PUBLICATIONS EN SOINS PALLIATIFS PEDIATRIQUES

2000/01 – 2009/07 : 197 références

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Nombre d'articles de soins palliatifs pédiatriques indexés dans Pubmed de 2000 à 2009

1: Cochrane Database Syst Rev. 2009 Apr 15;(2):CD003968.

Psychological therapies for the management of chronic and recurrent pain in children and adolescents.

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BACKGROUND: Headache, recurrent abdominal pain, and musculoskeletal pain affect many children, who report severe pain, distressed mood, and disability. Psychological therapies are emerging as effective interventions to treat children with chronic or recurrent pain. This is a substantially updated and expanded version of the Cochrane review published in 2003. OBJECTIVES: To assess the effectiveness of psychological therapies for reducing pain, disability, and improving mood in children and adolescents with recurrent, episodic, or persistent pain. SEARCH STRATEGY: Searches were undertaken of MEDLINE, PsycLIT, EMBASE and CONSORT. RCTs were sought in references of all identified studies, meta-analyses and reviews. Date of most recent search: August 2008. SELECTION CRITERIA: Randomised Controlled Trials (RCTs) with at least ten participants in each arm post-treatment comparing psychological therapies with placebo, waiting list or standard medical care for children or adolescents with episodic, recurrent or persistent pain, were eligible for inclusion. DATA COLLECTION AND ANALYSIS: All included studies were analysed and the quality of the studies recorded. All treatments were combined into one class: psychological treatments; headache and non-headache outcomes were separately analysed on three outcomes: pain, disability, and mood. MAIN RESULTS: Thirty-four RCT studies were recovered; 29 met the inclusion criteria. The total number of participants completing treatments was 1432. Twenty studies addressed treatments for headache (including migraine); six for abdominal pain; one for both headache and abdominal pain, one study was for fibromyalgia, and one was for pain associated with sickle cell disease. The analysis of headache treatment versus control differences immediately post-treatment for pain gave an odds ratio (OR) of 5.51 (95% CI 3.28 to 9.24; $z = 6.46$, $P < 0.05$); NNT = 2.57 (CI 2.2 to 3.13). At follow-up, the OR was 9.91 (95% CI 3.73 to 26.33); $z = 9.91$, $P < 0.05$); NNT = 1.99 (CI 1.63 to 2.72). Analysis of non-headache treatment versus control differences immediately post-treatment for pain found a large effect size of -0.94 (95% CI -1.43 to -0.44) $Z = 3.71$, $P < 0.05$. At follow-up, a large effect size was found of -1.08 (95%CI -1.84 to -0.33); $Z = 2.82$, $P < 0.05$). There were no other significant effects. AUTHORS' CONCLUSIONS: Psychological treatments are effective in pain control for children with headache and benefits appear to be maintained. Psychological treatments may also improve pain control for children with musculoskeletal and recurrent abdominal pain. There is little evidence available to estimate effects on disability or mood.

2: Curr Pain Headache Rep. 2009 Apr;13(2):100-9.

The use of virtual reality for pain control: a review.

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Virtual reality (VR) is a relatively new technology that enables individuals to immerse themselves in a virtual world. This multisensory technology has been used in a variety of fields, and most recently has been applied clinically as a method of distraction for pain management during medical procedures. Investigators have posited that VR creates a nonpharmacologic form of analgesia by changing the activity of the body's intricate pain modulation system. However, the efficacy of VR has not been proven and the exact mechanisms behind VR's action remain unknown. This article presents a comprehensive review of the literature to date exploring the clinical and experimental applications of VR for pain control. The review details specific research methodologies and popular virtual environments. Limitations of the research, recommendations for improvement of future studies, and clinical experiences with VR are also discussed.

3: Neuromuscul Disord. 2009 Jan;19(1):76; author reply 76. Epub 2008 Dec 12.

Survival in SMA type 1.

Kaufmann P, **Greiss C**, **Brown J**.

4: J Palliat Care. 2008 Winter;24(4):265-9.

Is there a role for palliative care in progressive pediatric neuromuscular diseases? The answer is "Yes!

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The consequences of prolongation of survival can be oversimplified, for example, by equating technologically prolonged survival with indefinitely prolonged high quality of life. When this oversimplified view is embraced, the prognosis of ultimately fatal diseases like DMD may be viewed with unrealistic optimism and palliative care may seem irrelevant or misguided. However, we have shown that the sequelae of prolonged survival are complex. For example, NPPV does not protect prolonged survivors of progressive NMDs from potentially debilitating medical complications that can cause elevated burden of disease, high burden of care, and the potential for impaired quality of life. Also, the sequelae of prolonged survival can negatively affect a wide variety of stakeholders, including patients and their families, medical professionals, and society. It is our view that, when the implications of prolonged survival are examined carefully, their complexity is revealed, and the potential for palliative care to provide support and to relieve suffering in prolonged survivors of progressive NMDs becomes apparent. Thus, we advocate development of an integrative care model for patients with progressive NMDs, blending technological therapies with adoption of palliative strategies as patients approach end of life.

5: Lancet Oncol. 2008 Nov;9(11):1102-7.

