.6%; 95% CI, -12.7% to 7.4%). The adjusted hazard ratio was 0.87 (95% CI, 0.63-1.19; P = .37).

Conclusions and Relevance: In the current study, pasteurized donor milk and preterm formula as supplemental feeding during the first 10 days of life yielded similar short-term outcomes in very low-birth-weight infants regarding safety and efficacy when own mother's milk availability was insufficient. Future studies investigating longer duration of use of human donor milk on short-term and long-term outcomes are necessary.

Trial Registration: trialregister.nl Identifier: NTR3225.

PMID: 27135598

22. Klin Padiatr. 2016 Apr;228(3):145-8. doi: 10.1055/s-0042-103327. Epub 2016 May 2.

[Constitution of a New Specialised Pediatric Home Care Team - First Year Experience].

[Article in German]

Hauch H¹, Klinkel N¹, Chao CM¹, Behrje J¹, Kreuzaler P¹, Bagheri A¹, Sibelius U², Berthold D².

Abstract

BACKGROUND: Since the amendment of the Social Law V in Germany in 2007 the financial basis for a Specialised Home Palliative Care for Children (SHPC) for children was established. In Hesse 3 different SHPC teams entered into collective negotiations with health insurance companies. In 2014, the team of the University Children's Hospital in Giessen started to treat the first patient with a lead time of two months.

METHODS: Thus in this paper the development of a SHPC team is described. After the first year anonymized patients data were retrospectively analyzed.

RESULTS: Within 12 months 35 patients, 24 females and 11 males, were treated. All of the 6 patients who died, died at home. Calculated 48 weeks survival was 78%. 45% of the patients suffered from malignancies, 34% of malformations and 34% had metabolic disorders. 51% needed crisis intervention and 51% infusion therapy. Only 26% of parents denied cardiopulmonary resuscitation (CPR). Only 10% of the patients or their families received professional psychological care.

CONCLUSION: Formation of a SHPC is feasible within a short time period once a financial basis is established. So, empathic guidance of families to help decision making for emergency situations are considered to be important. Analysis of patient's data after one year could help to improve the quality of care. Our data provides information for developing a palliative care team und could motivate colleagues to start the job.

PMID: 27135272

23. Am J Crit Care. 2016 May;25(3):235-42.

Cause of Death of Infants and Children in the Intensive Care Unit: Parents' Recall vs Chart Review.

Brooten D¹, Youngblut JM², Caicedo C², Seagrave L², Cantwell GP², Totapally B².

Abstract

BACKGROUND: More than 55 000 children die annually in the United States, most in neonatal and pediatric intensive care units. Because of the stress and emotional turmoil of the deaths, the children's parents have difficulty comprehending information.

OBJECTIVES: To compare parents' reports and hospital chart data on cause of death and examine agreement on cause of death according to parents' sex, race, participation in end-of-life decisions, and discussion with physicians; deceased child's age; unit of care (neonatal or pediatric); and hospital and intensive care unit lengths of stay.

METHODS: A descriptive, correlational design was used with a structured interview of parents 1 month after the death and review of hospital chart data. Parents whose children died in intensive care were recruited from 4 South Florida hospitals and from Florida Department of Health death records.

RESULTS: Among 230 parents, 54% of mothers and 40% of fathers agreed with the chart cause of death. Agreement did not differ significantly for mothers or fathers by race/ethnicity, participation in end-of-life decisions, discussions with physicians, or mean length of hospital stay. Agreement was better for mothers when the stay in the intensive care unit was the shortest. Fathers' agreement with chart data was best when the deceased was an infant and death was in the pediatric intensive care unit.

CONCLUSIONS: Death of a child is a time of high stress when parents' concentration, hearing, and information processing are diminished. Many parents have misconceptions about the cause of the death 1 month after the death.

PMID: 27134230

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

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

[Article in French]

Toulouse J¹, Leneveu MC², Brouard J³, Alexandre M⁴.

Abstract

BACKGROUND: Pediatrics residents treat patients who are particularly vulnerable and they care for many patients in palliative situations. The purpose of this study was to build a typology detailing the representations of pediatrics and

oncology residents on palliative care and how these transfer to their practice, and to determine their knowledge of euthanasia and end-of-life legislation.

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

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

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

PMID: 27133365

25. Eur J Cancer. 2016 Apr 27;61:11-19.

European Survey on Standards of Care in paediatric oncology centres.

