

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

“Good information is the best medicine...”

Donald A.B. Lindberg



A new collaboration

This bimonthly newsletter contains a selection of the most recent articles published in the international scientific literature on the subject of palliative care and pain management in children.

Generated from the collaboration between the **Foundation 3Bi**, Biomedical Library Biella (www.3bi.info) and the **Maruzza Lefebvre d'Ovidio Foundation** (www.maruzza.org), the aim of this initiative is to improve the knowledge, skills and the quality of care offered to patients and their families by providing a constant update for professionals working in this complex field of medicine.

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April 2014

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*“Medicine and literature
have always been
good friends”*

Carlo Dossi

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1. *J Opioid Manag.* 2014 Jan-Feb;10(1):47-56. doi: 10.5055/jom.2014.0191.

[Monitoring oxycodone use in patients with chronic pain: analysis of oxycodone and metabolite excretion in saliva and urine.](#)

Moy KV¹, Ma JD², Morello CM³, Atayee RS², Best BM⁴.

ABSTRACT

OBJECTIVE: Saliva is purported to have a close correspondence to plasma concentrations due to a passive diffusion process from plasma to saliva. However, limited data are available characterizing oxycodone and its metabolites in saliva. The purpose of this analysis was to evaluate the use of saliva monitoring in patients prescribed oxycodone and to compare the disposition of oxycodone in saliva and urine.

DESIGN: This retrospective analysis examined deidentified urine and saliva specimens collected from patients with chronic pain. These specimens were received at Millennium Laboratories between March and June 2012 and analyzed using LCMS/MS to quantitate oxycodone, noroxycodone, and oxymorphone concentrations.

RESULTS: The geometric mean metabolic ratio (MR) of noroxycodone to oxycodone in saliva was 0.11, whereas the geometric mean MR in urine was 1.7. The geometric mean oxycodone concentration in saliva was 860 ng/mL (range, 1.5-8,600,000 ng/mL; 95% CI, 770-950 ng/mL), whereas the geometric mean noroxycodone concentration was 98 ng/mL (range, 2.3-8,800 ng/mL; 95% CI, 90-107 ng/mL). Fifty-four of the saliva specimens (6 percent) had oxycodone concentrations between 10,000 and 9,000,000 ng/mL.

CONCLUSIONS: Oxycodone is predominant over noroxycodone in saliva (similar to plasma), while the reverse relationship exists in urine. Much greater oxycodone concentrations were found in saliva than are expected in plasma (up to a 1,000-fold difference). Saliva concentrations are lower than urine concentrations but still may not reflect plasma disposition. Possible explanations include medication residue in the mouth (recent medication use or misuse) or active secretion into saliva. Saliva analysis may be used for qualitative drug monitoring of oxycodone, with detection rates similar to urine; however, further characterization is needed for appropriate interpretation.

PMID:24604569

2. *Adv Neonatal Care.* 2014 Feb;14(1):7.

[Pediatric palliative care.](#)

[No authors listed]

Letter to Editor.

PMID:24616938

3. *BMC Palliat Care.* 2014 Mar 13;13(1):9. doi: 10.1186/1472-684X-13-9.

[Regoaling: a conceptual model of how parents of children with serious illness change medical care goals.](#)

Hill DL, Miller V, Walter JK, Carroll KW, Morrison WE, Munson DA, Kang TI, Hinds PS, Feudtner C¹.

ABSTRACT

BACKGROUND: Parents of seriously ill children participate in making difficult medical decisions for their child. In some cases, parents face situations where their initial goals, such as curing the condition, may have become exceedingly unlikely. While some parents continue to pursue these goals, others relinquish their initial goals and generate new goals such as maintaining the child's quality of life. We call this process of transitioning from one set of goals to another regoaling.

DISCUSSION: Regoaling involves factors that either promote or inhibit the regoaling process, including disengagement from goals, reengagement in new goals, positive and negative affect, and hopeful thinking. We examine these factors in the context of parental decision making for a seriously ill child, presenting a dynamic conceptual model of regoaling. This model highlights four research questions that will be empirically tested in an ongoing longitudinal study of medical decision making among parents of children with serious illness. Additionally, we consider potential clinical implications of regoaling for the practice of pediatric palliative care.

SUMMARY: The psychosocial model of regoaling by parents of children with a serious illness predicts that parents who experience both positive and negative affect and hopeful patterns of thought will be more likely to relinquish one set of goals and pursue a new set of goals. A greater understanding of how parents undergo this transition may enable clinicians to better support them through this difficult process.

PMID:24625345

4. *J Palliat Med.* 2014 Mar 14. [Epub ahead of print]

[End-of-life Care for Children Enrolled in a Community-Based Pediatric Palliative Care Program.](#)

Niswander LM¹, Cromwell P, Chirico J, Gupton A, Korones DN.

ABSTRACT BACKGROUND: Despite recent strides in pediatric palliative care (PPC), there are few published data on community-based care of dying children.

OBJECTIVE: Our aim was to describe end-of-life care during the last 6 months of life for children on a community-based PPC program. **METHODS:** We conducted a retrospective review of children <21 years old who died while enrolled in a community-based PPC program (CompassionNet) from December 2004 through May 2008. Data were extracted on the last 6 months of life from hospital records (University of Rochester) and records of CompassionNet and its home-nursing team.

RESULTS: Thirty-six children died while enrolled in the CompassionNet program; diagnoses included cancer 20 (56%), genetic/neurologic disorders 7 (19%), cardiac anomalies 6 (17%), and other 3 (8%). In the last 6 months of life, there were a median of 2 emergency room visits (range 0-12) and 2 unplanned hospitalizations (range 0-6). Home visits by CompassionNet (case manager, physician, nurse) ranged from 1 to 121 (median 24). A "goals of care" discussion was documented for 29 children (81%), occurring a median of 16 days before death (range 0-118). Sixteen children died at home (44%); 20 died in the hospital (56%). Of the 16 families with a documented preference for location of death, 14 children died in this location (88%). Thirty-two families (89%) had bereavement support through CompassionNet.

CONCLUSIONS: Children who die of complex chronic conditions spend the majority of their last 6 months of life at home. Community-based PPC can contribute substantially to their care and comfort.

PMID:24628107

5. *J Pain Res.* 2014 Mar 7;7:117-123. eCollection 2014.

[Management of breakthrough pain in children with cancer.](#)

Friedrichsdorf SJ¹, Postier A².

ABSTRACT

Breakthrough pain in children with cancer is an exacerbation of severe pain that occurs over a background of otherwise controlled pain. There are no randomized controlled trials in the management of breakthrough pain in children with cancer, and limited data and considerable experience indicate that breakthrough pain in this pediatric patient group is common, underassessed, and undertreated. An ideal therapeutic agent would be rapid in onset, have a relatively short duration, and would be easy to administer. A less effective pharmacologic strategy would be increasing a patient's dose of scheduled opioids, because this may increase the risk of oversedation. The most common and effective strategy seems to be multimodal analgesia that includes an immediate-release opioid (eg, morphine, fentanyl, hydromorphone, or diamorphine) administered intravenously by a patient-controlled analgesia pump, ensuring an onset of analgesic action within minutes. Intranasal fentanyl (or hydromorphone) may be an alternative, but no pediatric data have been published yet for commercially

available fentanyl transmucosal application systems (ie, sublingual tablets/spray, buccal lozenge/tablet/film, and nasal spray), and these products cannot yet be recommended for use with children with cancer and breakthrough pain. The aim of this paper was to emphasize the dearth of available information on treatment of breakthrough pain in pediatric cancer patients, to describe the treatment protocols we currently recommend based on clinical experience, and to suggest future research on this very important and under-researched topic.

KEYWORDS: adjuvant analgesia, breakthrough pain, cancer, integrative medicine, opioid, pediatric

PMID:24639603

6. *BMJ Support Palliat Care*. 2014 Mar 5. doi: 10.1136/bmjspcare-2012-000407. [Epub ahead of print]

The Spectrum of Children's Palliative Care Needs: a classification framework for children with life-limiting or life-threatening conditions.

Shaw KL¹, Brook L, Mpundu-Kaambwa C, Harris N, Lapwood S, Randall D.

ABSTRACT

OBJECTIVES: This paper examined the potential of a new classification framework, The Spectrum of Children's Palliative Care Needs, to facilitate identification of children with palliative care needs for the purposes of minimum data set collection and population needs assessment.

METHODS: Health and social care professionals (n=50) in a range of paediatric palliative care settings applied The Spectrum to (i) clinical vignettes and (ii) consecutive children on their caseloads. They also provided confidence ratings and written comments about their experiences. Inter-rater reliability, conceptual validity, acceptability, feasibility and sustainability were examined. A subset of professionals (n=9) also participated in semistructured telephone interviews to provide further insight.

RESULTS: Inter-rater reliability for the vignettes ($\kappa=0.255$) was fair. However, professionals were more confident applying The Spectrum to their caseloads, which included children (n=74) with a range of life-limiting/life-threatening conditions. The Spectrum made conceptual sense in relation to these children and was considered to offer a meaningful way to define the eligible population in service mapping. Benefits for clinical work (eg, facilitating patient review, workload management, clinical audit) and research were also identified. However, important threats to reliability were highlighted.

CONCLUSIONS: Preliminary assessment of The Spectrum confirms its potential to promote consistent data set collection in children's palliative care. The results have been used to produce a revised version and user guidelines to address issues raised by participants. However, further research is required to further validate the framework and establish its relevance to families' self-defined needs.

KEYWORDS: Paediatrics, Palliative Care, Prognosis

PMID:24644200

7. *BMJ Support Palliat Care*. 2014 Mar 5. doi: 10.1136/bmjspcare-2013-000558. [Epub ahead of print]

Parents and end-of-life decision-making for their child: roles and responsibilities.

Sullivan J¹, Gillam L, Monagle P.

ABSTRACT

BACKGROUND: Whether parents want to be and should be the decision-maker for their child in end-of-life matters are contested clinical and ethical questions. Previous research outcomes are equivocal.

METHOD: A qualitative interview method was used to examine the views and experiences of 25 bereaved parents in end-of-life decision-making for their child. Data were analysed thematically.

RESULTS: Three types of decision-making roles were identified: self-determined, guided (both involving active decision-making) and acquiescent (passive). The majority of parents had been active in the decision-making process for their child. They perceived themselves as the ultimate end-of-life decision-maker. This was perceived as part of their parental responsibility. A minority of parents did not consider that they had been an active, ultimate decision-maker. Generally, parents in the self-determined and guided groups reported no negative consequences from their decision-making involvement. Importantly, parents in the acquiescent group described their experience as difficult at the time and subsequently, although not all difficulties related directly to decision-making. Parents considered that in principle parents should be the end-of-life decision-maker for their child, but understood personal characteristics and preference could prevent some parents from taking this role.

CONCLUSIONS: This study unequivocally supports parents' desire to fulfil the end-of-life decision-making role. It provides a nuanced understanding of parents' roles and contributes evidence for the ethical position that parents should be the end-of-life decision-makers for their child, unless not in the child's best interests. On the whole, parents want this role and can manage its consequences. Indeed, not being the end-of-life decision-maker could be detrimental to parents' well-being.

KEYWORDS: Bereavement, Paediatrics

PMID:24644205

8. *BMJ Support Palliat Care*. 2014 Mar;4(1):110. doi: 10.1136/bmjspcare-2014-000653.17.

Recruiting parents to paediatric palliative care research: impact of low invitation rates on sample bias.

Crocker J¹, Beecham E, Kelly P, Dinsdale A, Hemsley J, Jones L, Bluebond-Langner M.

ABSTRACT

INTRODUCTION: Recruitment in paediatric palliative care is widely reported as challenging, with low rates of invitation by clinicians. The impact of this on sample bias is unknown.

AIM(S) AND METHOD(S): We studied recruitment to a qualitative interview study about parental decision making for children cared for by a specialist palliative care (PC) team. PC clinicians were encouraged to introduce the study to parents over 12 months. With ethical approval, we used information from the PC team database and feedback from clinicians to explore the impact of low invitation rates on sample bias.

RESULTS: The families of 519 living and 73 deceased patients were retrospectively identified as potentially eligible for recruitment. Clinicians invited parents of 28 (5.4%) living patients compared to 21 (28.8%) deceased patients (p=0.0001). On multivariable analyses, there was no association between patient demographics and invitation, but for living patients, total and out-of-hours contact time between family and PC team while eligible were independently associated with invitation (p<0.05). The most common reasons clinicians gave for not inviting parents of living and deceased patients were little or no contact with them and perceived burden.

CONCLUSION(S): Invitation rates were especially low among parents of living patients. There was no evidence that this led to major demographic bias. However, the strong influence of family contact may have introduced bias potentially relevant to the project (e.g. patient stability and parent-clinician relationships) that we were unable to measure. We recommend that researchers consider levels of patient contact when planning studies requiring recruitment via clinicians.

KEYWORDS: Supportive care

PMID:24644799

9. [BMJ Support Palliat Care](#). 2014 Mar;4(1):112-3. doi: 10.1136/bmjspcare-2014-000653.24.

[Palliative care in the young person's community: support for schools.](#)

Craig F¹, Kelly P, Boden C, Samuel J.

ABSTRACT

INTRODUCTION: Being part of a school community, where young people develop peer relationships and experience a sense of their value in society, is integral to childhood/young adulthood. Supporting terminally ill young people to maintain a role within this community can be crucial to their overall well-being. Essential to this is the ability of school staff to support their physical and psychological health while in school, yet little is known about the support they require to facilitate this.

AIM(S) AND METHOD(S): We utilised survey methods to investigate the confidence and support needs of school staff.

