

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

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

Donald A.B. Lindberg



Il quinto numero

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N° 5

1. Pediatrics. 2014 Dec;134(6):e1670-7. Epub 2014 Nov 17.

[Developing competencies for pediatric hospice and palliative medicine.](#)

[Klick JC¹, Friebert S², Hutton N³, Osenga K⁴, Pituch KJ⁵, Vesel T⁶, Weidner N⁷, Block SD⁸, Morrison LJ⁹; American Board of Hospice and Palliative Medicine Competencies Work Group.](#)

Abstract

In 2006, hospice and palliative medicine (HPM) became an officially recognized subspecialty. This designation helped initiate the Accreditation Council of Graduate Medical Education Outcomes Project in HPM. As part of this process, a group of expert clinician-educators in HPM defined the initial competency-based outcomes for HPM fellows (General HPM Competencies). Concurrently, these experts recognized and acknowledged that additional expertise in pediatric HPM would ensure that the competencies for pediatric HPM were optimally represented. To fill this gap, a group of pediatric HPM experts used a product development method to define specific Pediatric HPM Competencies. This article describes the development process. With the ongoing evolution of HPM, these competencies will evolve. As part of the Next Accreditation System, the Accreditation Council of Graduate Medical Education uses milestones as a framework to better define competency-based, measurable outcomes for trainees. Currently, there are no milestones specific to HPM, although the field is designing curricular milestones with multispecialty involvement, including pediatrics. These competencies are the conceptual framework for the pediatric content in the HPM milestones. They are specific to the pediatric HPM subspecialist and should be integrated into the training of pediatric HPM subspecialists. They will serve a foundational role in HPM and should inform a wide range of emerging innovations, including the next evolution of HPM Competencies, development of HPM curricular milestones, and training of adult HPM and other pediatric subspecialists. They may also inform pediatric HPM outcome measures, as well as standards of practice and performance for pediatric HPM interdisciplinary teams.

PMID: 25404726 [PubMed - in process]

2. Pediatrics. 2014 Dec;134(6):e1678-85. doi: 10.1542/peds.2014-0582. Epub 2014 Nov 17.

[Preventing CLABSIs Among Pediatric Hematology/Oncology Inpatients: National Collaborative Results.](#)

[Bundy DG¹, Gaur AH², Billett AL³, He B⁴, Colantuoni EA⁴, Miller MR⁵; Children's Hospital Association Hematology/Oncology CLABSI Collaborative.](#)

OBJECTIVES:

Central lines (CLs) are essential for the delivery of modern cancer care to children. Nonetheless, CLs are subject to potentially life-threatening complications, including central line-associated bloodstream infections (CLABSIs). The objective of this study was to assess the feasibility of a multicenter effort to standardize CL care and CLABSI tracking, and to quantify the impact of standardizing these processes on CLABSI rates among pediatric hematology/oncology inpatients.

METHODS:

• We conducted a multicenter quality improvement collaborative starting in November 2009. Multidisciplinary teams at participating sites implemented a standardized bundle of CL care practices and adopted a common approach to CLABSI surveillance.

RESULTS:

Thirty-two units participated in the collaborative and reported a mean, precollaborative CLABSI rate of 2.85 CLABSIs per 1000 CL-days. Self-reported adoption of the CL care bundle was brisk, with average compliance approaching 80% by the

end of the first year of the collaborative and exceeding 80% thereafter. As of August 2012, the mean CLABSI rate during the collaborative was 2.04 CLABSIs per 1000 CL-days, a reduction of 28% (relative risk: 0.71 [95% confidence interval: 0.55-0.92]). Changes in self-reported CL care bundle compliance were not statistically associated with changes in CLABSI rates, although there was little variability in bundle compliance rates after the first year of the collaborative.

CONCLUSIONS:

A multicenter quality improvement collaborative found significant reductions in observed CLABSI rates in pediatric hematology/oncology inpatients. Additional interventions will likely be required to bring and sustain CLABSI rates closer to zero for this high-risk population.

PMID: 25404721

3. J Spec Pediatr Nurs. 2014 Nov 30. [Epub ahead of print]

[Parents' experiences of healthcare provider actions when their child dies: An integrative review of the literature.](#)

Butler A¹, Hall H, Willetts G, Copnell B.

PURPOSE:

To review, critique and synthesise current research studies that examine parental perceptions of healthcare provider actions during and after the death of a child.

CONCLUSIONS:

Five main themes were synthesised from the literature: staff attitudes and affect; follow-up care and ongoing contact; communication; attending to the parents; and continuity of care.

PRACTICE IMPLICATIONS:

This review helps to identify important aspects of paediatric end-of-life care as recognised by parents, with the intention of placing the family at the centre of any future end-of-life care education or policy/protocol development.

PMID: 25443391 [PubMed - as supplied by publisher]

4. J Nurs Scholarsh. 2014 Nov 29. doi: 10.1111/jnu.12115. [Epub ahead of print]

[Moral Distress Among Healthcare Professionals: Report of an Institution-Wide Survey.](#)

Whitehead PB¹, Herbertson RK, Hamric AB, Epstein EG, Fisher JM.

PURPOSE:

Moral distress is a phenomenon affecting many professionals across healthcare settings. Few studies have used a standard measure of moral distress to assess and compare differences among professions and settings.

DESIGN:

A descriptive, comparative design was used to study moral distress among all healthcare professionals and all settings at one large healthcare system in January 2011.

METHODS:

Data were gathered via a web-based survey of demographics, the Moral Distress Scale-Revised (MDS-R), and a shortened version of Olson's Hospital Ethical Climate Scale (HECS-S).

FINDINGS:

Five hundred ninety-two (592) clinicians completed usable surveys (22%). Moral distress was present in all professional groups. Nurses and other professionals involved in direct patient care had significantly higher moral distress than physicians ($p = .001$) and other indirect care professionals ($p < .001$). Moral distress was negatively correlated with ethical workplace climate ($r = -0.516$; $p < .001$). Watching patient care suffer due to lack of continuity and poor communication were the highest-ranked sources of moral distress for all professional groups, but the groups varied in other identified sources. Providers working in adult or intensive care unit (ICU) settings had higher levels of moral distress than did clinicians in pediatric or non-ICU settings ($p < .001$). Providers who left or considered leaving a position had significantly higher moral distress levels than those who never considered leaving ($p < .001$). Providers who had training in end-of-life care had higher average levels of moral distress than those without this training ($p = .005$).

CONCLUSIONS:

Although there may be differences in perspectives and experiences, moral distress is a common experience for clinicians, regardless of profession.

CLINICAL RELEVANCE:

Moral distress is associated with burnout and intention to leave a position. By understanding its root causes, interventions can be tailored to minimize moral distress with the ultimate goal of enhancing patient care, staff satisfaction, and retention.

PMID: 25440758

5. Support Care Cancer. 2014 Nov 29. [Epub ahead of print]

[The interaction between informal cancer caregivers and health care professionals: a survey of caregivers' experiences of problems and unmet needs.](#)

Lund L¹, Ross L, Petersen MA, Groenvold M.

PURPOSE:

In order to meet the caregiving challenges, informal caregivers often need a substantial level of interaction with health care professionals (HCPs). This study investigated to which extent the cancer caregivers' needs regarding the interaction with HCPs are met and the associations between dissatisfaction with the interaction and socio-demographic and disease-related variables.

METHODS:

In a cross-sectional questionnaire study, cancer patients with various diagnoses and disease stages were invited to pass on the 'cancer caregiving tasks, consequences and needs questionnaire' (CaTCoN) to up to three of their caregivers.

RESULTS:

A total of 590 caregivers (related to 415 (55 %) of 752 eligible patients) participated. Although many caregivers were satisfied, considerable proportions experienced problems or had unmet needs regarding the interaction with HCPs. Prominent problematic aspects included optimal involvement of the caregivers in the patients' disease, treatment and/or care (30 % were dissatisfied), attention to the caregivers' wellbeing (e.g., 51 % of the caregivers reported that HCPs only sometimes or rarely/never had shown interest in how the caregivers had been feeling), and provision of enough information to the caregivers (e.g. 39 % were dissatisfied with the amount of time spent on informing caregivers). The patients' adult children and siblings, younger caregivers and caregivers to younger patients tended to report the highest levels of interaction problems and unmet needs.

CONCLUSIONS:

The caregivers' dissatisfaction with the interaction with HCPs was pronounced. More focus on and involvement of the caregivers, in a way that matches the caregivers' needs, is still warranted.

PMID: 25432867

6. Am J Hosp Palliat Care. 2014 Nov 28. [Epub ahead of print]

[Comparison of the Educational Needs of Neonatologists and Neonatal Nurses Regarding Palliative Care in Taiwan.](#)

Lee MC¹, Chen YC², Chen CH², Lu FL³, Hsiao CC⁴, Peng NH⁵.