Kowalczyk JR¹, Samardakiewicz M², Pritchard-Jones K³, Ladenstein R⁴, Essiaf S⁵, Fitzgerald E⁵, Petrarulo G⁵, Vassal G⁶.

Abstract

BACKGROUND: In recent years, the European Commission has supported an increased focus on rare cancers in order to improve quality of care, disseminate best practice and set up networks to improve access that is essential to continued progress. At European Union (EU) conference in 2009, an agreement was reached to create a 'European Standard of Care for Children with Cancer'. In 2013, the European Paediatric Oncology Society launched a Europe-wide survey in order to assess the implementation of the Standards.

METHODS: Representative experts from 36 countries, including 27 EU members, were invited to complete a questionnaire describing the quality of treatment and care received by young cancer patients in their country, together with the characteristics of the health care infrastructure and paediatric haematology-oncology (PHO) teams.

FINDINGS: Thirty-five European countries provided comprehensive responses. Within the responding countries, 341 PHO centres were identified. Only 18 countries consider they have full diagnostic services, all necessary drugs and supportive care. The annual incidence rate is approximately 146.1 new cancer cases/million children and adolescents. In 24 countries, paediatric haematology and oncology is officially recognised as a specific qualification. A total of 1178 specialists certified in PHO are currently working in Europe. Finally, 31 (88.6%) countries provide a multidisciplinary palliative care for terminally ill children.

INTERPRETATION: This survey provides quantitative data that demonstrate the current healthcare inequalities for children and adolescents with cancer in Europe. This variability in care provision and quality is likely to underlie the variation in childhood cancer survival rate in these countries.

PMID: 27131152

26. Palliat Med. 2016 Apr 29. [Epub ahead of print]

Healthcare staff 's experience in providing end-of-life care to children: A mixed-method review.

McConnell T¹, Scott D², Porter S².

Abstract

BACKGROUND: Staff who provide end-of-life care to children not only have to deal with their own sense of loss but also that of bereaved families. There is a dearth of knowledge on how they cope with these challenges.

AIM: The aim of this review is to explore the experiences of healthcare professionals who provide end-of-life care to children in order to inform the development of interventions to support them, thereby improving the quality of paediatric care for both children and their families.

DATA SOURCES: Searches included CINAHL, MEDLINE, Web of Science, EMBASE, PsychINFO and The Cochrane Library in June 2015, with no date restrictions. Additional literature was uncovered from searching reference lists of relevant studies, along with contacting experts in the field of paediatric palliative care.

DESIGN: This was a systematic mixed studies review. Study selection, appraisal and data extraction were conducted by two independent researchers. Integrative thematic analysis was used to synthesise the data.

RESULTS: The 16 qualitative, 6 quantitative and 8 mixed-method studies identified included healthcare professionals in a range of settings. Key themes identified rewards and challenges of providing end-of-life care to children, the impact on staff's personal and professional lives, coping strategies and key approaches to help support staff in their role.

CONCLUSION: Education focusing on the unique challenges of providing end-of-life care to children and the importance of self-care, along with timely multidisciplinary debriefing, are key strategies for improving healthcare staff's experiences, and as such the quality of care they provide.

PMID: 27129677

27. Int J Palliat Nurs. 2016 Apr 2;22(4):176-84.

Development of a logic model to support a network approach in delivering 24/7 children's palliative care: part one.

Maynard L¹, Lynn D².

Abstract

AIM: This research aimed to develop and evaluate a 24/7 symptom-management service for children with life-limiting conditions and a model for palliative care nursing.

STUDY DESIGN: A combination of audit and qualitative and quantitative evaluation.

SAMPLE AND SETTING: A consultant nurse-led service (n=5 clinical nurse specialists) provided care and support to children and their families, which spanned a range of settings (home, hospital, hospice) supported by a managed clinical network of consultant paediatricians (n=4) with postgraduate expertise in palliative care.

METHODS: A pluralistic evaluation was conducted where the predefined service standards were audited and the predetermined service objectives were evaluated using daily diary data from the nursing team (micro), qualitative and quantitative survey data of stakeholders using the service (mezzo) and family assessment of children's palliative care (CPC) standards across the CPC network (macro).

PMID: 27119405

28. Z Geburtshilfe Neonatol. 2016 Apr;220(2):53-7.

[Palliative Care in the Delivery Room](#).

[Article in German]

Garten L¹, von der Hude K¹.