RESULTS: 78% of the target population completed the survey. In discussions with students, staff were confident ascertaining concerns about the effect of their condition on schooling and participation in activities, but less confident discussing concerns about illness, death and dying. In discussions with parents, staff were relatively confident exploring concerns the child might have about illness and dying and symptoms they may experience. However, they were less confident discussing the option of the child staying at school. Respondents identified meetings in school with Health Care Professionals, the availability of telephone advice during the school day and written medical plans amongst the most valuable forms of support.

CONCLUSION(S): School staff are confident when talking to parents/students about symptom progression and impact on education, but are uncertain what this means in terms of school participation. HCP's must work directly with schools to provide real-time advice and written plans, to enable our patients to be supported within their school community.

KEYWORDS: Supportive care

PMID:24644806

10. [BMJ Support Palliat Care](#). 2014 Mar;4(1):113-4. doi: 10.1136/bmjspcare-2014-000653.27.

[Home deaths are more common at weekends and holiday periods among children and young people \(cyp\) who die from cancer.](#)

Gao W¹, Verne J, Davies J, Peacock J, Gordon E, Morris C, Greenough A, Higginson I.

ABSTRACT

INTRODUCTION: Healthcare staffing and service levels during weekends and holiday (WH) periods are lower than other periods. It is unclear if such configuration plays a role in place of death (PoD) for CYP cancer deaths. Healthcare staffing and service levels during weekends and holiday (WH) periods are lower than other periods. It is unclear if such configuration plays a role in place of death (PoD) for CYP cancer deaths.

AIM(S) AND METHOD(S): TO evaluate the relationship between CYP cancer deaths during WH periods and PoD. 5,432 CYP cancer deaths (≤ 24 years) in England in 2001-2010 were extracted from ONS death registration database. The outcome was PoD. WH periods were defined as Saturday or Sunday, two days before or after Christmas, and one day before or after New Year's Day or Easter.

RESULTS: Overall, 30% of CYP cancer deaths occurred in WH periods. Compared to other periods (47.7% [46.2-49.3%]), there was a reduced proportion of deaths in hospital during WH periods (-3.5% [-6.4 to -0.6%]), and an increased proportion of home deaths during WH periods (3.5% [0.6-6.3%]). Deaths in other places remained stable regardless of period. Multivariate log-binomial analysis (adjusting for age, gender, cancer site, year of death and deprivation) confirmed that CYP cancer deaths were more likely to occur at home during WH periods than in other periods (PR: 1.06 [1.01-1.12], P=0.017).

CONCLUSION(S): Relatively more CYP cancer deaths occurred at home during WH periods than in other periods, mirroring a decrease in hospital deaths. Further research is needed to understand the reasons for this pattern, particularly the roles of service users' preferences, service provision and care quality. Our results highlight a need for well co-ordinated community palliative and primary care support at WH periods.

KEYWORDS: Supportive care

PMID:24644809

11. [BMJ Support Palliat Care](#). 2014 Mar;4 Suppl 1:A109. doi: 10.1136/bmjspcare-2014-000654.314.

[An audit of documented referral information for children referred to a uk paediatric and young person's hospice.](#)

McKeating C¹, Koodiyedath B, Nicholson J, Miller M.

ABSTRACT

BACKGROUND: Recent research shows a rising national prevalence of Life Limiting Conditions in children identifying an escalating need for paediatric palliative care services in the UK. (1) Hospice services must ensure quality, sustainable care and essential to providing this is the careful documentation and consideration of all referred patients. The services offered by paediatric hospice settings vary widely throughout the UK. Such individual care settings require individualised referral processes and individualised referral documentation. Martin House Children's Hospice in Yorkshire looks after 340 children and young people with life limiting illnesses from birth to age 35 years. The hospice receives approximately 87 new referrals on average (mean) per calendar year for children aged 0-19 years.

AIMS: To undertake an audit assessing the quality of information recorded on hospice referral forms against the Scottish Intercollegiate Guidelines Network 31 template. (2) SIGN 31 is a valid "gold standard" for audit of current practice and recommended as a suitable tool to ensure quality in referral communication. Half of all referrals received during a 6 month period at Martin House were retrospectively examined for the recommended minimum essential information within SIGN 31.

RESULTS: The audit identified incomplete and inconsistent documentation in recording of referrer contact information, reason for referral and child/young person's location at the time of referral. The audit highlighted other inconsistently documented information out-with the recommendations of SIGN 31 guidance considered important for paediatric palliative care referrals. This included the order of referral (i.e. first/second), parental and child's consent to and awareness of the referral, languages and religious beliefs of the child and family, parent's names and legal guardianship status.

CONCLUSIONS: The audited referral documentation and referral system is not presently in-line with the 'gold standard' SIGN 31 guidance and requires improved consistency in documentation of the required minimum data set to ensure quality care for children referred to the hospice service.

PMID:24644862

12. [Aust Fam Physician](#). 2014 Apr;43(4):176-80.

[Paediatric palliative care - the role of the GP.](#)

Armitage N¹, Trethewie S.

ABSTRACT

BACKGROUND: Paediatric palliative care (PPC) is a growing specialty area in Australia and many families aim to care for their child at home as much as possible, including during the terminal phase.

OBJECTIVE: This article aims to highlight the important role of the general practitioner (GP) in the management of PPC patients, especially if families want to care for their child at home. The support that specialist PPC teams can offer the GP is also emphasised.

DISCUSSION: The GP has much to offer in conjunction with other local services, being part of a team managing the child with palliative care needs. Specialist PPC services can provide the GP with relevant information, specific education, advice and ongoing support to fulfil their important role for the child and family.

PMID:24701618

13. *Indian J Anaesth.* 2014 Jan;58(1):100-1. doi: 10.4103/0019-5049.126855.

[Airway management techniques for one lung ventilation in children - what else!](#)

Garg R.

ABSTRACT

Airway management for one lung ventilation (OLV) for thoracic surgery is challenging for children not only because of unique airway anatomy, but also different physiology when compared with adults. After the first reported independent lung ventilation in adults by Carlon and co-workers in 1978, the airway gadgets for OLV still remains limited in children.

The provision for OLV for open thoracic procedures may be achieved by direct manipulation using the lung retractors or packs by the surgeons.[1] With the advancement of technology, the thoroscopic procedures in children are increasingly being performed in all age groups. This requires a deflated and silent lung to provide an "adequate working space in a relatively small anatomic compartment".

PMID:24700923

14. *Palliat Med.* 2014 Apr 3. [Epub ahead of print]

[Patterns of diagnoses among children and young adults with life-limiting conditions: A secondary analysis of a national dataset.](#)

Fraser LK¹, Lidstone V, Miller M, Aldridge J, Norman P, McKinney PA, Parslow RC.

ABSTRACT

BACKGROUND: Numbers of children and young people with life-limiting conditions are rising, and increasing lifespans require young adults with life-limiting condition to transit to appropriate adult services.

AIM: To describe the prevalence of life-limiting condition in children and young adults by age, sex, diagnostic group, ethnicity and deprivation.

DESIGN: A secondary analysis of the English Hospital Episode Statistics dataset was undertaken to calculate prevalence per 10,000 population.

SETTING/PARTICIPANTS: Individuals (0-40 years) with life-limiting conditions were identified within an English Hospital Episode Statistics dataset by applying a customised coding framework of International Classification of Diseases, 10th Edition, disease codes.

RESULTS: There were 462,962 inpatient hospital admissions for 92,129 individual patients with a life-limiting condition. Prevalence-by-age group curve is U shaped with the highest overall prevalence in the under 1-year age group (127.3 per 10,000), decreasing until age 21-25 years (21.1 per 10,000) before rising steeply to reach 55.5 per 10,000 in the 36-40-year age group. The distribution by diagnostic group varies by age: congenital anomalies are most prevalent in children until age 16-20 years with oncology diagnoses then becoming the most prevalent.

CONCLUSION: Non-malignant diagnoses are common in children and young adults, and services that have historically focussed on oncological care will need to widen their remit to serve this population of life-limited patients. The diagnosis determining a patient's life-limiting condition will strongly influence their palliative care service needs. Therefore, understanding the diagnostic and demographic breakdown of this population of teenagers and young adults is crucial for planning future service provision.

KEYWORDS: Hospital Episode Statistics, Life-limiting conditions, end-of-life care, palliative care

PMID:24699788

15. *Pediatrics.* 2014 Apr;133(4):e1117. doi: 10.1542/peds.2014-0046. Epub 2014 Mar 31.

[Clinical practice guidelines for quality palliative care.](#)

[No authors listed]

ABSTRACT:

In January 2013, the American Academy of Pediatrics endorsed the following publication: National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 3rd ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2013. Available at:http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

PMID:24685952

16. *Rev Paul Pediatr.* 2014 Mar;32(1):99-106.

[Assistance in palliative care in the Brazilian scientific literature.](#)

Garcia-Schinzari NR¹, Santos FS².

ABSTRACT

OBJECTIVE: To describe what has been published in Brazilian scientific literature regarding pediatric palliative care. Data sources: Bibliographic review with a descriptive approach. In LILACS and SciELO databases, the descriptors "palliative care", "child", "pediatrics", "terminal illness" and "death" were sought, from January 2002 to December 2011. The eight selected articles were analyzed according to year of publication, type of study, data collected, target population, pathology, professionals involved, types of care and main findings. Data synthesis: Regarding the year of publication, there was an increase in the number of publications related to pediatric palliative care. Regarding the type of study, four articles were literature reviews and four were qualitative researches. Data was collected mainly by semi-structured interviews. The participants of the majority of the studies were children's relatives and health professionals. The main pathology addressed was cancer and the nurses were the most frequently cited professionals. The types of care provided were related to physical aspects, general care and psychological, social and spiritual aspects (less emphasis). The main findings were: little emphasis on the children's needs, the importance of including the family in the care provided and the lack of preparation of the health team. Conclusions: Despite the difficulties and the challenges in establishing pediatric palliative care, many articles brought important considerations for the development of this practice in the country.

PMID:24676197

17. *Rev Bras Enferm.* 2014 Jan;67(1):28-35.

[\[Children and adolescents with cancer under palliative care: experience of family members\]. \[Article in Portuguese\]](#)

Sanches MV¹, Nascimento LC², Lima RA².

ABSTRACT

This study's objective was to investigate the experience of family members of children and adolescents with cancer in terms of palliative care, especially the care provided in the final stage of life. This is a descriptive and exploratory study with qualitative data analysis. A total of 14 family members participated in the study. They were the caregivers of children and adolescents with cancer who died, and were followed up by a teaching hospital in the state of São Paulo. Empirical data were organized around three themes: "The impact of the worsening

of the disease on the family's dynamics", "Communicating bad news" and "The experience of the family concerning palliative care". This study is relevant to children and adolescents with cancer in the end-of life care because the complex, dynamics, and comprehensive experiences of families in the care of children and adolescents in this period can contribute to better understanding of the process of providing care in light of the fundamentals of palliative care.

PMID:24676065

18. *Int J Palliat Nurs.* 2014 Mar 28;20(3):143-8.

[Perinatal palliative care: a developing specialty.](#)

Kimman R¹, Doumic L².

ABSTRACT

Neonates and babies have the highest death rate in the paediatric population. Perinatal palliative care aims to enhance the quality of life of babies with a life-limiting condition and their families. However, very little data is available on perinatal palliative care and its impact on babies and families along their journey. End-of-life decision-making for babies with an adverse prognosis also remains ethically challenging. This paper provides an overview of perinatal palliative care and its development, and then considers some of the issues affecting this field by looking at single national, institutional, and patient case studies.

PMID:24675541

19. *Int J Palliat Nurs.* 2014 Mar 28;20(3):130-4.

[Assessment of the need for palliative care for children in South Africa.](#)

Connor S¹, Sisimayi C², Downing J³, King E⁴, Lim Ah Ken P⁵, Yates R⁶, Marston J⁷.

ABSTRACT

UNICEF and the International Children's Palliative Care Network undertook a joint analysis in three sub-Saharan countries-Zimbabwe, South Africa, and Kenya-to estimate the palliative care need among their children and to explore these countries' capacities to deliver children's palliative care (CPC). This report concerns the findings from South Africa. The study adopted a cross-sectional mixed-methods approach using both quantitative and qualitative data obtained from primary and secondary sources. CPC need was estimated using prevalence and mortality statistics. The response to the need and existing gaps were analysed using data obtained from a literature review, interviews with key persons, and survey data from service providers. The findings show very limited CPC service coverage for children in the public sector. In addition, services are mainly localised, with minimal reach. Less than 5% of the children needing care in South Africa are receiving it, with those receiving it being closer to the end of life. Barriers to the delivery of CPC include fear of opioid use, lack of education on CPC, lack of integration into the primary care system, lack of policies on CPC, and lack of community and health professional awareness of CPC needs and services. Estimating the need for CPC is a critical step in meeting the needs of children with life-threatening conditions and provides a sound platform to advocate for closure of the unacceptably wide gaps in coverage.

PMID:24675539

20. *Support Care Cancer.* 2014 Mar 27. [Epub ahead of print]

[Referral practices of pediatric oncologists to specialized palliative care.](#)

Wentlandt K¹, Krzyzanowska MK, Swami N, Rodin G, Le LW, Sung L, Zimmermann C.

Abstract

PURPOSE: The aims of this study are to describe the attitudes and referral practices of pediatric oncologists (POs) to specialized palliative care (SPC), and to compare them with those of adult oncologists (AOs).

METHODS: Canadian members of the American Society of Pediatric Hematology/Oncology (ASPHO), Canadian Association of Medical Oncologists (CAMO), Canadian Association of Radiation Oncologists (CARO), and the Canadian Society of Surgical Oncology (CSSO) participated in an anonymous survey assessing SPC referral practices.