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

7. Pediatr Transplant. 2014 Nov 25. [Epub ahead of print]

[Palliative and end-of-life care in pediatric solid organ transplantation.](#)

Fowler A¹, Freiberger D, Moonan M.

Abstract

End-of-life care is a component of palliative care and takes a holistic, individualized approach to patients, focusing on the assessment of quality of life and its maintenance until the end of life, and beyond, for the patient's family. Transplant teams do not always make timely referrals to palliative care teams due to various clinician and perceived family barriers, an important one being the simultaneous, active care plan each patient would have alongside an end-of-life plan. Application of findings and further research specific to the pediatric solid organ population would be of significant benefit to guide transplant teams as to the most effective time to introduce end-of-life care, who to involve in ongoing discussions, and important ethical and cultural considerations to include in care planning. Attention must also be paid to clinician training and support in this challenging area of health care.

PMID: 25422076

8. J Pediatr Oncol Nurs. 2014 Nov 21. [Epub ahead of print]

[Contributions of Advanced Practice Nurses With a DNP Degree During Palliative and End-of-Life Care of Children With Cancer.](#)

Hendricks-Ferguson VL¹, Akard TF², Madden JR³, Peters-Herron A⁴, Levy R⁵.

Abstract

The doctorate in nursing practice (DNP) degree is recommended as the terminal degree for advanced practice nurses by 2015. Improvement in the quality of palliative and end-of-life care for children with cancer is recognized as a health care priority. The purpose of this article is to describe: (a) how the American Association of Colleges of Nursing's 8 core elements and competencies can be used by DNP-advanced practice nurses in pediatric oncology settings and (b) the DNP-advanced practice nurses' leadership role to advocate translation of evidence in the care of pediatric oncology patients and to promote interdisciplinary collaboration to improve health care outcomes for pediatric oncology patients.

PMID: 25416517

9. J Palliat Med. 2014 Nov 17. [Epub ahead of print]

[Improved Quality of Life at End of Life Related to Home-Based Palliative Care in Children with Cancer.](#)

Friedrichsdorf SJ¹, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J.

Abstract

Nearly 2000 children die due to a malignancy in the United States annually. Emerging data suggest that home is the desired location of care for children with cancer at end of life. However, one obstacle to enrollment in a pediatric palliative care (PPC) home care program may be fear that distressing symptoms at end of life cannot be adequately managed outside the hospital. Objective: To compare the symptom distress and quality-of-life experience for children who received concurrent end-of-life care from a PPC home care program (PPC/Oncology) with that of those who died without exposure to the PPC program (Oncology). Methods: We conducted a retrospective survey study of a cohort of bereaved parents of children who died of cancer between 2002 and 2008 at a U.S. tertiary pediatric institution. Results: Sixty bereaved parents were surveyed (50% PPC/Oncology). Prevalence of constipation and high distress from fatigue were more common in the PPC/Oncology group; other distressing symptoms were similar between groups, showing room for improvement. Children who received PPC/Oncology were significantly more likely to have fun (70% versus 45%), to experience events that added meaning to life (89% versus 63%), and to die at home (93% versus 20%). Conclusions: This is the first North American study to assess outcomes among children with cancer who received concurrent oncology and palliative home care compared with those who received oncology care alone. Symptom distress experiences were similar in groups. However, children enrolled in a PPC home care program appear to have improved quality of life and are more likely to die at home.
PMID: 25401507

10. Nurse Pract. 2014 Nov 16;39(11):22-31; quiz 31-2.

[Pediatric migraine: common, yet treatable.](#)

Harding A¹, Clark L.

Abstract

Migraine headache is a common problem among children and adolescents that is now recognized as a significant and often debilitating condition in this population. Improved recognition and management of pediatric migraine in primary care is necessary, as there is a knowledge gap in understanding the unique features of this condition and a general reluctance to treat children.

PMID: 25286367 [PubMed - in process]

11. J Child Health Care. 2014 Nov 13. [Epub ahead of print]

[Improving and validating children's nurses communication skills with standardized patients in end of life care.](#)

Kenny G¹, Cargil J², Hamilton C³, Sales R³.

Abstract

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

PMID: 25395598 [PubMed - as supplied by publisher]

12. Palliat Med. 2014 Nov 13. [Epub ahead of print]

[Hospital-based bereavement services following the death of a child: A mixed study review.](#)

Donovan LA¹, Wakefield CE², Russell V³, Cohn RJ².

BACKGROUND:

There has been a breadth of research on the grief experience of parents following the death of a child. However, the role and impact of hospital-based bereavement services remain unclear.

AIM:

To identify services offered to bereaved families in perinatal, neonatal, and pediatric hospital settings and summarize the psychosocial impact of these services and published recommendations for best practice hospital-based bereavement care.

DESIGN:

Systematic review of qualitative, quantitative, and mixed method studies guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist and methodological quality appraised in accordance with the Mixed Method Appraisal Tool.

DATA SOURCES:

MEDLINE, EMBASE, Cumulative Index to Nursing and Allied Health, and PsychINFO were searched to find studies describing hospital-based bereavement services/interventions for parents, siblings, and grandparents.

RESULTS:

In all, 14 qualitative, 6 quantitative, and 10 mixed method studies were identified. Nine descriptive articles were also included. Qualitatively, family members described feeling cared for and supported by staff, a reduction in sense of isolation, and improved coping and personal growth. Quantitatively, bereavement services have most effect for parents experiencing more complex mourning. It is recommended that bereavement services be theoretically driven and evidence based, offer continuity of care prior to and following the death of a child, and provide a range of interventions for the "whole family" and flexibility in service delivery.

CONCLUSIONS:

There is a role for transitional hospital-based services/interventions for families in the lead up to and following the death of a child. Further mixed method research is required to inform best practice bereavement care guidelines in the perinatal, neonatal, and pediatric hospital settings.

PMID: 25395578

13. Palliat Med. 2014 Nov 11. [Epub ahead of print]

[Pediatric advance care planning from the perspective of health care professionals: A qualitative interview study.](#)

Lotz JD¹, Jox RJ², Borasio GD³, Führer M⁴.

BACKGROUND:

Pediatric advance care planning differs from the adult setting in several aspects, including patients' diagnoses, minor age, and questionable capacity to consent. So far, research has largely neglected the professionals' perspective.

AIM:

~~We aimed to investigate the attitudes and needs of health care professionals with regard to pediatric advance care planning.~~

DESIGN:

This is a qualitative interview study with experts in pediatric end-of-life care. A qualitative content analysis was performed.

SETTING/PARTICIPANTS:

We conducted 17 semi-structured interviews with health care professionals caring for severely ill children/adolescents, from different professions, care settings, and institutions.

RESULTS:

Perceived problems with pediatric advance care planning relate to professionals' discomfort and uncertainty regarding end-of-life decisions and advance directives. Conflicts may arise between physicians and non-medical care providers because both avoid taking responsibility for treatment limitations according to a minor's advance directive. Nevertheless, pediatric advance care planning is perceived as helpful by providing an action plan for everyone and ensuring that patient/parent wishes are respected. Important requirements for pediatric advance care planning were identified as follows: repeated discussions and shared decision-making with the family, a qualified facilitator who ensures continuity throughout the whole process, multi-professional conferences, as well as professional education on advance care planning.

CONCLUSION:

Despite a perceived need for pediatric advance care planning, several barriers to its implementation were identified. The results remain to be verified in a larger cohort of health care professionals. Future research should focus on developing and testing strategies for overcoming the existing barriers.

PMID: 25389347

14. Nurs Crit Care. 2014 Nov 7. [Epub ahead of print]

[Caring until the end: a systematic literature review exploring Paediatric Intensive Care Unit end-of-life care.](#)

Howes C.

AIMS AND OBJECTIVES:

A systematic review of the literature focusing on the provision of end-of-life care (EOLC) on Paediatric Intensive Care Units (PICUs) and the options available to children and families within contemporary clinical practice.

BACKGROUND:

The death of a child is recognized as a uniquely traumatic experience for a parent. The care delivered to a child and family surrounding death can have a lasting effect on the grieving process. The majority of paediatric deaths occur within PICUs, often as a result of withdrawing or withholding treatment. Withdrawal of intensive care is becoming more common within UK PICUs, and this review will focus on the options available when a child's on-going treatment is deemed to be futile.

SEARCH STRATEGIES:

Literature published from 2002 to 2013 was obtained from a range of sources and critically reviewed. Cormack's (2000) framework for systematic literature review was utilized to critically review literature before analysis and synthesis of the literature was undertaken within the qualitative approach.

INCLUSION/EXCLUSION CRITERIA:

Each article focused on issues surrounding the topic area, excluded adult and neonatal intensive care and was published in English.

CONCLUSIONS:

Eight papers met the inclusion criteria and were suitable for review (highlighting difficulties in reviewing a small, complex subject area). Key themes identified included family views, staff views, decision-making, medico-legal issues and resources.