Off-label use of anticancer drugs.

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Use of a drug outside the terms of its official labelling is referred to as off-label prescription. Many categories of use exist because labelling of anticancer agents is very precise in terms of type or subtype of tumour, association, line, and duration of treatment. Off-label prescription of anticancer drugs is thought to be frequent but, in fact, very few surveys have been done to ascertain its real extent. Findings of prospective studies undertaken between 1990 and 2002 showed proportions of off-label drug use in children and adults of 6.7-33.2%. Most off-label prescription was reported in patients treated with palliative intent, some was associated with clinical benefits, and in specific cancers it formed the standard of care. Off-label use can lead to reimbursement restrictions. Regulatory agencies have created incentives to extend indications for approved drugs to remove them from the off-label area. Proposals have also been made to gather and disseminate accurate and unbiased information on off-label use and to record unapproved indications.

6: J Pediatr Hematol Oncol. 2008 Nov;30(11):829-30.

A systematic review of treatments for constipation in children and young adults undergoing cancer treatment. **Phillips RS**, **Gibson F**.

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Constipation is a common problem in children and young people with cancer. Treatment of this complication is subject to wide variation in practice. We undertook a systematic review of randomized controlled trials to build a rational approach to prophylaxis and treatment of this complication. Randomized controlled trials of any intervention (pharmacologic, physical, complementary, or alternative) to prevent or treat constipation were to be included if they included children and young people 16 years old and younger who were undergoing treatment for malignancy. Of the 1336 abstracts retrieved from the searches, only 3 papers were identified for further assessment, and no studies were suitable for inclusion. There are no good data on which to base the management of constipation in children and young people with cancer. This is not to say that we do not know if laxatives work-they are clearly effective. Our ignorance is of the comparative value of different agents. The practical problems with undertaking specific trials of supportive care measures are large, and integration of such questions into treatment trials is essential.

7: Congenit Heart Dis. 2008 Sep;3(5):317-24.

Home videoconferencing for patients with severe congential heart disease following discharge.

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BACKGROUND: Centralization of pediatric cardiology services into a small number of tertiary centers and the particular stress that accompanies diagnosis and surgical management of severe congenital heart disease (CHD) renders psychological support for families and clinical monitoring of patients following discharge increasingly important. Telemedicine has an increasing role in clinical and academic medicine. Improvements in quality and reliability of videoconferencing systems have allowed this to become a useful diagnostic tool. OBJECTIVE: This study aimed to assess the benefits of home monitoring by videoconferencing compared with contacting by telephone only, in terms of decreasing anxiety levels and clinical monitoring in the postdischarge period. METHODS: We performed a prospective, controlled study of children with a recent diagnosis of severe CHD and those recovering from palliative or corrective surgery for severe CHD. We used standardized anxiety scores to assess anxiety after discharge in families followed up by home videoconferencing or telephone calls and assessed the clinical information available through videoconferencing or telephone calls by structured questionnaires. RESULTS: Videoconferencing decreased anxiety levels compared with telephone calls ($P < .05$). Improved clinical information was available in the videoconferencing group, resulting in more appropriate and timely hospital attendance. CONCLUSION: Videoconferencing is acceptable to parents and physicians and provides a more effective form of follow-up in terms of clinical observation and parental anxiety levels.

8: J Clin Oncol. 2008 Oct 1;26(28):4646-50.

Availability and use of palliative care and end-of-life services for pediatric oncology patients.

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PURPOSE: Palliative care prevents or relieves the symptoms caused by life-threatening medical conditions. Previous surveys have shown both underuse and lack of availability of these services for children with cancer throughout North America. We sought to investigate the current practices and resources surrounding palliative and end-of-life care among participating institutions of the Children's Oncology Group (COG). METHODS: A survey regarding practices and resources was developed by the COG palliative care subcommittee and was sent to all 232 institutions to complete for the calendar year 2005. RESULTS: The survey was completed by 81% of the institutions. Per institution, there were a mean of 64.6 newly diagnosed patients and 17.7 patients experiencing relapse. A palliative care team was available in 58% of institutions, a pain service in 90%, a hospice in 60%, a psychosocial support team in 80%, and a bereavement program in 59%. Complementary and alternative medicine was available in 39% of institutions and in 95% of the COG institution's community. Most services, even when available, were not well used by patients. CONCLUSION: Despite the well-established benefit of pediatric palliative care, it is only offered in 58% of COG institutions caring for children with cancer. In an era where the benefit of palliative care has been clearly established, this number should approach 100%. Efforts should be directed toward understanding barriers to provision of such services, so that they are available and well used at all childhood cancer centers.

9: Bull Acad Natl Med. 2008 Feb;192(2):393-400; discussion 401-3.

[How to discuss death with a dying child: can a story help?]