RESULTS: The response rate was 70 % (646/921), 52 % (43/82) for ASPHO members; 5 CARO members self-identified as POs, for a total of 48 POs and 595 AOs. Ninety-six percent of POs had access to inpatient SPC consultation services (vs. 48 % AOs), 31 % to a PCU (vs. 82 % AOs), and 27 % to an outpatient SPC clinic (vs. 73 % AOs). POs more often stated their SPC services accepted patients on chemotherapy than AOs (64 vs. 37 %, $p = 0.0004$). POs were less likely to refer only after chemotherapy had been stopped (13 vs. 29 % for AOs) and more likely to state that ideally referral should occur at the diagnosis of cancer/incurable cancer (73 vs. 43 %). POs were more likely to agree they would refer earlier if palliative care were renamed "supportive care" (58 vs. 33 %, $p < 0.0001$), that palliative care adds too many providers (17 vs. 7 %, $p = 0.002$), and that palliative care was perceived negatively by their patients (60 vs. 43 %, $p = 0.02$).

CONCLUSIONS: Although POs acknowledge the importance of early referral to SPC for children with cancer, there remain resource and attitudinal barriers to overcome in this regard.

PMID:24671435

21. *South Asian J Cancer.* 2014 Jan;3(1):78-82. doi: 10.4103/2278-330X.126548.

[Overview of pediatric oncology and hematology in Myanmar.](#)

Halbert J¹, Khaing AA².

ABSTRACT: Myanmar is a country in southeast Asia in political, economic and healthcare transition. There are currently only two pediatric oncology centers serving a population of almost 19 million children. An estimated 85-92% of children with cancer are undiagnosed or not receiving treatment. Abandonment of treatment is as high as 60%. Although a number of chemotherapy agents are available, difficulties remain concerning treatment costs, quality control and the availability of supportive care. Radiotherapy services are also limited and not usually included in pediatric protocols. Healthcare professional training, improved diagnostics, strategies to tackle abandonment of treatment and the development of a parents' support group are major priorities. Local and international partnerships including a recent partnership with world child cancer are essential in the interim to support the development of pediatric oncology and hematology in Myanmar. A unique opportunity exists to support the development of preventive, diagnostic, curative and palliative care for children's cancer in Myanmar from the outset.

KEYWORDS: Burma, Myanmar, hematology, oncology, pediatric

PMID:24665454

22. *BMJ Support Palliat Care.* 2014 Mar;4 Suppl 1:A49-50. doi: 10.1136/bmjspcare-2014-000654.140.

[Who responds to a bereaved family survey about acute hospital care at the end of life?](#)

Iwaniszak C¹, Kite S, Rees E, Henry K, Hicks F, Gibson K, Stothard C.

Abstract

AIM: To explore who responded to the Leeds Teaching Hospitals Trust (LTHT) bereaved family survey.

BACKGROUND: The LTHT Specialist Palliative Care Team (SPCT) locally adapted a bereavement survey for families (Worcestershire Acute Hospital NHS Trust, 2012). This was developed to give bereaved relatives the opportunity to provide feedback on their experience of the

care their relative received at the end of life in the acute setting. The LHTT SPCT Bereaved Carers Service User (BCSU) group contributed to the design of the survey at the outset.

METHOD: Over a 10 week period, March to May 2013, the survey was given to bereaved relatives of adult patients when they collected medical cause of death certificates from the bereavement office. Patients who died in A&E were excluded.

RESULTS: There were 146 respondents (response rate 23%). Trends identified from the demographics were that respondents tended to be from children of the deceased (son 23%, daughter 40%) and most responses came from older peoples' services (27%). The most prevalent age of death was 86-90. There was a low response rate from oncology wards (1%). Results were presented to the BCSU group.

CONCLUSION: The highest response was from daughters of older adults. Further exploration is needed into the low response rate from oncology, and spouses of the deceased. The timing of the survey may have influenced the group of respondents. It may have been too early on in their bereavement. Delaying the time that the survey is sent to bereaved relatives/carers may help increase the response rate. Opinions from the BCSU group and experience from other hospital trusts will be considered to inform changes to the next survey to gain feedback from a more representative population and improve the care patients receive at the end of life.

PMID:24644987

23. *BMJ Support Palliat Care*. 2014 Mar;4 Suppl 1:A49. doi: 10.1136/bmjspcare-2014-000654.138.

When should we tell the children?

Foulkes M¹, Hampton-Matthews J, Coackley A.

Abstract

BACKGROUND: In recent years, there has been growing recognition that the needs of dependent children should be considered when dealing with a parent with a life-threatening illness. Much patient distress can be associated with worries about the children and also, many children welcome the opportunity to talk with parents or professionals about the illness, treatments, survival and coping strategies. Many Hospices/Palliative Care Units in the UK provide support for dependent children, however, there is very little face-to-face support at diagnosis or subsequent care, in the acute setting.

AIM: To provide an individualised service for families and children, depending on age, stage of development, family values, patterns and culture, from diagnosis to bereavement.

METHOD: During the past five years, this tertiary Cancer Centre has provided a family service for patients with children. There is a weekly specialist service where patients can discuss the needs of their children or can access individual support for the children themselves. Parents are helped to discuss issues with their children and provided with resources such as leaflets, books, internet sites, discussion of memory boxes and DVDs. Some children may prefer to talk to a professional on their own or with a family member/friend. They are encouraged to ask questions about what is happening, look at options for support and have a point of contact if they wish to return at any future date.

RESULTS: Patients and their families have benefitted from support in all stages of their cancer journey. Education and advice has been available for generalist staff and support has been augmented by the Specialist Palliative Care Team. A wide range of resources for children and their relatives are available in the Unit.

PMID:24644985

24. *BMJ Support Palliat Care*. 2014 Mar;4 Suppl 1:A21. doi: 10.1136/bmjspcare-2014-000654.58.

Patterns of diagnoses amongst children and young adults with life-limiting conditions: implications for service provision.

Fraser L¹, Lidstone V, Miller M, Aldridge J, Norman P, McKinney P, Parslow R.

Abstract

BACKGROUND: The numbers of children and young people with Life-Limiting Conditions (LLC) are rising due in part to increased survival. Therefore the teenagers and young adults with LLC require transition to appropriate adult services but the models of care for these services need to be aware of the diagnostic and demographic makeup of this population.

AIMS: This study aimed to describe the patterns of diagnoses by age group in children and young adults with Life-Limiting Conditions.

METHODS: Individuals (0-40 years) with LLCs were identified within an English Hospital Episode Statistics dataset by applying a customized coding framework of the ICD-10 disease codes. Prevalence per 10 000 population was calculated by five year age groups for each diagnostic group, stratified by gender.

RESULTS: There is a U shaped prevalence with the highest overall prevalence in the under one age group (127 per 10000), decreasing until age 21-25 years (21 per 10000) before rising steeply to reach 55 per 10000 in the 36-40 year age group. Prevalence is higher in males than females until the age group 21-25 years where females predominate and the gap widens to 61.8 per 10000 female (95% CI 59.5-60.7) and 51.1 per 10000 male (95% CI 49.0-50.1) by age 36-40 years. Congenital Anomalies are the highest prevalence in children until age 16-20 years when oncology diagnoses become the most prevalent, rising steeply in early adulthood to 25 per 10000 by age 36-40 years. The second most prevalent diagnoses after age 25 years are neurology diagnoses in females and genitourinary diagnoses in males.

CONCLUSIONS: Patients with oncology diagnoses usually have different needs from a palliative care service than patients with slowly degenerative diseases. The diagnostic and demographic breakdown of the population of teenagers and young adults with LLCs is important when planning future service provision.

PMID:24644900

25. *R I Med J (2013)*. 2014 Mar 3;97(3):26-30.

Spirituality and coping with chronic disease in pediatrics.

Drutchas A¹, Anandarajah G².

Abstract

Chronic illnesses represent a growing burden of disease among children and adolescents, making it imperative to understand the factors that affect coping and medical adherence in this population. Spirituality has been identified as an important factor in the overall health and wellbeing of pediatric patients; however, in this regard, most studies have focused on pediatric palliative and end-of-life care. This article reviews childhood spirituality related to chronic disease coping. The existing literature, though sparse, reveals that children have a rich and complex spiritual life; one which often goes beyond religiosity to examine purpose in the context of illness. Studies suggest that spiritual beliefs have the potential to support as well as hinder children's ability to cope with chronic illness. More research is needed to better understand and meet the spiritual needs of children with chronic illnesses. [Full text available at <http://rimed.org/rimedicaljournal-2014-03.asp>, free with no login].

KEYWORDS: children, chronic disease, pediatrics, spirituality

PMID: 24596927

26. *Am J Hosp Palliat Care*. 2014 Mar 4. [Epub ahead of print]

Mortality Trends for Pediatric Life-Threatening Conditions.

Chavoshi N¹, Miller T, Siden H.

Abstract

Internal data from the sole pediatric hospice in British Columbia were utilized to investigate mortality trends among children dying from life-threatening conditions. Characteristics of the sample (hospice) were compared to that of the population (province) for individuals aged 0 to 18 years from 2002 to 2011. The provincial death rate was 2.30 per 10 000. The sample did not significantly vary with respect to sex and geographic distribution when compared to the population. Infants contributed to a significantly larger proportion of pediatric deaths in the population. Children referred to the hospice were more likely to be diagnosed with cancer and diseases of the nervous system. Only 15% of all pediatric deaths due to disease in the province were cared for by the hospice, calling for the strengthening of interdisciplinary palliative care programs.

KEYWORDS: hospice, illness, life-threatening conditions, mortality, palliative, pediatric

PMID:24595320

27. *Death Stud.* 2014 May-Jun;38(5):302-7. doi: 10.1080/07481187.2012.753555. Epub 2013 Sep 17.

Disclosing terminal diagnosis to children and their families: palliative professionals' communication barriers.

Coad J1, Patel R, Murray S.

Abstract

Few studies have fully explored the problem of communication barriers in pediatric palliative care, particularly the detrimental effects of poor interaction between staff and families on children's health and well-being. A literature review was undertaken to expand the current body of knowledge about staff to patient communications. Articles meeting the inclusion criteria (N = 15) were systematically read and summarized using a data extraction sheet. A narrative synthesis identified 5 overarching themes as barriers to communication. Improvements in staff education and individualized palliative care plans for children and their families may help to overcome communication barriers.

PMID:24593008

28. *Pediatr Crit Care Med.* 2014 Feb 26. [Epub ahead of print]

Parental Perspectives on Suffering and Quality of Life at End-of-Life in Children With Advanced Heart Disease: An Exploratory Study.

Blume ED1, Balkin EM, Aiyagari R, Ziniel S, Beke DM, Thiagarajan R, Taylor L, Kulik T, Pituch K, Wolfe J.

Abstract

OBJECTIVE: To describe parent perspectives regarding the end-of-life experience of children with advanced heart disease.

DESIGN: Cross-sectional multicenter survey study of bereaved parents.

SETTING: Two tertiary care pediatric hospitals.

SUBJECTS: Parents of children younger than 21 years with primary cardiac diagnoses who died in the hospital 9 months to 4 years before the survey date. Parents were excluded if they were non-English speakers or had previously denied permission to contact.

INTERVENTION: The Survey for Caring for Children with Advanced Heart Disease was developed, piloted, and then sent to parents of all children who died at two sites.

MEASUREMENTS AND MAIN RESULTS: Fifty bereaved parents responded (39% response rate) a mean of 2.7 years after their child's death. Median age at death was 6 months (3.6 d to 20.4 yr). At end-of-life, 86% of children were intubated and 46% were receiving mechanical circulatory support. Seventy-eight percent died during withdrawal of life-sustaining interventions and 16% during resuscitative efforts. Parents realized that their child had no realistic chance of survival a median of 2 days prior to death (0-30 d). According to parents, 47% of children suffered "a great deal," "a lot," or "somewhat" during the end-of-life period. The symptoms parents perceived to be causing the most suffering were breathing and feeding difficulties in children under 2 years and fatigue and sleeping difficulties in older children. Seventy-one percent of parents described the quality of life of their child during the last month of life as "poor" or "fair." Most parents (84%) described the quality of care delivered as "very good" or "excellent."

CONCLUSIONS: According to their parents, many children with advanced heart disease experience suffering in the end-of-life care period. For most, realization that their child has no realistic chance of survival does not occur until late, some not until death is imminent. Once this realization occurs, however, parents perceive peacefulness, a "good death," and excellent quality of care. Strategies for improved communication around symptom management, quality of life, prognosis, and advance care planning are needed for families of children with advanced heart disease.

PMID:24583501

29. *J Palliat Med.* 2014 Feb 27. [Epub ahead of print]

Referrals to a New Pediatric Palliative Care Team: Details of the First 12 Months of Operation.

Frizzola M1, Miller EG.

Abstract Background: Although the field of pediatric palliative care (PPC) remains in its infancy, over the past decade it has grown in practice and scope. We report on patient referral patterns to a new PPC team at a free-standing children's hospital. Objective: Our aim is to provide a descriptive comparison of the patient population seen by our new program as compared to existing literature. Methods: We examined our database of patient referral and demographic data and compared our data with published reports. Conclusions: Our team was operating beyond its predicted year-one volume with a patient population that mirrored larger, more established programs. In an era of growth and acceptance of PPC, hospitals that have undergone a strong needs assessment, significant educational effort, and have a strong prediction of patient volume should expect to be operating at projected capacity quickly.

PMID:24576099

30. *Palliat Support Care.* 2014 Feb 24:1-5.

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

García-Salido A1, de Paso-Mora MG2, Monleón-Luque M2, Martino-Alba R2.