Abstract

Palliative care in the delivery room is a multiprofessional challenge directed to the dying newborn and the parents as well as to the care-givers. Clinical experience shows that many aspects regarding this unique palliative care situation are not well known and cause relevant emotional distress to the health care providers. In this article basic background information of palliative care of newborns in the delivery room are presented. Furthermore, recommendations are given focusing on 2 main aspects: 1. non-pharmacological and pharmacological ways of symptom control in palliative care of dying newborns and 2. meeting the individual psychological, emotional and spiritual needs of the parents.

PMID: 27111592

29. Arch Dis Child. 2016 Apr 21. [Epub ahead of print]

[The importance of early involvement of paediatric palliative care for patients with severe congenital heart disease](#).

Bertaud S¹, Lloyd DF², Laddie J³, Razavi R².

Abstract

Growing numbers of patients with severe congenital heart disease (CHD) are surviving into late childhood and beyond. This increasingly complex patient group may experience multiple formidable and precarious interventions, lifelong morbidity and the very real risk of premature death on many occasions throughout their childhood. In this paper, we discuss the advantages of a fully integrated palliative care ethos in patients with CHD, offering the potential for improved symptom control, more informed decision-making and enhanced support for patients and their families throughout their disease trajectory. These core principles may be delivered alongside expert cardiac care via non-specialists within pre-existing networks or via specialists in paediatric palliative care when appropriate. By broaching these complex issues early-even from the point of diagnosis-an individualised set of values can be established around not just *end-of-life* but also *quality-of-life* decisions, with clear benefits for patients and their families regardless of outcome.

PMID: 27102758

30. BMJ Support Palliat Care. 2016 Apr 21. pii: bmjpspcare-2015-000946. doi: 10.1136/bmjpspcare-2015-000946. [Epub ahead of print]

[Ectopia cordis: a novel palliative care technique](#).

Berry MJ¹, Saito-Benz M², Klein T², Bowkett B², Richardson VF².

Abstract

Complete ectopia cordis in the newborn represents a significant management challenge. There are minimal data available to inform optimal clinical care for those infants with coexisting complex congenital heart disease who are therefore not candidates for surgical intervention. The exteriorisation of the heart and absence of the pericardial sac requires meticulous wound care to prevent desiccation of the myocardium and to minimise infection risk. Additionally, the technique selected must address the risk of occlusion of the cardiac vascular pedicle and abrasion between the mobile myocardium and dressing surface. We report a novel approach to wound management and integrated palliative care that enabled community-based care. Our patient, a full-term male infant with complete ectopia cordis was born in good condition by assisted vaginal delivery. He was discharged from hospital on day 8 and was cared for in the community until his demise from cardiac failure on day 15.

PMID: 27101836

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

[Response: A Call for Psychosocial and Palliative Care Training Standards for Pediatric Hematology-Oncology Physicians, A Reply To: Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology](#).

Patenaude AF¹, Pelletier W², Bingen K³.

PMID: 27082206

32. BMJ. 2016 Apr 14; 353:i1010.

[Palliative care in patients with heart failure](#).

McIlvennan CK¹, Allen LA².

Abstract

Despite advances in cardiac therapy, heart failure (HF) remains a progressive, highly symptomatic, and deadly disease that places great demands on patients, caregivers, and healthcare systems. Palliative care is a multidisciplinary approach to care that focuses on communication, shared decision making, and advance care planning; provides relief from pain and other distressing symptoms; integrates psychological and spiritual aspects of care; and offers a support system to help families cope during illness and bereavement. Palliative care has applications across the stages of heart failure, including early in the course of illness, often in conjunction with other therapies that are intended to prolong life. However, the incorporation of palliative care into the management of heart failure has been suboptimal for several reasons: uncertainty

in the disease trajectory, failure to reward communication between healthcare providers and patients, siloed care, lack of knowledge, overlay of comorbidity and frailty, life saving devices with complex trade-offs, and a limited evidence base. This review will summarize the current literature on the emerging role of palliative care in patients with heart failure and the challenges and opportunities for its integration into routine care. It will discuss current initiatives and future directions of the collaborative relationship between the palliative care and heart failure disciplines.

Free Article

PMID: 27079896

33. Support Care Cancer. 2016 Apr 11. [Epub ahead of print]

The Italian version of the FAMCARE scale: a validation study.

Chattat R¹, Ottoboni G¹, Zeneli A², Berardi MA³, Cossu V¹, Maltoni M⁴.

Abstract

PURPOSE: Evaluation of the quality of care is a key element that healthcare providers now take into consideration to meet patients' needs, expectations, and values. The FAMCARE scale is one of the most important instruments available to assess the level of satisfaction about care received by patients and families. We describe the validation process used to develop an Italian version (IF) of the original FAMCARE scale for caregivers.