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Is it necessary--and possible--to discuss death with a terminally ill child? How should one approach the subject? A recent Swedish study demonstrates the benefits for parents who discuss with their child his or her imminent death, and examines the ways in which caregivers can help such parents. The mother of one child treated in our unit recently wrote a story 48 hours before her child's death. The story served to broach a number of questions often raised by dying children and their families: fear of the unknown, of being replaced, the inevitability of death, grief and fear of being forgotten... Since 2004, the story has been given to several families with dying children in our unit. In order to evaluate the story's impact on families and to determine whether a document which stimulates dialogue should continue to be given to parents, we asked the first thirteen to fill out a questionnaire. The results confirmed that the story was experienced as something positive and that it helped parents to talk with their children. The results of our study lead us to conclude that the medical profession should lend its full support to families who wish to engage in this dialogue with their

children. This study also raises many questions and should be part of a global accompaniment strategy. With our support, an illustrated story book called Falikou was published in October 2006.

10: Am J Hosp Palliat Care. 2008 Dec-2009 Jan;25(6):427-30. Epub 2008 Sep 23.

The use of pediatric advance directives: a tool for palliative care physicians.

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Although laws such as the Patient Self-Determination Act encourage individuals to address their end-of-life treatment preferences using advance directives, the wishes of children have traditionally been ignored or, perhaps even worse, overruled. Given that there is a substantial body of research indicating that children are capable of making mature decisions when faced with terminal illness, the author proposes granting minors, especially older minors, the right to participate in making end-of-life decisions. Children who complete advance directives benefit in multiple ways. Adopting this approach could benefit patients by demonstrating respect for patient autonomy and informing parents and providers that the minor may be ready to stop aggressive treatment.

11: Pediatrics. 2008 Sep;122(3):574-82.

What accounts for differences or disparities in pediatric palliative and end-of-life care? A systematic review focusing on possible multilevel mechanisms.

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OBJECTIVE: The goal was to clarify potential mechanisms underlying differences/disparities in pediatric palliative and end-of-life care. METHODS: We systematically searched online databases to identify articles relating to differences/disparities in pediatric palliative and end-of-life care, retaining 19 studies for evaluation. We then augmented this search with a broader review of the literature on the mechanisms of differences/disparities in adult palliative and end-of-life care, general pediatrics, adult medicine, and pain. RESULTS: The concept of reciprocal interaction can organize and illuminate interacting mechanisms across 3 levels of human organization, namely, broader contextual influences on patients and clinicians, specific patient-provider engagements, and specific patients. By using this rubric, we identified 10 distinct mechanisms proposed in the literature. Broader contextual influences include health care system structures; access to care; and poverty, socioeconomic status, social class, and family structure. Patient-clinician engagements encompass clinician bias, prejudice, and stereotypes; concordance of race; quality of information exchange; and trust. Patient-specific features include perceptions of control; religion and spirituality; and medical conditions. CONCLUSIONS: Differences and disparities in pediatric palliative and end-of-life care can be understood as arising from various mechanisms that interact across different levels of human organization, and this interactive multilevel model should be considered in designing studies or planning interventions to understand differences and to ameliorate disparities.

12: Palliat Med. 2008 Oct;22(7):831-4. Epub 2008 Aug 21.

A report on location of death in paediatric palliative care between home, hospice and hospital.

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This retrospective study analysed data for 703 children who died from 2000 to 2006 to examine where children with a broad range of progressive, life-limiting illnesses actually die when families are able to access hospital, paediatric hospice facility and care at home. There was an overall even distribution for location of death in which 35.1% of children died at home, 32.1% died in a paediatric hospice facility, 31.9% in hospital and 0.9% at another location. Previous research suggests a preference for home as the location of death, but these studies have primarily focused on adults, children with cancer or settings without paediatric hospice facilities available as an option. Our results suggest that the choice of families for end-of-life care is equally divided amongst all three options. Given the increasing numbers of children's hospices worldwide, these findings are important for clinicians, care managers and researchers who plan, provide and evaluate the care of children with life-limiting illness.

13: Lancet. 2008 Jun 28;371(9631):2169.

Paediatric palliative care.

Darlington AS, **van den Heuvel-Eibrink MM**, **Passchier J**.

14: Lancet. 2008 Jun 28;371(9631):2169.

Paediatric palliative care.
Vissers KC, **Engels Y**, **Verhagen C**.

15: Int J Palliat Nurs. 2008 May;14(5):212.

Children's palliative care: 'thinking outside the box'.
Downing J.

16: Arch Dis Child. 2008 Dec;93(12):1067-70. Epub 2008 Jun 18.

Predicting death in children.
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Rarely do paediatric palliative medicine physicians have to break the news of a diagnosis of a life-limiting condition. It is much commoner for us to be faced with the question: "how long?". This cannot be answered with certainty, and yet a great deal may depend on it. While palliative care should ideally be available from diagnosis, the need for "active" practical palliative care intervention will fluctuate during the course of a child's illness, often over months or years, sometimes decades. Typically, there will be several periods during which death seems likely before the final terminal episode, particularly among children with non-malignant life-limiting condition. Optimal management of all episodes depends on anticipating the child's needs, which in turn depends on recognising that such an episode has begun. Providing adequate palliative care critically depends on making a diagnosis of dying. In this article, we will consider why it is important to make a diagnosis of dying, briefly review some of the helpful tools available, and examine some of the evidence from published literature in children and adults.

17: J Palliat Care. 2008 Spring;24(1):41-8.

