

Newsletter with bibliographic updates on Paediatric Palliative Care and Pain Management

“Good information is the best medicine...”

Donald A.B. Lindberg



The second number

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1. **Depression (PDQ®): Patient Version [Internet].**

Authors

PDQ Supportive and Palliative Care Editorial Board.

PDQ Cancer Information Summaries [Internet]. Bethesda (MD): National Cancer Institute (US); 2002-. 2014 Dec 3.

Excerpt

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

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PMID: 26389474

2. **Depression (PDQ®): Health Professional Version [Internet].**

Authors

PDQ Supportive and Palliative Care Editorial Board.

PDQ Cancer Information Summaries [Internet]. Bethesda (MD): National Cancer Institute (US); 2002-. 2016 Jan 4.

Excerpt

This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about cancer-related depression and suicide risk in both the adult and the pediatric population. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making health care decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive and Palliative Care Editorial Board,

which is editorially independent of the National Cancer Institute (NCI). The summary reflects an independent review of the literature and does not represent a policy statement of NCI or the National Institutes of Health (NIH).

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PMID: 26389407

3. Cancer Radiother. 2016 Mar 28. [Epub ahead of print]

[Prevention and treatment of mucositis in children with oral cancers: Practical recommendations].

[Article in French]

El Bousaadani A¹, Eljahd L², Abada R², Rouadi S², Roubal M², Mahtar M².

Abstract

Oral mucositis is an inflammation of the mucosa of the oral cavity of various etiologies. This is a common and debilitating complication in children treated with chemoradiotherapy for cancer. Its management remains a major concern both for the doctor than the patient. It affects the quality of life of patients and families. It may initiate the functional and vital prognosis because of the judgment of cancer treatment. Several treatment options are available, but there is no clear consensus therapeutic especially for the pediatric population. We have identified, through a comprehensive literature search indexed publications on this subject in order to review the pharmacological and non-pharmacological approaches that have been used to prevent and treat oral mucositis. Thus, current recommendations for the management of oral mucositis are very limited, and therefore the standard of care for this complication was palliative. In recent years several studies have revealed that the use of low-energy laser was particularly interesting in the prevention and treatment of radiation-induced or chemically induced mucositis. It significantly reduces the pain, the severity and duration of the ulcer by promoting wound healing. Randomized controlled trials with a large number of patients are expected to establish preventive and therapeutic protocols. Treatment with low power laser, known devoid of side effects, is a very promising oncology care to support radio-induced mucositis and chemotherapy.

PMID: 27032624

4. Cochrane Database Syst Rev. 2016 Mar 31;3:CD008796.

Physical exercise training interventions for children and young adults during and after treatment for childhood cancer.

Braam KI¹, van der Torre P, Takken T, Veening MA, van Dulmen-den Broeder E, Kaspers GJ.

Abstract

BACKGROUND: A decreased physical fitness has been reported in patients and survivors of childhood cancer. This is influenced by the negative effects of the disease and the treatment of childhood cancer. Exercise training for adult cancer patients has frequently been reported to improve physical fitness. In recent years, literature on this subject has also become available for children and young adults with cancer, both during and after treatment. This is an update of the original review that was performed in 2011.

OBJECTIVES:

To evaluate the effect of a physical exercise training intervention on the physical fitness (i.e. aerobic capacity, muscle strength, or functional performance) of children with cancer within the first five years from their diagnosis (performed either during or after cancer treatment), compared to a control group of children with cancer who did not receive an exercise intervention. To determine whether physical exercise within the first five years of diagnosis has an effect on fatigue, anxiety, depression, self efficacy, and HRQoL and to determine whether there are any adverse effects of the intervention.

SEARCH METHODS:

We searched the electronic databases of Cochrane Register of Controlled Trials (CENTRAL), MEDLINE, EMBASE, CINAHL, and PEDro; ongoing trial registries and conference proceedings on 6 September 2011 and 11 November 2014. In addition, we performed a handsearch of reference lists.

SELECTION CRITERIA: The review included randomized controlled trials (RCTs) and clinical controlled trials (CCTs) that compared the effects of physical exercise training with no training, in people who were within the first five years of their diagnosis of childhood cancer.

DATA COLLECTION AND ANALYSIS: Two review authors independently identified studies meeting the

inclusion criteria, performed the data extraction, and assessed the risk of bias using standardized forms. Study quality was rated by the Grading of Recommendation Assessment, Development and Evaluation (GRADE) criteria.

MAIN RESULTS: Apart from the five studies in the original review, this update included one additional RCT. In total, the analysis included 171 participants, all during treatment for childhood acute lymphoblastic leukaemia (ALL). The duration of the training sessions ranged from 15 to 60 minutes per session. Both the type of intervention and intervention period varied in all the included studies. However, the control group always received usual care. All studies had methodological limitations, such as small numbers of participants, unclear randomization methods, and single-blind study designs in case of one RCT and all results were of moderate to very low quality (GRADE). Cardiorespiratory fitness was evaluated by the 9-minute run-walk test, timed up-and-down stairs test, the timed up-and-go time test, and the 20-m shuttle run test. Data of the 9-minute run-walk test and the timed up-and-down stairs test could be pooled. The combined 9-minute run-walk test results showed significant differences between the intervention and the control groups, in favour of the intervention group (standardized mean difference (SMD) 0.69; 95% confidence interval (CI) 0.02 to 1.35). Pooled data from the timed up-and-down stairs test showed no significant differences in cardiorespiratory fitness (SMD -0.54; 95% CI -1.77 to 0.70). However, there was considerable heterogeneity ($I^2 = 84\%$) between the two studies on this outcome. The other two single-study outcomes, 20-m shuttle run test and the timed up-and-go test, also showed positive results for cardiorespiratory fitness in favour of the intervention group. Only one study assessed the effect of exercise on bone mineral density (total body), showing a statistically significant positive intervention effect (SMD 1.07; 95% CI 0.48 to 1.66). The pooled data on body mass index showed no statistically significant end-score difference between the intervention and control group (SMD 0.59; 95% CI -0.23 to 1.41). Three studies assessed flexibility. Two studies assessed ankle dorsiflexion. One study assessed active ankle dorsiflexion, while the other assessed passive ankle dorsiflexion. There were no statistically significant differences between the intervention and control group with the active ankle dorsiflexion test; however, in favour of the intervention group, they were found for passive ankle dorsiflexion (SMD 0.69; 95% CI 0.12 to 1.25). The third study assessed body flexibility using the sit-and-reach distance test, but identified no statistically significant difference between the intervention and control group. Three studies assessed muscle strength (knee, ankle, back and leg, and inspiratory muscle strength). Only the back and leg strength combination score showed statistically significant differences on the muscle strength end-score between the intervention and control group (SMD 1.41; 95% CI 0.71 to 2.11). Apart from one sub-scale of the cancer scale (Worries; P value = 0.03), none of the health-related quality of life scales showed a significant difference between both study groups on the end-score. For the other outcomes of fatigue, level of daily activity, and adverse events (all assessed in one study), there were no statistically significant differences between the intervention and control group. None of the included studies evaluated activity energy expenditure, time spent on exercise, anxiety and depression, or self efficacy as an outcome.

AUTHORS' CONCLUSIONS: The effects of physical exercise training interventions for childhood cancer participants are not yet convincing. Possible reasons are the small numbers of participants and insufficient study designs, but it can also be that this type of intervention is not as effective as in adult cancer patients. However, the first results show some positive effects on physical fitness in the intervention group compared to the control group. There were positive intervention effects for body composition, flexibility, cardiorespiratory fitness, muscle strength, and health-related quality of life (cancer-related items). These were measured by some assessment methods, but not all. However, the quality of the evidence was low and these positive effects were not found for the other assessed outcomes, such as fatigue, level of daily activity, and adverse events. There is a need for more studies with comparable aims and interventions, using a higher number of participants that also include diagnoses other than ALL.

PMID: 27030386

5. Child Care Health Dev. 2016 Mar 29. [Epub ahead of print]

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

Liberman DB^{1,2}, Song E³, Radbill LM^{2,4}, Pham PK¹, Derrington SF⁵.

Abstract

Children with complex chronic medical conditions benefit from early introduction of palliative care services and advanced care planning for symptom management and to support quality of life and medical decision-

making. This study evaluated whether introducing palliative care during primary care appointments (1) was feasible; (2) increased access and improved knowledge of palliative care; and (3) facilitated advanced care planning.

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

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

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

PMID: 27028099

6. J Palliat Med. 2016 Mar 29. [Epub ahead of print]

[Conversation Game Effectively Engages Groups of Individuals in Discussions about Death and Dying.](#)

[Van Scoy LJ](#)¹, [Reading JM](#)¹, [Scott AM](#)², [Green MJ](#)³, [Levi BH](#)⁴.

Abstract

BACKGROUND: Discussions about end-of-life (EOL) values, wishes, and beliefs are critical for effective advance care planning (ACP). New strategies are needed to engage individuals in EOL conversations.

OBJECTIVE: The study objective was to test the feasibility of using a conversation game to engage individuals in EOL discussions.

METHODS: This study used a mixed-methods approach. Participants played a conversation game that prompts players to answer and discuss 20 questions about death, dying, and EOL care. Participants completed pre- and postgame questionnaires and participated in postgame focus groups. Subjects were 70 healthy volunteers (18 groups of families, friends, or strangers). Demographics, emotional state, and perceived relational closeness were measured using preintervention questionnaires. Postintervention questionnaires measured conversation satisfaction, realism, self-rated quality, and emotional state. Postgame focus groups evaluated players' experiences playing the game.

RESULTS: Using a seven-point Likert scale (1 = low score, 7 = high score), players rated game conversations as satisfying (mean [M] = 6.1, SD = 0.9), realistic (M = 5.6, SD = 0.8), and of high quality (M = 5.7, SD = 0.9). There were no negative effects on emotional state immediately postgame (M = 1.3, SD = 0.5). A thematic analysis of participants' experiences (n = 55) revealed that (1) playing the game was an enjoyable, positive experience; (2) a game is a good framing for EOL discussions; and (3) there were mixed opinions about ideal game group composition.

CONCLUSIONS: This study established that healthy volunteers enjoyed engaging in a two-hour discussion about EOL issues when framed as a game. The game experience was a positive, satisfying, and enjoyable activity for participants. Further studies are needed to determine if health games can promote effective ACP.

PMID: 27022862

7. Palliat Support Care. 2016 Mar 29:1-15. [Epub ahead of print]

[A systematic review of instruments assessing dimensions of distress among caregivers of adult and pediatric cancer patients.](#)

[Tanco K](#)¹, [Park JC](#)², [Cerana A](#)¹, [Sisson A](#)³, [Sobti N](#)⁴, [Bruera E](#)¹.

OBJECTIVE: Caregivers of cancer patients face intense demands throughout the course of the disease,

survivorship, and bereavement. Caregiver burden, needs, satisfaction, quality of life, and other significant areas of caregiving are not monitored regularly in the clinic setting, resulting in a need to address the availability and clinical effectiveness of cancer caregiver distress tools. This review aimed to determine the availability of cancer caregiver instruments, the variation of instruments between different domains of distress, and that between adult and pediatric cancer patient populations.

METHOD: A literature search was conducted using various databases from 1937 to 2013. Original articles on instruments were extracted separately if not included in the original literature search. The instruments were divided into different areas of caregiver distress and into adult versus pediatric populations. Psychometric data were also evaluated.