Abstract

OBJECTIVE: Our aim was to describe the clinical evolution and needs of children with spinal muscular atrophy type I treated in a domiciliary palliative care program. Method: We undertook a retrospective chart review of nine consecutive patients. Descriptions of the clinical and demographic profile of children with spinal muscular atrophy (SMA) type I were referred to a pediatric palliative care team (PPCT). Results: Six males and three females were admitted to the PPCT, all before six months of age, except for one afflicted with SMA type I with respiratory distress. The median time of attention was 57 days (range 1-150). The domiciliary attention mainly consisted of respiratory care. The patient with SMA type I with respiratory distress required domiciliary mechanical ventilation by tracheotomy. In all cases, a nasogastric tube (NT) was indicated. As end-of-life care, eight required morphine to manage the dyspnea, four received it only by enteral (oral or NT) administration, and four received it first by enteral administration with continuous subcutaneous infusion (CSI) later. Three of the four patients with CSI also received benzodiazepines. While they were attended by the PPCT, none required hospital admission. All the patients died at home except for the one attended to for just one day. Significance of Results: Domiciliary care for these patients is possible. The respiratory morbidity and its management are the main issues. Application of an NT is useful to maintain nutritional balance. Morphine administration is necessary to manage the dyspnea. Palliative sedation is not always necessary. PMID:24565112

31. *J Pediatr Hematol Oncol*. 2014 Mar;36(2):111-7. doi: 10.1097/MPH.0b013e31829cdd49.

Malignancies in South African Children With HIV.

Davidson A1, Wainwright RD, Stones DK, Kruger M, Hendricks M, Geel J, Poole J, Reynders D, Omar F, Mathew R, Stefan DC.

Abstract

OBJECTIVES: In 2008 the South African Children's Cancer Study Group decided to review the epidemiology, management, and chemotherapy response of HIV-positive children with malignancy.

METHODS: This is a retrospective analysis of data collected from the records of HIV-positive children diagnosed with malignancy at 7 university-based pediatric oncology units serving 8 of the 9 provinces in South Africa.

RESULTS: Two hundred eighty-eight HIV-positive children were diagnosed with 289 malignancies between 1995 and 2009. Age at diagnosis ranged from 17 days to 18.64 years; median 5.79 years. Of the 220 HIV-associated malignancies, there were 97 Kaposi sarcomas, 61 Burkitt lymphomas, 47 other B-cell lymphomas including 2 primary central nervous system lymphomas, 12 Hodgkin lymphomas, and 3 leiomyosarcomas. Sixty-nine patients presented with non-AIDS-defining malignancies. More than 80% presented with advanced disease. Most patients (76.7%) were naive to antiretroviral therapy; 22.2% did not have access because it only became available in public hospitals in 2004. One hundred ninety-seven children were treated with curative intent; 91 received palliative care due to advanced malignancy and/or advanced HIV disease. Nearly one third had coexisting pathology, mostly tuberculosis. Overall survival for the whole group was 33.7%, but was 57.8% for those treated with antiretroviral therapy and chemotherapy.

CONCLUSIONS: The study shows more Kaposi sarcoma and fewer primary central nervous system lymphomas among HIV-positive children than that is reported in the developed world, but confirms a higher incidence of non-Burkitt B-cell lymphoma than in HIV-negative children. The high number of non-AIDS-defining malignancies underscores the prevalence of HIV-AIDS in South Africa. The overall survival should improve with universal access to antiretrovirals and earlier diagnosis.

PMID:24552745

32. *J Palliat Med*. 2014 Feb 14. [Epub ahead of print]

Development of a State-Wide Pediatric Palliative Care Service in Australia: Referral and Outcomes over Two Years.

Herbert A1, Bradford N, Donovan L, Pedersen LA, Irving H.

ABSTRACT BACKGROUND: Pediatric palliative care is an evolving specialty that aims to improve the lives of children with a life-limiting condition. As an emerging specialty, there is much to be learned about service provision and the expected outcomes that can be achieved. Additionally, quantification of the needs for pediatric palliative care is complicated by the uncertainty of defining the population that requires care. **OBJECTIVES:** Our aim was to define the characteristics of the population cared for by a newly formed state-wide service in Queensland, Australia, and describe the development of the service over a 24-month period. **Design:** Data on all referrals and outcomes were collected. Descriptive statistics were used to describe patterns including the variation in outcomes between children with oncology and non-oncology diagnoses. Other factors influencing the development of the service including involved health professionals and the model of the Australian health care system are also described. **RESULTS:** Over a 24-month period, 150 patients were referred of whom 117 subsequently died. There was a wide range of diseases and ages, and significantly, 58% of children were from regional or rural locations where there are can be limited access to specialist pediatric services. The average length of service was 83 days. A variety of factors were identified as being important for providing optimal care including ensuring equity in access, timing of referral, and continuity of care.

CONCLUSION: The importance of a population-based approach to pediatric palliative care in a state that is geographically large and diverse like Queensland is highlighted. This article may provide valuable information to other health care providers who care for children with life-limiting illnesses.

PMID:24528125

33. *Palliat Support Care*. 2014 Feb 13:1-10. [Epub ahead of print]

Understanding parental behavior in pediatric palliative care: Attachment theory as a paradigm.

Kearney JA, Byrne MW.

Abstract

OBJECTIVE: The objective of this conceptual paper was to present important constructs in attachment theory as they apply to parent and caregiver behavior in pediatric palliative care. Clarification of these constructs is provided with specific reference to their clinical application as well as their reflection in current empirical literature. Social attachment theory is proposed as a developmentally contextual model for the study of parenting in pediatric palliative and end-of-life care.

METHOD: A comprehensive search was conducted of pertinent literatures. These included classic as well as recent theory and research in attachment theory in addition to the empirical literatures on parent and family experience in pediatric palliative care, serious illness, and beyond to parental bereavement. Other relevant literature was examined with respect to the phenomena of concern.

RESULTS: The empirical literature in pediatric palliative care supports the use of central concepts in attachment theory as foundational for further inquiry. This is evidenced in the emphasis on the importance of parental protection of the child, as well as executive activities such as decision making and other prominent parental operations, parental psychological resolution of the child's diagnosis and illness as well as coping and meaning making, and the core significance of parental relationships with providers who provide secure-base and safe-haven functions.

SIGNIFICANCE OF RESULTS: The promise for developing integrated, conceptually based interventions from construction through implementation is of urgent importance to children and families receiving pediatric palliative care services. Focusing on key parental behaviors and processes within the context of a well-studied and contextually appropriate model will inform this task efficiently. The attachment paradigm meets these criteria and has promise in allowing us to move forward in developing well-defined, inclusive, and conceptually grounded protocols for child and family psychosocial research, practice, and education in this specialty.

PMID:24524227

34. *Pediatrics*. 2014 Feb;133 Suppl 1:S8-S15. doi: 10.1542/peds.2013-3608C.

The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring.

Jones BL1, Contro N, Koch KD.

Abstract

Pediatric palliative care physicians have an ethical duty to care for the families of children with life-threatening conditions through their illness and bereavement. This duty is predicated on 2 important factors: (1) best interest of the child and (2) nonabandonment. Children exist in the context of a family and therefore excellent care for the child must include attention to the needs of the family, including siblings. The principle of nonabandonment is an important one in pediatric palliative care, as many families report being well cared for during their child's treatment, but feel as if the physicians and team members suddenly disappear after the death of the child. Family-centered care requires frequent, kind, and accurate communication with parents that leads to shared decision-making during treatment, care of parents and siblings during end-of-life, and assistance to the family in bereavement after death. Despite the challenges to this comprehensive care, physicians can support and be supported by their transdisciplinary palliative care team members in providing compassionate, ethical, and

holistic care to the entire family when a child is ill.

KEYWORDS: autonomy, communication, ethics, palliative care, relational autonomy

PMID:24488541

35. *Pediatrics*. 2014 Feb;133 Suppl 1:S31-6. doi: 10.1542/peds.2013-3608F.

[Judging the quality of mercy: drawing a line between palliation and euthanasia.](#)

[Morrison W1, Kang T.](#)

Abstract

Clinicians frequently worry that medications used to treat pain and suffering at the end of life might also hasten death. Intentionally hastening death, or euthanasia, is neither legal nor ethically appropriate in children. In this article, we explore some of the historical and legal background regarding appropriate end-of-life care and outline what distinguishes it from euthanasia. Good principles include clarity of goals and assessments, titration of medications to effect, and open communication. When used appropriately, medications to treat symptoms should rarely hasten death significantly. Medications and interventions that are not justifiable are also discussed, as are the implications of palliative sedation and withholding fluids or nutrition. It is imperative that clinicians know how to justify and use such medications to adequately treat suffering at the end of life within a relevant clinical and legal framework.

KEYWORDS: end-of-life care, ethics, euthanasia, palliative therapy

PMID:24488538

36. *Pediatrics*. 2014 Feb;133 Suppl 1:S16-23. doi: 10.1542/peds.2013-3608D.

[Relational autonomy: moving beyond the limits of isolated individualism.](#)

[Walter JK1, Ross LF.](#)

Abstract

Although clinicians may value respecting a patient's or surrogate's autonomy in decision-making, it is not always clear how to proceed in clinical practice. The confusion results, in part, from which conception of autonomy is used to guide ethical practice. Reliance on an individualistic conception such as the "in-control agent" model prioritizes self-sufficiency in decision-making and highlights a decision-maker's capacity to have reason transcend one's emotional experience. An alternative model of autonomy, relational autonomy, highlights the social context within which all individuals exist and acknowledges the emotional and embodied aspects of decision-makers. These 2 conceptions of autonomy lead to different interpretations of several aspects of ethical decision-making. The in-control agent model believes patients or surrogates should avoid both the influence of others and emotional persuasion in decision-making. As a result, providers have a limited role to play and are expected to provide medical expertise but not interfere with the individual's decision-making process. In contrast, a relational autonomy approach acknowledges the central role of others in decision-making, including clinicians, who have a responsibility to engage patients' and surrogates' emotional experiences and offer clear guidance when patients are confronting serious illness. In the pediatric setting, in which decision-making is complicated by having a surrogate decision-maker in addition to a patient, these conceptions of autonomy also may influence expectations about the role that adolescents can play in decision-making.

KEYWORDS: autonomy, communication, ethics, palliative care, relational autonomy

PMID:24488536

37. *Pediatrics*. 2014 Feb;133 Suppl 1:S1-7. doi: 10.1542/peds.2013-3608B.

[Pediatric palliative care and pediatric medical ethics: opportunities and challenges.](#)

[Feudtner C1, Nathanson PG.](#)

Abstract

The fields of pediatric palliative care (PPC) and pediatric medical ethics (PME) overlap substantially, owing to a variety of historical, cultural, and social factors. This entwined relationship provides opportunities for leveraging the strong communication skills of both sets of providers, as well as the potential for resource sharing and research collaboration. At the same time, the personal and professional relationships between PPC and PME present challenges, including potential conflict with colleagues, perceived or actual bias toward a palliative care perspective in resolving ethical problems, potential delay or underuse of PME services, and a potential undervaluing of the medical expertise required for PPC consultation. We recommend that these challenges be managed by: (1) clearly defining and communicating clinical roles of PPC and PME staff, (2) developing questions that may prompt PPC and PME teams to request consultation from the other service, (3) developing explicit recusal criteria for PPC providers who also provide PME consultation, (4) ensuring that PPC and PME services remain organizationally distinct, and (5) developing well-defined and broad scopes of practice. Overall, the rich relationship between PPC and PME offers substantial opportunities to better serve patients and families facing difficult decisions.

KEYWORDS: hospital care, medical ethics, palliative care, pediatrics

38. *J Pediatr Hematol Oncol*. 2014 Jan 30. [Epub ahead of print]

[Childhood Cancer in Africa: An Overview of Resources.](#)

[Stefan DC.](#)

Abstract

BACKGROUND: Information about pediatric oncology in most of Africa is not widely available. The aim of this study was to provide an overview of childhood cancer and resources for patient care in a cross-section of African hospitals.

METHODS: Between 2011 and 2013, 49 health professionals involved in the care of children with cancer, from 38 hospitals in 29 African countries, were asked to respond to a questionnaire about the types and number of childhood cancers seen in their facilities; types and numbers of health care professionals; diagnostic, therapeutic, and palliative capabilities; survival statistics and compliance with treatment; support from parent groups; opportunities for ongoing medical training; and perceived challenges to care delivery.

RESULTS:

New diagnoses annually ranged from 10 to 350 with nephroblastoma, leukemia, retinoblastoma, and Burkitt lymphoma being the most common in most centers. Care was provided often by nonpediatric oncologists. Radiotherapy was available in 21/38 hospitals, palliation in 27/38, and tumor registries in 21/38 centers.

CONCLUSIONS: Capabilities for care of children with cancer varied widely. Recommendations for improving care are discussed.

PMID: 24487917

39. *J Pediatr Hematol Oncol*. 2014 Jan 30. [Epub ahead of print]

[Patient Involvement in Informed Consent for Pediatric Phase I Cancer Research.](#)

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

Abstract

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

40. *J Am Dent Assoc*. 2014 Feb;145(2):141-9. doi: 10.14219/jada.2013.20.

[Parents' understanding of and accuracy in using measuring devices to administer liquid oral pain medication.](#)

[Tanner S1, Wells M, Scarbecz M, McCann BW Sr.](#)

Abstract

BACKGROUND: Dentists recommend over-the-counter medications for postoperative pain in children, and parents often make dosing errors when administering these medications. The authors compared the dosing accuracy when parents used various measuring devices and aimed to identify risk factors associated with dosing errors.

METHODS: The authors recruited parent-child pairs visiting the Pediatric Clinic at the College of Dentistry at The University of Tennessee Health Science Center, Memphis, and three private dental offices. The parents completed a survey and a liquid measuring exercise. The authors instructed parents to measure 5 milliliters of liquid by using a medicine cup with clear markings, a medicine cup with printed markings, a cylindrical measuring spoon and an oral syringe. For the medicine cup with printed markings, the authors placed the parents randomly into one of two groups: those receiving text-only instructions or those receiving text-pictogram instructions. The authors weighed each device before and after the measuring exercise and compared the difference in weight with a reference weight of 5 mL.