Pediatric palliative care online: the views of health care professionals.
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The purpose of the study was to evaluate the role of an online resource for dying children, their family members, and health care providers from the perspective of pediatric palliative care experts. Semistructured interviews with 12 leaders in pediatric palliative care in North America were conducted, exploring their perceptions and attitudes towards various aspects of Web-based resources for dying children and their care providers. Informants felt that an online resource may allow for a different form of expression, a connection between people undergoing a rare event, and an increase in education and support. Major challenges, such as accessibility, monitoring, and remaining current, would be ongoing. Other key themes included access, information, and anonymity. The data suggest that developing Web-based resources for dying young patients and their families may have merit. Should this take place, a feasibility study will be necessary to further determine the value of such a Web site for these vulnerable populations.

18: Eur J Cancer. 2008 May;44(8):1139-45. Epub 2008 Apr 11.

Paediatric palliative care: coming of age in oncology?
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Palliative care in children has been emerging as a clinical subspecialty of paediatrics for many years. It requires the knowledge and experience of a paediatrician, combined with the skills of a palliative care specialist. Both are essential, as a paediatrician may not have advanced knowledge of palliative care and a palliative care specialist is unlikely to be familiar with the complexity of working with families where the child is the patient. This paper reviews recent literature and discusses advances in the development of palliative care services for children and young people with incurable cancer. It highlights key areas where paediatric palliative care differs from that of adults and outlines the barriers to providing palliation and conducting evidence-based research in children and young people dying from cancer.

19: Asia Pac J Clin Nutr. 2008;17(1):17-22.

Effectiveness of Taiwanese traditional herbal diet for pain management in terminal cancer patients.
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In addition to modern medicinal therapy, many cancer patients in Taiwan are treated regularly with herbal medicines or prescribed a traditional herbal diet. In this paper, the effect of a Taiwanese traditional herbal diet (TTHD) on pain in terminal cancer patients was investigated. A total of 2,466 patients diagnosed with a variety of cancers were included. The most common patient-reported symptoms included troublesome pain (79.2%), weakness (69.0%), anorexia (46.4%), fever (36.5%), dyspnea (31.1%), and leg edema (30.9%). The 2,466 terminal cancer patients included in the study were randomly divided into three groups. The TTHD group (n=1044; 42.3%) were given the TTHD consisting of analgesic herbs (paeony root: licorice root=1:1) and a Taiwanese tonic vegetable soup (Lilii bulbus, Nelumbo seed, and Jujube fruit). The remaining patients were divided into a reference group, given the regular hospital diet, (n=909, 36.9%) and a control group, given the Taiwanese tonic vegetable soup without analgesic herbs, (n=513, 20.8%). All patients maintained their assigned diets for one week. A verbal numerical scale was used to assess pain. Results revealed that the patients given TTHD reported enhanced pain relief (p<0.05) compared to the reference and control groups. We found that TTHD could alleviate the pain among terminal cancer patients thereby supporting the supposition that Eastern and Western medicines can be effectively co-administered to enhance terminal patient's quality of life. Further research is warranted.

20: J Palliat Med. 2008 Apr;11(3):459-69.

Do-not-resuscitate orders and/or hospice care, psychological health, and quality of life among children/adolescents with acquired immune deficiency syndrome.

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OBJECTIVE: The frequency of do-not-resuscitate (DNR) orders and hospice enrollment in children/adolescents living with acquired immune deficiency syndrome (AIDS) and followed in Pediatric AIDS Clinical Trials Group (PACTG) Study 219C was examined, and evaluated for any association with racial disparities or enhanced quality of life (QOL), particularly psychological adjustment. METHODS: A cross-sectional analysis of children with AIDS enrolled in this prospective multicenter observational study between 2000 and 2005 was conducted to evaluate the incidence of DNR/hospice overall and by calendar time. Linear regression models were used to compare caregivers' reported QOL scores within 6 domains between those with and without DNR/hospice care, adjusting for confounders. RESULTS: Seven hundred twenty-six (726) children with AIDS had a mean age of 12.9 years (standard deviation [SD]=4.5), 51% were male, 60% black, 25% Hispanic. Twenty-one (2.9%) had either a DNR order (n=16), hospice enrollment (n=7), or both (n=2). Of 41 children who died, 80% had no DNR/hospice care. Increased odds of DNR/hospice were observed for those with CD4% less than 15%, no current antiretroviral use, and prior hospitalization. No differences by race were detected. Adjusted mean QOL scores were significantly lower for those with DNR/hospice enrollment than those without across all domains except for psychological status and health care utilization. Poorer psychological status correlated with higher symptom distress, but not with DNR/hospice enrollment after adjusting for symptoms. CONCLUSIONS: Children who died of AIDS rarely had DNR/hospice enrollment. National guidelines recommend that quality palliative care be integrated routinely with HIV care. Further research is needed to explore the barriers to palliative care and advance care planning in this population.

21: J Pediatr Nurs. 2008 Apr;23(2):120-5.

Can the death of a child be good?