RESULTS: A total of 5,541 articles were reviewed, and 135 articles (2.4%) were accepted based on our inclusion criteria. Some 59 instruments were identified, which fell into the following categories: burden (n = 26, 44%); satisfaction with healthcare delivery (n = 5, 8.5%); needs (n = 14, 23.7%); quality of life (n = 9, 15.3%); and other issues (n = 5, 8.5%). The median number of items was 29 (4-125): 20/59 instruments (33.9%) had ≤20 items; 13 (22%) had ≤20 items and were psychometrically sound, with 12 of these 13 (92.3%) being self-report questionnaires. There were 44 instruments (74.6%) that measured caregiver distress for adult cancer patients and 15 (25.4%) for caregivers of pediatric patients.

SIGNIFICANCE OF RESULTS: There is a significant number of cancer caregiver instruments that are self-reported, concise, and psychometrically sound, which makes them attractive for further research into their clinical use, outcomes, and effectiveness.

PMID: 27021206

8. J Palliat Med. 2016 Mar 23. [Epub ahead of print]

The Role of Psychology in Pediatric Palliative Care.

Edlynn E^{1,2}, Kaur H³.

Abstract

Pediatric medicine increasingly has recognized the value of integrating behavioral health in medical care, but this trend has not yet extended to pediatric palliative care. Results from a recent survey of pediatric palliative care programs across the United States indicate that team composition almost never included a psychologist. This article presents a model of collaborative care to optimize the integration of psychosocial and medical aspects of treatment in pediatric palliative care, delineating how a psychologist adds to this model. This article argues that psychology brings specialized skills in assessment, intervention, and research that fit with the premise of palliative care as a holistic approach that relieves symptoms. Systematic inclusion of psychologists on pediatric palliative care teams may help to improve effectiveness of services as well as extend the knowledge base of mental health in pediatric palliative care.

PMID: 27008276

9. JAMA Pediatr. 2016 Mar 21. doi: 10.1001/jamapediatrics.2015.4689. [Epub ahead of print]

Cancer in Adolescents and Young Adults: A Narrative Review of the Current Status and a View of the Future.

Barr RD¹, Ferrari A², Ries L³, Whelan J⁴, Bleyer WA⁵.

Abstract

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

Observations: Many of the challenges faced by AYAs with a diagnosis of malignant disease are shared by others with chronic medical conditions and even their healthy peers, such as a sense of invulnerability that may contribute to delays in diagnosis. A particular need for psychological support has been identified for AYAs with cancer, even after active therapy has been completed and especially in the context of palliative care. Notable needs also include fertility preservation and navigation through the multiple transitions in the

cancer journey. Additionally, there is a "cost of cure." This is not only in the form of short-term, treatment-related morbidity and mortality but also in the burden of "late effects," including second cancers, that compromise quality of life and limit life expectancy. Establishing clinical programs devoted to AYAs with cancer, with complementary educational initiatives, will strengthen the advances made. It is anticipated that clinical trial accrual will increase substantially, providing further gains in survival. Likewise, addressing the challenges of survivorship, including secondary prevention of long-term morbidity and mortality, will lead to additional improvements in clinical outcomes.

Conclusions and Relevance:

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

PMID: 26999630

10. *Annu Rev Public Health*. 2016 Mar 18;37:357-74.

Opportunities for Palliative Care in Public Health.

De Lima L¹, Pastrana T².

Abstract

In May 2014, the World Health Assembly, of the World Health Organization (WHO), unanimously adopted a palliative care (PC) resolution, which outlines clear recommendations to the United Nations member states, such as including PC in national health policies and in the undergraduate curricula for health care professionals, and highlights the critical need for countries to ensure that there is an adequate supply of essential PC medicines, especially those needed to alleviate pain. This resolution also carries great challenges: Every year over 20 million patients (of which 6% are children) need PC at the end of life (EOL). However, in 2011, approximately three million patients received PC, and only one in ten people in need is currently receiving it. We describe this public health situation and systems failure, the history and evolution of PC, and the components of the WHO public health model. We propose a role for public health for PC integration in community settings to advance PC and relieve suffering in the world.

PMID: 26989831

11. *Palliat Med*. 2016 Mar 15. [Epub ahead of print]

Death after cessation of treatment by cystic fibrosis patients: An international survey of clinicians.

Pisaturo M¹, Deppen A², Rochat I³, Robinson WM⁴, Hafen GM⁵.

Abstract

BACKGROUND: Little is known about cystic fibrosis patients, who are not considered to be terminally ill, and who die after voluntary cessation of treatment.

AIM: This study was undertaken to provide an international snapshot of this issue.

DESIGN: An online survey was distributed across three continents.

SETTING: Distribution to the medical directors of the cystic fibrosis centres affiliated with the US Cystic Fibrosis Foundation, Cystic Fibrosis Australia (inclusion of New Zealand) and to every clinician member of the European Cystic Fibrosis Society.

RESULTS: More than 200 cystic fibrosis patients not considered to be terminally ill and, who voluntarily ceased treatment, were reported by the clinicians surveyed. Detailed data were reported in 102 patients (4 children, 25 adolescents and 73 adults). Only one child, six adolescents and one adult were judged by clinicians not to be competent to make the decision to stop treatment. Time-consuming and low immediate-impact therapies, such as respiratory physiotherapy, were most frequently discontinued. Resignation was the main reported reason for discontinuing treatment, followed by reactive depression and lack of familial support. A total of 69% of the patients received palliative care and 72% died in the 6 months following cessation of treatment.

CONCLUSION: Death of cystic fibrosis patients, not considered to be terminally ill, is reported in Europe, the United States and Australia due to voluntary cessation of treatment.

PMID: 26979669

12. *J Med Ethics*. 2016 Mar 17. [Epub ahead of print]

In what circumstances will a neonatologist decide a patient is not a resuscitation candidate?

Murray PD¹, Esserman D², Mercurio MR³.

Abstract

OBJECTIVE: The purpose of this study was to determine the opinions of practising neonatologists regarding the ethical permissibility of unilateral Do Not Attempt Resuscitation (DNAR) decisions in the neonatal intensive care unit.

STUDY DESIGN: An anonymous survey regarding the permissibility of unilateral DNAR orders for three clinical vignettes was sent to members of the American Academy of Pediatrics Section of Perinatal Medicine.

RESULTS: There were 490 out of a possible 3000 respondents (16%). A majority (76%) responded that a unilateral DNAR decision would be permissible in cases for which survival was felt to be impossible. A minority (25%) responded 'yes' when asked if a unilateral DNAR order would be permissible based solely on neurological prognosis.

CONCLUSIONS: A majority of neonatologists believed unilateral DNAR decisions are ethically permissible if survival is felt to be impossible, but not permissible based solely on poor neurological prognosis. This has significant implications for clinical care.

PMID: 26988548

13.] Pain Symptom Manage. 2016 Mar 14. [Epub ahead of print]

Palliative Care Education in Emergency Medicine Residency Training: A Survey of Program Directors, Associate Program Directors, and Assistant Program Directors.

Kraus CK¹, Greenberg MR², Ray DE³, Dy SM⁴.

Abstract

CONTEXT: Emergency Medicine (EM) residents perceive palliative care (PC) skills as important and want training, yet there is a general lack of formal PC training in EM residency programs. A clearer definition of the PC educational needs of EM trainees is a research priority.

OBJECTIVES: To assess PC competency education in EM residency programs.

METHODS: This was a mixed-mode survey of residency program directors (PDs), associate PDs (APDs), and assistant PDs (aPDs) at accredited EM residency programs, evaluating four educational domains: 1) importance of specific competencies for senior EM residents; 2) senior resident skills in PC competencies; 3) effectiveness of educational methods; and, 4) barriers to training.

RESULTS: Response rate was 50% from more than 100 residency programs. Most respondents (64%) identified PC competencies as important for residents to learn and 59% reported that they teach PC skills in their residency program. In Domains 1 and 2, crucial conversations, management of pain, and management of the imminently dying had the highest scores for importance and residents' skill. In Domain 3, bedside teaching, mentoring from hospice and palliative medicine (HPM) faculty, and case-based simulation were the most effective educational methods. In Domain 4, lack of PC expertise among faculty and lack of interest by faculty and residents were the greatest barriers. There were differences between competency importance and senior resident skill level for: management of the dying child, withdrawal/withholding of non-beneficial interventions, and ethical/legal issues.

CONCLUSION: There are specific barriers and opportunities for PC competency training and gaps in resident skill level. Specifically, there are discrepancies in competency importance and residency skill in the management of the dying child, non-beneficial interventions, and ethical and legal issues that could be a focus for educational interventions in PC competency training in EM residencies.

PMID: 26988848

14. BMC Palliat Care. 2016 Mar 9;15(1):30.

When parents face the death of their child: a nationwide cross-sectional survey of parental perspectives on their child's end-of life care.

Zimmermann K^{1,2}, Bergstraesser E³, Engberg S⁴, Ramelet AS^{5,6}, Marfurt-Russenberger K⁷, Von der Weid N⁸, Grandjean C⁹, Fahrni-Nater P¹⁰, Cignacco E^{11,12}; PELICAN Consortium.

Abstract

BACKGROUND: Parents facing the death of their child have a strong need for compassionate professional support. Care services should be based on empirical evidence, be sensitive to the needs of the families concerned, take into account the heterogeneity within the medical field of paediatrics, and fit into the local

health care system. We need to better understand the perspectives of parents facing the death of their child in order to guide further development and evaluation of specialised paediatric palliative and end-of-life (EOL) care services.

METHODS: Questionnaire survey to assess the EOL care perspectives of a Swiss population-based sample of bereaved parents who had lost a child due to a cardiac, neurological or oncological condition, or during the neonatal period in the years 2011 or 2012. The parental perspective was assessed with a newly developed and tested instrument that was structured according to six evidence-based quality domains. Responses regarding parental experiences and perceived satisfaction are described. Differences between the four diagnostic groups are analysed using a generalized estimation equation to account for the dyadic data structure.

RESULTS: Of 307 eligible families, 267 could be contacted and 135 (51 %) consented to participate in this questionnaire survey. Our findings show positive parental experiences of their child's EOL care and high perceived satisfaction with the care their child received. Parents of a child with cancer rated their experiences highest in most of the six quality domains and reported the highest satisfaction with care. The lowest scores were mainly reported by parents from the neurology group, with the exception of the shared decision making domain, where parents of neonates reported significantly less positive experiences.

CONCLUSIONS: Although positive in general, our study results suggest some areas for improvement. The integration of specialised paediatric palliative care has the potential to minimise lost opportunities to support and assist parents.

PMCID: PMC4784404 **Free PMC Article**

PMID: 26956995

15. Paediatr Drugs. 2016 Mar 7. [Epub ahead of print]

Pediatric Oncology: Managing Pain at the End of Life.

Snaman JM¹, Baker JN¹, Ehrentraut JH², Anghelescu DL³.

Abstract

Pain is a common and highly distressing symptom in pediatric patients with advanced malignancies. Prompt recognition, assessment, and treatment of pain are necessary, especially at the end of life. Opioid medications remain the mainstay of treatment of malignant pain in children at the end of life and the amount of opioids required for adequate pain control in patients is highly variable. Nonpharmacological approaches including behavioral and physical approaches in addition to non-opioid pain medications should be used when possible to augment pain control. Identification and treatment of any underlying pathology is important and use of adjuvant medications based on pathophysiology and source of pain should be considered. In cases where adequate pain control is not achieved through these multiple modalities, an interdisciplinary approach including potential interventional techniques and alternative treatments is required. This multimodal approach to pain management is best provided by interdisciplinary teams, as these teams can best address the complex causes of pain and associated distress that occurs in patients and within families.