RESULTS: A total of 120 parent-child pairs participated. The results of a McNemar test revealed a significant difference in parents' ability to measure accurate doses with the various devices. The results of a Pearson $\chi(2)$ test showed no statistically significant difference between the control and study groups for dosing accuracy. The $\chi(2)$ analysis results showed no significant differences in risk factors that could be associated with dosing errors.

CONCLUSIONS: Medicine cups were the devices parents reported using most frequently. Medicine cups had a higher occurrence of dosing errors when compared with the other devices. No sociodemographic factors were associated with dosing errors. Practical Implications. Dentists can improve pain management in pediatric patients by educating parents about accurate measuring devices, weight-based dosing and correct interpretation of medication dosing charts.

KEYWORDS: Dental care for children, drugs, pain, palliative care, pediatric dentistry

PMID: 24487605

41. *Semin Perinatol*. 2014 Feb;38(1):38-46. doi: 10.1053/j.semperi.2013.07.007.

[Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology.](#)

[Janvier A1, Barrington K2, Farlow B3.](#)

Abstract

The nature and content of the conversations between the healthcare team and the parents concerning withholding or withdrawing of life-sustaining interventions for neonates vary greatly. These depend upon the status of the infant; for some neonates, death may be imminent, while other infants may be relatively stable, yet with a potential risk for surviving with severe disability. Healthcare providers also need to communicate with prospective parents before the birth of premature infants or neonates with uncertain outcomes. Many authors recommend that parents of fragile neonates receive detailed information about the potential outcomes of their children and the choices they have provided in an unbiased and empathetic manner. However, the exact manner this is to be achieved in clinical practice remains unclear. Parents and healthcare providers may have different values regarding the provision of life-sustaining interventions. However, parents base their decisions on many factors, not just probabilities. The role of emotions, regret, hope, quality of life, resilience, and relationships is rarely discussed. End-of-life discussions with parents should be individualized and personalized. This article suggests ways to personalize these conversations. The mnemonic "SOBPIE" may help providers have fruitful discussions: (1) What is the Situation? Is the baby imminently dying? Should withholding or withdrawing life-sustaining interventions be considered? (2) Opinions and options: personal biases of healthcare professionals and alternatives for patients. (3) Basic human interactions. (4) Parents: their story, their concerns, their needs, and their goals. (5) Information: meeting parental informational needs and providing balanced information. (6) Emotions: relational aspects of decision making which include the following: emotions, social supports, coping with uncertainty, adaptation, and resilience. In this paper, we consider some aspects of this complex process.

KEYWORDS: BPD, CPR, Communication, ELGAN, Emotions, Empathy, End-of-life decisions, Extreme prematurity, Family-centered care, GA, Life-sustaining interventions, NEC, NICU, Neonatology, PMA, Palliative care, Personalized medicine, Withhold and withdraw intensive care, bronchopulmonary dysplasia, cardiopulmonary resuscitation, extremely low-gestational-age infants, gestational age, necrotizing enterocolitis, neonatal intensive care unit, post-menstrual age

PMID: 24468568

42. *J Pain Symptom Manage*. 2014 Jan 10. pii: S0885-3924(13)00604-0. doi: 10.1016/j.jpainsymman.2013.08.015. [Epub ahead of print]

[A Relational Ethical Approach to End-of-Life Delirium.](#)

[Wright DK1, Brajtman S2, Macdonald ME3.](#)

Abstract

Delirium is a condition of acute onset and fluctuating course in which a person's level of consciousness and cognition become disturbed. Delirium is a common and distressing phenomenon in end-of-life care, yet it is underrecognized and undertreated. In this article, we review qualitative descriptions of the delirium experience in end-of-life care, found through a systematic search of academic databases, to generate insight into the intersubjective nature of the delirium experience. Our analysis of retrieved studies advances an understanding of the relational ethical dimensions of this phenomenon, that is, how delirium is lived by patients, families, and health care providers and how it affects the relationships and values at stake. We propose three themes that explain the distressing nature of delirium in palliative care: 1) experiences of relational tension; 2) challenges in recognizing the delirious person; and 3) struggles to interpret the meaning of delirious behaviors. By approaching end-of-life delirium from a perspective of relational ethics, attention is focused on the implications for the therapeutic relationship with patients and families when delirium becomes part of the dying trajectory.

KEYWORDS: Delirium, end-of-life care, hospice, palliative care, qualitative research, relational ethics PMID:24417807

43. *J Palliat Med.* 2014 Jan;17(1):80-4. doi: 10.1089/jpm.2013.0227.

The impact of a palliative care team on residents' experiences and comfort levels with pediatric palliative care.

Wu KL1, Friderici J, Goff SL.

Abstract

BACKGROUND: 8,600 children are eligible for palliative care services each day in the US, yet many pediatric residents and pediatricians do not feel comfortable providing palliative/end of life care.

OBJECTIVE: To evaluate the impact of a palliative care team (PCT) on pediatric and internal medicine/pediatric (IM/Peds) residents knowledge, comfort level and experience providing pediatric palliative care (PPC).

DESIGN: Electronic 32-item questionnaire.

SUBJECTS: Pediatric and IM/Peds residents at ACGME accredited programs during the 2011-2012 academic year.

MEASUREMENTS: Residents' PPC training, knowledge, comfort levels and experiences.

RESULTS: Nearly two-thirds of 294 respondents (63.6%; 95% CI: 58.2, 69.1) selected a description of PPC that describes palliative care as starting at the time of diagnosis regardless of treatment goals. Participants who reported the presence of a PCT at their institution selected this accurate description of PPC more often than those who did not report the presence of a PCT (72.3% vs. 53.3%; $p < 0.001$, Fisher's Exact Test). Overall, 55.3% (95% CI: 49.2, 61.3) were comfortable providing PPC. Reporting the presence of a PCT was also associated with more comfort in providing PPC ($p < 0.01$).

CONCLUSIONS: Reported presence of a PCT may be associated with greater resident comfort in providing PPC and a more accurate understanding of PPC. There remains ample opportunity to educate pediatric and IM/Peds residents in PPC.

PMID:24410421

44. *Indian J Pediatr.* 2014 Jan 11. [Epub ahead of print]

The Need of Pediatric Palliative Care Education Among Pediatric Postgraduates in South India.

Latha MS1, Thirugnanasambandam RP, Balakrishnan N, Meghanathan HS, Moorthy A, Venkatraman P, Paramasivam V, Scott JX.

Abstract

OBJECTIVES: To assess the status of Pediatric Palliative care education among the pediatric postgraduates in South India and reinforce the need to introduce a targeted curriculum to improve their skills and confidence levels in handling terminally ill children.

METHODS: The study was conducted in a 2 d workshop attended by 180 pediatric postgraduates from South India. An 18 point questionnaire was given to the participants and the questions were to test their clinical knowledge and confidence levels in treating terminally ill children. SPSS 18.V software was used for statistical analysis.

RESULTS: Eighty eight percent of the postgraduates had never received any training in any aspect of palliative care. 77.3 % felt uncomfortable in initiating a discussion about palliative care with the family members. 60.7 % were not comfortable with the care of the dying patient. 87.3 % strongly supported that a formal training in palliative care would improve their competence in this field.

CONCLUSIONS: There is a huge lacunae in the delivery of palliative care services and hence an urgent need to inculcate targeted curriculum to provide focused skills and training for the pediatric postgraduates.

PMID:24408397

45. *Child Abuse Negl.* 2014 Jan 3. [Epub ahead of print]

Care taker blogs in caregiver fabricated illness in a child: A window on the caretaker's thinking?

Brown AN1, Gonzalez GR1, Wiester RT2, Kelley MC3, Feldman KW2.

Abstract

Three recently diagnosed cases of caregiver-fabricated illness in a child at Seattle Children's Hospital shed light on a new manifestation of their caretakers' attention seeking. The patients' mothers were actively blogging about their children's reputed illnesses. Although it is not uncommon for parents of chronically ill children to blog about their child's medical course, specific themes in these blogs of parents suspected of medically abusing their children were noted. In particular, gross distortions of the information parents had received from medical providers were presented online, describing an escalation of the severity of their children's illnesses. The mothers reported contacting palliative care teams and Wish organizations, independently from their medical providers' recommendations. They sought on-line donations for their children's health needs. We believe these blogs provide additional direct evidence of the suspected caregivers' fabrications. Although we have not performed formal content analysis, blogs might also provide insight into the caretakers' motivations. Protective Services and/or police investigators could consider querying the internet for blogs related to children at risk for caregiver-fabricated illness in a child. These blogs, if viewed in parallel with the children's medical records, could assist medical diagnosis and legal documentation of medical fabrication and assist in protective planning for the affected children.

KEYWORDS: Caregiver-fabricated illness in a child, Fundraising, Internet fraud, Medical child abuse, Munchausen by proxy, On-line blogging

PMID:24393290

46. *Cult Med Psychiatry.* 2014 Jan 3. [Epub ahead of print]

Some General Considerations of a Human-Based Medicine's Palliative Approach to the Vulnerability of the Multiply Disabled Child Before the End of Life.

Viallard ML.

Abstract

Specificities of situation of individuals with multiple disabilities and pediatric neurological pathologies call for specialized and multi-field competences that are commonly allowed and disallowed in contemporary clinical contexts. However what must be questioned in this matter is not only the meaning of the clinical, social, and human approach that is implemented, but also its spirit. The aim of medicine is double: to offer a technoscientific capacity (to cure as much as it is possible and always relieve suffering) and guarantee the meaning and value of the child's human and social capacities. We suggest the importance of a medicine always as care-giving whose aim(s) can be either curative or palliative, or even both at the same time with possibilities for moving back and forth between each one, is easily understandable by all professional groups and patients. It is not at the time of the death, at the last moments, that we will be able to introduce what could have given meaning, spirit and comfort in life. It is very early in the life, in the approach of care, to precisely preserve a meaning of life and to take adapted and shared care as a precious tool that we will propose to the patients, to the parents, and to the professionals. Palliative medicine can support a caring and human approach that takes account of the handicapped child's vulnerabilities not only at the end of his life, but throughout his/her life. The palliative approach and reasoning approach requires a specific, adapted training and the development of shared knowledge. Without giving up the indisputable contributions of the Evidence-Based Medicine (EBM), it is necessary to develop, in a scientific way, what we could call Human-Based Medicine (HBM).

PMID:24385205

47. *J Palliat Med.* 2014 Feb;17(2):183-8. doi: 10.1089/jpm.2013.0287. Epub 2013 Dec 31.

Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution.

Postier AL, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ.

Abstract

ABSTRACT BACKGROUND: Pediatric palliative care (PPC) aims to promote quality of life for children and their families through prevention and relief of physical and psychosocial symptoms. Little is known about how PPC/hospice services impact health care resource utilization in an uncertain financial landscape.

OBJECTIVE: The study objective was to compare pediatric hospital health care resource utilization before and after enrollment in a home PPC/hospice program.

DESIGN: The study was a retrospective administrative data analysis. Setting/subjects: The study took place in a pediatric multispecialty hospital. Data were analyzed for 425 children ages 1-21 years who received home-based PPC/hospice services between 2000 and 2010.

MEASUREMENTS: Hospitalization and emergency room (ER) administrative data were examined to determine whether or not there were changes in total number of hospital admissions, length of stay (LOS), and hospital billed charges before compared to after PPC/hospice exposure.

RESULTS: There was no change in average total number of admissions pre-/post-PPC/hospice exposure; however, we found a significant increase in hospital/ER admissions for children with cancer diagnoses with longer exposure to PPC/hospice services. There were statistically significant reductions in LOS and total charges for hospital-based care; reductions were more pronounced in the noncancer group. Noncancer patients with at least six months of PPC exposure showed a significant decrease in total LOS from pre- to post-program admission by an average of 38 days, and an average decrease in total hospital charges of nearly \$275,000.

CONCLUSION: Enrollment in home-based PPC/hospice was associated with lower hospital and ER LOS and total hospital charges as compared with the period prior to enrollment for children with noncancer diagnoses.

PMID:24380448

48. *Arch Pediatr.* 2014 Jan;21(1):34-43. doi: 10.1016/j.arcped.2013.10.018. Epub 2013 Dec 4.

[French law related to patient's rights and end of life: pediatric intensive care unit's health professionals' opinions]. [Article in French]

de Saint Blanquat L1, Cremer R2, Elie C3, Lesage F4, Dupic L4, Hubert P5; pour le Groupe francophone de réanimation et urgences pédiatriques (GFRUP).

Abstract

INTRODUCTION AND OBJECTIVES: To identify the knowledge of caregivers of pediatric intensive care units (PICUs) on the French law related to patients' rights and end of life, their views on withholding/withdrawing life-sustaining treatment (WWLST) decisions, and their feelings about how these decisions were made and implemented.

MATERIALS AND METHODS: A multicenter survey in 24 French PICUs during the fourth trimester 2010.

RESULTS: One thousand three hundred and thirty-nine professional healthcare workers (1005 paramedics and 334 physicians) responded. Over 85% of caregivers had good knowledge of the WWLST decision-making processes required by law. More than 80% of caregivers accepted mechanical ventilation, hemodiafiltration, or hemodynamic support withdrawal or withholding. Nevertheless, the withdrawal of artificial nutrition and hydration generated reluctance or opposition for the majority of respondents. While paramedics' participation in the decision-making process was deemed necessary by all caregivers, paramedics found more often than physicians that they were insufficiently involved. The quality of end-of-life care was judged very positively by caregivers. The answers on how WWLST was applied suggest very different interpretations of the law. Some caregivers respect the principles of palliative care as stated in the public health code and 40% of doctors and 64% of caregivers consider it "acceptable" to hasten death if resulting from a collaborative decision-making process.

CONCLUSION: This study is the first to show that caregivers of French PICUs have good knowledge of the French law concerning the end of life. Yet, there is still confusion about the limits of practice during the end-of-life period.