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Fifty-four thousand children die each year despite the advances in care for children with acute and chronic illnesses. Demands for improved palliative and end-of-life care for children exist. Good death is a concept frequently used in the adult hospice movement. However, how can the death of a child be good? Analysis of good death can assist pediatric nurses to understand the concept and provide a framework for nurses in the clinical and research arenas to work together to develop and provide evidence-based, developmentally appropriate care for dying children and their families.

22: Lancet. 2008 Mar 8;371(9615):786.

Paediatric palliative care.

[No authors listed]

23: J Clin Oncol. 2008 Mar 10;26(8):1310-5.

Understanding of prognosis and goals of care among couples whose child died of cancer.

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PURPOSE: Little is known about how couples care for the terminally ill child with cancer. We assessed both parents' understanding of prognosis and treatment goals for children with cancer and explored whether sex mediates these views. We also investigated whether discordance within couples regarding treatment goals was related to parental perception of the child's end-of-life (EOL) experience. METHODS: We surveyed mothers and fathers of children who died of cancer and were cared for at Children's Hospital (Boston, MA) and the Dana-Farber Cancer Institute (Boston, MA) between 2000 and 2004. Our sample included 38 couples (response rate, 56%). RESULTS: Willingness to participate did not differ by sex. At diagnosis, fathers and mothers held a similar understanding of the child's prognosis, and 58% of couples agreed on the goal of cure. During the EOL period, a majority of fathers and mothers reported lessening suffering as the primary goal. However, within couples there was poor agreement about the primary goal of care (kappa = 0.07). When parents did not agree on the primary goal of lessening suffering, both parents were more likely to report that the child suffered significantly from cancer-directed treatment (P = .03). CONCLUSION: Though parent goals are often concurrent at diagnosis, they frequently differ during the EOL period. Parent disagreement about the goal of lessening suffering at the EOL appears to impact how parents describe their child's experience of suffering. Creating opportunities for parents to work through their goals together may lead to improvements in the child's EOL experience.

24: Eur J Pain. 2008 Oct;12(7):819-33. Epub 2008 Jan 25.

Stop the pain! A nation-wide quality improvement programme in paediatric oncology pain control.

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INTRODUCTION: Little is known about the impact of translation of pain management clinical practice guidelines on pain control in paediatrics. In an effort to overcome this, a longitudinal, nation-wide, multi-centre paediatric quality improvement (QI) study was initiated by the German Society of Pediatric Haematology and Oncology (GPOH) entitled Schmerz-Therapie in der Onkologischen Paediatrie (STOP). OBJECTIVE: The project's primary major aims were to improve paediatric oncology pain control in Germany, and to evaluate the project's impact on the pain management quality. To achieve these aims, STOP encompassed six sequential phases to evaluate present practice, develop recommendations for practical pain control, actively engage participants in improvement strategies, and assess change. The purpose of this paper is to briefly describe STOP in its entirety, report on comparisons between active quality management (QM) departments that actively participated in the project and non-active QM departments regarding differences in pain control, patients' and parents' perspectives on pain control and health professionals' knowledge, and to discuss the impact of STOP as a whole. METHODS: Four hypotheses were examined: (1) changes in health care professionals' knowledge on pain in paediatric oncology and pain management after a three-year period (2) impact of active participation in the STOP-project; (3) differences in patients' and parents' perspective in active QM versus non-active QM departments; (4) impact of the STOP-project on the health care professionals' knowledge in active QM versus non-active QM departments. Data included surveys, interviews, and standardised pre-/post-intervention documentation of pain control. All German paediatric oncology departments were invited to participate. The prime means of intervention was education (printed material, passive participation; additional lectures and feed-back, active participation). Quality indicators were defined and compared with regards to the four hypotheses. RESULTS: Sixty-eight departments participated passively. Eight departments participated actively, enrolling 224 patients (median age, 9 years) and documenting a total of 2265 treatment days. In the areas addressed, all health professionals demonstrated increases in knowledge on pain and pain control after a three-year period. STOP objectively improved pain control in the actively participating departments. Painful modes of drug administration were used less frequently; the usage of mixed opioid agonists-antagonists was reduced; the physicians' knowledge of the treatment of neuropathic pain increased; pain ratings significantly decreased, and less episodes of strong pain were observed. There was a significant increase in the proportion of health-care professionals who post-interventionally judged that pain therapy had been initiated earlier and at exactly the right time. Neither patients nor parents felt, however, that there was any quality improvement. According to participants' self-assessment, STOP improved practical pain management in actively participating departments, while in passively participating departments the change to the better was negligible. CONCLUSION: STOP predominantly aimed at and succeeded in the improvement of structure, process and outcome quality. With regard to patients' and parents' opinions, the interview tools

might have been unsuited to measure the quality of pain control, or STOP was insufficient to improve pain control to a magnitude significant to the patient.

25: Palliat Med. 2008 Jan;22(1):59-69.

Supportive and palliative care needs of families of children who die from cancer: an Australian study.