METHODS: The IF was prepared according to standard guidelines for translation and transcultural adaptation of self-reported measures. The scale was self-administered to 132 informal caregivers of patients with cancer treated with curative and/or palliative care in a hospice, outpatient, or inpatient setting for at least 1 month. The participant group was composed of spouses (47.73 %), children (31.82 %), siblings (3.03 %), or other relatives (17.42 %). All participants simultaneously completed the EuroQol-5D (EQ-5D) questionnaire to test the construct validity. Twenty-two percent of randomly chosen participants re-completed the test after 1 month to evaluate IF test-retest stability.

RESULTS: The IF showed a strong reliability with internal consistency [$\alpha = 0.93$, confidence intervals (CI) = 0.91-0.95] and test-retest stability (Pearson $r = 0.38$; Kendall's tau-b = 0,25; Spearman's rho =0.34). Factor analysis identified four factors capable of explaining the 63 % total variance which did not change after the Varimax normalized rotation. Notwithstanding the lack of correlation with the VAS component of the EQ-5D questionnaire, our results highlighted robust psychometric properties of the IF.

CONCLUSIONS: IF is a valid translation of the FAMCARE scale and can be used to assess caregiver satisfaction within the Italian context of cancer palliative care.

PMID: 27067593

34. BMC Palliat Care. 2016 Apr 9;15:41. doi: 10.1186/s12904-016-0114-7.

Development and pilot evaluation of a home-based palliative care training and support package for young children in southern Africa.

Naicker SN^{1,2}, Richter L^{3,4}, Stein A^{5,6}, Campbell L⁷, Marston J⁸.

Abstract

BACKGROUND: The leading cause of death among young children in southern Africa is complications due to HIV infection and, in South Africa, over a third of all deaths of children younger than five are associated with HIV infection. There is a great and urgent need for children's palliative care in Africa, whether HIV-related or not. It is often not possible for sick children and their carers to attend clinics and hospitals cannot accommodate children for long periods of time. As a result children are often cared for in their own homes where caregivers require support to provide informed and sensitive care to reduce children's suffering. Home-care places a heavy burden on families, communities and home- and community-based care workers.

METHODS: This project involved the development and pilot evaluation of a training and support package to guide home and community-based care workers to help caregivers of seriously ill young children at home in southern Africa. A number of research methods were used, including a cross-sectional survey of content experts using the Delphi technique, participatory action research with photo elicitation and qualitative thematic analysis.

RESULTS: Because the palliative care needs of these children are complex, the package focuses on delivering 9 key messages essential to improving the quality of care provided for young children. Once the key messages were developed, culturally relevant stories were constructed to enhance the understanding, retention and enactment of the messages. The various research methods used, including literature reviews, the Delphi technique and photo-elicitation ensured that the content included in the package was medically sound and culturally relevant, acceptable, feasible, and comprehensive. The end product is a home-based paediatric palliative care training and support package in English designed to help train community workers who are in a position to support families to care for very sick young children at home as well as to support families in looking after a very sick child.

CONCLUSION:

A pilot study to assess the training and support package found it to be useful in delivering the key messages to caregivers. The training component was found to be feasible. It is concluded that the package offers a practical means of integrating palliative care with home-based care. Further implementation and evaluation is needed to establish its utility and impact.

PMCID: PMC4826506 **Free PMC Article**

PMID: 27061570

35. J Racial Ethn Health Disparities. 2016 Apr 8. [Epub ahead of print]

Nursing Unit Environment Associated with Provision of Language Services in Pediatric Hospices.

Lindley LC¹, Held ML², Henley KM³, Miller KA³, Pedziwol KE³, Rumley LE³.

Abstract

BACKGROUND: Provision of language services in pediatric hospice enables nurses to communicate effectively with patients who have limited English proficiency. Language barriers contribute to ethnic disparities in health care. While

language service use corresponds with improved patient comprehension of illness and care options, we lack an understanding of how the nurse work environment affects the provision of these services.

METHODS: Data were obtained from the 2007 National Home and Hospice Care Survey and included a study sample of 1251 pediatric hospice agencies. Variable selection was guided by structural contingency theory, which posits that organizational effectiveness is dependent upon how well an organization's structure relates to its context. Using multivariate logistic regression, we analyzed the extent to which nursing unit environment predicted provision of translation services and interpreter services.