PMID: 26951239

16. Palliat Med. 2016 Mar 2. [Epub ahead of print]

A descriptive report of end-of-life care practices occurring in two neonatal intensive care units.

Lam V¹, Kain N², Joynt C³, van Manen MA⁴.

Abstract

BACKGROUND: In Canada and other developed countries, the majority of neonatal deaths occur in tertiary neonatal intensive care units. Most deaths occur following the withdrawal of life-sustaining treatments.

AIM: To explore neonatal death events and end-of-life care practices in two tertiary neonatal intensive care settings.

DESIGN: A structured, retrospective, cohort study.

SETTING/PARTICIPANTS: All infants who died under tertiary neonatal intensive care from January 2009 to December 2013 in a regional Canadian neonatal program. Deaths occurring outside the neonatal intensive care unit in delivery rooms, hospital wards, or family homes were not included. Overall, 227 infant deaths were identified.

RESULTS: The most common reasons for admission included prematurity (53.7%), prematurity with

congenital anomaly/syndrome (20.3%), term congenital anomaly (11.5%), and hypoxic ischemic encephalopathy (12.3%). The median age at death was 7 days. Death tended to follow a decision to withdraw life-sustaining treatment with anticipated poor developmental outcome or perceived quality of life, or in the context of a moribund dying infant. Time to death after withdrawal of life-sustaining treatment was uncommonly a protracted event but did vary widely. Most dying infants were held by family members in the neonatal intensive care unit or in a parent room off cardiorespiratory monitors. Analgesic and sedative medications were variably given and not associated with a hastening of death.

CONCLUSION: Variability exists in end-of-life care practices such as provision of analgesic and sedative medications. Other practices such as discontinuation of cardiorespiratory monitors and use of parent rooms are more uniform. More research is needed to understand variation in neonatal end-of-life care.

PMID: 26934947

17. Palliat Med. 2016 Mar 7. [Epub ahead of print]

Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study.

Collins A¹, Hennessy-Anderson N², Hosking S³, Hynson J⁴, Remedios C⁵, Thomas K⁶.

Abstract

BACKGROUND: Experiential studies in paediatric palliative care are needed to enable an ongoing international agenda which supports the development of responsive family supports.

AIM: To provide an in-depth exploration of the prevalent lived experiences of parents who are currently providing care for a child with a life-limiting condition in Australia.

DESIGN: Cross-sectional, prospective, qualitative study guided by an advisory group and reported according to the consolidated criteria for reporting qualitative studies. Transcripts were subjected to a thematic analysis, underpinned by an interpretative phenomenological framework.

SETTING/PARTICIPANTS: Purposively sampled parents (n = 14) recruited from a statewide paediatric hospice who self-identified as a 'primary caregiver' for one or more children and/or adolescents (≤ 18 years) with a life-limiting condition.

RESULTS:

Four key themes represented the prevalent experiences of parents: (1) trapped inside the house, (2) the protector, (3) living with the shadow and (4) travelling a different pathway. They describe parents' physical and social isolation, exclusion from the workforce, pervasive grief and associated impacts to their health and well-being. Limited professional and diminished social supports resulted in full ownership of care responsibility. Yet, parents embraced their role as 'protector', reporting acquired meaning and purpose.

CONCLUSION: This study builds upon the growing body of evidence available in paediatric palliative care internationally. The key themes highlight the substantial demand for both physical and emotional support beyond what is currently offered and call for the implementation of carefully planned support services and other societal initiatives which seek to alleviate the broad health impacts to caregivers.

PMID: 26951065

18. Int J Palliat Nurs. 2016 Feb 2;22(2):90-7.

Evaluating a pilot paediatric hospice-at-home service: a literature review.

Hillis R¹, Ling J², Quinn C³, Brenner M⁴.

Abstract

BACKGROUND: This literature review aims to offer practitioners an overview of the key components involved in designing the evaluation of a paediatric hospice-at-home pilot that will assess the effectiveness, efficiency and sustainability of the programme. The literature was reviewed in two stages: the first examined existing literature in the area of paediatric palliative care. The second looked at the wider field of adult palliative care to gain further insights into evaluation tool design. The findings are presented as a conceptual model to highlight each component of the pilot development stage as identified for evaluation purposes, emphasising their role and impact on the resultant delivery of integrated care. The clarity and transparency of this model offers a comprehensive overview of the evaluation process to all involved in the pilot.

PMID: 26926349

19. Int J Palliat Nurs. 2016 Feb 2;22(2):82-9.

Circumstances surrounding deaths from the perspective of bereaved Honduran families.

Stone A¹, LaMotta CP², Baudino MN³, Akard TF⁴, Gilmer MJ⁵.

Abstract

PURPOSE: This qualitative study examined how bereaved individuals from Honduras responded to deaths of loved ones, particularly through exploring circumstances surrounding deaths and various coping strategies.

METHODS: With the help of a translator, bereaved family members in Honduras were interviewed using a semi-structured format. The interactions were audio-recorded and later translated and transcribed.

RESULTS: Some 60% of individuals spent time with other family members during their loved one's end of life and 22.5% of grieving individuals took solace in spirituality or religious practices and connecting with God. Some 40% wanted to speak with others through support groups. When individuals spoke about remembering the deceased, both comforting and discomfoting effects were expressed.

CONCLUSIONS: Further research is needed to learn more about coping strategies in various cultures and support mechanisms that health professionals can use or suggest when working with bereaved individuals.

PMID: 26926348

20. Int J Palliat Nurs. 2016 Feb 2;22(2):57-65.

Short break and emergency respite care: what options for young people with life-limiting conditions?

Mitchell TK¹, Knighting K², O'Brien MR³, Jack BA⁴.

Abstract

BACKGROUND:

Service providers face difficult decisions about how best to develop services for the increasing numbers of young people with life-limiting conditions who require palliative care.

OBJECTIVE:

To explore alternative short break and emergency respite care options to children's hospice care.

METHODS:

A two-phase evaluation with young people, families and professionals. Phase 1: qualitative semi-structured interviews and focus groups (n=53). Phase 2: mixed-method survey (n=82), qualitative findings only.

RESULTS:

There were few, or no, appropriate short break and emergency respite care alternatives when children's hospice care was not available that can meet the need of young people with life-limiting conditions, creating anxiety for children's hospice users and those leaving the service as a result of reaching transition age or through no longer meeting the children's hospice eligibility criteria.

CONCLUSION:

Access to appropriate short break and emergency respite care is required to prevent lifelong negative consequences for young people with life-limiting conditions, their family and society. Research is undoubtedly required to explore the impact and outcomes of children's hospice discharge for young people and their family. Particular attention should be paid to the lack of services for an increasing population making the transition from children's hospices.

PMID: 26926345

21. Pediatrics. 2016 Mar;137(3):1-8.

Screening for Depression in Children and Adolescents: US Preventive Services Task Force Recommendation Statement.

Siu AL¹; US Preventive Services Task Force.

Abstract

DESCRIPTION: This article describes the update of the 2009 US Preventive Services Task Force (USPSTF) recommendation on screening for major depressive disorder (MDD) in children and adolescents.

METHODS: The USPSTF reviewed the evidence on the benefits and harms of screening, accuracy of primary care-feasible screening tests, and benefits and harms of treatment with psychotherapy, medications, and collaborative care models in patients aged 7 to 18 years.

POPULATION: This recommendation applies to children and adolescents aged ≤18 years who do not have an MDD diagnosis.

RECOMMENDATION: The USPSTF recommends screening for MDD in adolescents aged 12 to 18 years. Screening should be implemented with adequate systems in place to ensure accurate diagnosis, effective treatment, and appropriate follow-up (B recommendation). The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for MDD in children aged ≤ 11 years (I statement). PMID: 26908686

22. Biol Blood Marrow Transplant. 2016 Feb 20. [Epub ahead of print] **End-of-Life Care Patterns Associated with Pediatric Palliative Care among Children Who Underwent Hematopoietic Stem Cell Transplant.**

Ullrich CK¹, Lehmann L², London WB², Guo D², Sridharan M², Koch R³, Wolfe J⁴.

Abstract: Stem cell transplantation (SCT) is an intensive therapy offering the possibility of cure for life-threatening conditions but with risk of serious complications and death. Outcomes associated with pediatric palliative care (PPC) for children who undergo SCT are unknown. Therefore, we evaluated whether PPC consultation is associated with differences in end-of-life (EOL) care patterns for children who underwent SCT and did not survive. Medical records of children who underwent SCT at Boston Children's Hospital/Dana-Farber Cancer Institute for any indication from September 2004 to December 2012 and did not survive were reviewed. Child demographic and clinical characteristics and PPC consultation and EOL care patterns were abstracted. Children who received PPC (PPC group) were compared with those who did not (non-PPC group). Children who received PPC consultation (n = 37) did not differ from the non-PPC group (n = 110) with respect to demographic or clinical characteristics, except they were more likely to have undergone unrelated allogeneic SCT (PPC, 68%; non-PPC, 39%; P = .02) or to have died from treatment-related toxicity (PPC, 76%; non-PPC, 54%; P = .03). PPC consultation occurred at a median of .7 months (interquartile range [IQR], .4 to 4.2) before death. PPC consultations most commonly addressed goals of care/decision-making (92%), psychosocial support (84%), pain management (65%), and non-pain symptom management (70%). Prognosis discussions (ie, the likelihood of survival) occurred more commonly in the PPC group (PPC, 97%; non-PPC, 83%; P = .04), as did resuscitation status discussions (PPC, 88%; non-PPC, 58%; P = .002). These discussions also occurred earlier in the PPC group, for prognosis a median of 8 days (IQR, 4 to 26) before death compared with 2 days (IQR, 1 to 13) in the non-PPC group and for resuscitation status a median of 7 days (IQR, 3 to 18) compared with 2 days (IQR, 1 to 5) in the non-PPC group (P < .001 for both of the timing of prognosis and resuscitation status discussions). The PPC group was also more likely to have resuscitation status documented (PPC, 97%; non-PPC, 68%; P = .002). With respect to patterns of care, compared with non-PPC, the PPC group was as likely to die in a medicalized setting (ie, the hospital) (PPC, 84%; non-PPC, 77%; P = .06) or have hospice care (PPC, 22%; non-PPC, 18%; P = .6). However, among children who died in the hospital, those who received PPC were more likely to die outside the intensive care unit (PPC, 80%; non-PPC, 58%; P = .03). In addition, the PPC group was less likely to receive intervention-focused care such as intubation in the 24 hours before death (PPC, 42%; non-PPC, 66%; P = .02) or cardiopulmonary resuscitation (PPC, 3%; non-PPC, 20%; P = .03) at EOL. Children who received PPC for at least a month were more likely to receive hospice care (PPC, 41%; non-PPC, 5%; P = .01). Children who underwent SCT and did not survive were likely to die in a medicalized setting, irrespective of PPC. However, PPC was associated with less intervention-focused care and greater opportunity for EOL communication and advance preparation. In the intense, cure-oriented SCT setting, PPC may facilitate advance care planning in this high-risk population.

PMID: 26903381

23. Clin Pediatr (Phila). 2016 Feb 18. [Epub ahead of print]

Patient End-of-Life Experiences for Pediatric Trainees: Spanning the Educational Continuum.

Senthil K¹, Serwint JR², Dawood FS³.

Abstract

BACKGROUND: End-of-life care for a child is an emotionally charged experience for pediatric trainees.

OBJECTIVES: Describe the progression of medical trainee experiences with end-of-life care and determine personal/professional experiences that facilitated integration of experiences.

METHODS: Medical students (MS4) and pediatric residents (PL-1-3) completed a 30-question survey about experiences with patient deaths and integration of these experiences.