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OBJECTIVE: To obtain feedback from parents of children who died from cancer about their understanding of palliative care, their experiences of palliative and supportive care received during their child's illness, and their palliative and supportive care needs. DESIGN: A qualitative study with semi-structured interviews. PARTICIPANTS: 24 parents from Perth (n = 10), Melbourne (n = 5), Brisbane (n = 5) and Sydney (n = 4). Setting: Five Australian tertiary paediatric oncology centres. Results Parents whose children died from cancer live within a context of chronic uncertainty and apprehension. Parents construed palliative care negatively as an independent process at the end of their children's lives rather than as a component of a wider and continuous process where children and their families are offered both curative and palliative care throughout the cancer trajectory. The concept of palliative care was perceived to be misunderstood by key health professionals involved in the care of the child and family. The importance and therapeutic value of authentic and honest relationships between health professionals and parents, and between health professionals and children were highlighted as a critical aspect of care. Also highlighted was the need to include children and adolescents in decision making, and for the delivery of compassionate end-of-life care that is sensitive to the developmental needs of the children, their parents and siblings. CONCLUSIONS: There is a need for health professionals to better understand the concept of palliative care, and factors that contribute to honest, open, authentic and therapeutic relationships of those concerned in the care of the dying child. This will facilitate a better understanding by both parents and their children with cancer, and acceptance of the integration of palliative and supportive care in routine cancer care.

26: J Pediatr. 2008 Jan;152(1):6-8.

Pain still lords over children.
Baker JN, **Anghelescu DL**, **Kane JR**.

27: Lancet. 2008 Mar 8;371(9615):852-64.

Paediatric palliative care: challenges and emerging ideas.
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Paediatric palliative care is an emerging subspecialty that focuses on achieving the best possible quality of life for children with life-threatening conditions and their families. To achieve this goal, the individuals working in this field need to: clearly define the population served; better understand the needs of children with life-threatening conditions and their families; develop an approach that will be appropriate across different communities; provide care that responds adequately to suffering; advance strategies that support caregivers and health-care providers; and promote needed change by cultivating educational programmes. Despite these challenges, advances in paediatric palliative care have been achieved in a short period of time; we expect far greater progress as the field becomes more formalised and research networks are established.

28: Curr Oncol Rep. 2007 Nov;9(6):437-9.

Pediatric palliative care.
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Pediatric medicine is moving toward a greater appreciation that the delivery of quality medical care involves a partnership including the health care team, the child, and the family. Pediatric medicine now emphasizes the importance of information exchange among these groups. This paper discusses two models for communicating with children and their families throughout a complex life-threatening illness. Both models serve as a framework for integrating the medical and nonmedical aspects of the illness experience.

29: Bull Cancer. 2007 Oct 1;94(10):915-22.

[An overview of the 2001-2002 cancer activity in the 30 French Regional and University Hospitals, based on PMSI data]

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This study is intended to describe the cancer-related hospitalisations in the thirty French University and Regional Hospitals (CHR&U). The analysis is carried out on the years 2001 and 2002 databases and uses a relevant PMSI (Medicalisation Program Information System, the French DRG) data analysis program, which is an adapted version of the DAC (Cancer Activity Description) analysis program. Cases are selected from cancer-related diagnoses and procedures. The results provided have been classified according to paediatric and adult populations, to the organ anatomical localisations and to the different types of care : one-day hospitalisations or hospitalisations of more than one day, medical or surgical care, cares which include chemotherapy, radiation therapy or palliative procedures. Cancer-related hospitalisations amount to almost 25 % of the total CHR&U hospitalisations and add up to over a million stays per year. One-day hospitalisations amount to 25% of the cancer-related stays and essentially consist in radiation therapy (50% within the adult category) and for chemotherapy (30%). 26% of the hospitalisations of more than one day are surgical. This study is a first descriptive analysis of cancer-related hospital activity in CHR&U. The next stage will see this analysis applied to patients, using the anonymous patient identification number contained in the PMSI coding.

30: Cochrane Database Syst Rev. 2007 Oct 17;(4):CD003868.

Oral morphine for cancer pain.