RESULTS: The majority of hospices provided translation services (74.9 %) and interpreter services (87.1 %). Four variables predicted translation services: registered nurse (RN) unit size, RN leadership, RN medical expertise, and for-profit status. RN medical expertise and having a safety climate within the hospice corresponded with provision of interpreter services.

CONCLUSIONS: Findings indicate that nursing unit environment predicts provision of language services. Hospices with more specialized RNs and a stronger safety climate might include staffs who are dedicated to best care provision, including language services. This study provides valuable data on the nurse work environment as a predictor of language services provision, which can better serve patients with limited English proficiency and ultimately reduce ethnic disparities in end-of-life care for children and their families.

PMID: 27059050

36. Heart. 2016 May;102 Suppl 2:ii1-ii13.

Diagnosics, monitoring and outpatient care in children with suspected pulmonary hypertension/paediatric pulmonary hypertensive vascular disease. Expert consensus statement on the diagnosis and treatment of paediatric pulmonary hypertension. The European Paediatric Pulmonary Vascular Disease Network, endorsed by ISHLT and DGPK.

Lammers AE¹, Apitz C², Zartner P³, Hager A⁴, Dubowy KO⁵, Hansmann G⁶.

Abstract

Pulmonary hypertension (PH) is a condition of multiple aetiologies with underestimated prevalence and incidence. Indeed, despite access to modern therapies, pulmonary hypertensive vascular disease (PHVD) remains a progressive, usually life-limiting condition, severely impacting on the patients' well-being. We herein provide practical, expert consensus recommendations on the initial diagnostic work-up, clinical management and follow-up of children and adolescents with PH/PHVD, including a diagnostic algorithm. The major topics and methods that need to be tailored and put into context of the individual patient include PH classification, clinical signs and symptoms, basic diagnostic and advanced imaging measures (ECG, chest X-ray, transthoracic echocardiography, cardiac magnetic resonance, chest CT angiography, cardiac catheterisation, ventilation-perfusion lung scan, abdominal ultrasound), lung function tests, 6 min walk and cardiopulmonary exercise testing, sleep study (polysomnography), laboratory/immunological tests, considerations for elective surgery/ general anaesthesia, physical education and exercise, flying on commercial airplanes, vaccinations, care of central intravenous lines and palliative care. Due to the complexity of PH/PHVD, the clinical care has to be multidisciplinary and coordinated by a dedicated specialist paediatric PH centre, not only to decrease mortality but to allow children with PH/PHVD to reach a reasonable quality of life.

PMID: 27053692

37. Cancer Nurs. 2016 Apr 1. [Epub ahead of print]

Communication During Palliative Care and End of Life: Perceptions of Experienced Pediatric Oncology Nurses.

Montgomery KE¹, Sawin KJ, Hendricks-Ferguson V.

Abstract

BACKGROUND: Communication between patients, families, and healthcare providers is a central component of end-of-life care. Nurse communication during palliative care (PC) and end of life (EOL) is a phenomenon with limited research. It is unclear how the level of nursing experience influences the perspectives of nurses communicating during EOL.

OBJECTIVE: The aim of this study is to describe the commonalities of experienced nurses' perceptions of communicating during PC and EOL and perceptions of barriers and facilitators to effective communication.

METHODS: This study was part of a larger multisite study that used a qualitative, empirical phenomenology design and represents focus group data gathered from pediatric oncology nurses with more than 5 years of experience or who were advanced practice nurses not involved in the direct evaluation of other nurses.

RESULTS:

Five core themes with corresponding themes and subthemes were identified. The core themes included (a) Evolution of PC/EOL, (b) Skill of Knowing, (c) Expanded Essence of Caring, (d) Experienced Nurse as Committed Advocate, and (e) Valuing Individual Response to Grief.

CONCLUSIONS: Findings reflect how the concept of experience transcended the 5 core themes and captured how experience provided nurses the know-how to fulfill the roles of communication, caring, and advocacy for children and families.

IMPLICATIONS FOR PRACTICE: Enhancing nurse communication skills during EOL requires opportunities to gain experience coupled with clinical strategies, such as standardized curricula, simulation, competency-based orientation programs, mentorship, and peer support.

PMID: 27044058

38. J Pediatr Nurs. 2016 May-Jun;31(3):353-5.

When Technology Fails: Community-Based Pediatric Hospice.

Ryan JG¹, Haas K², Kramer N³, Vizzachero N⁴, Butler S⁵, Waechter E⁶.