RESULTS: A total of 307 of 404 residents (76%) participated. Mean number of deaths ranged from 3.0 to 6.5

in the prior 12 months, and the most common location was neonatal intensive care unit or pediatric intensive care unit. In total, 18% to 27% experienced a death in their personal life. Between 26% and 41% of the residents made contact with a family after death, and 15% to 35% attended a funeral. Characteristics of good deaths included good communication and discussion of end-of-life issues.

CONCLUSIONS: Trainees experienced patient deaths along the educational continuum. These findings have implications for the optimal timing and method of end-of-life care education.

PMID: 26896342

24. J Palliat Med. 2016 Mar;19(3):300-5.

The Impact of Advance Directives on End-of-Life Care for Adolescents and Young Adults Undergoing Hematopoietic Stem Cell Transplant.

Needle J¹, Smith AR².

Abstract

BACKGROUND: Little is known about the role of advance directives (AD) in end-of-life (EOL) care for adolescents and young adults (AYA) undergoing hematopoietic stem cell transplant (HSCT).

OBJECTIVE: The study objective was to describe the frequency, type, and influence of AD on the use of life-sustaining treatment (LST) in AYA patients undergoing HSCT.

METHODS: We performed a retrospective chart review of 96 patients aged 14-26 undergoing HSCT between April 2011 and January 2015 at the University of Minnesota. LST was defined as the use of positive pressure ventilation (PPV), dialysis, or CPR.

RESULTS: Of the 96 patients, survival was 72.9%, and 23% had an AD. Of the 26 patients who died, 13 (50%) had an AD. Among the 19 patients who died in the ICU, there was no significant difference in PPV, dialysis, withholding or withdrawing of LST, or timing of do not resuscitate (DNR) orders between those with ADs preferring LST (n = 5), those naming proxies only (n = 4), and those without ADs (n = 10). Patients with ADs expressing preference for LST were significantly more likely to receive CPR than those with proxies or those without ADs (p = 0.02).

CONCLUSION: A minority of AYA patients undergoing HSCT had ADs. Patients received care that was strongly associated with their preferences. With the exception of CPR, the use of LST did not differ between those with ADs and those without.

PMCID: PMC4779294

PMID: 26895198

25. J Palliat Med. 2016 Apr;19(4):394-9.

Prospective Study on Music Therapy in Terminally Ill Cancer Patients during Specialized Inpatient Palliative Care.

Kordovan S¹, Preissler P^{1,2}, Kamphausen A³, Bokemeyer C¹, Oechsle K¹.

Abstract

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

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

RESULTS: A total of 166 music therapy sessions were performed with 41 patients (average, 4; range, 2-10). Average session duration was 41 minutes (range, 20-70). Most favored methods were therapeutic conversation in 84% of sessions; listening to relaxing music, 39%; playing an instrument, 31%; and music-lead imagination, 11%. Receptive music therapy was applied in 45%, active forms in 25%, a combination of both in 7%, and therapeutic conversation only in 23%. Music therapy was rated to be "helpful" in 68%. Positive effects were significantly associated with frequency (p = 0.009) and duration (p = 0.040), living in a partnership (p = 0.017), having children (p = 0.035), psycho-oncologic therapy (p = 0.043), experience with music therapy (p = 0.007), role of music in life (p = 0.035), playing an instrument (p = 0.021), and singing regularly (p = 0.003).

CONCLUSION: Music therapy techniques, especially receptive methods, are feasible and well accepted in

terminally ill cancer patients. Therapeutic conversation seems to play an important role. Frequency and duration of music therapy, previous experience with music and music therapy, as well as sociodemographic factors influence positive effects of music therapy.

PMID: 26894922

26. Singapore Med J. 2016 Feb;57(2):77-80.

Paediatric palliative care at home: a single centre's experience.

Chong LA¹, Khalid F².

Abstract

INTRODUCTION: There is increased awareness of paediatric palliative care in Malaysia, but no local published data on home care services. We aimed to describe the paediatric experience at Hospis Malaysia, a community-based palliative care provider in Malaysia.

METHODS: We conducted a retrospective case note review of patients aged up to 21 years who were referred to Hospis Malaysia from 2009 to 2013.

RESULTS: A total of 137 patients (92 male, 45 female) with a median age of 140 (3-250) months were included in this study. The majority (71.5%) had malignancies. At referral, 62 patients were still in hospital and 17 died prior to discharge. A total of 108 patients received home visits. At the first home visit, 89.8% of patients had at least one physical symptom. Pain was the most common (52.5%) symptom. Patients had various supportive devices: 39 were on feeding tubes, ten had tracheostomies, five were on bilevel positive airway pressure and ten had urinary catheters. 66 families discussed the preferred location of care at end-of-life. Among those who died, 78.9% died at home, as they preferred ($p < 0.001$). Regression analysis showed no statistically significant association between a home death and age, diagnosis and number of home visits. Bereavement follow-up occurred for 93.3% of families.

CONCLUSION: Community care referrals tend to occur late, with 25.5% of patients dying within two weeks of referral. At referral, patients often had untreated physical symptoms. The majority of families preferred and had a home death.

PMCID: PMC4759379 **Free PMC Article**

PMID: 26893078

27. J Pain Symptom Manage. 2016 Feb 16. [Epub ahead of print]

Role of the Nasogastric Tube and Lingzhi (*Ganoderma lucidum*) in Palliative Care.

Wang X¹, Huang Y¹, Radha Krishna L², Puvanendran R³.

Abstract

Decision-making on behalf of an incapacitated patient at the end of life is a complex process, particularly in family-centric societies. The situation is more complex when attempts are made to accommodate Eastern concepts of end-of-life care with more conventional Western approaches. In this case report of an incapacitated 74-year-old Singaporean man of Malay descent with relapsed Stage 4 diffuse large B cell lymphoma who was without an established lasting power of attorney, we highlight the difficult deliberations that ensue when the patient's family, acting as his proxy, elected to administer lingzhi through his nasogastric tube (NGT). Focusing on the questions pertaining to end-of-life decision-making in Asia, we consider the issues surrounding the use of NGT and lingzhi in palliative care (PC) and the implementation of NGT for administering lingzhi in a PC setting, particularly in light of a dearth of data on such treatment measures among PC patients.

PMID: 26891608

28. J Dev Behav Pediatr. 2016 Feb 17. [Epub ahead of print]

Early Predictors of Childhood Restrictive Eating: A Population-Based Study.

Micali N¹, Rask CU, Olsen EM, Skovgaard AM.

Abstract

OBJECTIVE: Childhood eating problems, in particular restrictive eating, are common. Knowledge and understanding of risk mechanisms is still scarce. We aimed to investigate prospective early risk factors for restrictive eating across child, maternal, obstetric, and sociodemographic domains in a population-based sample of Danish 5 to 7 year olds.

METHOD: Data on restrictive eating patterns (picky eating, slow/poor eating, and emotional undereating) collected on 1327 children from the Copenhagen Child Cohort 2000 were linked with registered and routinely collected health nurse data (during the first year of life). Prospective risk factors were investigated in univariable and multivariable regression models.

RESULTS: Feeding problems in infancy were prospectively associated with childhood picky eating (odds ratio [OR] = 2.02, 95% confidence interval [CI], 1.20-3.40) and emotional undereating (OR = 1.49, 95% CI, 1.05-2.11). A high thriving index in infancy was inversely associated with both picky and slow/poor eating. Having 2 non-Danish-born parents predicted slow/poor eating (OR = 5.29, 95% CI, 1.16-24.09) in multivariable analyses, as did maternal diagnosis of a psychiatric disorder before child age 5 years in univariable analyses (OR = 6.08, 95% CI, 1.70-21.72).

CONCLUSIONS: Feeding problems and poor growth in the first year of life show high continuity into childhood restrictive eating. Maternal psychopathology is an important and modifiable risk factor. These findings confirm that early signs of poor eating and growth are persistent and might be useful in predicting eating problems in mid-childhood.

PMID: 26890561

29. *Pediatr Crit Care Med.* 2016 Feb 17. [Epub ahead of print]

Parental Physical Proximity in End-of-Life Care in the PICU.

Falkenburg JL¹, Tibboel D, Ganzevoort RR, Gischler S, Hagoort J, van Dijk M.

Abstract

OBJECTIVE: Health professionals in PICUs support both child and parents when a child's death is imminent. Parents long to stay connected to their dying child but the high-tech environment and treatment implications make it difficult to stay physically close. This study explores in what sense physical aspects of end-of-life care in the PICU influence the parent-child relationship.

DESIGN: Retrospective, qualitative interview study.

SETTING: Level 3 PICU in Erasmus Medical Center in the Netherlands.

PARTICIPANTS: Thirty-six parents of 20 children who had died in this unit 5 years previously.

MEASUREMENTS AND MAIN RESULTS: Parents vividly remembered the damage done to the child's physical appearance, an inevitable consequence of medical treatment. They felt frustrated and hurt when they could not hold their child. Yet they felt comforted if facilitated to be physically close to the dying child, like lying with the child in one bed, holding the child in the hour of death, and washing the child after death.

CONCLUSIONS: End-of-life treatment in the PICU presents both a barrier and an opportunity for parents to stay physically connected to their child. Parents' experiences suggest that aspects of physicality in medical settings deserve more attention. Better understanding of the significance of bodily aspects-other than pain and symptom management-improves end-of-life support and should be part of the humane approach to families.

PMID: 26890197

30. *Nutr Clin Pract.* 2016 Feb 17. [Epub ahead of print]

Incorporating Palliative Care Concepts Into Nutrition Practice: Across the Age Spectrum.

Schwartz DB¹, Olfson K², Goldman B³, Barrocas A⁴, Wesley JR⁵.

Abstract: A practice gap exists between published guidelines and recommendations and actual clinical practice with life-sustaining treatments not always being based on the patient's wishes, including the provision of nutrition support therapies. Closing this gap requires an interdisciplinary approach that can be enhanced by incorporating basic palliative care concepts into nutrition support practice. In the fast-paced process of providing timely and effective medical treatments, communication often suffers and decision making is not always reflective of the patient's quality-of-life goals. The current healthcare clinical ethics model does not yet include optimum use of advance directives and early communication between patients and family members and their healthcare providers about treatment choices, including nutrition support. A collaborative, proactive, integrated process in all healthcare facilities and across levels of care and age groups, together with measurable sustained outcomes, shared best practices, and preventive ethics, will be needed to change the culture of care. Implementation of a better process, including basic palliative care concepts, requires improved communication skills by healthcare professionals. Formalized palliative care

consults are warranted early in complex cases. An education technique, as presented in this article, of how clinicians can engage in critical and crucial conversations early with patients and family members, by incorporating the patient's values and cultural and religious diversity in easily understood language, is identified as an innovative tool.

PMID: 26888858

31. J Psychosoc Oncol. 2016 Jan-Apr;34(1-2):39-59.

Pediatric oncologists' coping strategies for dealing with patient death.

Granek L¹, Barrera M², Scheinemann K^{3,4}, Bartels U^{4,5}.

Abstract: This research examined pediatric oncologists coping strategies when their patients died of cancer. Twenty-one pediatric oncologists at 2 Canadian pediatric academic hospitals were interviewed about their coping strategies when patients died or were in the process of dying. The grounded theory method of data collection and data analysis were used. Line-by-line coding was used to establish codes and themes and constant comparison was used to establish relations among emerging codes and themes. Pediatric oncologists used engagement coping strategies with primary and secondary responses including emotional regulation (social support and religion), problem solving (supporting families at end of life), cognitive restructuring (making a difference and research), and distraction (breaks, physical activity, hobbies and entertainment, spending time with own children). They also used disengagement coping strategies that included voluntary avoidance (compartmentalization and withdrawing from families at end of life). Given the chronic nature of patient death in pediatric oncology and the emotionally difficult nature of this work, medical institutions such as hospitals have a responsibility to assist pediatric oncologists in coping with this challenging aspect of their work. Future research is needed to evaluate how best to implement these changes on the institutional level to help oncologists cope with patient death and the effect of using these strategies on their quality of life.

