Una nuova collaborazione

Questa è il primo numero di una Newsletter che contiene una selezione dei più recenti articoli apparsi sulla letteratura scientifica internazionale in tema di Cure Palliative e Terapia del dolore in ambito pediatrico.

È una nuova iniziativa, nata dalla collaborazione fra la Fondazione 3Bi, Biblioteca Biomedica Biellese (www.3bi.info) e la Fondazione Maruzza Lefebvre d’Ovidio Onlus (www.maruzza.org), che ha l’obiettivo di garantire un aggiornamento costante nel tempo agli operatori che in Italia operano in questo settore particolarmente delicato della medicina, con lo scopo di migliorare le loro competenze e la qualità delle cure offerte a malati e familiari.

Un augurio di buon lavoro a tutti!

Carlo Peruselli
Presidente Fondazione 3Bi

Silvia Lefebvre d’Ovidio
Fondazione Maruzza Lefebvre d’Ovidio Onlus

“La Buona informazione è la miglior medicina…”
Donald A.B. Lindberg

Aprile 2014
N° 1

TABLE OF CONTENTS

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Una nuova collaborazione</td>
<td>pag. 1</td>
</tr>
<tr>
<td>Abstracts Articoli</td>
<td>pag. 2 a pag. 13</td>
</tr>
</tbody>
</table>

“Tra Medicina e letteratura corse sempre amicizia”
Carlo Dossi

Fondazione 3Bi
Biblioteca Biomedica Biellese

Sito: www.3bi.info
tel.: 015-15153132

Dott.ssa Roberta Maoret
Responsabile
Documentalista biomedico
biblioteca@3bi.info

Maruzza Lefebvre d’Ovidio Foundation

Site: www.maruzza.org
tel.: 06-3290609

info@maruzza.org
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.

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, 1.8-9,600,000 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

Pediatric palliative care.
[No authors listed]
Letter to Editor.
PMID:24616893

Regoaling: a conceptual model of how parents of children with serious illness change medical care goals.
Hill DL, Miller V, Walter IK, Carroll KW, Morrison WE, Munson DA, Kang TI, Hinds PS, Feudtner C.

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

End-of-life Care for Children Enrolled in a Community-Based Pediatric Palliative Care Program.
Niswander LM, 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

Management of breakthrough pain in children with cancer.
Friedrichsdorf SJ, Postier A.

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 overedation. 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
CONCLUSION(S): Invitations 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.

OBJECTIVES: To investigate parental decision making for children cared for by the palliative care team while eligible for recruitment. To explore reasons for non-participation. To understand the impact of this on sample bias.

METHOD: A qualitative interview method was used to examine the views and experiences of 25 bereaved parents in end-of-life care. 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, although not all difficulties were related directly to decision-making. Parents considered that the principal parents should be the end-of-life decision-maker for their child, but understood personal characteristics and preferences could prevent some parents from taking this role.

CONCLUSIONS: This study unequivocally supports parents' desire to fulfill 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.

ABSTRACT: 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
Palliative care in the young person’s community: support for schools.
Craig F, Kelly P, Boden C, Samuel I.
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 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.
RESULT(S): Overall, 30% of CYP cancer deaths occurred in WH periods. Compared to other periods (35.7% [48.2-49.3%], 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, Residential care, Healthcare staffing and service levels during weekends and holiday periods among children and young people (CYP) who die from cancer.
PMD:24644806

An audit of documented referral information for children referred to a UK paediatric and young person’s hospice.
McKeating C, Koodyvedath 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. Hospice staff must ensure quality, sustainable care and essential levels of care provision to this vulnerable group of children.
AIM(S) AND METHOD(S): 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.
RESULT(S): 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), parent 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.
CONCLUSION(S): 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.
PMD:24644809

Paediatric palliative care - the role of the GP.
Armitage N, Trethevie 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.
A support that specialist PPC teams can offer the GP is also emphasised.
PMD:24644852
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, type 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: 24678187
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:24678065


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:24678065


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 (PCC). 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. PCC 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 PCC 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 PCC include fear of opioid use, lack of education on PCC, lack of integration into the primary care system, lack of policies on PCC, and lack of community and health professional awareness of PCC needs and services. Estimating the need for PCC 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:24678589