RELEVANCE TO CLINICAL PRACTICE:

Although the number of relevant articles is limited, a wide range of challenges facing children, parents and staff are highlighted, whilst generally supporting the facilitation of transferring children to their homes or hospice for withdrawal of intensive care and continuing EOLC. Further research is required, particularly regarding long-term implications, legal issues and the effectiveness of clinical protocols.

PMID: 25378129

15. Am J Hosp Palliat Care. 2014 Nov 5. pii: 1049909114556878. [Epub ahead of print]

[Nursing Staff's Perception of Barriers in Providing End-of-Life Care to Terminally Ill Pediatric Patients in Southeast Iran.](#)

OBJECTIVE:

To determine pediatric nurses' perceptions of intensity, frequency occurrence, and magnitude score of selected barriers in providing pediatric end-of-life (EOL) care.

METHOD:

A translated modified version of National Survey of critical care Nurses' s Regarding End-of-Life Care questionnaire was used to assess 151 nurses' perceptions of intensity and frequency occurrence of barriers in caring for dying children.

RESULTS:

The highest/lowest perceived barriers magnitude scores were "families not accepting poor child prognosis" (5.04) and "continuing to provide advanced treatment to dying child because of financial benefits to the hospital" (2.19).

CONCLUSION:

More high perceived barriers by nurses were family-related issues. One of the possible causes of such deficiencies was lack

of palliative care (PC) education/PC units in Iran. Thus, developing EOL/PC education may enhance nurses' knowledge/skill to face EOL care challenges.

PMID: 25376225

16. Pain Manag Nurs. 2014 Nov 4. [Epub ahead of print]

[Can Presence of a Dog Reduce Pain and Distress in Children during Venipuncture?](#)

[Vagnoli L¹](#), [Caprilli S²](#), [Vernucci C²](#), [Zagni S²](#), [Mugnai F²](#), [Messerì A²](#).

Abstract

The aim of this study was to investigate the effectiveness of animal-assisted intervention as distraction for reducing children's pain and distress before, during, and after standard blood collection procedure. Fifty children (ages 4-11 years) undergoing venipuncture were randomly assigned to the experimental group (EG; n = 25) or to the control group (CG; n = 25). The blood collection procedure was carried on the children in the EG arm in the presence of a dog, whereas no dog was present when venipuncture was conducted on children in CG. In both cases, parents accompanied the child in the procedure room. Distress experienced by the child was measured with the Amended Observation Scale of Behavioral Distress, while perceived pain was measured with a visual analog scale or the Wong Baker Scale (Faces Scale); levels of cortisol in blood also were analyzed. Parental anxiety during the procedure was measured with State Trait Anxiety Inventory. Children assigned to the EG group reacted with less distress than children in the CG arm. Furthermore, cortisol levels were lower in the EG group compared with the CG group. There were no significant differences in pain ratings and in the level of parental anxiety. It appears that the presence of dogs during blood draw procedures reduces distress in children.

PMID: 25439114

17. Clin J Pain. 2014 Nov 3. [Epub ahead of print]

[Pain Management in Neonatal Intensive Care: Evaluation of the Compliance with Guidelines.](#)

[Aukes DI¹](#), [Roofthoof DW](#), [Simons SH](#), [Tibboe D](#), [van Dijk M](#).

Abstract

BACKGROUND::

A pain management protocol was implemented in our Neonatal Intensive Care Unit in 2005, including individual pain assessments and pain treatment guidelines with a decision tree.

OBJECTIVES::

To prospectively evaluate the degree of compliance of medical and nursing staff with the pain protocol.

METHODS:

Prospectively recorded pain scores (COMFORTneo score) and all prescribed analgesics and sedatives for the calendar year 2011 were retrieved. The primary outcome is the degree of compliance to the protocol with respect to pain assessments and treatment; the secondary outcome consists of reasons for non-compliance.

RESULTS::

Of the 732 included patients, 660 (90%) received fewer than the stipulated 3 assessments per day. Eighty-six per cent of all assessments yielded a score between 9 and 14, suggesting a comfortable patient. In cases of high pain scores (≥ 14), reassessment within 60 minutes took place in 31% of cases and in 40% treatment was started or adjusted. In cases of low pain scores (≤ 8) during treatment, 13% of the 457 assessments were reassessed within 120 minutes and in 17% a dose reduction was performed.

CONCLUSIONS::

Although the majority of pain assessments suggested comfortable patients, there is room for improvement with respect to reassessments after adjustment of analgesic/sedative treatment. Some protocol violations such as oversedation in palliative patients are acceptable but should be well documented.

PMID: 25370139

18. Int J Palliat Nurs. 2014 Nov 2;20(11):542-8.

[Perspectives of an international education initiative in children's palliative care.](#)

[Price J¹](#), [Janicki JS](#), [McKee H](#), [Nurse S](#), [Gray E](#).

Abstract

Education is viewed as central to improving future palliative care for children and families across all countries. International education initiatives will ensure practitioners are aware of global health issues and can provide culturally sensitive care. Creative and innovative means of meeting such directives are required to achieve meaningful student learning. This paper focuses on one innovation, a children's palliative care workshop using case studies as a teaching method, with nursing students from the USA and nursing and midwifery students from the UK. Key learning points arising from student evaluation were recorded under three main themes, these were: differences across countries, similarities across countries, and making learning fun and memorable. Findings indicated that this joint learning activity was viewed positively by all students and has enabled them to learn with and from each other, potentially impacting on their future practice.

PMID: 25426881

19. Am J Hosp Palliat Care. 2014 Nov;31(7):765-70.

[End-of-life care policies and practices in pediatric skilled nursing facilities.](#)

[Friedman SL¹](#), [Helm DT²](#), [Woodman AC³](#).

Abstract

Although most children with intellectual and developmental disabilities reside in the community, a subset of children with severe intellectual disability and complex medical needs reside in pediatric skilled nursing facilities. These children have elevated mortality with end-of-life care (EOLC) routinely provided. The present study explored policies and practice in such settings by surveying administrators, nursing directors, and medical directors in facilities across the United States. In addi-

tion to EOLC policies and practices, staff reported on their understanding of definitions of do-not-resuscitate orders, family involvement in EOLC planning, and the availability of in-service training. The presence of an official EOLC policy was associated with higher ratings of perception of effectiveness among staff. Staff felt more prepared and comfortable providing EOLC when in-service training was provided.

PMID: 24097839

20. Ann N Y Acad Sci. 2014 Nov;1330(1):101-4.

[Life, death, and the bridges in-between.](#)

[Shemie SD.](#)

Abstract

Remarkable advances in the technological capacity of modern medicine now permit the use of mechanical organ failure support deployed primarily to save life. Such technology serves as a bridge to either recovery or, when feasible, organ transplantation. However, when effective treatment options are exhausted, technological advances can be burdensome bridges to death. This paper briefly reviews the principles of management of life-threatening critical illness and the corresponding biological aspects of life, death, and organ donation, which are both informed and complicated by these technological and scientific achievements.

PMID: 25351389

21. Epilepsia. 2014 Nov;55(11):1722-31.

[Risk factors for health-related quality of life in children with epilepsy: A meta-analysis.](#)

[Ferro MA.](#)

OBJECTIVE:

The aims of this study were to conduct a meta-analysis of risk factors for health-related quality of life (HRQL) in children with epilepsy; interpret the results in terms of study quality; and, assess the nature and source of heterogeneity of estimates.

METHODS:

Databases were searched for studies that examined HRQL in pediatric epilepsy. The inclusion criteria were original studies published in English from 1994 through to the end of January 2014; children ≤ 18 years of age with epilepsy; included a parent- or self-reported measure of HRQL; and, data were presented such that the calculation of a correlation coefficient was possible. Study quality was measured using a modified Quality Index.

RESULTS:

A total of 12 risk factors from 21 studies were analyzed. The mean Quality Index score was 10.4 (standard deviation [SD] 1.9). Correlations between risk factors and HRQL had a minimum of $r = -0.03$ and a maximum of $r = -0.44$. Child sex, age, and age at onset were not significantly associated with HRQL. Duration of epilepsy, seizure type, frequency, and severity, number of antiepileptic drugs, side effects of antiepileptic drugs, presence of a comorbidity, parental anxiety, and family socioeconomic status were significantly associated with HRQL. Informant (child vs. parent), year of publication, and study quality were found to be sources of heterogeneity for certain risk factors.

SIGNIFICANCE:

Results demonstrated that a variety of clinical and family factors are associated with HRQL in children with epilepsy and have implications for research and practice. Future research should focus on longitudinal studies to identify predictors of HRQL that are amenable to intervention and should evaluate whether changes in these predictors result in more favorable HRQL in children with epilepsy.

PMID: 25243908

22. J Pain Symptom Manage. 2014 Nov;48(5):893-902.

[Quality of Life in Patients With Advanced Cancer at the End of Life as Measured by the McGill Quality of Life Questionnaire: A Survey in China.](#)

[Cui J¹, Fang F², Shen F³, Song L⁴, Zhou L⁵, Ma X⁶, Zhao J⁷.](#)

CONTEXT:

Quality of life (QOL) is the main outcome measure for patients with advanced cancer at the end of life. The McGill Quality of Life Questionnaire (MQOL) is designed specifically for palliative care patients and has been translated and validated in Hong Kong and Taiwan.