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BACKGROUND: This is an updated version of a previous Cochrane review first published in Issue 4, 2003 of The Cochrane Library. Morphine has been used for many years to relieve pain. Oral morphine in either immediate release or modified release form remains the analgesic of choice for moderate or severe cancer pain. OBJECTIVES: To determine the efficacy of oral morphine in relieving cancer pain and to assess the incidence and severity of adverse effects. SEARCH STRATEGY: The following databases were searched: Cochrane Pain, Palliative and Supportive Care Group Trials Register (December 2006); Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library 2006, Issue 4); MEDLINE (1966 to December 2006); and EMBASE (1974 to December 2006). SELECTION CRITERIA: Published randomised controlled trials (RCTs) reporting on the analgesic effect of oral morphine in adults and children with cancer pain. Any comparator trials were considered. Trials with fewer than ten participants were excluded. DATA COLLECTION AND ANALYSIS: One review author extracted data, which was checked by the other review author. There were insufficient comparable data for meta-analysis to be undertaken or to produce numbers-needed-to-treat (NNT) for the analgesic effect. MAIN RESULTS: In this update, nine new studies with 688 participants were added. Fifty-four studies (3749 participants) met the inclusion criteria. Fifteen studies compared oral modified release morphine (Mm/r) preparations with immediate release morphine (MIR). Twelve studies compared Mm/r in different strengths, five of these included 24-hour modified release products. Thirteen studies compared Mm/r with other opioids. Six studies compared MIR with other opioids. Two studies compared oral Mm/r with rectal Mm/r. Two studies compared MIR with MIR by a different route of administration. One study was found comparing each of the following: Mm/r tablet with Mm/r suspension; Mm/r with non-opioids; MIR with non-opioids; and oral morphine with epidural morphine.Morphine was shown to be an effective analgesic. Pain relief did not differ between Mm/r and MIR. Modified release versions of morphine were effective for 12 or 24-hour dosing depending on the formulation. Daily doses in studies ranged from 25 mg to 2000 mg with an average of between 100 mg and 250 mg. Dose titration were undertaken with both instant release and modified release products. Adverse effects were common but only 4% of patients discontinued treatment because of intolerable adverse effects. AUTHORS' CONCLUSIONS: The randomised trial literature for morphine is small given the importance of this medicine. Most trials recruited fewer than 100 participants and did not provide appropriate data for meta-analysis. Trial design was frequently based on titration of morphine or comparator to achieve adequate analgesia, then crossing participants over in crossover design studies. It was not clear if these trials are sufficiently powered to detect any clinical differences between formulations or comparator drugs. Studies added to the review reinforce the view that it is possible to use modified release morphine to titrate to analgesic effect. There is qualitative evidence for effectiveness of oral morphine which compares well to other available opioids. There is limited evidence to suggest that transmucosal fentanyl provides more rapid pain relief for breakthrough pain compared to morphine.

31: Pediatr Clin North Am. 2007 Oct;54(5):813-27, xiii.

Issues related to providing quality pediatric palliative care in the community.
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The medical practitioner in the community is in a unique position to assist children and their families from the time of diagnosis with a life-threatening condition through to the end of life. The purpose of this article is to inform medical practitioners who care for children with complex, chronic, and life-limiting conditions about pediatric palliative care in the community. It is intended as a guide to improve understanding about (1) the misconceptions and barriers surrounding the provision of care in the community for children with chronic, complex, and life-limiting conditions; (2) the availability of services for care in the community; (3) challenges concerning out-of hospital do-not-attempt-resuscitation orders for children; and (4) reimbursement issues that impact the provision of care.

32: Pediatr Clin North Am. 2007 Oct;54(5):773-85, xii.

Withdrawal of mechanical ventilation in pediatric and neonatal intensive care units.
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Withdrawing life-sustaining technologies requires all of the resources and concepts that the field of palliative care has to offer. By learning some fundamental principles of medical management at the time of withdrawal and by mastering a few communication techniques, pediatricians, neonatologists, and pediatric intensivists can dramatically improve the care provided to their patients at the end of life. Although we may argue in pediatrics if there is ever such a thing as a good death, we should all strive to ensure one that is free of suffering, and one that supports the family in moving down a path of healthy grief and recovery.

33: Pediatr Clin North Am. 2007 Oct;54(5):757-71, xi-xii.

Do not attempt resuscitation orders in pediatrics.
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Do-not-attempt resuscitation orders are becoming more common in pediatrics, particularly as programs for hospice and palliative care in children develop. Concomitantly, there arises the need to decide when it is appropriate to use these technologies. It is at this point that the skills of relationship building, listening, and empathic concern become indispensable.

34: Pediatr Clin North Am. 2007 Oct;54(5):735-56, xi.

Assessment and management of fatigue and dyspnea in pediatric palliative care.

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Fatigue is one of the most prevalent symptoms in patients with a life-threatening illness. Untreated, fatigue can impair quality of life and prohibit addressing practical needs, psychosocial and spiritual distress, and opportunities for growth and closure at life's end. To this end addressing fatigue is a crucial component of the provision of effective palliative care. Dyspnea is the sensation of breathlessness. The challenge in treating it, however, is that it can come from various different abnormalities so understanding the underlying disorder and the acute abnormality are critical. With that understanding several different treatments can be offered to treat the cause of the dyspnea or palliate the symptom itself.

35: Pediatr Clin North Am. 2007 Oct;54(5):709-33, xi.

Management of common neurologic symptoms in pediatric palliative care: seizures, agitation, and spasticity. **Wusthoff CJ**, **Shellhaas RA**, **Licht DJ**.
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Palliative care for children is complex and focuses on patients' comfort. Some of the most troublesome symptoms as patients approach the end of life are seizures, agitation, and spasticity. Many doctors caring for children at the end of life are uncomfortable or untrained in managing these symptoms in children. Our goal is to help physicians recognize and treat these neurologic symptoms optimally.

36: Pediatr Clin North Am. 2007 Oct;54(5):691-708, xi.

Depression and anxiety in children at the end of life.

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A significant component of palliative care is the prompt diagnosis and management of distress, anxiety, and depression. This article reviews the symptoms and treatment of anxiety and depressive disorders in children at the end of life. Distinguishing between symptoms and disorders, the importance of open communication, consideration of the child's understanding of death, diagnostic challenges in chronically ill children, and suicidality are discussed. Because treatment options are available, it is imperative that symptoms are recognized and addressed. Understanding the issues involved in screening and diagnosis and the risks and benefits of available treatments can lead to an informed approach to the management of these disorders in the palliative care setting.