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 93 AOs. Ninety-six percent of POs had access to inpatient SPC consultation services (vs. 48% AOs), 31% to a PCC (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/ircurable 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 procedures (17 vs. 7%, p = 0.002), and that palliative care was perceived negatively by their patients (40 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


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 50%. 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


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
Abstract

26. KEYWORDS: children, chronic disease, pediatrics, spirituality

03.asp, free with no login].

understand and meet the spiritual needs of children with chronic illnesses. [Full text available at http://rimed.org/rimedicalj

beliefs have the potential to support as well as hinder children's ability to cope with chronic illness. More research is nee

wellbeing of pediatric patients; however, in this regard, most studies have focused on pediatric palliative and end

Chronic illnesses represent a growing burden of disease among children and adolescents, making it imperative to understand th

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 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

When should we tell the children?

Foulkes M, Hampton-Matthews J, Coachley 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 have expressed the need to talk to 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 cancer nurse contact time for patients and their family. Patients 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

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


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: In the calendar year 2013, cases of children and young people aged 0-40 years with LLCs were identified within an English Hospital Episode Statistics dataset by applying a custom-designed 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 59.5-64.7) and 50.0 per 10000 male (95% CI 48.0-52.1) 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:24644980

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 belief systems can provide support as well as hinder children’s ability to cope with chronic illness. More research is needed to 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: 24986957

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:24593532


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

Coad I1, 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:24593000


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


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 one or both 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


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

Friszola 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 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 hard work may be rewarded with an increased referral rate.

PMID:24576099


Palliative Care in Children with Spinal Muscular Atrophy Type I: What do they need?

García-Salido A1, de Paso-Mora MG1, Monléon-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 87 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 (84%) 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:24585112
The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring.

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 by 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 compassion, ethical, and
holistic care to the entire family when a child is ill.

KEYWORDS: autonomy, communication, ethics, palliative care, relational autonomy
PMID: 24488536


Relational autonomy: moving beyond the limits of isolated individualism.
Walter JK., 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 a 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


Pediatric palliative care and pediatric medical ethics: opportunities and challenges.
Feudtner C., 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

PMID: 24487917


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


Patient Involvement in Informed Consent for Pediatric Phase I Cancer Research.
Miller VA., Baker JN, Leek AC, Drobat 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 1 trial. Consent conferences were audio-taped, transcribed, and coded for communication between patients and physicians and between patients and parents.

RESULTS: Of 29 children enrolled, 27 had delirium episodes. We report on five children and six episodes of delirium. The majority of episodes started during or immediately post-dosing with antipsychotics, with the vast majority (75%) 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 assistance of parents 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


Parents' understanding of and accuracy in using measuring devices to administer liquid oral pain medication.

Tanner SJ, Wells M, Scarbacz 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 participant after the measuring exercise in weight and compared the difference in weight with 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 χ² test showed no statistically significant difference between the control and study groups for dosing accuracy. The χ² 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: 24467605


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 "STOPIE" 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


A Relational Ethical Approach to End-of-Life Delirium.

Wright DK1, Brajman 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 relational 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
The impact of a palliative care team on residents' experiences and comfort levels with pediatric palliative care.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

The Need of Pediatric Palliative Care Education Among Pediatric Postgraduates in South India.
Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution.

Poster A1, Chrostek I, Nugent S, Osenga K, Friedrichsdorf S.

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 428 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

---

Siblings caring for and about pediatric palliative care patients.

Gaab EM, Owens GR, MacLeod BD.

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 analysis.

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

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 allowed mechanical ventilation, hemodialfiltration, 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. Concerns were expressed about the quality of treatment, the involvement of the patient, hospitalization and emergency room admissions, and the quality of end-of-life care. Some caregivers feel that the law is not clear.

CONCLUSION: This study is the first to show that caregivers of French PICUs have good knowledge of the French law concerning the withdrawal of life-sustaining treatment (WWLST) decisions, and their feelings about how these decisions were made and implemented.

PMID: 24315107

---

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

Talley JA, Marie 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:24626864


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 PI, Hirsch J2, Wager J1, Dobe M1, Krummenauer F2, Zernikow B3.