OBJECTIVES:

This study aimed to investigate the QOL of patients with advanced cancer using the MQOL-Taiwan version after cultural adaptation to the Chinese mainland.

METHODS:

A cross-sectional survey design was used. QOL data from patients with advanced cancer were gathered from 13 hospitals including five tertiary hospitals, six secondary hospitals, and community health care service centers in Shanghai and analyzed. QOL was assessed using the MQOL-Chinese version. Statistical analyses were performed using descriptive statistics, multiple regression analysis, and Spearman rank correlation analysis.

RESULTS:

A total of 531 cancer patients (297 male and 234 female) in 13 hospitals were recruited into the study and administered the MQOL-Chinese. The score of the support subscale was highest (6.82), and the score of the existential well-being subscale was the lowest (4.65). The five physical symptoms most frequently listed on the MQOL-Chinese were pain, loss of appetite, fatigue, powerless, and dyspnea. Participants' sex, educational level, number of children, disclosure of the disease, and hospital size were associated with their overall QOL. The Spearman rank correlation analysis found that Karnofsky Performance Status scores correlated with the MQOL-Chinese single-item score, physical well-being, psychological well-being, existential well-being, and support domains ($P < 0.05$).

CONCLUSION:

Our results revealed the aspects of QOL that need more attention for Chinese palliative care patients with advanced cancer. The association between the characteristics of patients, Karnofsky Performance Status, and their QOL also was identified.
PMID: 24793079

23. J Pain Symptom Manage. 2014 Nov;48(5):968-74.

[Palliative sedation at home for terminally ill children with cancer.](#)

[Korzeniewska-Eksterowicz A¹, Przyslo L², Fendler W³, Stolarska M⁴, Mlynarski W³.](#)

CONTEXT:

The presence of symptoms that are difficult to control always requires adjustment of treatment, and palliative sedation (PS) should be considered.

OBJECTIVES:

We analyzed our experience in conducting PS at home for terminally ill children with cancer during a seven-year period.

METHODS:

We performed a retrospective analysis of medical records of children with cancer treated at home between the years 2005 and 2011.

RESULTS:

We analyzed the data of 42 cancer patients (18% of all patients); in 21 cases, PS was initiated (solid tumors n = 11, brain tumors [5], bone tumors [4], leukemia [1]). Sedation was introduced because of pain (n = 13), dyspnea (9), anxiety (5), or two of those symptoms (6). The main drug used for sedation was midazolam; all patients received morphine. There were no significant differences in the dose of morphine or midazolam depending on the patient's sex; age was correlated with an increase of midazolam dose (R = 0.68; P = 0.005). Duration of sedation (R = 0.61; P = 0.003) and its later initiation (R = 0.43; P = 0.05) were correlated with an increase of the morphine dose. All patients received adjuvant treatment; in patients who required a morphine dose increase, metoclopramide was used more often (P = 0.0002). Patients did not experience any adverse reactions. Later introduction of sedation was associated with a marginally higher number of intervention visits and a significantly higher number of planned visits (R = 0.53; P = 0.013).

CONCLUSION:

Sedation may be safely used at home. It requires close monitoring and full cooperation between the family and hospice team. Because of the limited data on home PS in pediatric populations, further studies are needed.

PMID: 24751437

24. J Pain Symptom Manage. 2014 Nov;48(5):903-14.

[Variation of opioid use in pediatric inpatients across hospitals in the u.s.](#)

[Womer J¹, Zhong W¹, Kraemer FW², Maxwell LG², Ely EA³, Faerber JA¹, Dai D¹, Feudtner C⁴.](#)

CONTEXT:

Appropriate use of opioids is essential to manage moderate-to-severe pain in children safely and effectively, yet published guidance regarding opioid treatment for pediatric patients is limited, potentially resulting in excessive variation in opioid use in pediatric patients across hospitals in the U.S.

OBJECTIVES:

The aim was to evaluate hospital variation in opioid use in pediatric inpatients.

METHODS:

Using data from the Pediatric Health Information System and the Premier Perspective Database regarding all pediatric inpatients in 626 hospitals, we examined hospital variation in opioid use and the length of opioid use, adjusting for patient demographic and clinical characteristics and for hospital type (children's vs. general) and hospital patient volume, using multi-level generalized linear regression modeling.

RESULTS:

Overall, 41.2% of all pediatric hospitalizations were exposed to opioids. Among the exposed patients, the mean length of exposure was 4.6 days. Exposure proportion and exposure length varied substantially across hospitals, even after accounting for patient demographic and clinical characteristics, hospital type and hospital patient volume, especially among terminal hospitalizations. For patients discharged alive vs. died, the adjusted exposure percentage for each hospital ranged from 0.7% to 99.1% (interquartile range [IQR]: 35.3%-59.9%) vs. 0.1% to 100.0% (IQR: 29.2%-66.2%), respectively, and the adjusted exposure length ranged from 1.0 to 8.4 days (IQR: 2.2-2.7 days) vs. 0.9 to 35.2 days (IQR: 4.0-7.4 days).

CONCLUSION:

The substantial hospital-level variation in opioid use in pediatric inpatients suggests room for improvement in clinical practice.

PMID: 24703942

25. J Palliat Med. 2014 Nov;17(11):1206-13.

[Components and principles of a pediatric palliative care consultation: results of a delphi study.](#)

[Bradford N¹, Herbert A, Mott C, Armfield N, Young J, Smith A.](#)

Abstract

Pediatric palliative care is a distinct specialty that requires input from pediatric and palliative medicine specialists to provide comprehensive high-quality care. Consultations undertaken early in a child's illness trajectory, when end-of-life care is not anticipated to be required, enables relationships to be established and may enhance the quality of care provided.

OBJECTIVE:

To define optimal components of an early pediatric palliative care consultation.

DESIGN:

Consensus of an expert group was sought in a five-round Delphi study.

SETTING/PARTICIPANTS:

Based on the literature and existing standards for specialist palliative care, components of an early pediatric palliative care consultation were derived. In rounds 2 and 3, experts from around Australia participated in online surveys to review and prioritize the components and principles. Consensus of survey items was determined by defined criteria. A flowchart was developed in the fourth round and the final round involved review and refinement of the flowchart by the expert group.

RESULTS:

Nineteen experts participated and prioritized 34 components and principles in the first survey round, and 36 statements in the second survey round. There was consensus from all participants that the first priority of a consultation was to establish rapport with the family, and examples of how to achieve this were defined. Other components of a consultation included: establishing the family's understanding of palliative care; symptom management; an emergency plan; discussion of choices for location of care, and a management plan. Components considered suitable to defer to later consultations, or appropriate to address if initiated by family members, included: spiritual or religious issues; discussion around resuscitation and life-sustaining therapies; end-of-life care; and the dying process.

CONCLUSION:

We have provided the first published framework from expert consensus that defines the components and principles of an early pediatric palliative care consultation. This framework will provide guidance for clinical practice as well as being useful for education and research in this area.

PMID: 25006759

26. J Pediatr Hematol Oncol. 2014 Nov;36(8):635-40.

[Patient involvement in informed consent for pediatric phase I cancer research.](#)

[Miller VA¹](#), [Baker JN](#), [Leek AC](#), [Drotar D](#), [Kodish E](#).

OBJECTIVE:

To examine children's and adolescents' involvement in the informed consent conference for phase I cancer trials and test associations with patient age, ease of understanding, and pressure to participate.

PROCEDURE:

Participants included 61 patients aged 7 through 21 years who were offered participation in a phase I trial. Consent conferences were audiotaped, transcribed, and coded for communication between patients and physicians and between patients and parents.

RESULTS:

On the basis of word counts, the mean proportion of the consent conference in which the physician was talking to the patient was 36%; the vast majority (73%) of this communication consisted of giving information. Physician-patient communication increased with age, but overall levels of patient-to-physician communication were low (3%). After controlling for patient age, greater physician-to-patient communication was associated with greater ease of understanding.

CONCLUSIONS:

The focus on providing information in the context of informed consent may come at the expense of other communication exchanges that are important to patients, especially in the context of end-of-life decisions. Children and adolescents may benefit from the assent process when physicians direct more of their communication to them. Future research should identify the reasons for low patient communication during the consent conference and strategies to enhance their participation in decision making about phase I trial enrollment.

PMID: 24487916

27. J Pediatr Nurs. 2014 Nov-Dec;29(6):660-9.

[When a child dies: parents' experiences of palliative care-an integrative literature review.](#)

[Melin-Johansson C¹](#), [Axelsson I²](#), [Jonsson Grundberg M³](#), [Hallqvist F³](#).