PMID: 26865337

32. J Palliat Med. 2016 Mar;19(3):326-32.

Parental Perspectives of Communication at the End of Life at a Pediatric Oncology Institution.

Snaman JM¹, Torres C², Duffy B, Levine DR^{1,3}, Gibson DV^{1,3}, Baker JN^{1,3}.

Abstract

BACKGROUND: The interaction of health care providers and hospital staff with patients and families at the end of life affects the parental grief experience. Both verbal and nonverbal communication are key components of this interaction.

OBJECTIVE: The study objective was to explore the communication between hospital staff members and patients and families at the time of patients' health decline near the end of life.

METHODS: Twelve bereaved parents participated in a focus group. Semantic content analysis was used to analyze the transcript.

RESULTS: Parents' responses to the prompt about typical ways the medical team communicated yielded 109 codes, which were grouped into 12 themes. The most common themes were "patient inclusion" and "explanation of medical plan," both used in 17% of responses. Responses to the prompt about positive and negative aspects of communication generated 208 codes, yielding 15 different themes. The most common theme about positive communication was the "strong relationship between family and staff." The theme "variations in care with a negative impact" was used most frequently in describing negative communication.

CONCLUSION: This study helps to identify techniques that should be used by clinicians as they work with children with cancer and their families, particularly including patients in treatment decisions, ongoing relationship building, communicating with caring and empathy, using an interdisciplinary team for additional support, and pairing bad news with a plan of action.

PMID: 26862782

33. J Palliat Med. 2016 Apr;19(4):451-5.

A Hospital-Based Advance Care Planning Intervention for Patients with Heart Failure: A Feasibility Study.

Sadeghi B¹, Walling AM^{1,2}, Romano PS³, Ahluwalia SC^{4,5}, Ong MK^{1,2}.

Abstract

BACKGROUND: Early discussions about advance care planning (ACP) have been associated with improved patient and caregiver outcomes for patients with serious illness. Many patients with heart failure (HF) may benefit from more timely ACP, in part due to the unpredictable trajectory of the disease.

OBJECTIVES: The purpose of this study was to evaluate the feasibility of implementing a multiple-component hospital-based intervention on completion of ACP forms among HF patients.

METHODS: A brief hospital-based ACP intervention was led by a nonclinician health educator that included (1) an educational video about shared decision making and (2) a protocol to engage HF providers in patients' ACP decision making after the hospitalization. We surveyed patients regarding attitudes toward the ACP intervention and studied completion rates of advance directives (ADs) or physician orders for life sustaining treatment (POLST) forms six months following discharge.

RESULTS: The educational video component of this intervention was considered helpful by 92% of participants, and 70% said they were more likely to talk with their physician about their end-of-life preferences after watching the video and interacting with the health educator. Of 37 participants, 49% had evidence of completion of an AD or POLST in their medical records six months after the index hospitalization compared to 32% before the intervention. The number of patients having a signed scanned POLST form increased from 10 (27%) before the intervention to 16 (43%) six months after the intervention ($p = 0.03$).

CONCLUSIONS: A hospital-based ACP intervention using nonclinician health educators is feasible to implement and has the potential to facilitate the ACP process.

PMID: 26862682

34. Am J Hosp Palliat Care. 2016 Feb 9. [Epub ahead of print]

Liminality in Pediatric Palliative Care.

Carter BS¹.

Abstract

Palliative care for infants, children, and adolescents encompasses numerous transitions and thresholds of uncertainty that challenge conventional clinical medicine. Palliative care clinicians have opportunities to be more comfortable amid such challenges, or perhaps even overcome them, if they are attuned to the unique times and places in which patients, their families, and caregivers find themselves throughout illness and recovery or transitioning toward the end of life. Patient-clinician encounters often dwell in these liminal places. The concept of liminality gives validation to the patient or family's being "stuck in places betwixt and between" a past life rich with relationship and purpose and an acute, chronic, or critical illness. Or having resolved the acute crisis of hospitalization that place between the past bounds of illness and the uncertain path forward, perhaps even toward death. Liminality provides a framework for addressing the unbound spaces that patients and families occupy: What is past is behind-the present place is tenuous and temporary, and what is ahead uncertain. This place is where palliative care clinicians can offer clinicians and families guidance.

PMID: 26861443

35. Am J Hosp Palliat Care. 2016 Feb 7. [Epub ahead of print]

Reiki Therapy for Symptom Management in Children Receiving Palliative Care: A Pilot Study.

Thrane SE¹, Maurer SH², Ren D³, Danford CA³, Cohen SM³.

Abstract

BACKGROUND: Pain may be reported in one-half to three-fourths of children with cancer and other terminal conditions and anxiety in about one-third of them. Pharmacologic methods do not always give satisfactory symptom relief. Complementary therapies such as Reiki may help children manage symptoms.

OBJECTIVE: This pre-post mixed-methods single group pilot study examined feasibility, acceptability, and the outcomes of pain, anxiety, and relaxation using Reiki therapy with children receiving palliative care.

METHODS: A convenience sample of children ages 7 to 16 and their parents were recruited from a palliative care service. Two 24-minute Reiki sessions were completed at the children's home. Paired t tests or Wilcoxon signed-rank tests were calculated to compare change from pre to post for outcome variables. Significance was set at $P < .10$. Cohen d effect sizes were calculated.

RESULTS: The final sample included 8 verbal and 8 nonverbal children, 16 mothers, and 1 nurse. All mean

scores for outcome variables decreased from pre- to posttreatment for both sessions. Significant decreases for pain for treatment 1 in nonverbal children ($P = .063$) and for respiratory rate for treatment 2 in verbal children ($P = .009$). Cohen d effect sizes were medium to large for most outcome measures.

DISCUSSION: Decreased mean scores for outcome measures indicate that Reiki therapy did decrease pain, anxiety, heart, and respiratory rates, but small sample size deterred statistical significance. This preliminary work suggests that complementary methods of treatment such as Reiki may be beneficial to support traditional methods to manage pain and anxiety in children receiving palliative care.

PMID: 26858170

36. Palliat Med. 2016 Feb 4. [Epub ahead of print]

Medical indication regarding life-sustaining treatment for children: Focus groups with clinicians.

Lotz JD¹, Jox RJ², Meurer C², Borasio GD³, Führer M⁴.

Abstract

BACKGROUND: Decisions about medical indication are a relevant problem in pediatrics. Difficulties arise from the high prognostic uncertainty, the decisional incapacity of many children, the importance of the family, and conflicts with parents. The objectivity of judgments about medical indication has been questioned. Yet, little is known about the factors pediatricians actually include in their decisions.

AIM: Our aims were to investigate which factors pediatricians apply in deciding about medical indication, and how they manage conflicts with parents.

DESIGN: We performed a qualitative focus group study with experienced pediatricians. The transcripts were subjected to qualitative content analysis.

SETTING/PARTICIPANTS: We conducted three focus groups with pediatricians from different specialties caring for severely ill children/adolescents. They discussed life-sustaining treatment in two case scenarios that varied according to diagnosis, age, and gender.

RESULTS: The decisions about medical indication were based on considerations relating to the individual patient, to the family, and to other patients. Individual patient factors included clinical aspects and benefit-burden considerations. Physicians' individual views and feelings influenced their decision-making. Different factors were applied or weighed differently in the two cases. In case of conflict with parents, physicians preferred solutions aimed at establishing consensus.

CONCLUSION: The pediatricians defined medical indication on a case-by-case basis and were influenced by emotional reasoning. In contrast to prevailing ethico-legal principles, they included the interests of other persons in their decisions. Decision-making strategies should incorporate explicit discussions of social aspects and physicians' feelings to improve the transparency of the decision-making process and reduce bias.

PMID: 26847523

37. BMJ Support Palliat Care. 2016 Feb 4. [Epub ahead of print]

The death of patients with terminal cancer: the distress experienced by their children and medical professionals who provide the children with support care.

Otani H¹, Ozawa M², Morita T³, Kawami A⁴, Sharma S⁴, Shiraishi K⁴, Oshima A⁴.

Abstract

BACKGROUND: Few studies have been conducted on the experiences of children of terminally ill patients or hospital-based medical professionals supporting such children.

AIM: This study explored distress among individuals whose parents died of cancer in childhood and among hospital-based medical professionals supporting such children.

DESIGN: A qualitative study.

SETTING/PARTICIPANTS: The sample was 12 adults whose parents had died of cancer in childhood and 20 hospital-based medical professionals supporting children of patients' with terminal cancer. In-depth interviews were conducted, focusing on the distress experienced by the participants. The data were analysed thematically.

RESULTS: Among adults whose parents died of cancer in childhood, we identified themes related to the period before death (eg, concealing the parent's illness), the time of death (eg, alienation due to isolation from the parent), soon after death (eg, fear and shock evoked by the bizarre circumstances, regrets regarding the relationship with the deceased parent before death), several years thereafter (ie, distinctive

reflection during adolescence, prompted by the parent's absence) and the present time (ie, unresolved feelings regarding losing the parent). We identified seven themes among the medical professionals (eg, lack of knowledge/experience with children, the family's attempts to shield the child from the reality of death, estrangement from the family once they leave the hospital).

CONCLUSIONS: An important finding of the study is that the participants' grief reaction to their parents' deaths during childhood was prolonged. Moreover, hospital medical professionals may find it difficult to directly support affected children. Comprehensive support involving organisations (eg, local communities) may be necessary for children who have lost a parent.

PMID: 26847034

38. *Pediatr Crit Care Med.* 2016 Feb;17(2):167-8.

Measuring and Improving, Not Just Describing-The Next Imperative for End-of-Life Care.
van der Velden M¹, Burns JP.

PMID: 26841027

39. *J Palliat Med.* 2016 Feb;19(2):195-201.

Palliative Care Teams as Advocates for Adults with Sickle Cell Disease.

Ajayi TA^{1,2}, Edmonds KP³, Thornberry K³, Atayee RA^{3,4}.

Abstract

Medical advances have improved the overall life expectancy of patients with sickle cell disease (SCD). Unfortunately, the quality of life for patients with SCD remains a struggle. As the goal of palliative care (PC) is to improve quality of life for patients with serious illnesses, many PC teams are now asked to be involved in the care of these patients and may have variable levels of experience with SCD. Caring for patients with SCD is a complex and difficult task that often causes a reflexive "groan" from health care providers, which usually signifies a negative health care provider attitude stemmed from feeling uncomfortable in treating this complex patient population. It is important to be aware of these implicit biases and to overcome these feelings by becoming more familiar with the lives and experiences of those with SCD. This report provides an overview of SCD, context for the complexity of caring for this patient population, and areas for partnering in care.

PMID: 26840856

40. *Support Care Cancer.* 2016 Feb 2. [Epub ahead of print]

Use of complementary and alternative medicine by pediatric oncology patients during palliative care.

Schütze T¹, Längler A¹, Zuzak TJ^{2,3,4}, Schmidt P⁵, Zernikow B⁵.

Abstract

PURPOSE: Although the popularity of complementary and alternative medicine (CAM) has risen in the last decade, information about its use by pediatric patients in palliative care is still scarce. The purpose of the study was to assess the frequency and types of CAM administered by parents with children suffering from cancer during the palliative phase.