Abstract

Pediatric chronic pain can result in deleterious effects for the child, which result from pain aggravation into adulthood. Intensive interdisciplinary pain treatment (IPT) might be an effective treatment, given the advantage of consulting with multiple professionals on a daily basis. Evidence for the effectiveness of IPT is scarce. We investigated the efficacy of an IPT 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 (58% 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 IPT. 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:24660069


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

OBJECTIVES: This study aimed to evaluate the effect of a palliative care consultation service (PCCS) on DNR designation and treatment.-related complications and distal branch pulmonary artery stenosis. Palliative ductal stenting appears to be a safe and effective alternative to modified Blalock-Taussig shunt.

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 shunt in selected infants.


PMID:24071468


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 GC2, Huang KG3, Jaing TH4, Liu CY5, Liu KH6, Shen WC1, Wu HI1, Hung YS1, Hsu HC1, Chen JS1, Liau 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 benefit from care by the PCCS with respect to DNR designation.

METHODS: In total, 2985 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:23858089

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%) 532 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:24038868


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


The CHANGE study: a healthy-lifestyle 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 promote healthy 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=1.5; 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:24192895


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 236 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.

PMD: 23989499


Communicating about prognosis: ethical responsibilities of pediatricians and parents.

Mack IW1, 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

PMD: 24468837


Patient Involvement in Informed Consent for Pediatric Phase I Cancer Research.

Miller VA1, Baker IN, Leek AC, Drota 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

PMD: 24582644


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

Mazille N1, Lizler-Renault B1, Weider H1, Donato L1, Astruc D1, Kuhn P2.

Abstract

The "Parents' 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 program" (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. 5/39 (P=0.05) 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.

PMD: 24398077


Quality of dying and death with cancer in Israel.

Braun M1, Hasson-Chavoy I, Hales S, Zimmermann C, Rydall A, Peretz T, Rodin O.

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:24596406


Prognostic indicators for children at the end of life: A Delphi study.
Shaw KL1, Brook L, Cuddiford 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) 8-12 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


Self-requested euthanasia for children in Belgium.
Dan B1, Fosteyne C2, de Cléty SC3.

PMID: 24550065


Norman P1, Fraser L2.

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 old. Using the prevalence of LLCs, we determined that life expectancy is lowest for children aged less than five years and highest for children aged between five and nine years old. The prevalence of LLCs is highest in disadvantaged areas and lowest in the highest socio-economic areas. The prevalence of LLCs is stable in the last ten years.

CONCLUSIONS: This study provides an understanding of the prevalence and trends of LLCs in children in England, which can be used to inform public health policy and service planning.

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

PMID:24468834


Being a presence: The ways in which family support workers encompass, embrace, befriend, accompany and endure with families of life-limiting 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 expanding 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:24499101


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 anticipated 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, ideally, team resilience. 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 relationships in the midst of tragedy.

PMID: 24445436

Interventional radiology in paediatric palliative care.
Roebuck DJ.

Abstract
Paediatric palliative care is a distinct sub-specialty 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

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 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

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 semi-structured 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 justifying the decision that was 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

Managing End Stage Lung Disease in Children.
Ringholtz P1, 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

Palliative care research in Africa: consensus building for a prioritized agenda.
Powell RA1, Harding R2, Namisango E3, Kataebra E4, Gwyrther L5, Radbruch L6, Murray SA7, Leng M9, Ajayi IO10, Blanchard C11, Karubi H12, Kasirye I13, Namukwaya E9, Gafer N14, Casaret 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: 18 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 Pediatric Care Research Network and other partners to help implement it.

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

PMID: 23870840


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


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 24/7 hours 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, Domiciliar care, Extubación, Intensive care, Paediatrics, Palliative care, Pediatrics, Tratamiento domiciliario

PMID: 23796610


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: 23903683


Beringer AI1, 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


The impact of pediatric palliative care education on medical students’ knowledge and attitudes.


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: 43.3S 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

End-of-life decisions for extremely low-gestational-age infants: Why simple rules for complicated decisions should be avoided.
Dupont-Thibodeau A1, Barrington KE2, 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: 24468867