Abstract

The aim of this integrative review was to increase knowledge about parents' experiences of palliative care when their child is dying or has died due to illness using Whittemore and Knafl (2005) analysis process. Computerized databases were used to search the literature. Nine papers met the inclusion criteria. The analysis resulted in five categories: genuine communication, sincere relationships, respect as an expert, and alleviation of suffering and need of support, including 15 subcategories. Health professionals need education to provide high-quality pediatric palliative care. They especially need training concerning existential issues, and further studies need to be performed.

PMID: 25038375

28. Pediatr Blood Cancer. 2014 Nov;61(11):2004-11.

[End-of-life care in pediatric neuro-oncology.](#)

[Vallero SG¹](#), [Lijoi S](#), [Bertin D](#), [Pittana LS](#), [Bellini S](#), [Rossi F](#), [Peretta P](#), [Basso ME](#), [Fagioli F](#).

BACKGROUND:

The management of children with cancer during the end-of-life (EOL) period is often difficult and requires skilled medical professionals. Patients with tumors of the central nervous system (CNS) with relapse or disease progression might have additional needs because of the presence of unique issues, such as neurological impairment and altered consciousness. Very few reports specifically concerning the EOL period in pediatric neuro-oncology are available.

PROCEDURE:

Among all patients followed at our center during the EOL, we retrospectively analyzed data from 39 children and adolescents with brain tumors, in order to point out on their peculiar needs.

RESULTS:

Patients were followed-up for a median time of 20.1 months. Eighty-two percent were receiving only palliative therapy before death. Almost half the patients (44%) died at home, while 56% died in a hospital. Palliative sedation with midazolam was performed in 58% of cases; morphine was administered in 51.6% of cases. No patient had uncontrolled pain.

CONCLUSIONS:

The EOL in children with advanced CNS cancer is a period of active medical care. Patients may develop complex neurological symptoms and often require long hospitalization. We organized a network-based collaboration among the reference pediatric oncology center, other pediatric hospitals and domiciliary care personnel, with the aim to ameliorate the quality of care during the EOL period. In our cohort, palliative sedation was widely used while no patients died with uncontrolled pain. A precise process of data collection and a better sharing of knowledge are necessary in order to improve the management of such patients.

PMID: 25131215

29. Rev Bras Hematol Hemoter. 2014 November - December;36(6):403-408.

[Palliative care in pediatric hematological oncology patients: experience of a tertiary hospital.](#)

[Valadares MT¹, Mota JA¹, de Oliveira BM².](#)

OBJECTIVE:

To evaluate the approach to palliative care for hematological oncology patients in the pediatric ward of a tertiary hospital.

METHODS:

This was a retrospective, descriptive study of 29 hematological oncology patients who died between 2009 and 2011. Data regarding the approach and prevalence of pain, prevalence of other symptoms, multidisciplinary team participation, communication between staff and family and limited invasive therapy were collected from the medical records.

RESULTS:

Twenty-seven (93.1%) patients displayed disease progression unresponsive to curative treatment. The median age at death was ten years old. Pain was the most prevalent symptom with all patients who reported pain receiving analgesic medications. The majority took weak (55.2%) and/or strong (65.5%) opioids. The patients were followed by pediatricians and a pediatric hematologist/oncologist. Participation of other professionals was also documented: 86.2% were followed by social services and 69% by psychologists, among others. There were explicit descriptions of limitation of invasive therapy in the medical records of 26 patients who died with disease progression. All these decisions were shared with the families.

CONCLUSION:

Although the hospital where this study was conducted does not have a specialized team in pediatric palliative care, it meets all the requirements for developing a specific program. The importance of approaching pain and other prevalent symptoms in children with cancer involving a comprehensive multidisciplinary team is evident. Discussions were had with most of the families on limiting invasive therapy, but no record of a well-defined and coordinated treatment plan for palliative care was found.

PMID: 25453649

30. Rev Bras Hematol Hemoter. 2014 November - December;36(6):388-389.

[Scientific comment on the theme of palliative care in pediatric hematological oncology patients.](#)

[Jankovic M.](#)

PMID: 25453645

31. J Palliat Med. 2014 Oct 29. [Epub ahead of print]

[Assessing Need for Palliative Care Services for Children in Mexico.](#)

[Cardenas-Turanzas M¹, Tovalin-Ahumada H, Romo CG, Okhuysen-Cawley R.](#)

Abstract

Pediatric palliative care increasingly became integrated into health care institutions worldwide over the last decade. However, in Mexico and other developing countries with large populations of children, little is known regarding the need for palliative care services. We aimed to assess the need for palliative and end-of-life care for children dying in public hospitals affiliated with Secretaria de Salud in Mexico. Measurement: We conducted a retrospective review of deaths of children (1-17 years old) occurring during 2011 and determined deaths associated with underlying complex chronic conditions by reviewing the four causes of death listed in the death certificate. We collected sociodemographic and clinical data and utilized univariate and multivariate analyses to determine factors associated with complex chronic conditions. Results: A total of 2715 pediatric deaths were studied. We found 41% were associated with a complex chronic condition. The most frequent types of conditions were malignancies (47%), neuromuscular (18%), cardiovascular (12%), and renal (10%). Children with renal and malignant conditions died at an older age than children with other types of complex chronic conditions. Multivariate analysis indicated the independent predictors of death with complex chronic condition were no indigenous ethnicity, lack of admission to the intensive care unit during the final hospital stay, and having affiliation with an institution for health care. Conclusions: A large proportion of pediatric deaths are associated with complex chronic conditions indicating the provision of adequate funding for professional education and palliative care initiatives for children in Mexico, should be a topic of the national health care agenda.

PMID: 25353338

32. J Perinatol. 2014 Oct 23. doi: 10.1038/jp.2014.189. [Epub ahead of print]

[End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative.](#)

[Samsel C¹, Lechner BE².](#)

Abstract

Objective: We hypothesized that the implementation of a neonatal palliative care initiative will result in improved markers of end-of-life care. Study design: A retrospective and prospective chart review of neonatal intensive care unit deaths was performed for 24 months before, 16 months during and 24 months after the implementation of palliative care provider education and practice guidelines (n=106). Ancillary care, redirection of care, palliative medication usage and outcome meetings in the last 48 h of life and basic demographic data were compared between epochs. Parametric and nonparametric analysis

was performed. Result: There was an increase in redirection of care and palliative medication usage and a decrease in variability of use of end-of-life interventions ($P=0.012$, 0.022 and <0.001). Conclusion: The implementation of a neonatal palliative care initiative was associated with increases in palliative interventions for neonates in their final 48 h of life, suggesting that such an initiative may enhance end-of-life care.

PMID: 25341197

33. J Perinatol. 2014 Oct 23. [Epub ahead of print]

[Impact of a palliative care program on end-of-life care in a neonatal intensive care unit.](#)

[Younge N, Smith PB, Goldberg RN, Brandon DH, Simmons C, Cotten CM, Bidegain M.](#)

Abstract

Objective: Evaluate changes in end-of-life care following initiation of a palliative care program in a neonatal intensive care unit. Study design: Retrospective study comparing infant deaths before and after implementation of a Palliative Care Program comprised of medication guidelines, an individualized order set, a nursing care plan and staff education. Result: Eighty-two infants died before (Era 1) and 68 infants died after implementation of the program (Era 2). Morphine use was similar (88% vs 81%; $P=0.17$), whereas benzodiazepines use increased in Era 2 (26% vs 43%; $P=0.03$). Withdrawal of life support (73% vs 63%; $P=0.17$) and do-not-resuscitate orders (46% vs 53%; $P=0.42$) were similar. Do-not-resuscitate orders and family meetings were more frequent among Era 2 infants with activated palliative care orders ($n=21$) compared with infants without activated orders ($n=47$). Conclusion: End-of-life family meetings and benzodiazepine use increased following implementation of our program, likely reflecting adherence to guidelines and improved communication.

PMID: 25341195

34. Pediatr Nephrol. 2014 Oct 21. [Epub ahead of print]

[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. PMID: 25330877

35. BMC Pediatr. 2014 Oct 13;14:262.

[Chronic pain treatment in children and adolescents: less is good, more is sometimes better.](#)

[Hechler T¹, Wager J, Zernikow B.](#)

BACKGROUND:

In children with chronic pain, interdisciplinary outpatient and intensive inpatient treatment has been shown to improve pain intensity and disability. However, there are few systematic comparisons of outcomes of the two treatments. The present naturalistic study aimed to compare the clinical presentation and achieved changes at return in three outcome domains (pain intensity, disability, school absence) between a) outpatients vs. inpatients and b) patients who declined intensive inpatient treatment and completed outpatient treatment instead (decliners) vs. those who completed inpatient treatment (completers).

METHODS:

The study compared treatment outcomes between $n = 992$ outpatients vs. $n = 320$ inpatients (Analysis A) who were treated at a tertiary treatment centre and returned for a return visit within a one-year interval. In Analysis B, treatment outcomes were compared between $n = 67$ decliners vs. $n = 309$ completers of inpatient treatment. The three outcome domains were compared by calculating standardized change scores and clinically significant changes.