METHODS: All parents who lost their child due to cancer in the federal state North Rhine Westfalia/Germany were eligible for the study. The first group of eligible parents was contacted in 1999-2000 and a second group of parents in 2005-2006. Upon agreement, parents were asked to complete a semi-structured questionnaire about the frequency of CAM use and the specific treatments that had been used. The types of CAM were categorized according to the National Center for Complementary and Alternative Medicine (NCCAM).

RESULTS: A total of 96 parents participated in the study (48 in each cohort). Forty-three percent of all parents in both groups reported CAM use. The results show an increase of CAM use from 38 % in the first group to 49 % in the second cohort of pediatric patients during palliative care. The most common types of CAM used in both groups were homeopathy and treatment with mistletoe preparations.

CONCLUSIONS: The study provides information about usage of CAM in children suffering from cancer during the palliative phase of the disease. Further research is required to investigate benefits, potential adverse effects, and the potential efficacy of CAM in this population.

PMID: 26838025

41. Child Youth Serv Rev. 2016 Feb 1;61:135-140.

Children's Hyperactivity, Television Viewing, and The Potential for Child Effects.

Ansari A¹, Crosnoe R¹.

Abstract

Using data from the Early Childhood Longitudinal Study-Birth Cohort (ECLS-B; $n = 6,250$), this study examined whether children who display difficult behaviors early in life watch more television from year-to-year. Results revealed that 4-year-old children's hyperactive, but not aggressive, behavior was associated with an increase in television watching over the ensuing year. These potential child effects, however, were embedded in both proximate and distal ecologies. That is, the association between children's hyperactivity and increases in their television exposure over time was strongest among those in the low-end of the socioeconomic distribution and those whose parents displayed less optimal mental health. It was also stronger among girls. These results underscore the importance of considering child effects in future research and how intra-familial dynamics vary across different types of family contexts.

PMCID: PMC4730879

PMID: 26834301

42. Am J Bioeth. 2016 Feb;16(2):72-3.

Thoughtfulness and Grace: End-of-Life Decision Making for Children With Severe Developmental Disabilities.

Jones PM¹.

PMID: 26832105

43. Am J Bioeth. 2016 Feb;16(2):70-1.

Commentary From a Pediatric Complexologist and a Pediatric Palliative Care and Ethics Consultant.

Tapia C¹, Jarrell JA¹.

PMID: 26832104

44. J Adolesc Young Adult Oncol. 2016 Mar;5(1):64-8.

Experiences of Parents and General Practitioners with End-of-Life Care in Adolescents and Young Adults with Cancer.

Kaal SE¹, Kuijken NM¹, Verhagen CA^{1,2}, Jansen R¹, Servaes P³, van der Graaf WT¹.

Abstract

This study aims to analyze the experiences of Dutch bereaved parents and general practitioners (GPs) with palliative care of AYAs (18-35 years) in the terminal stage. Fifteen parents and nine GPs involved with nine deceased AYAs filled out questionnaires and were interviewed by telephone, respectively. In general, the parents were satisfied with the emotional care they themselves received and the medical care that their child received. The GPs were very satisfied with the cooperation with the palliative team. Gaps are present in the areas of symptom control, communication between hospital professionals and parents, aftercare, and transition between hospital and GP.

PMID: 26812457

45. Clin J Oncol Nurs. 2016 Feb 1;20(1):E16-9.

Hospice and Palliative Care: Development and Challenges in China.

Wu Y¹, Li L², Su H³, Yao X¹, Wen M¹.

Abstract

BACKGROUND: Terminally ill patients can benefit from palliative care, including relief from physical and emotional suffering, improved quality of life, and longer survival rates. However, despite marked development in other countries, palliative care is still in its infancy in China.

OBJECTIVES: The general population and healthcare professionals in China have yet to realize the importance of palliative care services. This article describes the status of palliative care services in China, the historic development of palliative care, and the barriers to its advancement.

METHODS: The status quo of hospice and palliative care in China is reviewed, and suggestions are provided on how nurses can improve their abilities to care for patients with cancer at the end of life.

FINDINGS: A significant amount of work is needed in China to meet the standards of international palliative care societies. Palliative care training for nurses is still very limited. Nurses and other health providers who are engaged in palliative care should be well trained regarding the principles and procedures of palliative care to ensure quality care.

PMID: 26800417

46. J Palliat Med. 2016 Mar;19(3):306-13. An Order Protocol for Respiratory Distress/Acute Pain Crisis in Pediatric Palliative Care Patients: Medical and Nursing Staff Perceptions.

Bidet G¹, Daoust L¹, Duval M², Ducruet T³, Toledano B⁴, Humbert N¹, Gauvin F¹.

Abstract

BACKGROUND:

An order protocol for distress (OPD), including respiratory distress and acute pain crisis, has been established for pediatric palliative care patients at Sainte-Justine Hospital (SJH). After discussion with the patient/his or her family, the OPD is prescribed by the attending physician whenever judged appropriate. The OPD can then be initiated by the bedside nurse when necessary; the physician is notified after the first dose is administered.

OBJECTIVES:

The study objectives were to evaluate the perceptions and experience of the medical/nursing staff towards the use of the OPD.

METHODS:

A survey was distributed to all physicians/nurses working on wards with pediatric palliative care patients. Answers to the survey were anonymous, done on a voluntary basis, and after consent of the participant.

RESULTS:

Surveys (258/548) were answered corresponding to a response rate of 47%. According to the respondents, the most important motivations in using the OPD were the desire to relieve patient's distress and the speed of relief of distress by the OPD; the most important obstacles were going against the patient's/his or her family's wishes and fear of hastening death. The respondents reported that the OPD was frequently (56%) or always (36%) effective in relieving the patient's distress. The respondents felt sometimes (16%), frequently (34%), or always (41%) comfortable in giving the OPD. They thought the OPD could never (12%), rarely (32%), sometimes (46%), frequently (8%), or always (1%) hasten death. Physicians were less favorable than nurses with the autonomy of bedside nurses to initiate the OPD before notifying the physician ($p = 0.04$). Overall, 95% of respondents considered that they would use the OPD in the future.

CONCLUSIONS:

Data from this survey shows that respondents are in favor of using the OPD at SJH and find it effective. Further training as well as support for health care professionals are mandatory in such palliative care settings.

PMID: 26788836

47. Arch Pediatr. 2016 Feb;23(2):150-8.

[Newly formed French residents in pediatrics are not well prepared for conducting pediatric resuscitation after medical school].

[Article in French]

Drummond D¹, Arnaud C², Thouvenin G³, Guedj R², Duguet A⁴, de Suremain N², Petit A⁵.

Abstract

BACKGROUND:

Medical schools aim to prepare medical students for their residency responsibilities. However, in France, there is no assessment of medical students' skills when they start their residency.

GOAL:

The objective of this study was to assess the quality of basic life support delivered by first-year residents in pediatrics during a simulated pediatric cardiopulmonary arrest.

MATERIALS AND METHODS:

First-year residents in pediatrics were assessed during a simulated pediatric cardiopulmonary arrest. Their performance score (based on adherence to international guidelines) and no-flow and no-blow fractions were recorded.

RESULTS:

Forty-two first-year residents were evaluated. Their median performance score was 4 out of 13. No-blow and no-flow fractions were 55 and 81 %, respectively. There was no correlation between their skills and their knowledge assessed during the national ranking exam at the end of the 6th year of medical school.

CONCLUSION:

At the beginning of their residency, pediatric residents are not able to properly provide basic life support. The introduction of simulation in French medical schools may be an effective way to improve their skills.

PMID: 26774839

48. Eur J Paediatr Neurol. 2016 Mar;20(2):261-9. doi: 10.1016/j.ejpn.2015.12.004. Epub 2015 Dec 22.

Symptoms and management of pediatric patients with incurable brain tumors in palliative home care.

Kuhlen M¹, Hoell J², Balzer S², Borkhardt A², Janssen G².

Abstract

INTRODUCTION: Brain tumors have the highest disease-related mortality rate of all pediatric cancers. The goal of this study was to determine whether all children with incurable brain tumors cared for by a pediatric palliative care team in a home setting suffer from the same symptoms towards the end of their lives or whether there are differences between the tumor localizations with implications for palliative care.

PATIENTS AND METHODS: This study was conducted as a retrospective, single center chart review including all patients treated between January 1st 2000 and December 31st 2013.

RESULTS: 70 children, adolescents and young adults were included in the analysis. Symptom burden was high with a mean number of symptoms of 7.2 per patient. 74% of the symptoms already existed one week before death. Within the last week of life, impaired consciousness (75.7%) most often occurred. Furthermore, symptoms considerably depended on tumor localization. Patients with supratentorial tumors presented more frequently with seizures ($p < 0.05$), coma ($p < 0.01$), nausea and emesis ($p < 0.01$). Ataxia ($p < 0.001$) occurred most frequently in infratentorial tumors and speech disturbances ($p < 0.05$), cranial nerve paralysis ($p < 0.001$), and tetraparesis ($p < 0.001$) in brain stem tumors. 84.3% of the patients needed analgesics, only 64.4% WHO class III analgesics. Anticonvulsants were given more often in supratentorial tumors ($p < 0.01$).

CONCLUSIONS: Caring for a dying child suffering from a brain tumor needs increased awareness of the neurological deterioration. The symptom pattern strongly depends on the tumor localization and significantly differs between supratentorial, infratentorial and brain stem tumors.

PMID: 26753538

49. Res Dev Disabil. 2016 Feb-Mar;49-50:235-46. doi: 10.1016/j.ridd.2015.12.006. Epub 2015 Dec 29.

End-of-life decision-making for children with severe developmental disabilities: The parental perspective.

Zaal-Schuller IH¹, de Vos MA², Ewals FV³, van Goudoever JB⁴, Willems DL⁵.

Abstract

BACKGROUND AND AIMS: The objectives of this integrative review were to understand how parents of children with severe developmental disorders experience their involvement in end-of-life decision-making, how they prefer to be involved and what factors influence their decisions.

METHODS AND PROCEDURES: We searched MEDLINE, EMBASE, CINAHL and PsycINFO. The search was limited to articles in English or Dutch published between January 2004 and August 2014. We included qualitative and quantitative original studies that directly investigated the experiences of parents of children aged 0-18 years with severe developmental disorders for whom an end-of-life decision had been considered or made.

OUTCOMES AND RESULTS: We identified nine studies that met all inclusion criteria. Reportedly, parental involvement in end-of-life decision-making varied widely, ranging from having no involvement to being the sole decision-maker. Most parents preferred to actively share in the decision-making process regardless of their child's specific diagnosis or comorbidity. The main factors that influenced parents in their decision-making were: their strong urge to advocate for their child's best interests and to make the best (possible) decision. In addition, parents felt influenced by their child's visible suffering, remaining quality of life and the will they perceived in their child to survive.

CONCLUSIONS AND IMPLICATIONS: Most parents of children with severe developmental disorders wish to actively share in the end-of-life decision-making process. An important emerging factor in this process is the parents' feeling that they have to stand up for their child's interests in conversations with the medical team.

PMID: 26741261

50. J Palliat Med. 2016 Mar;19(3):286-91.

The Effect of Palliative Care Team Design on Referrals to Pediatric Palliative Care.

Keele L¹, Keenan HT², Bratton SL².

Abstract

BACKGROUND: The American Academy of Pediatrics (AAP) and the American Academy of Hospice and Palliative Medicine (AAHPM) have recommended minimal standards for palliative care (PC) team composition and availability. It is unknown whether team composition affects utilization of PC.