PMID:24315107

49. *J Palliat Med.* 2014 Jan;17(1):62-7. doi: 10.1089/jpm.2013.0117. Epub 2013 Dec 6.

Siblings caring for and about pediatric palliative care patients.

Gaab EM1, Owens GR, MacLeod RD.

Abstract

BACKGROUND: The experiences of young people who have siblings with life-limiting illnesses are not well understood.

AIM: The study proposed to identify the concerns of siblings of pediatric palliative care (PPC) patients.

DESIGN AND MEASUREMENT: Semistructured interviews were administered to participants and analyzed using qualitative inductive thematic analysis.

SETTING AND PARTICIPANTS: Study subjects were 18 siblings of PPC patients aged 9 to 22 living in the Auckland area.

RESULTS: The siblings of PPC patients held concerns about their siblings' impending death and desires to be involved in their lives and care.

CONCLUSIONS: Siblings may benefit from opportunities to be involved in conversations about mortality and the care of their ill sibling. They are able to express their concerns and help provide care to PPC patients.

PMID:24313781

50. *Acad Med.* 2014 Jan;89(1):43-7. doi: 10.1097/ACM.000000000000078.

The integration of the "spirituality in medicine" curriculum into the osteopathic communication curriculum at Kansas City University of Medicine and Biosciences.

Talley JA1, Magie R.

Abstract

With grant funding from the John Templeton Spirituality and Medicine Curricular Award to the George Washington Institute for Spirituality and Health, faculty at Kansas City University of Medicine and Biosciences (KCUMB) developed the "Spirituality in Medicine" curriculum. In developing the curriculum, faculty took into consideration competencies required by the Association of American Medical Colleges and qualitative results from surveys of medical school applicants and enrolled students. Strategies for curriculum delivery included lectures, panel discussions, role-playing, and training in the use of a spirituality assessment tool. A majority of the 250 students who received the training in 2010-2011 were able to demonstrate the following competencies: (1) being sensitive to patients' spiritual and cultural needs, (2) assessing patients' and their own spiritual needs, (3) appropriately using chaplain services for patient care, and (4) understanding the effects of health disparities and ethical issues on patient care. Challenges to implementation included a reduction in chaplain availability due to the economic downturn, a lack of student exposure to direct patient care during shadowing, too little religious diversity among chaplains,

and changes in assignment schedules. New competencies required by the National Board of Osteopathic Medical Examiners overlap with and help ensure sustainability of the Spirituality in Medicine curriculum. KCUMB leaders have incorporated the use of the spirituality assessment tool into other parts of the curriculum and into service experiences, and they have introduced a new elective in palliative care. Synergistic efforts by faculty leaders for this initiative were critical to the implementation of this curriculum.

PMID:24280841

51. *Pain*. 2014 Jan;155(1):118-28. doi: 10.1016/j.pain.2013.09.015. Epub 2013 Sep 21.

Inpatient-based intensive interdisciplinary pain treatment for highly impaired children with severe chronic pain: randomized controlled trial of efficacy and economic effects.

Hechler T1, Ruhe AK1, Schmidt P1, Hirsch J2, Wager J1, Dobe M1, Krummenauer F2, Zernikow B3.

Abstract

Pediatric chronic pain, which can result in deleterious effects for the child, bears the risk of aggravation into adulthood. Intensive interdisciplinary pain treatment (IIPT) might be an effective treatment, given the advantage of consulting with multiple professionals on a daily basis. Evidence for the effectiveness of IIPT is scarce. We investigated the efficacy of an IIPT within a randomized controlled trial by comparing an intervention group (IG) (n=52) to a waiting-list control group (WCG) (n=52). We made assessments before treatment (PRE), immediately after treatment (POST), as well as at short-term (POST6MONTHS) and long-term (POST12MONTHS) follow-up. We determined a combined endpoint, improvement (pain intensity, disability, school absence), and investigated 3 additional outcome domains (anxiety, depression, catastrophizing). We also investigated changes in economic parameters (health care use, parental work absenteeism, subjective financial burden) and their relationship to the child's improvement. Results at POST showed that significantly more children in the IG than in the WCG were assigned to improvement (55% compared to 14%; Fisher P<.001; 95% confidence interval for incidence difference: 0.21% to 0.60%). Although immediate effects were achieved for disability, school absence, depression, and catastrophizing, pain intensity and anxiety did not change until short-term follow-up. More than 60% of the children in both groups were improved long-term. The parents reported significant reductions in all economic parameters. The results from the present study support the efficacy of the IIPT. Future research is warranted to investigate differences in treatment response and to understand the changes in economic parameters in nonimproved children.

KEYWORDS: Financial burden, Health care utilization, Intensive interdisciplinary pain treatment, Parental work absenteeism, Pediatric chronic pain, Randomized controlled trial

PMID:24060708

52. *J Thorac Cardiovasc Surg*. 2014 Jan;147(1):397-401. doi: 10.1016/j.jtcvs.2013.07.052. Epub 2013 Sep 23.

Modified Blalock-Taussig shunt versus ductal stenting for palliation of cardiac lesions with inadequate pulmonary blood flow.

McMullan DM1, Permut LC2, Jones TK3, Johnston TA3, Rubio AE3.

Abstract

OBJECTIVE: The modified Blalock-Taussig shunt is the most commonly used palliative procedure for infants with ductal-dependent pulmonary circulation. Recently, catheter-based stenting of the ductus arteriosus has been used by some centers to avoid surgical shunt placement. We evaluated the durability and safety of ductal stenting as an alternative to the modified Blalock-Taussig shunt.

METHODS: A single-institution, retrospective review of patients undergoing modified Blalock-Taussig shunt versus ductal stenting was performed. Survival, procedural complications, and freedom from reintervention were the primary outcome variables.

RESULTS: A total of 42 shunted and 13 stented patients with similar age and weight were identified. Survival to second-stage palliation, definitive repair, or 12 months was similar between the 2 groups (88% vs 85%; P = .742). The incidence of surgical or catheter-based reintervention to maintain adequate pulmonary blood flow was 26% in the shunted patients and 25% in the stented patients (P = 1.000). Three shunted patients (7%) required intervention to address contralateral pulmonary artery stenosis and 3 (7%) required surgical reintervention to address nonpulmonary blood flow-related complications. The need for ipsilateral or juxtaductal pulmonary artery intervention at, or subsequent to, second-stage palliation or definitive repair was similar between the 2 groups.

CONCLUSIONS: Freedom from reintervention to maintain adequate pulmonary blood flow was similar between infants undergoing modified Blalock-Taussig shunt or ductal stenting as an initial palliative procedure. However, a greater percentage of shunted patients experienced procedure-related complications and distal branch pulmonary artery stenosis. Palliative ductal stenting appears to be a safe and effective alternative to modified Blalock-Taussig in selected infants.

KEYWORDS: 20, 28, DS, STS, Society of Thoracic Surgeons, ductal stenting, mBTS, modified Blalock-Taussig systemic-to-pulmonary shunt

Comment in Discussion. [*J Thorac Cardiovasc Surg*. 2014]

Discussion.[No authors listed]*J Thorac Cardiovasc Surg*. 2014 Jan; 147(1):401-3. Epub 2013 Sep 23.

PMID:24071469

53. *J Pain Symptom Manage*. 2014 Feb;47(2):271-82. doi: 10.1016/j.jpainsymman.2013.03.020. Epub 2013 Jul 12.

Predictive factors for do-not-resuscitate designation among terminally ill cancer patients receiving care from a palliative care consultation service.

Kao CY1, Wang HM1, Tang SC2, Huang KG3, Jaing TH4, Liu CY5, Liu KH6, Shen WC1, Wu JH1, Hung YS1, Hsu HC1, Chen JS1, Liao CT1, Lin YC1, Su PJ1, Hsieh CH1, Chou WC7.

Abstract

CONTEXT: Since the development of palliative care in the 1980s, "do not resuscitate" (DNR) has been promoted worldwide to avoid unnecessary resuscitation in terminally ill cancer patients.

OBJECTIVES: This study aimed to evaluate the effect of a palliative care consultation service (PCCS) on DNR designation and to identify a subgroup of patients who would potentially benefit from care by the PCCS with respect to DNR designation.

METHODS: In total, 2995 terminally ill cancer patients (with a predicted life expectancy of less than six months by clinician estimate) who received care by the PCCS between January 2006 and December 2010 at a single medical center in Taiwan were selected. Among these, the characteristics of 2020 (67.4%) patients who were not designated as DNR at the beginning of care by the PCCS were retrospectively analyzed to identify variables pertinent to DNR designation.

RESULTS: A total of 1301 (64%) of 2020 patients were designated as DNR at the end of care by the PCCS. Male gender and primary liver cancer were characteristics more predominantly found among DNR-designated patients who also had worse performance status, higher prevalence of physical distress, and shorter intervals from palliative care referral to death than did patients without DNR designation. On univariate analysis, a higher probability of DNR designation was associated with male gender, duration of care by the PCCS of more than 14 days, patients' prognostic awareness, family's diagnostic and prognostic awareness, and high Palliative Prognostic Index (PPI) scores. On multivariate analysis, duration of care by the PCCS, patients' prognostic awareness, family's diagnostic and prognostic awareness, and a high PPI score constituted independent variables predicting DNR-designated patients at the end of care by the PCCS.

CONCLUSION: DNR designation was late in terminally ill cancer patients. DNR-designated cancer patient indicators were high PPI scores,

patients' prognostic awareness, family's diagnostic and prognostic awareness, and longer durations of care by the PCCS.

KEYWORDS: Palliative Prognostic Index, Terminal cancer, do-not-resuscitate, palliative care

PMID:23856097

54. *Pediatr Blood Cancer*. 2014 Mar;61(3):488-92. doi: 10.1002/pbc.24769. Epub 2013 Sep 13.

Differences in use of complementary and alternative medicine between children and adolescents with cancer in Germany: a population based survey.

Gottschling S1, Meyer S, Längler A, Scharifi G, Ebinger F, Gronwald B.

Abstract

BACKGROUND: Use of complementary and alternative medicine (CAM) in children with cancer is common and probably increasing. However, data concerning differences between children and adolescents focusing on prevalence, reasons for use/non-use, costs, adverse effects, and socio-demographic factors are lacking.

PROCEDURE: A population-based survey over a 1 year period with 497 participants was conducted.

RESULTS: Of the 457 respondents (92%) 322 were children and 135 adolescents (>16 years of age) with malignancies. 31% reported CAM use from the time when being diagnosed, compared to an overall lifetime prevalence rate of 41% before cancer diagnosis. Among CAM users the most prevalent therapies were homeopathy, massage, anthroposophic medicine, acupuncture, and Bach flowers. The main reasons for use were to reduce therapy-related side effects, to strengthen the immune system, to achieve physical stabilization and to increase healing chances. Socio-demographic factors associated with CAM use were higher parental education and higher family income. A majority of CAM users (97%) would recommend CAM use. Most users (78%) informed a physician about CAM use. Side effects were rarely reported (5%), minor and self-limiting.

CONCLUSIONS: The high prevalence rates seem to represent the parental or patients needs for additional treatment perceived as successful and devoid of side-effects. Clinical care and the physician-patient relation would profit from an enhanced understanding of CAM and a greater candidness towards the parental needs. Safety and efficacy - especially of CAM with high prevalence rates - should be studied in rigorous basic and clinical research.

KEYWORDS: CAM, alternative therapies, complementary therapies, pediatric oncology

PMID:24038864

55. *Am J Hosp Palliat Care*. 2014 Mar;31(2):161-5. doi: 10.1177/1049909113483539. Epub 2013 Apr 2.

Professional boundary issues in pediatric palliative care.

Jankowski JB.

Abstract

This article explores the hypothesis that when a child has a life-limiting illness, the interpersonal boundaries between the patient, the patient's parents, and the health care team members differ from traditional provider, patient, and parent boundaries because of the unique dynamics of palliative care in pediatrics. Providers from the Journey's Palliative Care Team at Albany Medical Center completed a brief survey about working in pediatric palliative care and what ethical challenges they have faced in trying to maintain professional boundaries as new palliative care providers. A retrospective review of survey responses and a review of relevant literature offer insight into the various concerns reported by the Journey's team. Conclusions about delivering comprehensive ethically sound palliative care services may serve as a pathway for future studies.

KEYWORDS: end of life, ethics, multidisciplinary, palliative care, pediatrics, professional boundaries

PMID:23552661

56. *J Acad Nutr Diet*. 2014 Jan;14(1):48-53. doi: 10.1016/j.jand.2013.08.014. Epub 2013 Oct 11.

The CHANGE study: a healthy-lifestyles intervention to improve rural children's diet quality.

Cohen JF, Kraak VI, Choumenkovitch SF, Hyatt RR, Economos CD.

Abstract

BACKGROUND: Despite the high rates of overweight and obesity among rural children, there have been limited interventions reported to improve the diet quality of rural, low-income children in the United States.

OBJECTIVE: Our aim was to evaluate students' diet quality at baseline and after implementing the CHANGE (Creating Healthy, Active and Nurturing Growing-Up Environments) study, a 2-year (2007-2009) randomized, controlled, community- and school-based intervention to prevent unhealthy weight gain among rural school-aged children.

DESIGN: We used a school and community-based group randomized, controlled design.

PARTICIPANTS/SETTING: Data were collected in eight rural communities in California, Kentucky, Mississippi, and South Carolina (one elementary school per community). Children in grades 1 to 6 participated in the study (n=432; mean age=8.65 years ± 1.6 years). Students' diets were assessed at baseline (spring or early fall 2008) and post intervention (spring 2009) using the Block Food Screener for ages 2 to 17 years.