RESULTS:

In analysis A, outpatients and inpatients reported comparably low levels of pain intensity (NRS 0-10; mean = 4, SD = 2.7) and disability (Paediatric Pain Disability Index (PPDI): 12-60; mean = 24; SD = 10) at the return visit. Compared to outpatients, more inpatients achieved clinically significant changes in pain intensity (52% vs. 45%) and disability (46% vs. 31%). There were also significantly greater changes in disability in the inpatient group (change score outpatients = 1.0; change score inpatients = 1.4; $F(1,1138) = 12.6$, $p = .011$). School absence was substantially reduced, with approximately 80% in each group attending school regularly. Analysis B showed that even though inpatient decliners achieved improvements in the outcome domains, they reported greater disability at the return visit (PPDI mean decliners = 27, SD = 9.9; PPDI mean completers = 24, SD = 10) because they had achieved fewer changes in disability (change score decliners = 0.9; change score completers = 1.4; $F(1,334) = 5.7$, $p = .017$). In addition, less decliners than completers achieved clinically significant changes in disability (25% vs. 47%).

CONCLUSIONS:

Inpatient and outpatient treatments are able to elicit substantial changes in pain intensity, disability and school absence. The results highlight the necessity of intensive inpatient pain treatment for highly affected children, as children who declined

inpatient treatment and were treated as outpatients did less well.

PMID: 25308551

36. J Palliat Med. 2014 Oct 10. [Epub ahead of print]

[Evaluating Palliative Care Needs in Middle Eastern Countries.](#)

[Silbermann M¹](#), [Fink RM](#), [Min SJ](#), [Mancuso MP](#), [Brant J](#), [Hajjar R](#), [Al-Alfi N](#), [Baider L](#), [Turker I](#), [ElShamy K](#), [Ghrayeb I](#), [Al-Jadiry M](#), [Khader K](#), [Kav S](#), [Charalambous H](#), [Uslu R](#), [Kebudi R](#), [Barsela G](#), [Kuruku N](#), [Mutafoglu K](#), [Ozalp-Senel C](#), [Oberman A](#), [Kislev L](#), [Khleif M](#), [Keoppi N](#), [Nestoros S](#), [Abdalla RF](#), [Rassouli M](#), [Morag A](#), [Sabar R](#), [Nimri O](#), [Al-Oadire M](#), [Al-Khalaileh M](#), [Tayyem M](#), [Dourmit M](#), [Punjwani R](#), [Rasheed O](#), [Fallatah F](#), [Can G](#), [Ahmed J](#), [Strode D](#).

Abstract

Abstract Background: Cancer incidence in Middle Eastern countries, most categorized as low- and middle-income, is predicted to double in the next 10 years, greater than in any other part of the world. While progress has been made in cancer diagnosis/treatment, much remains to be done to improve palliative care for the majority of patients with cancer who present with advanced disease. Objective: To determine knowledge, beliefs, barriers, and resources regarding palliative care services in Middle Eastern countries and use findings to inform future educational and training activities. Design: Descriptive survey. Setting/Subjects: Fifteen Middle Eastern countries; convenience sample of 776 nurses (44.3%), physicians (38.3%) and psychosocial, academic, and other health care professionals (17.4%) employed in varied settings. Measurements: Palliative care needs assessment. Results: Improved pain management services are key facilitators. Top barriers include lack of designated palliative care beds/services, community awareness, staff training, access to hospice services, and personnel/time. The nonexistence of functioning home-based and hospice services leaves families/providers unable to honor patient wishes. Respondents were least satisfied with discussions around advance directives and wish to learn more about palliative care focusing on communication techniques. Populations requiring special consideration comprise: patients with ethnic diversity, language barriers, and low literacy; pediatric and young adults; and the elderly. Conclusions: The majority of Middle Eastern patients with cancer are treated in outlying regions; the community is pivotal and must be incorporated into future plans for developing palliative care services. Promoting palliative care education and certification for physicians and nurses is crucial; home-based and hospice services must be sustained.

PMID: 25302525

37. J Palliat Med. 2014 Oct 9. [Epub ahead of print]

[Pediatric Palliative Care Consultation Services in California Hospitals.](#)

[Reid T¹](#), [O'Riordan DL](#), [Mazzini A](#), [Bruno KA](#), [Pantilat SZ](#).

Abstract

Background: The American Academy of Pediatrics recommends that palliative care be available to seriously ill hospitalized children, yet little is known about how these services are structured. Objective: The study's aim is to report the prevalence of pediatric palliative care services (PCS) and compare the structure of pediatric PCS to adult PCS within California hospitals. Methods: We surveyed 377 hospitals to assess the prevalence, structure, and characteristics of pediatric and adult PCS. Hospitals were categorized as children's hospitals with a pediatric-only PCS, mixed hospitals with pediatric and adult PCS, and hospitals with adult-only PCS. Results: All 8 children's hospitals in the state reported having a pediatric PCS, and 36 pediatric PCSs were in mixed hospitals. Mixed hospitals saw fewer ($p=0.0001$) children per year (mean=5.6, standard deviation [SD]=3.6) than pediatric-only PCSs (mean=168, SD=73). Pediatric-only PCSs treated more patients for noncancer-related illness (82.5%) than pediatric PCSs in mixed hospitals (34.5%, $p=0.03$) or adult-only PCSs (52.4%, $p=0.001$). All PCSs were universally available (100%) during weekday business hours and half were available during weekend business hours. Pediatric-only PCSs had a mean total full-time equivalent (FTE) of 1.9, which was not significantly different ($p=0.3$) from the total FTE for pediatric PCSs in mixed hospitals (mean=1.1, SD=1.4) or for adult-only PCSs (mean=2.7, SD=2.0). However, in mixed hospitals the adult PCS had a significantly higher ($p=0.005$) total FTE (mean=2.4, SD=1.3) than the pediatric PCS (mean=1.1, SD=1.4). Conclusion: All children's hospital and a few mixed hospitals offer pediatric PCS. Better understanding of the palliative care needs of seriously ill children in mixed hospitals and assessment of the quality of care provided will help ensure that children seen in these hospitals receive necessary care.

PMID: 25299845

38. Adv Neonatal Care. 2014 Oct;14(5):322-8.

[The relationship between providing neonatal palliative care and nurses' moral distress: an integrative review.](#)

[Cavinder C](#).

Abstract

Moral distress has been identified in multiple clinical settings especially in critical care areas. The neonatal intensive care unit (NICU) has frequent situations in which moral distress may occur including providing palliative care. The purpose of this integrative review was to determine the relationship between the provision of palliative care in a NICU and nurses' moral distress. The evidence reviewed supports that moral distress does occur with the provision of neonatal palliative care. An interdisciplinary care team, an established protocol, and educational interventions may decrease moral distress in nurses providing end-of-life care to infants in the NICU.

PMID: 25022749

39. Arch Dis Child. 2014 Oct 1. [Epub ahead of print]

[Advance Care Planning: practicalities, legalities, complexities and controversies.](#)

[Horridge KA](#).

Abstract

Increasing numbers, complexities and technology dependencies of children and young people with life-limiting conditions require paediatricians to be well prepared to meet their changing needs. Paediatric Advance Care Planning provides a

framework for paediatricians, families and their multidisciplinary teams to consider, reflect and record the outcome of their conversations about what might happen in the future in order to optimise quality of clinical care and inform decision-making. For some children and young people this will include discussions about the possibility of death in childhood. This may be unexpected and sudden, in the context of an otherwise active management plan or may be expected and necessitate discussions about the process of dying and attention to symptoms. Decision-making about appropriate levels of intervention must take place within a legal and ethical framework, recognising that the UK Equality Act (2010) protects the rights of disabled children and young people and infants and children of all ages to the same high quality healthcare as anyone else. Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>.

40. Clin Pediatr (Phila). 2014 Oct;53(11):1030-1.

[Palliative care is critical to the changing face of child mortality and morbidity in the United States.](#)

Bogetz JF¹, Schroeder AR², Bergman DA³, Cohen HJ³, Sourkes B³.

PMID: 24817074

41. J Palliat Care. 2014 Autumn;30(3):179-87.

[An integrative approach to music therapy in pediatric palliative care.](#)

Clark BA, Siden H, Straatman L.

PMID: 25265742 [PubMed - indexed for MEDLINE]

42. J Spec Pediatr Nurs. 2014 Oct;19(4):308-15.

[Who are the children using hospice care?](#)

Lindley LC¹, Shaw SL.

PURPOSE: The purpose was to examine the characteristics of children who use hospice care.

DESIGN AND METHODS:

Using the Andersen Model of Health Services Use, California Medicaid administrative databases were analyzed to describe the characteristics of 76 children in hospice.