OBJECTIVE: The study objective was to describe pediatric PC team composition, evaluate whether composition and availability are associated with utilization, and examine PC referral patterns.

METHODS: The study was a descriptive survey. Subjects were pediatric PC team directors or hospital administrators at Pediatric Health Information System (PHIS) hospitals (N = 44).

RESULTS: The overall response rate was 86%. Teams varied in size from <1 to 9 full-time members. Average referrals per hospital bed were 0.46, range 0.05-2.13. Among individual PC team roles, referral rates were 34% greater in teams with an advanced nurse practitioner (ANP) (p = 0.07). Likewise, teams with acute pain, chronic pain, or hospice palliative medicine specialists tended to have greater referral rates (39%, 36%, and 25%), though reported differences were not statistically significant. Teams adherent to the original AAP recommendations had a 31% greater referral rate (p = 0.22). Teams available 24 hours daily had similar referral rates to those with less availability (0.47 versus 0.46 [p = 0.94]).

CONCLUSIONS: Team composition and availability are not crucial to PC utilization. Hospitals with some personnel but not all recommended team members should create formal teams and modify them over time. The addition of team members that tend to increase referrals, namely ANPs and acute pain, chronic pain, or hospice palliative medicine specialists, should be considered.

PMID: 26670933

51. J Palliat Med. 2016 Mar;19(3):279-85.

Provision of Services in Perinatal Palliative Care: A Multicenter Survey in the United States.

Wool C¹, Côté-Arsenault D², Perry Black B³, Denney-Koelsch E⁴, Kim S⁵, Kavanaugh K⁶.

Abstract

BACKGROUND: Congenital anomalies account for 20% of neonatal and infant deaths in the United States. Perinatal palliative care is a recent addition to palliative care and is meant to meet the needs of families who choose to continue a pregnancy affected by a life-limiting diagnosis.

OBJECTIVE: To examine characteristics of programs and services provided, assess alignment with the National Consensus Project domains of care, and identify providers and disciplines involved in programs.

DESIGN: A cross-sectional survey design included 48 items addressing funding and domains of quality care.

SUBJECTS: Program representatives from 30 states (n = 75).

PRINCIPAL RESULTS: Perinatal palliative care programs are housed in academic medical centers, regional or community hospitals, local hospices, or community-based organizations. Significant differences by program setting were observed for type of fetal diagnoses seen, formal training in communicating bad news to parents, mechanisms to ensure continuity of care, and reimbursement mechanisms. One hundred percent of programs provided attention to spiritual needs and bereavement services; 70% of programs are less than 10 years old. Follow-up with parents to assess whether goals were met occurs at 43% of the perinatal palliative care programs. Formal measures of quality assessment were articulated in 38% of programs.

CONCLUSION: This study dramatically adds to the literature available on perinatal palliative care program settings, types, and domains of care. It is clear that there are a variety of types of programs and that the field is still developing. More work is needed to determine which quality measures are needed to address perinatal care needs in this population.

PMID: 26652200

52. J Perinatol. 2016 Mar;36(3):190-5.

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

Kaempf JW¹, Tomlinson MW², Tuohey J³.

Abstract

OBJECTIVE: Review all live births 22 0/7 through 26 6/7 weeks gestation born 1996 through 2013 at our

institution to describe the decision process and immediate outcomes of palliative comfort care (PCC) versus neonatal intensive care (NICU) and whether any significant family complaints or quality assurance concerns arose.

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

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

CONCLUSION: Most pregnant women and families choose NICU care for their extremely premature infant, but if given the option via shared decision making, a significant proportion will choose PCC at gestational ages that some NICUs mandate resuscitation. We support a reasoned dialogue and bioethical framework that recognizes human values to be irreducibly diverse, sometimes conflicting, and ultimately incommensurable-value pluralism. Respectful shared decision making requires thoughtful and compassionate flexibility, nuanced and individualized suggestions for PCC or NICU and the reduction of hierarchical directives from physicians to families. We continue to advocate and rely upon informed family preference between 23 and 25 weeks gestation in our updated 2015 periviability guidelines.

PMID: 26583942

53. J Pain Symptom Manage. 2016 Mar;51(3):520-8.

Advance Care Discussions: Pediatric Clinician Preparedness and Practices.

Sanderson A¹, Hall AM², Wolfe J³.

Abstract

CONTEXT: Few data exist regarding clinician preparedness to participate in advance care discussions (ACD) and the practices surrounding these discussions for children with life-threatening conditions.

OBJECTIVES: We sought to understand pediatric clinician preparedness to participate in ACD and the practices surrounding these discussions.

METHODS: A survey was administered to assess clinician attitudes and behaviors regarding ACD.

RESULTS: Two hundred sixty-six clinicians (107 physicians and 159 nurses) responded to the survey (response rate 53.6%). Seventy-five percent of clinicians felt prepared to participate in ACD. Most clinicians believed they were prepared to express empathy (98.8%), discuss goals of care for an adolescent patient (90.3%), and elicit a parent's hopes (90.3%). Conversely, several felt unprepared to discuss resuscitation status with school-aged (59.7%) and adolescent (48.5%) patients and to conduct a family conference (39.5%). The most frequent topics addressed were: parents' understanding of the patient's illness (75.5%), primary goals of the parent (75.1%), and the parents' understanding of prognosis (71.1%). Conversely, the topics least commonly discussed were as follows: belief system of the patient/family (22.0%), patient's hopes (21.2%), and the patient's perceptions of his/her quality of life (19.8%). Notably, 40% of clinicians believe that caring for patients with poor prognoses is depressing, and this was more common among less-experienced clinicians (P = 0.048).

CONCLUSION: Many clinicians believe they are prepared to participate in ACD, but practices are not consistent with expert recommendations for optimal ACD. Educational interventions aimed at improving clinician knowledge, attitudes, and behavior, and greater clinician support may enhance health care provider ACD preparedness and skills.

PMID: 26550935

54. Arch Dis Child Fetal Neonatal Ed. 2016 Mar;101(2):F92-3.

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

Carter BS.

PMID: 26542878

55. Pediatr Blood Cancer. 2016 Mar;63(3):516-22. doi: 10.1002/pbc.25822. Epub 2015 Oct 29.

Trends in End-of-Life Care in Pediatric Hematology, Oncology, and Stem Cell Transplant Patients.Brock KE¹, Steineck A², Twist CJ¹.**Abstract**

BACKGROUND: Decisions about end-of-life care may be influenced by cultural and disease-specific features. We evaluated associations of demographic variables (race, ethnicity, language, religion, and diagnosis) with end-of-life characteristics (Phase I enrollment, do-not-resuscitate (DNR) orders, hospice utilization, location of death), and trends in palliative care services delivered to pediatric hematology, oncology, and stem cell transplant (SCT) patients.

PROCEDURE: In this single-center retrospective cohort study, inclusion criteria were as follows: patients aged 0-35 who died between January 1, 2002 and March 1, 2014, and had been cared for in the pediatric hematology, oncology, and SCT divisions. The era of 2002-2014 was divided into quartiles to assess trends over time.

RESULTS: Of the 445 included patients, 64% of patients had relapsed disease, 45% were enrolled in hospice, and 16% had received palliative care consultation. Patients with brain or solid tumors enrolled in hospice ($P < 0.0001$) and died at home more frequently than patients with leukemia/lymphoma ($P < 0.0001$). Patients who received Phase I therapy or identified as Christian/Catholic religion enrolled in hospice more frequently ($P < 0.0001$ and $P = 0.03$, respectively). When patient deaths were analyzed over quartiles, the frequency of DNR orders ($P = 0.02$) and palliative care consultation ($P = 0.04$) increased over time. Hospice enrollment, location of death, and Phase I trial enrollment did not change significantly.

CONCLUSIONS: Despite increases in palliative care consultation and DNR orders over time, utilization remains suboptimal. No increase in hospice enrollment or shift in death location was observed. These data will help target future initiatives to achieve earlier discussions of goals of care and improved palliative care for all patients.

PMID: 26513237

56. Eur J Pediatr. 2016 Mar;175(3):321-7.

Experiences in palliative home care of infants with life-limiting conditions.Kuhlen M¹, Höll JI², Sabir H³, Borkhardt A⁴, Janßen C⁵.**Abstract**

The aim of this study was to determine the distinct issues neonates/infants with life-limiting conditions and their families face during palliative home care and to enable physicians/caregivers to carefully address their needs. Data on home-based palliative care of all neonates and infants, who were being taken care of by our paediatric palliative care team between 2007 and 2014, was analysed. A total of 31 patients (pts) were analysed. The majority of patients ($n = 17$) were diagnosed with congenital malformations or chromosomal abnormalities. Twenty pts died, five of them in hospital. A high percentage of pts presented with swallowing incoordination (83.9 %) and was fed either by nasogastric tube or percutaneous endoscopic gastrostomy. Of the pts, 71.0 % were treated with analgesics, 45.2 % were oxygen dependent, and 9.7 % required mechanical ventilation. Highest mortality was seen in pts with perinatal complications (75 %). In four (12.9 %) pts, palliative home care could come to an end as their conditions substantially improved.

CONCLUSIONS: Palliative treatment of neonates/very young infants with terminal conditions at home seems to be similar to that of older children and feasible in children even with unstable conditions. The spectrum of diagnoses, signs and symptoms varies from older children with swallowing incoordination and artificial nutrition being of particular importance.

PMID: 26411975

57. Arch Dis Child Fetal Neonatal Ed. 2016 Mar;101(2):F102-7.

Neonatal deaths: prospective exploration of the causes and process of end-of-life decisions.Hellmann J¹, Knighton R², Lee SK³, Shah PS³, Canadian Neonatal Network End of Life Study Group.**Abstract**

OBJECTIVE: To determine the causes and process of death in neonates in Canada.

DESIGN: Prospective observational study.

SETTING: Nineteen tertiary level neonatal units in Canada.

PARTICIPANTS: 942 neonatal deaths (215 full-term and 727 preterm).

EXPOSURE AND OUTCOME: Explored the causes and process of death using data on: (1) the rates of withdrawal of life-sustaining treatment (WLST); (2) the reasons for raising the issue of WLST; (3) the extent of consensus with parents; (4) the consensual decision-making process both with parents and the multidisciplinary team; (5) the elements of WLST; and (6) the age at death and time between WLST and actual death.

RESULTS: The main reasons for deaths in preterm infants were extreme immaturity, intraventricular haemorrhage and pulmonary causes; in full-term infants asphyxia, chromosomal anomalies and syndromic malformations. In 84% of deaths there was discussion regarding WLST. WLST was agreed to by parents with relative ease in the majority of cases. Physicians mainly offered WLST for the purpose of avoiding pain and suffering in imminent death or survival with a predicted poor quality of life. Consensus with multidisciplinary team members was relatively easily obtained. There was marked variation between centres in offering WLST for severe neurological injury in preterm (10%-86%) and severe hypoxic-ischaemic encephalopathy in full-term infants (5%-100%).

CONCLUSIONS AND RELEVANCE: In Canada, the majority of physicians offered WLST to avoid pain and suffering or survival with a poor quality of life. Variation between units in offering WLST for similar diagnoses requires further exploration.

PMID: 26253166

58. J Child Neurol. 2016 Mar;31(4):488-505.

Improving Care in Pediatric Neuro-oncology Patients: An Overview of the Unique Needs of Children With Brain Tumors.

Fischer C¹, Petriccione M², Donzelli M², Pottenger E².