STATISTICAL ANALYSES: Mixed-model analysis of variance was used to examine the effect of the CHANGE study intervention on students' diets. Results were adjusted for corresponding baseline dietary values, sex, age, grade, race/ethnicity, and state, with school included as a random effect nested within condition.

RESULTS: At the end of 1 year, students enrolled in the CHANGE study intervention schools consumed significantly more vegetables (0.08 cups/1,000 kcal/day; P=0.03) and combined fruits and vegetables (0.22 cups/1,000 kcal/day; P<0.05) compared with students in control schools. Students in the intervention schools also showed a reduction in the average daily dietary glycemic index (GI=-1.22; P<0.05) and a trend toward more fruit consumption (0.15 cups/1,000 kcal/day; P=0.07). There were no significant differences in students' consumption of whole grains, legumes, dairy, potatoes/potato products, saturated fat, added sugars, or dietary fiber consumption.

CONCLUSIONS: The CHANGE study enhanced some aspects of rural students' dietary intake. Implementing similar interventions in rural America can be promising to support vegetable consumption.

KEYWORDS: Children, Diet, Healthy-lifestyle behaviors, Rural, Vulnerable populations

PMID:24126295

57. *Support Care Cancer*. 2014 Jan;22(1):43-52. doi: 10.1007/s00520-013-1933-1. Epub 2013 Aug 29.

Together and apart: providing psychosocial support for patients and families living with brain tumors.

Kanter C1, D'Agostino NM, Daniels M, Stone A, Edelstein K.

Abstract

PURPOSE: Brain tumors are associated with neurological sequelae and poor survival, contributing to distress in patients and their families. Our institution has conducted separate support groups for brain tumor patients and caregivers since 1999. This retrospective cohort study aimed to identify characteristics of brain tumor group participants in relation to attendance frequency, and compare themes of discussion in patient and caregiver groups.

METHODS: Demographic and medical characteristics were obtained from patient and caregiver group registration sheets and medical chart review. We quantified discussion topics recorded by group facilitators between 1999 and 2006, extracted themes, and examined similarities and differences in the way these themes were expressed.

RESULTS: A total of 137 patients and 238 caregivers attended the groups; about half attended more than one session. The chart review of a randomly selected subset of patient participants revealed that 57.5 % were married, 58.8 % had high-grade gliomas, and 55 % attended their first group within 3 months of diagnosis or at tumor progression. Both groups discussed physical and cognitive consequences, emotional reactions, relationships, coping, end of life, and practical issues. Caregivers discussed difficulties [achieving self-care and caregiver burden](#).

CONCLUSIONS: Brain tumor support group facilitators can expect to encounter a range of medical and psychosocial issues in accommodating patients' and caregivers' diverse concerns. Separate brain tumor patient and caregiver groups may allow participants to explore those concerns without worrying about effects on their friends or family. It remains to be seen whether the groups meet the needs of attendees, and whether those who do not attend the groups have unmet needs.

PMID: 23989499

58. [Pediatrics](#). 2014 Feb;133 Suppl 1:S24-30. doi: 10.1542/peds.2013-3608E.

[Communicating about prognosis: ethical responsibilities of pediatricians and parents.](#)

[Mack JW1, Joffe S.](#)

Abstract

Clinicians are sometimes reluctant to discuss prognosis with parents of children with life-threatening illness, usually because they worry about the emotional impact of this information. However, parents often want this prognostic information because it underpins informed decision-making, especially near the end of life. In addition, despite understandable clinician concerns about its emotional impact, prognostic disclosure can actually support hope and peace of mind among parents struggling to live with a child's illness. Children, too, may need to understand what is ahead to manage uncertainty and make plans for the ways their remaining life will be lived. In this article, we describe the ethical issues involved in disclosure of prognostic information to parents and children with life-threatening illness and offer practical guidance for these conversations.

KEYWORDS: communication, decision, end-of-life, hope, prognosis

PMID: 24488537

59. [J Pediatr Nurs](#). 2014 Feb 7. pii: S0882-5963(14)00045-1. doi: 10.1016/j.pedn.2014.01.014. [Epub ahead of print]

[Patient Involvement in Informed Consent for Pediatric Phase I Cancer Research.](#)

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

Abstract

The aim of this study was to describe how the parents of premature infants experience the transportation of their baby from the neonatal intensive care unit at a university hospital (NICU-U) to such a unit at a local hospital (NICU-L). This descriptive qualitative study comprises interviews with nine sets of parents and two mothers. The qualitative content analysis resulted in one theme: living in uncertainty about whether the baby will survive, and three categories: being distanced from the baby; fearing that something would happen to the baby during transportation; and experiencing closeness to the baby. The results also revealed that the parents experienced developmental, situational and health-illness transitions.

KEYWORDS: Experience, Parents, Premature, Transition, Transportation

PMID: 24582644

60. [Arch Pediatr](#). 2014 Feb;21(2):177-83. doi: 10.1016/j.arcped.2013.10.024. Epub 2014 Jan 4.

[\[Palliative care for newborns: Practices in a level-III unit during a 5-year period\]. \[Article in French\]](#)

[Mazille N1, Litzler-Renault S1, Weider I1, Donato L1, Astruc D1, Kuhn P2.](#)

Abstract

The "Patients' rights and end-of-life care" act known as "Leonetti's Law" promulgated in 2005 has promoted the use of palliative care to avoid unreasonable obstinacy when life-sustaining treatment appears disproportionate. Very little is known about this new practice for newborns in French neonatal units.

AIMS: To describe and evaluate the practice of palliative care in the newborn (mode of entry, characteristics, and modalities) and its evolution over time.

PATIENTS AND METHODS: Ambispective observational study conducted in a level III neonatal center. We included all newborns presenting conditions for which palliative care was introduced. Quantitative and qualitative analyses of routinely collected data, recorded from medical and nursing charts. We compared the recorded data between periods P1 (2006-2007) and P2 (2008-2010) using the Chi(2) test to assess changes over time.

RESULTS: A total of 93 newborns benefited from palliative care during the study period. The main medical conditions motivating palliative care initiation in the newborns were severe complications of prematurity (36/93, 39%), anoxic-ischemic encephalopathy (19/93, 20.5%), severe malformations (8/93, 8.5%), severe congenital heart disease (8/93, 8.5%), and other various etiologies (22/93, 23.5%). Both the number of newborns in palliative care/total number of births and the number of deaths after palliative care/total number of neonatal deaths remained stable. In case of prenatal diagnosis (n=31), there was an increase in the number of "palliative care from birth projects" (13/22 in P2 vs. 1/9 in P1, P=0.02). Collective meetings during the decision process were significantly more frequently reported in the infants' charts in P2 (48/59 in P2 vs. 18/34 in P1, P<0.01). Withdrawing and withholding life-sustaining treatment and limiting procedures of care and/or procedures of surveillance/monitoring were more frequent in P2 as compared to P1, respectively 12/34 vs. 37/59 (P=0.02) and 14/34 vs. 39/59 (P=0.03). A titration of level III analgesics treatment was high in both periods and remained stable. However, a trend toward an increase of systematic pain evaluation over time was observed (81.6% in P2 vs. 64.5% in P1; P=0.085).

CONCLUSION: A significant number of newborns affected by various pathologies undergo neonatal palliative care. Despite their recent introduction in neonatal medicine, palliative care practices have changed significantly. These practices are mostly in compliance with the "patients' rights and end-of-life care" act promulgated in France in 2005.

PMID: 24398077

61. [Support Care Cancer](#). 2014 Mar 5. [Epub ahead of print]

[Quality of dying and death with cancer in Israel.](#)

[Braun M1, Hasson-Ohayon I, Hales S, Zimmermann C, Rydall A, Peretz T, Rodin G.](#)

Abstract

BACKGROUND: The quality of dying and death refers to the evaluation of the final days of life and the moment of death with respect to how it is prepared for, faced and experienced by those with a terminal illness. It includes experience in multiple domains: physical, psychological, social, spiritual or existential, the nature of health care, life closure and death preparation, and the circumstances of death.

AIM: To explore the quality of dying and death in cancer patients in Israel and its relationship to place of death and socio-demographic characteristics of the primary caregivers and the deceased.

DESIGN: Retrospective assessment of the quality of dying and death, based on caregiver responses to the Quality of Dying and Death (QODD) questionnaire (overall score ranges from 0 to 100; higher scores reflect better dying and death experiences) 8 to 10 months after the death.

PARTICIPANTS: Ninety-five caregivers of Jewish cancer patients, most of whom were female spouses or children of the deceased.

RESULTS: Mean QODD score was 57.2 (standard deviation [SD] = 15), which is in the low-moderate range. Place of death, gender and age of the caregiver, and age of the deceased, were associated with QODD score.

CONCLUSIONS: This retrospective study in Israel demonstrated that the overall quality of dying and death was regarded as poor by almost half of the caregivers. These findings may reflect the relative lack of specialized palliative care and advance care planning in Israel at the time of this study, which took place between 2006 and 2009. Further research and enhancement of palliative care resources may be needed in Israel and several encouraging recent developments (e.g. staff training and legislation) suggest that such changes are now underway.

PMID:24595406

62. *Palliat Med.* 2014 Feb 27. [Epub ahead of print]

Prognostic indicators for children and young people at the end of life: A Delphi study.

Shaw KLL, Brook L, Cuddeford L, Fitzmaurice N, Thomas C, Thompson A, Wallis M.

Abstract

BACKGROUND: Recognizing transitions in end of life care for children is difficult and hinders communication and care planning.

AIM: To identify the signs and symptoms that are most useful in signalling which children may have end of life care needs.

METHODS: A Delphi study was undertaken with palliative care professionals who rated the extent to which 75 symptoms alerted them that a child/young person may have moved into his or her last (a) weeks/days, (b) 6-12 months of life using a 7-point response scale. Level of support for items was indicated by the median, and consensus was shown by the mean absolute deviation from the median. The impact of the Delphi on final agreement and consensus was also assessed.

RESULTS: Second-round questionnaires were completed by 49 (89%) individuals. It was easier to identify prognostic items in the last weeks/days than earlier in the end of life trajectory. Items most indicative included failure of physiological systems, deteriorating level of consciousness, loss of autonomic control (e.g. breathing and peripheral circulation), together with a feeling of the professional that life is ending and an agreement that resuscitation would be futile. Items most indicative of last 6/12 months suggest a progressive decline in disease trajectory, increased chest infections or other complications from which the child has difficulty in making a full recovery and which may require high dependency or critical care.

CONCLUSION: This study provides important insight into which signs and symptoms are considered most valuable in identifying children approaching the end of the life.

KEYWORDS: Delphi technique, Palliative care, children, prognosis

PMID: 24577064

63. *Lancet.* 2014 Feb 22;383(9918):671-2. doi: 10.1016/S0140-6736(14)60110-0.

Self-requested euthanasia for children in Belgium.

Dan B1, Fonteyne C2, de Cléty SC3.

PMID: 24560045

64. *Health Place.* 2014 Mar;26:171-9. doi: 10.1016/j.healthplace.2014.01.002. Epub 2014 Jan 15.

Prevalence of life-limiting conditions in children and young people in England: Time trends by area type.

Norman P1, Fraser L2.

Abstract

Palliative care services in England lack data on the number of children with 'life limiting conditions' (LLCs). Recent research determined that the prevalence of LLCs in children in England was double previous estimates. We build on this by analysing time-trends in the prevalence of LLCs by small area deprivation and geodemographic area types. Prevalence is highest for children aged less than one year but time trends show no increase for the youngest age group but significant increases for older children. These increases are mirrored by a decrease in all cause mortality for children suggesting improved survival. Rates are highest in more deprived areas and those typified by multicultural populations. Increasing prevalence and number of cases over time may require increased paediatric palliative care service provision in the future.

KEYWORDS: Deprivation, Hospital Episode Statistics, Life-limiting conditions, ONS Supergroups, Palliative care

PMID:24468834

65. *J Child Health Care.* 2014 Jan 23. [Epub ahead of print]

'Being a presence': The ways in which family support workers encompass, embrace, befriend, accompany and endure with families of life-limited children.

Carter B1, Edwards M, Hunt A.

Abstract

Children with life-limiting and disabling conditions are surviving longer than previously, and many require palliative and supportive care, usually at home. Home-based care can put family life under considerable strain, as parents care for their child's complex, often unpredictable, continuing care needs. Rainbow Trust Children's Charity aims to bridge gaps in services for children with life-threatening or terminal conditions by providing family support workers (FSWs). The study used a range of methods (surveys, interviews and ethnographic observation) approach to explore key aspects of the work of the FSWs. The target population for the surveys was families with a child having complex, life-threatening or terminal conditions receiving care from FSWs. The participants included 55 families (12 bereaved) and 39 children aged 2-18 years. Thematic analysis revealed how the FSWs became a presence in families' lives in three main ways: (1) encompassing and embracing families through supporting needs and promoting resilience; (2) befriending and bonding through developing knowledge, trusting relationships and a sense of closeness; and (3) accompanying and enduring by 'being with' families in different settings, situations and crises and by enduring alongside the families. The study demonstrated the fundamental importance of workers who are able to provide aspects of support that is usually not provided by other services.

PMID:24459101

66. *MCN Am J Matern Child Nurs.* 2014 Jan 17. [Epub ahead of print]

Leaning In and Holding On: Team Support With Unexpected Death.

Kobler K.

Abstract

Integral to the care of medically fragile infants and children is the sobering reality that not all will survive. Supporting children and families through the dying process requires knowledge, skill, compassion, and a willingness to be present to the suffering of others. As healthcare professionals journey with a dying child, they experience an ongoing dual nature of their own grief, shifting between focusing on the loss at hand or avoiding the loss and refocusing their attention elsewhere. This internal conflict may be potentiated with the sudden, unexpected death of a patient, which affords little time for caregivers to process their own experience of the loss. When an unanticipated death occurs, a palpable grief ripples through the entire unit, impacting caregivers, the bereaved parents, and other patients and families. Such an event holds the potential for either team disorganization or growth. This article presents a case study of one unit's response to the unexpected death of a long-term patient, which caused caregivers to lean in to support each other. Using a case study approach, the author identifies strategies to best guide teams when death arrives without warning, and provides ideas for cocreating ritual to honor relationship in the midst of tragedy.