RESULTS:

The predisposing, enabling, and need characteristics of children were identified. Children who used hospice were a diverse group with community resources that enabled them to access care while presenting with serious health needs. Children enrolled in hospice were more likely older (15-20 years of age), resided nearer a pediatric hospice, and had a serious health condition such as neuromuscular disease with multiple comorbidities.

PRACTICE IMPLICATIONS:

With this knowledge, pediatric nurses can improve their clinical practice by targeting conversations with families and children most in need of hospice care.

PMID: 25131751

43. J Telemed Telecare. 2014 Oct;20(7):360-4.

[Principles of a paediatric palliative care consultation can be achieved with home telemedicine.](#)

Bradford NK¹, Armfield NR², Young J³, Herbert A⁴, Mott C⁵, Smith AC².

Abstract

We compared the records of paediatric palliative consultations undertaken face-to-face, with telemedicine consultations undertaken in patients' homes. A convenience sample of consecutive paediatric palliative care patients was identified from the hospital's palliative care database. A total of 100 consultations was reviewed (50 telemedicine consultations during home visits and 50 face-to-face consultations) according to 14 established principles and components of a paediatric palliative care consultation. In the telemedicine group there was a higher proportion of patients in a stable condition (58% vs 7%), and a lower proportion of patients in terminal phase (2% vs 17%). Discussion about pain and anorexia were significantly more common in the telemedicine group. Discussion about follow up was significantly more common in the telemedicine group (86% vs 56%), whilst resuscitation planning was more common in deteriorating patients receiving inpatient care. All other components and principles of a palliative care consultation were documented equally regardless of method of consultation. The findings confirm that palliative consultations via telemedicine are just as effective as face-to-face consultations in terms of the documented components of the consultation.

PMID: 25399995

44. Palliat Support Care. 2014 Oct;12(5):387-92. doi: 10.1017/S1478951513000229. Epub 2013 Aug 6.

[Understanding communication among health care professionals regarding death and dying in pediatrics.](#)

Harrison J¹, Evan E², Hughes A², Yazdani S³, Federman M¹, Harrison R¹.

OBJECTIVE:

Effective communication regarding death and dying in pediatrics is a vital component of any quality palliative care service. The goal of the current study is to understand communication among health care professionals regarding death and dying in children. The three hypotheses tested were: (1) hospital staff (physicians of all disciplines, nurses, and psychosocial clinicians) that utilize consultation services are more comfortable communicating about death and dying than those who do not use such services, (2) different disciplines of health care providers demonstrate varying levels of comfort communicating about a range of areas pertaining to death and dying, and (3) health care staff that have had some type of formal training in death and dying are more comfortable communicating about these issues.

METHODS:

A primary analysis of a survey conducted in a tertiary care teaching children's hospital.

RESULTS:

Health care professionals who felt comfortable discussing options for end of life care with colleagues also felt more comfortable: initiating a discussion regarding a child's impending death with his/her family (r = 0.42), discussing options for terminal care with a family (r = 0.58), discussing death with families from a variety of ethnic/cultural backgrounds (r = 0.51), guiding parents in developmentally age-appropriate discussions of death with their children (r = 0.43), identifying and seeking advice from a professional role model regarding management concerns (r = 0.40), or interacting with a family following the death of a child (r = 0.51). Among all three disciplines, physicians were more likely to initiate discussions with regards to a child's impending death (F = 13.07; p = 0.007). Health care professionals that received formal grief and bereavement training were more comfortable discussing death. Significance of the results: The results demonstrated that consultation practices are associated with a higher level of comfort in discussing death and dying in pediatrics.

45. *Pediatr Blood Cancer*. 2014 Oct;61(10):1840-5.

[Development of a quality of life instrument for children with advanced cancer: the pediatric advanced care quality of life scale \(PAC-QoL\).](#)

[Cataudella D¹](#), [Morley TE](#), [Nesin A](#), [Fernandez CV](#), [Johnston DL](#), [Sung L](#), [Zelcer S](#).

BACKGROUND:

There is currently no published, validated measures available that comprehensively capture quality of life (QoL) symptoms for children with poor-prognosis malignancies. The pediatric advanced care-quality of life scale (PAC-QoL) has been developed to address this gap. The current paper describes the first two phases in the development of this measure.

PROCEDURES:

The first two phases included: (1) construct and item generation, and (2) preliminary content validation. Domains of QoL relevant to this population were identified from the literature and items generated to capture each; items were then adapted to create versions sensitive to age/developmental differences. Two types of experts reviewed the draft PAC-QoL and rated items for relevance, understandability, and sensitivity of wording: bereaved parents (n = 8) and health care professionals (HCP; n = 7). Content validity was calculated using the index of content validity (CVI [Lynn. *Nurs Res* 1986;35:382-385]).

RESULTS:

One hundred and forty-one candidate items congruent with the domains identified as relevant to children with advanced malignancies were generated, and four report versions with a 5-choice response scale created. Parent mean scores for importance, understandability, and sensitivity of wording ranged from 4.29 (SD = 0.52) to 4.66 (SD = 0.50). The CVI ranged from 95% to 100%. These steps resulted in reductions of the PAC-QoL to 57-65 items, as well as a modification of the response scale to a 4-choice option with new anchors.

CONCLUSIONS:

The next phase of this study will be to conduct cognitive probing with the intended population to further modify and reduce candidate items prior to psychometric evaluation.

PMID: 24947134

46. *Pediatr Blood Cancer*. 2014 Oct;61(10):1835-9.

[Development of the Pediatric Advanced Care Quality of Life Scale \(PAC-QoL\): evaluating comprehension of items and response options.](#)

[Morley TE¹](#), [Cataudella D](#), [Fernandez CV](#), [Sung L](#), [Johnston DL](#), [Nesin A](#), [Zelcer S](#).

BACKGROUND:

Validated tools that measure quality of life (QoL) for children with poor prognosis malignancies are not available. We are developing a novel instrument, The Pediatric Advanced Care-Quality of Life Scale (PAC-QoL), in order to address this gap. Instrument development requires a phase of item reduction and assessment of item comprehension in the target population. This manuscript provides a report on this phase in the development of the PAC-QoL.

PROCEDURE:

Children with poor prognosis cancer and/or their parents were invited to participate in cognitive probing interviews. Participants' understanding of each item was rated from 0 (did not understand) to 4 (completely understood). To evaluate the response scale, an overall percentage of respondents' ability to accurately distinguish between the four response options was calculated.

RESULTS:

Four age- and reporter-specific versions of the PAC-QoL were tested with 74 participants. Mean (±SD) comprehension scores across versions ranged from 3.40 ± .030 (child self-report) to 3.69 ± 0.23 (parent of toddler report). The number of items deleted or modified to improve understandability ranged from 46% of all items on the parent-of-child report to 56% for the child and adolescent self-reports. Respondent's abilities to accurately distinguish between response-scale options ranged from 84% (child-report) to 98% (parent-toddler report).

CONCLUSIONS:

We demonstrate a high degree item understandability and response-scale separation in the current version of the PAC-QoL. The scale is ready for psychometric evaluation in its target population.

PMID: 24947009

47. *Pediatr Crit Care Med*. 2014 Oct;15(8):784-6.

[Palliative care in the ICU: together we can make a greater difference.](#)

[Custer JR](#).

Comment on

[Integrating palliative care into the PICU: a report from the Improving Palliative Care in the ICU Advisory Board.](#) [*Pediatr Crit Care Med*. 2014]

[Integrating palliative care into the PICU: a report from the Improving Palliative Care in the ICU Advisory Board.](#) [Boss R](#), [Nelson J](#), [Weissman D](#), [Campbell M](#), [Curtis R](#), [Frontera J](#), [Gabriel M](#), [Lustbader D](#), [Mosenthal A](#), [Mulkerin C](#), et al. *Pediatr Crit Care*



Med. 2014 Oct; 15(8):762-7.

PMID: 25280153

48. *Pediatr Crit Care Med.* 2014 Oct;15(8):777-8.

[Neonatal single-ventricle palliative surgery: lost in \(dead\) space?](#)

[Bhalla A¹](#), [Markovitz BP](#).

Comment on

Pulmonary deadspace and postoperative outcomes in neonates undergoing stage 1 palliation operation for single ventricle heart disease. [*Pediatr Crit Care Med.* 2014] Pulmonary deadspace and postoperative outcomes in neonates undergoing stage 1 palliation operation for single ventricle heart disease. [Shakti D](#), [McElhinney DB](#), [Gauvreau K](#), [Yarlagadda VV](#), [Laussen PC](#), [Betit P](#), [Myrer ML](#), [Thiagarajan RR](#). *Pediatr Crit Care Med.* 2014 Oct; 15(8):728-34.

PMID: 25280149

49. *Pediatr Crit Care Med.* 2014 Oct;15(8):762-7.