PMID: 27040187

39. Child Care Health Dev. 2016 May;42(3):439-49.

[Early introduction of palliative care and advanced care planning for children with complex chronic medical conditions: a pilot study.](#)

[Lieberman DB](#)^{1,2}, [Song E](#)³, [Radbill LM](#)^{2,4}, [Pham PK](#)¹, [Derrington SF](#)⁵.

Abstract

BACKGROUND: Children with complex chronic medical conditions benefit from early introduction of palliative care services and advanced care planning for symptom management and to support quality of life and medical decision-making. This study evaluated whether introducing palliative care during primary care appointments (1) was feasible; (2) increased access and improved knowledge of palliative care; and (3) facilitated advanced care planning.

METHODS: Pilot study of a multi-modal intervention including targeted education for primary care providers (PCPs), an informational packet for families and presence of a palliative care team member in the outpatient clinic. PCPs completed pre- and post-surveys assessing experience, knowledge and comfort with palliative care. Enrolled families received an information packet; a subset also met a palliative care team member. All families were encouraged to make an appointment with the palliative care team, during which the team assessed palliative care needs and goals of care. Upon study completion, the investigators assessed family and PCP satisfaction and collected feedback on project feasibility.

RESULTS: Twenty families were enrolled and received the information packet; 15 met a palliative care team member. Of the 17 participating families who were reached and completed a post-study survey, 11 families had never heard of palliative care and 13 were unaware that the palliative care team existed. Most families perceived palliative care information as 'very helpful' and 'very important'. All would recommend palliative care team services to others. Nine families followed up with the palliative care team, but none was prepared to complete an advanced care plan. PCPs reported lack of training in communicating bad news and conducting goals of care discussions. However, they felt increasingly comfortable introducing palliative care to families and supported program continuation.

CONCLUSIONS: Initiating palliative care services in the outpatient primary care setting is logistically challenging but increases access to palliative care for children with complex chronic medical conditions and improves palliative care knowledge and comfort for PCPs.

PMID: 27028099

40. JAMA Pediatr. 2016 May 1;170(5):495-501.

[Cancer in Adolescents and Young Adults: A Narrative Review of the Current Status and a View of the Future.](#)

[Barr RD](#)¹, [Ferrari A](#)², [Ries L](#)³, [Whelan J](#)⁴, [Bleyer WA](#)⁵.

Abstract

IMPORTANCE: Although cancer remains the most common cause of disease-related death in adolescents and young adults (AYAs) in high-income countries, their overall survival rates continue to increase and now exceed 80% at 5 years in several high-income countries. This has been accomplished through progressive improvements in active treatment and supportive care, although accrual rates to therapeutic clinical trials remain disappointing. Recognition of the unique distribution of diseases in the AYA population with cancer and further understanding of the distinctive biology of cancers in AYAs will lead to continuing gains in clinical outcomes.

OBSERVATIONS: Many of the challenges faced by AYAs with a diagnosis of malignant disease are shared by others with chronic medical conditions and even their healthy peers, such as a sense of invulnerability that may contribute to delays in diagnosis. A particular need for psychological support has been identified for AYAs with cancer, even after active therapy has been completed and especially in the context of palliative care. Notable needs also include fertility preservation and navigation through the multiple transitions in the cancer journey. Additionally, there is a "cost of cure." This is not only in the form of short-term, treatment-related morbidity and mortality but also in the burden of "late effects," including second cancers, that compromise quality of life and limit life expectancy. Establishing clinical programs devoted to AYAs with cancer, with complementary educational initiatives, will strengthen the advances made. It is anticipated that clinical trial accrual will increase substantially, providing further gains in survival. Likewise, addressing the challenges of survivorship, including secondary prevention of long-term morbidity and mortality, will lead to additional improvements in clinical outcomes.

CONCLUSIONS AND RELEVANCE: Transferring this knowledge to the care of an estimated 1 million incident cases of cancer in AYAs worldwide, most of whom do not live in high-income countries, remains a considerable challenge.

PMID: 26999630

41. J Palliat Med. 2016 Apr;19(4):394-9. doi: 10.1089/jpm.2015.0384. Epub 2016 Feb 19.

[Prospective Study on Music Therapy in Terminally Ill Cancer Patients during Specialized Inpatient Palliative Care.](#)

[Kordovan S](#)¹, [Preissler P](#)^{1,2}, [Kamphausen A](#)³, [Bokemeyer C](#)¹, [Oechsle K](#)¹.