PMID:24445436

67. *Pediatr Radiol.* 2014 Jan;44(1):12-7. doi: 10.1007/s00247-013-2815-x. Epub 2014 Jan 7.

[Interventional radiology in paediatric palliative care.](#)

Roebuck DJ.

Abstract

Paediatric palliative care is a distinct subspecialty that offers treatment to children with many types of illness, including oncological, neurological and respiratory problems. Paediatric interventional radiologists can make a useful contribution to symptom management as part of a multidisciplinary team. Interventions for pain management include local ablation or other treatment of painful lesions, image-guided nerve blocks and the insertion of devices for the delivery of analgesic drugs. Various techniques are also available for the management of ascites, pleural effusions and other symptomatic complications of the underlying disease process.

PMID:24395375

68. *Pediatr Radiol.* 2014 Jan;44(1):3-11. doi: 10.1007/s00247-012-2507-y. Epub 2014 Jan 7.

[Diagnostic radiology in paediatric palliative care.](#)

Patel P1, Koh M, Carr L, McHugh K.

Abstract

Palliative care is an expanding specialty within paediatrics, which has attracted little attention in the paediatric radiological literature. Paediatric patients under a palliative care team will have numerous radiological tests which we traditionally categorise under organ systems rather than under the umbrella of palliative medicine. The prevalence of children with life-limiting illness is significant. It has been estimated to be one per thousand, and this may be an underestimate. In this review, we will focus on our experience at one institution, where radiology has proven to be an invaluable partner to palliative care. We will discuss examples of conditions commonly referred to our palliative care team and delineate the crucial role of diagnostic radiology in determining treatment options.

PMID:24395374

69. *Arch Dis Child.* 2014 Mar;99(3):216-20. doi: 10.1136/archdischild-2013-304249. Epub 2013 Dec 5.

[What parents want from doctors in end-of-life decision-making for children.](#)

Sullivan J1, Monagle P, Gillam L.

Abstract

OBJECTIVE: End-of-life decision-making is difficult for everyone involved, as many studies have shown. Within this complexity, there has been little information on how parents see the role of doctors in end-of-life decision-making for children. This study aimed to examine parents' views and experiences of end-of-life decision-making.

DESIGN: A qualitative method with a semistructured interview design was used.

SETTING: Parent participants were living in the community.

PARTICIPANTS: Twenty-five bereaved parents.

MAIN OUTCOMES: Parents reported varying roles taken by doctors: being the provider of information without opinion; giving information and advice as to the decision that should be taken; and seemingly being the decision maker for the child. The majority of parents found their child's doctor enabled them to be the ultimate decision maker for their child, which was what they very clearly wanted to be, and consequently enabled them to exercise their parental autonomy. Parents found it problematic when doctors took over decision-making. A less frequently reported, yet significant role for doctors was to affirm decisions after they had been made by parents. Other important aspects of the doctor's role were to provide follow-up support and referral.

CONCLUSIONS: Understanding the role that doctors take in end-of-life decisions, and the subsequent impact of that role from the perspective of parents can form the basis of better informed clinical practice.

KEYWORDS: Evidence Based Medicine, Medical Education, Paediatric Practice, Palliative Care

PMID: 24311188

70. *Paediatr Respir Rev.* 2014 Mar;15(1):75-81. doi: 10.1016/j.prrv.2013.07.002. Epub 2013 Aug 13.

[Managing End Stage Lung Disease in Children.](#)

Ringholz F1, Devins M2, McNally P3.

Abstract

Over the course of a career most physicians will manage only a handful of children through End Stage Lung Disease. Nonetheless, the approach of the physician to this challenge will have a profound impact on the children and families they encounter. Managing the end of life well can bring personal growth and professional satisfaction. In this review we highlight aspects of the Palliative Care approach and its integration with restorative and life-prolonging care. We review the role of active treatment, respiratory support, symptom management and psychosocial aspects of the management of End Stage Lung Disease.

KEYWORDS:

Death, Lung disease, Palliative care, Psychosocial care, Symptom management

PMID: 23948571

71. *J Pain Symptom Manage.* 2014 Feb;47(2):315-24. doi: 10.1016/j.jpainsymman.2013.03.022. Epub 2013 Jul 18.

[Palliative care research in Africa: consensus building for a prioritized agenda.](#)

Powell RA1, Harding R2, Namisango E3, Katabira E4, Gwyther L5, Radbruch L6, Murray SA7, El-Ansary M8, Leng M9, Ajayi IO10, Blanchard C11, Kariuki H12, Kasirye I13, Namukwaya E9, Gafer N14, Casarett D15, Atieno M3, Mwangi-Powell FN16.

Abstract

CONTEXT: Palliative care research in Africa is in its relative infancy, with dedicated financial support extremely limited. Therefore, setting research priorities to optimize use of limited resources is imperative.

OBJECTIVES: To develop a prioritized research agenda for palliative care in Africa.

METHODS: We used a two-stage process involving palliative care professionals and researchers: 1) generation of an initial topic list at a consultative workshop of experts and 2) prioritization of that list using a consensus development process, the nominal group technique.

RESULTS: Phase 1: 41 topics were generated across five groups, with several topics nominated in more than one group. Phase 2: 16 topics and three broad thematic areas were identified. The two most prioritized topics within each of the three themes were the following: Theme 1: patient, family, and volunteers-1) care outcomes and the impact of palliative care as perceived by patients and caregivers and 2) palliative care needs of children; Theme 2: health providers-1) impact of palliative care training on care and practice and 2) integration of palliative care and antiretroviral therapy services; and Theme 3: health systems-1) palliative care needs assessments at the micro-, meso-, and macro-levels and 2) integration of palliative care into health systems and educational curricula.

CONCLUSION: Consensus-based palliative care topics determined by the study can assist researchers in optimizing limited research capacities by focusing on these prioritized areas. Subsequent to the identification and publication of the research agenda, concrete steps will be undertaken by the African Palliative Care Research Network and other partners to help implement it.

KEYWORDS: Africa, palliative care, participatory, priorities, research agenda

PMID: 23870840

72. *An Pediatr (Barc)*. 2014 Mar;80(3):181-3. doi: 10.1016/j.anpedi.2013.05.007. Epub 2013 Jun 21.

[\[Withdrawal of assisted ventilation in the home: Making decisions in paediatric palliative care\]. \[Article in Spanish\]](#)

García-Salido A1, Monleón-Luque M2, Barceló-Escario M2, Del Rincón-Fernández C2, Catá-Del Palacio E2, Martino-Alba R2.

Abstract

End-of-life care is of growing interest in Paediatrics. The number of children with diseases being treated using high-technology as palliative treatment has also increased. The creation of multidisciplinary care teams with 24/7hours home care may prevent prolonged hospital stays in these patients. To adapt the treatment in order to avoid new hospital admissions and to obtain a better quality of life is a desirable objective. The taking of decisions and subsequent withdrawal of mechanical ventilation in the home is presented, along with the underlying disease and the acute event that led to the worsening of the patient. The decision-making and clinical management until the death of the patient is then discussed and reviewed.

KEYWORDS: Airway extubation, Cuidados intensivos, Cuidados paliativos, Domiciliary care, Extubación, Intensive care, Paediatrics, Palliative care, Pediatría, Tratamiento domiciliario

PMID: 23796610

73. *Am J Hosp Palliat Care*. 2014 Feb;31(1):57-60. doi: 10.1177/1049909113481100. Epub 2013 Mar 15.

[Hardships of End-of-Life Care With Court-Appointed Guardians.](#)

Hastings KB.

Abstract

In the United States, the court-appointed guardians do not have the ability to make decisions regarding end-of-life (EOL) care for their clients. Additionally, the process of initiating EOL care measures can be slow and cumbersome, despite an existing process of getting approval for such care. This process has the potential to prolong suffering and delay imperative decisions. This article reviews the hardships that patients, court-appointed guardians, and health care staff endure while moving through the oppressive process of obtaining EOL care orders through the court. This article also proposes ways of tuning up the laws, regulations, and communications to make it easier and faster to obtain orders regarding EOL care to preserve the dignity of our patients and loved ones. "A guardianship is a legal relationship created when a person or institution named in a will or assigned by the court to take care of minor children or incompetent adults."(6.)

KEYWORDS: comfort care, end of life, guardianship, hospice, palliative care, surrogacy

PMID: 23503563

74. *Child Care Health Dev*. 2014 Mar;40(2):176-83. doi: 10.1111/cch.12020. Epub 2012 Nov 30.

[Was there a plan? End-of-life care for children with life-limiting conditions: a review of multi-service healthcare records.](#)

Berlinger AJ1, Heckford EJ.

Abstract

BACKGROUND: Planning for care at the end of life (EoL) is an essential component of support and care for families of children with life-limiting conditions. The purpose of this review was to compare documented EoL planning with published children's palliative care standards, across a range of children's healthcare services and to assess the impact on practice of written guidelines to support EoL care planning.

METHOD: A manual retrospective review of healthcare records using a purpose-built form. Inclusion criteria were the records of children with a diagnosed life-limiting or life-threatening condition, who had died before the age of 18 years, between October 2008 and March 2010, within a defined geographical area served by one or more of the participating services. The sample was 114 sets of notes relating to a cohort of 48 children: 24 girls and 24 boys, the majority of whose deaths were cancer related.

RESULTS: Examples of good practice were found in the records of individual services. Services had each developed their own systems and documents to support EoL care planning rather than using a unified documentation system. Where documented practice fell short, this was related to a lack of evidence that choice in location of death had been offered, delays in sharing of information between services, and information being buried in the narrative of the notes, making it difficult to find.

CONCLUSIONS: Current documented EoL planning varies between services. Those who are infrequently involved in the provision of EoL care may benefit from support by those for whom this is part of their daily working life. These professionals can help prepare staff to engage families in these difficult but important conversations - and encourage them to document them in a way that can be easily and readily accessed and shared.

KEYWORDS: advance planning, child and family wishes, documentation, end of life, review

PMID: 23198741

75. *ScientificWorldJournal*. 2013 Dec 31;2013:498082. doi: 10.1155/2013/498082. eCollection 2013.

[The impact of pediatric palliative care education on medical students' knowledge and attitudes.](#)

Korzeniewska-Eksterowicz A1, Przyslo Ł1, Kędzierska B2, Stolarska M3, Młynarski W4.

Abstract

PURPOSE: Most undergraduate palliative care curricula omit pediatric palliative care (PPC) issues. Aim of the study was to evaluate the pilot education programme.

METHODS: All 391 students of Faculty of Medicine (FM) and 59 students of Division of Nursing (DN) were included in anonymous questionnaire study. Respondents were tested on their knowledge and attitude towards PPC issues before and at the end of the programme and were expected to evaluate the programme at the end.

RESULTS: For final analysis, authors qualified 375 double forms filled in correctly (320 FM and 55 DN). Before the programme, students' knowledge assessed on 0-100-point scale was low (FM: median: 43.35 points; 25%-75%: (40p-53.3p); DN: 26.7p; 13.3p-46.7p), and, in addition, there were differences ($P < 0.001$) between both faculties. Upon completion of the programme, significant increase of the level of knowledge in both faculties was noted (FM: 80p; 73.3-100; DN: 80p; 66.7p-80p). Participation in the programme changed declared attitudes towards some aspects of withholding of special procedures, euthanasia, and abortion. Both groups of students positively evaluated the programme.

CONCLUSIONS: This study identifies medical students' limited knowledge of PPC. Educational intervention changes students' attitudes to the specific end-of-life issues. There is a need for palliative care curricula evaluation.

PMID: 24501581

76. [Semin Perinatol](#). 2014 Feb;38(1):31-7. doi: 10.1053/j.semperi.2013.07.006.

[End-of-life decisions for extremely low-gestational-age infants: Why simple rules for complicated decisions should be avoided.](#)

[Dupont-Thibodeau A1](#), [Barrington KJ2](#), [Farlow B3](#), [Janvier A4](#).

Abstract

Interventions for extremely preterm infants bring up many ethical questions. Guidelines for intervention in the "perivable" period generally divide infants using predefined categories, such as "futile," "beneficial," and "gray zone" based on completed 7-day periods of gestation; however, such definitions often differ among countries. The ethical justification for using gestational age as the determination of the category boundaries is rarely discussed. Rational criteria used to make decisions regarding life-sustaining interventions must incorporate other important prognostic information. Precise guidelines based on imprecise data are not rational. Gestational age-based guidelines include an implicit judgment of what is deemed to be an unacceptably poor chance of "intact" survival but fail to explore the determination of acceptability. Furthermore, unclear definitions of severe disability, the difficulty, or impossibility, of accurately predicting outcome in the prenatal or immediate postnatal period make such simplistic formulae inappropriate. Similarly, if guidelines for intervention for the newborn are based on the "qualitative futility" of survival, it should be explicitly stated and justified according to established ethical guidelines. They should discuss whether newborn infants are morally different to older individuals or explain why thresholds recommended for intervention are different to recommendations for those in older persons. The aim should be to establish individualized goals of care with families while recognizing uncertainty, rather than acting on labels derived from gestational age categories alone.

KEYWORDS: CPR, Disability, ELGAN, End-of-life decisions, Ethics, Experimental medicine, Extreme prematurity, Extremely low-gestational-age infants (ELgestational ageN), Futility, Informed consent, Life-sustaining interventions, NICU, Parental adaptation, Withhold and withdraw intensive care, cardiopulmonary resuscitation, extremely low-gestational-age infants, neonatal intensive care unit

PMID: 24468567