[Integrating palliative care into the PICU: a report from the Improving Palliative Care in the ICU Advisory Board.](#)

[Boss R¹](#), [Nelson J](#), [Weissman D](#), [Campbell M](#), [Curtis R](#), [Frontera J](#), [Gabriel M](#), [Lustbader D](#), [Mosenthal A](#), [Mulkerin C](#), [Puntillo K](#), [Ray D](#), [Bassett R](#), [Brasel K](#), [Hays R](#).

Comment in

Palliative care in the ICU: together we can make a greater difference. [*Pediatr Crit Care Med.* 2014]

Palliative care in the ICU: together we can make a greater difference. [Custer JR](#). *Pediatr Crit Care Med.* 2014 Oct; 15(8):784-6.

OBJECTIVE:

This review highlights benefits that patients, families and clinicians can expect to realize when palliative care is intentionally incorporated into the PICU.

DATA SOURCES:

We searched the MEDLINE database from inception to January 2014 for English-language articles using the terms "palliative care" or "end of life care" or "supportive care" and "pediatric intensive care." We also hand-searched reference lists and author files and relevant tools on the Center to Advance Palliative Care website.

STUDY SELECTION:

Two authors (physicians with experience in pediatric intensive care and palliative care) made final selections.

DATA EXTRACTION:

We critically reviewed the existing data and tools to identify strategies for incorporating palliative care into the PICU.

DATA SYNTHESIS:

The Improving Palliative Care in the ICU Advisory Board used data and experience to address key questions relating to: pain and symptom management, enhancing quality of life, communication and decision-making, length of stay, sites of care, and grief and bereavement.

CONCLUSIONS:

Palliative care should begin at the time of a potentially life-limiting diagnosis and continue throughout the disease trajectory, regardless of the expected outcome. Although the PICU is often used for short term postoperative stabilization, PICU clinicians also care for many chronically ill children with complex underlying conditions and others receiving intensive care for prolonged periods. Integrating palliative care delivery into the PICU is rapidly becoming the standard for high quality care of critically ill children. Interdisciplinary ICU staff can take advantage of the growing resources for continuing education in pediatric palliative care principles and interventions.

PMID: 25080152

50. *Pediatr Neurol.* 2014 Oct;51(4):527-31.

[Adjunctive levetiracetam treatment in pediatric Lennox-Gastaut syndrome.](#)

[Kim HJ¹](#), [Kim SH²](#), [Kang HC³](#), [Lee JS³](#), [Chung HJ⁴](#), [Kim HD⁵](#).

BACKGROUND:

Our aim was to investigate the efficacy and tolerability of levetiracetam as an add-on treatment in pediatric patients with Lennox-Gastaut syndrome.

METHODS:

The study was an open-label, multicenter, observational clinical trial of levetiracetam as an add-on treatment in Lennox-Gastaut syndrome. Fifty-five patients aged 1.1-18.6 years (mean, 10.0 years) were enrolled. The study included a 4-8-week titration period and an 8-week maintenance period. The maintenance dose of levetiracetam was 20-80 mg/kg/day, according to its effectiveness and tolerability. The primary end point was reduction in seizure frequency, and related variables were also evaluated.

RESULTS:

Among 55 patients, 51 patients (92.7%) completed the study. Thirty-two patients (58.2%) experienced a more than 50% reduction in seizure frequency, and 15 patients (27.3%) became seizure free. A reduction in seizure frequency of more than 50% was observed in 21 of 36 patients (58.3%) with convulsive seizures, 7 of 12 patients (58.3%) with drop attacks, 2 of 4 patients (50.0%) with myoclonic seizures, and 2 of 3 patients (66.7%) with epileptic spasms. Overall, 34.5% of patients reported adverse events. None of the adverse events were life threatening, and the most common adverse event was hyperactivity (12.7%).

CONCLUSIONS:

This study suggests that levetiracetam is a safe and effective treatment in pediatric patients with Lennox-Gastaut syndrome.

PMID: 25266616



51. Pediatrics. 2014 Oct;134 Suppl 2:S87-96.

[Deception and the death of Ilyusha: truth and the best interest of a dying child in The Brothers Karamazov.](#)

[Martin C.](#)

Abstract

For centuries, many physicians and parents assumed that it was ethically justifiable to lie to a dying child. The reasoning was clear. Because the lie would likely eliminate or prevent a concrete harm (the child's fear), and the lie is about a harm that is unavoidable anyway, a lie appeared to be the morally desirable thing to do. Today, the ethical consensus has shifted. Many doctors and other health professionals now argue that we have an obligation to tell children the cold, hard truth. In this article, I argue that "the cold, hard truth" (assuming we can know it with certainty) might not always be in the best interest of the patient. To illustrate the point, I analyze an episode in Dostoevsky's novel, The Brothers Karamazov, in which a child is dying, his father lies to him about it, and 2 doctors take very different approaches to the truth. Each of these individuals has a particular interest when it comes to the question of "the truth" about the death of Ilyusha. I use this story to ask whether it is ethically permissible to lie to a dying child and, if so, who has the moral authority to tell that lie.

PMID: 25274880

52. Pediatrics. 2014 Oct;134(4):e1163-8.

[Infants' best interests in end-of-life care for newborns.](#)

[Willems DL¹, Verhagen AA², van Wijlick E³, Committee End-of-Life Decisions in Severely Ill Newborns of Royal Dutch Medical Association.](#)

BACKGROUND AND OBJECTIVES:

Pediatric bioethics presumes that decisions should be taken in the child's best interest. If it's ambiguous whether a decision is in the child's interest, we defer to parents. Should parents be permitted to consider their own interests in making decisions for their child? In the Netherlands, where neonatal euthanasia is legal, such questions sometimes arise in deciding whether to hasten the death of a critically ill, suffering child. We describe the recommendations of a national Dutch committee. Our objectives were to analyze the role of competing child and family interests and to provide guidance on end-of-life decisions for doctors caring for severely ill newborns.

METHODS:

We undertook literature review, 7 consensus meetings in a multidisciplinary expert commission, and invited comments on draft report by specialists' associations.

RESULTS:

Initial treatment is mandatory for most ill newborns, to clarify the prognosis. Continuation of treatment is conditional on further diagnostic and prognostic data. Muscle relaxants can sometimes be continued after withdrawal of artificial respiration without aiming to shorten the child's life. When gasping causes suffering, or protracted dying is unbearable for the parents, muscle relaxants may be used to end a newborn's life. Whenever muscle relaxants are used, cases should be reported to the national review committee.

CONCLUSIONS:

New national recommendations in the Netherlands for end-of-life decisions in newborns suggest that treatment should generally be seen as conditional. If treatment fails, it should be abandoned. In those cases, palliative care should be directed at both infant and parental suffering. Sometimes, this may permit interventions that hasten death.

PMID: 25246628

53. Semin Fetal Neonatal Med. 2014 Oct;19(5):296-9.

[Neonatal euthanasia: lessons from the Groningen Protocol.](#)

[Eduard Verhagen AA.](#)

Abstract

Decisions about neonatal end-of-life care have been studied intensely over the last 20 years in The Netherlands. Nationwide surveys were done to quantify these decisions, provide details and monitor the effect of guidelines, new regulations and other interventions. One of those interventions was the Groningen Protocol for newborn euthanasia in severely ill newborns, published in 2005. Before publication, an estimated 20 cases of euthanasia per year were performed. After publication, only two cases in five years were reported. Studies suggested that this might be partly caused by the lack of consensus about the dividing line between euthanasia and palliative care. New recommendations about paralytic medication use in dying newborns were issued to increase transparency and to improve reporting of euthanasia. New surveys will be needed to measure the effects of these interventions. This cycle of interventions and measurements seems useful for continuous improvement of end-of-life care in newborns.

PMID: 25150794

54. Support Care Cancer. 2014 Oct;22(10):2621-8.

[The EAPC framework on palliative sedation and clinical practice--a questionnaire-based survey in Germany.](#)

[Klosa PR¹, Klein C, Heckel M, Bronnhuber AC, Ostgathe C, Stiel S.](#)

BACKGROUND:

Palliative sedation (PS) can be offered to patients with intolerable symptom burden refractory to comprehensive palliative care (PC) treatment. Little is known about the daily practice of using PS in German specialized PC institutions in the context of existing national and international recommendations.

PURPOSE:

This study's primary objective is to explore how PS is used in German specialized PC institutions with reference to the EAPC framework.

METHODS:

The heads of all palliative care units, hospices, specialized palliative home care teams, and specialized pediatric palliative



home care teams listed in the official address registers were invited to take part in a questionnaire survey about the clinical practice of PS in their institution.

RESULTS:

Considerable differences of the frequency of PS exist between institutions. The estimated frequency of PS ranges from 0 to 80 % of all patients treated per year (mean 6.7 %). Some PC specialists report to discuss PS as treatment option for every patient they encounter. Specific evaluation and documentation tools are rare. Of the study participants, 36.2 % are not familiar with international and national recommendations.

CONCLUSION:

Many differences exist in frequency and clinical handling of PS in Germany. Implementation of international and national recommendations into clinical practice remains inconsistent.

PMID: 24743852



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