Abstract

OBJECTIVE: This study was a prospective evaluation of feasibility, acceptance, and potential beneficial effects of music therapy in terminally ill cancer patients on a specialized palliative care inpatient ward.

METHODS: Intervention had to consist of at least two sessions, but frequency and duration was left to the patients' decision. Different music therapy methods were offered to the patient at the beginning of every session. Patients rated their subjective benefit. Disease-related and sociodemographic factors were considered as potentially influencing factors.

RESULTS: A total of 166 music therapy sessions were performed with 41 patients (average, 4; range, 2-10). Average session duration was 41 minutes (range, 20-70). Most favored methods were therapeutic conversation in 84% of sessions; listening to relaxing music, 39%; playing an instrument, 31%; and music-lead imagination, 11%. Receptive music therapy was applied in 45%, active forms in 25%, a combination of both in 7%, and therapeutic conversation only in 23%. Music therapy was rated to be "helpful" in 68%. Positive effects were significantly associated with frequency ($p = 0.009$) and duration ($p = 0.040$), living in a partnership ($p = 0.017$), having children ($p = 0.035$), psycho-oncologic therapy ($p =$

0.043), experience with music therapy ($p = 0.007$), role of music in life ($p = 0.035$), playing an instrument ($p = 0.021$), and singing regularly ($p = 0.003$).

CONCLUSION: Music therapy techniques, especially receptive methods, are feasible and well accepted in terminally ill cancer patients. Therapeutic conversation seems to play an important role. Frequency and duration of music therapy, previous experience with music and music therapy, as well as sociodemographic factors influence positive effects of music therapy.

PMID: 26894922

42. *Pediatr Blood Cancer*. 2016 Apr;63(4):583-4.

It is Time to Let in Pediatric Palliative Care.

Hilden J¹.

PMID: 26797913

43. *Pediatr Blood Cancer*. 2016 May;63(5):872-9.

Physician Perspectives on Palliative Care for Children With Neuroblastoma: An International Context.

Balkin EM¹, Thompson D¹, Colson KE², Lam CG³, Matthay KK⁴.

Abstract

BACKGROUND: Studies have shown that children with cancer globally lack access to palliative care. Little is known regarding physicians' perceptions of palliative care, treatment access, and self-reported competence in providing palliative care.

PROCEDURE: Members of the Global Neuroblastoma Network (online tumor board) were surveyed. Eighty-three respondents met inclusion criteria; 53 (64%) completed the survey.

RESULTS: Most respondents trained in high-income countries (HIC) but practice in low- and middle-income countries (LMIC), and care for more than five patients with neuroblastoma annually. WHO Essential Medicines in palliative care varied in availability, with incomplete access across LMIC centers. Nonpharmacologic therapies were inconsistently available. Contrary to international definitions, 17% of respondents inappropriately considered palliative care as that initiated only after curative therapy is stopped. Mean physician competence composite score (Likert scale 1-5, 5 = very competent) in providing symptomatic relief and palliative care across phases of care was 2.93 (95% CI 2.71-3.22). Physicians reported significantly greater competence in symptom management during cure-directed therapy than during end-of-life ($P = 0.02$) or when patients are actively dying ($P = 0.007$). Practicing in HIC, prior palliative care training, having access to radiotherapy, and not having to turn patients away due to bed shortages were significantly predictive of perceived competence in providing palliative care at end of life.

CONCLUSIONS: An international sample identified gaps in treatment and palliative care service availability, in understanding the definition of palliative care, and in self-reported competence in providing palliative care. Increased perceived competence was associated with training, which supports the need for increased palliative care education and advocacy, especially in LMIC.

PMID: 26784890

44. *J Palliat Med*. 2016 Apr;19(4):442-50.

Feasibility of a Comfort Care Protocol Using Oral Transmucosal Medication Delivery in a Palliative Neonatal Population.

Drolet C¹, Roy H¹, Laflamme J¹, Marcotte ME¹.

Abstract

BACKGROUND: The oral transmucosal (OTM) route for administration of comfort medication in infants at the end-of-life has long been favored by our pediatric palliative care team but has rarely been described in the literature.

OBJECTIVE: To determine the feasibility of implementing a standardized comfort care protocol using OTM medications in dying neonates.

METHOD: A comfort protocol prescribing medication by the OTM route and standardized assessment were established. Each infant included in the study was assessed with the Neonatal Pain, Agitation, and Sedation Scale (N-PASS). Caretakers' satisfaction was assessed using a questionnaire. The feasibility of implementing the protocol was determined by the proportion of assessments done when required, the rate of termination of the protocol, and the feedback from nurses using the protocol.