Abstract

Brain tumors represent the most common solid tumors in childhood, accounting for almost 25% of all childhood cancer, second only to leukemia. Pediatric central nervous system tumors encompass a wide variety of diagnoses, from benign to malignant. Any brain tumor can be associated with significant morbidity, even when low grade, and mortality from pediatric central nervous system tumors is disproportionately high compared to other childhood malignancies. Management of children with central nervous system tumors requires knowledge of the unique aspects of care associated with this particular patient population, beyond general oncology care. Pediatric brain tumor patients have unique needs during treatment, as cancer survivors, and at end of life. A multidisciplinary team approach, including advanced practice nurses with a specialty in neuro-oncology, allows for better supportive care. Knowledge of the unique aspects of care for children with brain tumors, and the appropriate interventions required, allows for improved quality of life.

PMID: 26245798

59. J Pediatr Oncol Nurs. 2016 Mar;33(2):85-104.

Experiences of Pediatric Oncology Patients and Their Parents at End of Life: A Systematic Review.

Montgomery K¹, Sawin KJ², Hendricks-Ferguson VL³.

Abstract

Improvement in pediatric palliative and end-of-life care has been identified as an ongoing research priority. The child and parent experience provides valuable information to guide how health care professionals can improve the transition to end of life and the care provided to children and families during the vulnerable period. The purpose of this systematic review was to describe the experience of pediatric oncology patients and their parents during end of life, and identify gaps to be addressed with interventions. A literature search was completed using multiple databases, including CINAHL, PubMed, and PsycInfo. A total of 43 articles were included in the review. The analysis of the evidence revealed 5 themes: symptom prevalence and symptom management, parent and child perspectives of care, patterns of care, decision making, and parent and child outcomes of care. Guidelines for quality end-of-life care are needed. More research is needed to address methodological gaps that include the pediatric patient and their sibling's experience.

PMID: 26219300

60. Scand J Caring Sci. 2016 Mar;30(1):5-25.

Palliative Care Research - A Systematic Review of foci, designs and methods of research conducted in Sweden between 2007 and 2012.

Henoch I^{1,2}, Carlander I^{3,4}, Holm M^{3,5}, James I⁶, Kenne Sarenmalm E^{3,7}, Lundh Hagelin C^{4,8,9}, Lind S^{3,5}, Sandgren A^{10,11}, Öhlén J^{1,2,3}.

Abstract

BACKGROUND: In 2007, a literature review was undertaken of palliative care research from Sweden during the 1970s-2006, paving the way for a follow-up study to explore the recent developments. The aim was to systematically examine palliative care research from Sweden between 2007 and 2012, with special attention to methods, designs and research foci.

METHODS: A literature review was undertaken. The databases Academic search elite, Age line, Ahmed, Cinahl, PsychInfo, PubMed, Scopus, Soc abstracts, Web of science and Libris were reviewed for Swedish palliative care research studies published from 2007 to 2012, applying the search criteria 'palliative care OR palliative medicine OR end-of-life care OR terminal care OR hospice care OR dying OR death'.

RESULTS: A total of 263 papers met the inclusion criteria, indicating an increased volume of research compared to the 133 articles identified in the previous review. Common study foci were symptom assessment and management, experiences of illness and care planning. Targeting non-cancer-specific populations and utilisation of population-based register studies were identified as new features. There was continued domination of cross-sectional, qualitative and mono-disciplinary studies, not including ethnic minority groups, nonverbally communicable people or children <18 years of age.

CONCLUSIONS: The trend is that Swedish palliative care research has expanded in volume from 2007 to 2012 compared to during the 1970s to 2006, with increasing participation of non-cancer-specific populations. A domination of qualitative approaches and small, cross-sectional studies with few interventions is still characteristic. Still more strategies are needed to expand the knowledge development of palliative care to respond to demographical, epidemiological, therapeutic and healthcare structure changes.

PMID: 26190052

61. Clin Pediatr (Phila). 2016 Feb;55(2):101-6.

Where Children Die: Obstacles to Quality End-of-Life Care.

Hinson AP¹, Rosoff PM².

PMID: 26116346

62. Palliat Support Care. 2016 Feb;14(1):13-9.

Listening to parents: The role of symptom perception in pediatric palliative home care.

Vollenbroich R¹, Borasio GD², Duroux A¹, Grasser M¹, Brandstätter M³, Führer M¹.

Abstract

OBJECTIVE: This study analyzes symptom perception by parents and healthcare professionals and the quality of symptom management in a pediatric palliative home care setting and identifies which factors contribute to a high quality of palliative and end-of-life care for children.

METHODS: In this retrospective, cross-sectional study, parents were surveyed at the earliest three months after their child's death. All children were cared for by a specialized home pediatric palliative care team that provides a 24/7 medical on-call service. Questionnaires assessed symptom prevalence and intensity during the child's last month of life as perceived by parents, symptom perception, and treatment by medical staff. The responses were correlated with essential palliative care outcome measures (e.g., satisfaction with the care provided, quality-of-life of affected children and parents, and peacefulness of the dying phase).

RESULTS: Thirty-eight parent dyads participated (return rate 84%; 35% oncological disorders). According to parental report, dyspnea (61%) and pain (58%) were the dominant symptoms with an overall high symptom load (83%). Pain, agitation, and seizures could be treated more successfully than other symptoms. Successful symptom perception was achieved in most cases and predicted the quality of symptom treatment (R 2, 0.612). Concordant assessment of symptom severity between parents and healthcare professionals (HCPs) improved the satisfaction with the care provided (p = 0.037) as well as the parental quality-of-life (p = 0.041). Even in cases with unsuccessful symptom control, parents were very satisfied with the SHPPC team's care (median 10; numeric rating scale 0-10) and rated the child's death as highly peaceful (median 9).

Significance of the results: The quality and the concordance of symptom perception between parents and

HCPs essentially influence parental quality-of-life as well as parental satisfaction and constitute a predictive factor for the quality of symptom treatment and palliative care.

63. Palliat Med. 2016 Mar;30(3):212-23.

Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review.

Weaver MS¹, Heinze KE², Bell CJ³, Wiener L⁴, Garee AM⁵, Kelly KP⁶, Casey RL⁷, Watson A⁸, Hinds PS; Pediatric Palliative Care Special Interest Group at Children's National Health System.

Abstract

BACKGROUND: Despite standardization in disease assessments and curative interventions for childhood cancer, palliative assessments and psychosocial interventions remain diverse and disparate.

AIM: Identify current approaches to palliative care in the pediatric oncology setting to inform development of comprehensive psychosocial palliative care standards for pediatric and adolescent patients with cancer and their families. Analyze barriers to implementation and enabling factors.

DESIGN: Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines framed the search strategy and reporting. Data analysis followed integrative review methodology.

DATA SOURCES: Four databases were searched in May 2014 with date restrictions from 2000 to 2014: PubMed, Cochrane, PsycINFO, and Scopus. A total of 182 studies were included for synthesis. Types of studies included randomized and non-randomized trials with or without comparison groups, qualitative research, prior reviews, expert opinion, and consensus report.

RESULTS: Integration of patient, parent, and clinician perspectives on end-of-life needs as gathered from primary manuscripts (using NVivo coding for first-order constructs) revealed mutual themes across stakeholders: holding to hope, communicating honestly, striving for relief from symptom burden, and caring for one another. Integration of themes from primary author palliative care outcome reports (second-order constructs) revealed the following shared priorities in cancer settings: care access; cost analysis; social support to include primary caregiver support, sibling care, bereavement outreach; symptom assessment and interventions to include both physical and psychological symptoms; communication approaches to include decision-making; and overall care quality.

CONCLUSION: The study team coordinated landmark psychosocial palliative care papers into an informed conceptual model (third-order construct) for approaching pediatric palliative care and psychosocial support in oncology settings.

PMCID: PMC4624613 **Free PMC Article**

PMID: 25921709

64. Am J Hosp Palliat Care. 2016 Mar;33(2):115-23.

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

Iranmanesh S¹, Banazadeh M², Forozy MA³.

Abstract

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

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

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

CONCLUSION: More high perceived barriers by nurses were family-related issues. One of the possible causes of such deficiencies was lack of palliative care (PC) education/PC units in Iran. Thus, developing EOL/PC education may enhance nurses' knowledge/skill to face EOL care challenges.

PMID: 25376225

65. Nurs Ethics. 2016 Feb;23(1):48-60.

Psychosocial determinants of nurses' intention to practise euthanasia in palliative care.Lavoie M¹, Godin C², Vézina-Im LA², Blondeau D³, Martineau I⁴, Roy L⁵.**Abstract****BACKGROUND:** Most studies on euthanasia fail to explain the intentions of health professionals when faced with performing euthanasia and are atheoretical.**RESEARCH OBJECTIVE:** The purpose of this study was to identify the psychosocial determinants of nurses' intention to practise euthanasia in palliative care if it were legalised.**RESEARCH DESIGN:** A cross-sectional study using a validated anonymous questionnaire based on an extended version of the Theory of Planned Behaviour.**PARTICIPANTS AND RESEARCH CONTEXT:** A random sample of 445 nurses from the province of Quebec, Canada, was selected for participation in the study.**ETHICAL CONSIDERATIONS:** The study was reviewed and approved by the Ethics Committee of the Centre hospitalier universitaire de Québec.**FINDINGS:** The response rate was 44.2% and the mean score for intention was 4.61 ± 1.90 (range: 1-7). The determinants of intention were the subjective (odds ratio = 3.08; 95% confidence interval: 1.50-6.35) and moral (odds ratio = 2.95; 95% confidence interval: 1.58-5.49) norms. Specific beliefs which could discriminate nurses according to their level of intention were identified.**DISCUSSION:** Overall, nurses have a slightly positive intention to practise euthanasia. Their family approval seems particularly important and also the approval of their medical colleagues. Nurses' moral norm was related to beneficence, an ethical principle.**CONCLUSION:** To our knowledge, this is the first study to identify nurses' motivations to practise euthanasia in palliative care using a validated psychosocial theory. It also has the distinction of identifying the ethical principles underlying nurses' moral norm and intention.

PMID: 25488755

66. Am J Hosp Palliat Care. 2016 Feb;33(1):5-7.

Why Palliative Care for Children is Preferable to Euthanasia.Carter BS¹.**Abstract:** Recent laws in Europe now allow for pediatric euthanasia. The author reviews some rationale for caution, and addresses why ensuring the availability of pediatric palliative care is an important step before allowing pediatric euthanasia.

PMID: 25007796

67. Nurse Educ Pract. 2016 Mar;17:60-6.

An evaluation of an interprofessional master's level programme in children's palliative care: The students' evaluation.Nicholl H¹, Price J², Tracey C³.**Abstract:** In 2010/12 an innovative children's palliative care interprofessional educational project funded by the Irish Hospice Foundation was undertaken in a University faculty (Trinity College Dublin). This initiative responded to international educational recommendations to meet the palliative care needs of children. The project involved the development and delivery of 3 standalone modules at Master's level and a substantive research evaluation of the project to examine stakeholders and students perspectives to provide an insight into their experiences and to gather data for future developments. The research evaluation was conducted in two parts, part one sought students' evaluation and part two sought stakeholders', curriculum developers and lecturers' feedback. This paper reports the students' evaluation. Findings indicate that students perceived undertaking the modules provided them with the opportunity for improved interprofessional learning and they found modular content and assessment challenging. They also found the modules met their educational needs and also promoted an awareness of interprofessional education and the collaborative teamwork involved in children's palliative care. These students already experienced in children's palliative care indicated that those teaching on programmes at this level need expertise and programme time needs to be available for sharing experiences and for consolidation of learning. PMID: 24746903