RESULTS: Twelve patients were enrolled. Regular evaluations were performed 85% of the time. When the medication was given as needed, 71% of cases were evaluated before versus 63% when regular doses were given. The as-needed doses were followed by an assessment 30 minutes later in 49% of cases and in 41%, 60 minutes later, for a total of 64% in the hour after medication administration. The protocol was discontinued only for two patients who were discharged to continue end-of-life care at home. There were no significant adverse events reported. Finally, 17 of 18 nurses said they would recommend this protocol to other institutions.

CONCLUSION: In the context of neonatal palliative care, the implementation of a standardized protocol for administration of drugs by the OTM route is feasible and safe. However, in the context of this study, adherence was limited because of too-frequent evaluations and misunderstanding of the protocol.

PMID: 26717305

45. *Intensive Crit Care Nurs*. 2016 Apr;33:5-11.

'Something normal in a very, very abnormal environment' - Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia.

Bloomer MJ¹, Endacott R², Copnell B³, O'Connor M⁴.

Abstract: The majority of deaths of children and infants occur in paediatric and neonatal intensive care settings. For nurses, managing an infant/child's deterioration and death can be very challenging. Nurses play a vital role in how the death occurs, how families are supported leading up to and after the infant/child's death. This paper describes the nurses' endeavours to create normality amidst the sadness and grief of the death of a child in paediatric and neonatal ICU. Focus groups and individual interviews with registered nurses from NICU and PICU settings gathered data on how neonatal and paediatric intensive care nurses care for families when a child dies and how they perceived their ability and preparedness to provide family care. Four themes emerged from thematic analysis: (1) respecting the child as a person; (2) creating opportunities for family involvement/connection; (3) collecting mementos; and (4) planning for death. Many of the activities described in this study empowered parents to participate in the care of their child as death approached. Further work is required to ensure these principles are translated into practice.

PMID: 26687773

46. Palliat Med. 2016 Apr;30(4):418.

Crocker, et al.: Reducing barriers to parent participation in pediatric palliative care research.

Siden HH¹, Steele R², Cadell S³.

PMID: 26684794

47. J Perinatol. 2016 May;36(5):331-7.

Palliative care in neonatal neurology: robust support for infants, families and clinicians.

Lemmon ME^{1,2}, Bidegain M³, Boss RD^{4,5}.

Abstract: Infants with neurological injury and their families face unique challenges in the neonatal intensive care unit. As specialty palliative care support becomes increasingly available, we must consider how to intentionally incorporate palliative care principles into the care of infants with neurological injury. Here, we review data regarding neonatal symptom management, prognostic uncertainty, decision making, communication and parental support for neonatal neurology patients and their families.

PMID: 26658120

48. Pediatr Blood Cancer. 2016 Apr;63(4):593-7.

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

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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.

PMID: 26579997

49. Neuro Oncol. 2016 Apr;18(4):582-8.

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

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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.

PMCID: PMC4799684 [Available on 2017-04-01]

PMID: 26459800

50. Am J Hosp Palliat Care. 2016 Apr;33(3):264-71.

Comparison of the Educational Needs of Neonatologists and Neonatal Nurses Regarding Palliative Care in Taiwan.

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Abstract

BACKGROUND: Education and training are very critical to development of high-quality neonatal palliative care. However, little investigation has been done into Taiwanese neonatal clinicians' educational needs regarding neonatal palliative care.

PURPOSES: The purposes of this study were to characterize and identify neonatal clinicians' educational needs regarding neonatal palliative care.

METHODS: A cross-sectional descriptive surveyed method via a self administered questionnaire was used in this research. Thirty neonatologists were recruited by a convenience sampling and 30 nurses were recruited by a randomized sampling.

RESULTS: Out of sixty neonatal clinicians' survey, few had received the education in neonatal palliative care. Most reported minimal training in, experience with, and knowledge of neonatal palliative care. For neonatologists, two of twelve most strongly-felt educational needs were "discussing palliative care and ethical decision-making with parents" (70%) and "informing parents the poor progress in neonates" (63.3%). In contrast, neonatal nurses wanted more training regarding pain control (50%). Communication skills, including the discussing poor prognosis, bad news, and code status and talking with neonates about end-of-life care, were the educational need most commonly felt by both neonatologists and nurses.

CONCLUSIONS: Survey data from neonatologists and neonatal nurses in Taiwan indicate a need for further training on a range of neonatal palliative care competencies.

PMID: 25433068