37: Pediatr Clin North Am. 2007 Oct;54(5):673-89, x.

Common gastrointestinal symptoms in pediatric palliative care: nausea, vomiting, constipation, anorexia, cachexia.

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Gastrointestinal symptoms are suffered commonly by children at the end of life. Diagnosis and management of these common symptoms include careful history and physical examination to assess for possible causes; treatment - pharmacologic and nonpharmacologic; and a discussion with patients and families of care goals. Aggressive management of these symptoms is essential to improving the quality of life for these children.

38: Pediatr Clin North Am. 2007 Oct;54(5):645-72, x.

The management of pain in children with life-limiting illnesses.

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The management of pain in children with life-limiting illnesses is complex and unfortunately not often done effectively. Pain is a multidimensional symptom that can overshadow all other experiences of both the child and family. This article focuses on topics common to practitioners caring for children with lifelimiting illnesses, including a review of myths and obstacles to achieving adequate pain control, a review of the pathophysiology of pain, an overview of the use of opioids in children, an approach to the management of neuropathic pain, and a brief discussion of nonpharmacologic pain management strategies.

39: Pediatr Clin North Am. 2007 Oct;54(5):631-44, x.

Compassion fatigue in pediatric palliative care providers.

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The experience of compassion fatigue is an expected and common response to the professional task of routinely caring for children at the end of life. Symptoms of compassion fatigue often mimic trauma reactions. Implementing strategies that span personal, professional, and organizational domains can help protect health care providers from the damaging effects of compassion fatigue. Providing pediatric palliative care within a constructive and supportive team can help caregivers deal with the relational challenges of compassion fatigue. Finally, any consideration of the toll of providing pediatric palliative care must be balanced with a consideration of the parallel experience of compassion satisfaction.

40: Pediatr Clin North Am. 2007 Oct;54(5):609-29, ix-x.

Psychosocial and spiritual needs of children living with a life-limiting illness.

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Quality end-of-life care includes the management of distressing symptoms; provisions of care, including the assessment and management of psychosocial and spiritual needs; and respite from diagnosis through death and bereavement. Meeting the palliative care goal of improved quality of life depends on medical and nursing practitioners understatnding and effectively assessing psychosocial symptoms.

41: Pediatr Clin North Am. 2007 Oct;54(5):583-607, ix.

Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making.

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In an ideal world, all of us - patients, parents, family members, nurses, physicians, social workers, therapists, pastoral care workers, and others - would always work together in a collaborative manner to provide the best care possible. This article bases the framework for this ideal upon studies of communication between patients, families, and clinicians, as well as more general works on communication, collaboration, decision-making, mediation, and ethics, and is comprised of four parts: what is meant by collaborative communication; key concepts that influence how we frame the situations that children with life-threatening conditions confront and how these frameworks shape the care we provide; general topics that are important to the task of collaborative communication, specifically how we use heuristics when we set about to solve complicated problems; and three common tasks of collaborative communication, offering practical advice for patient care.

42: J Clin Oncol. 2007 Oct 1;25(28):4472-6.

Place and provision of palliative care for children with progressive cancer: a study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group.

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PURPOSE: The purpose of this study was to describe and show effectiveness of the outreach team model of palliative care (PC) in allowing home death for children with incurable cancer. PATIENTS AND METHODS: Over 7 months, 185 children from 22 United Kingdom oncology centers were recruited to a prospective questionnaire survey. RESULTS: One hundred sixty-four children from 22 centers died (median age, 8.7 years; 88 boys, 76 girls). One hundred twenty-six families completed two or more questionnaires. One hundred twenty (77%) of 155 with complete data died at home. Preference for home death was recorded in 90 (68%) of 164 and 132 (80%) 164 at study entry and last month of life, respectively. Death occurred in preferred place for 84 (80%) of 105 with recorded preference at entry. Forty-one (25%) of 164 and 68 (41.5%) of 164 needed no outpatient or inpatient hospital visits, respectively. A named individual provided on-call PC advice by phone or home visit in 22 (100%) and 18 (82%) of 22 oncology centers, respectively. As PC progressed, involvement of oncologist and social worker appeared less, whereas pediatric oncology outreach nurse specialists (POONSs) remained prominent. CONCLUSION: Preference for home death expressed by families in our study is similar to others, but the proportion of children actually able to die there is higher. Home death is facilitated by this model. Key components are POONSs, pediatric palliative and/or oncology specialist, and general practitioner. Professional roles change during PC and after death. An ongoing role for the oncology team in bereavement support is highlighted.

43: Palliat Med. 2007 Jul;21(5):435-40.

Challenges to participation in paediatric palliative care research: a review of the literature.

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It has been identified that there is a need for increased palliative care research within the paediatric setting. The assessment of parental views is necessary for this population. However, the conduct of research and recruitment of participants is often challenging. While conducting a study that involved parents of children receiving palliative or end-of-life care, the authors found that there were particular challenges to recruiting these parents. This comprehensive review of the literature aims to address the ethical and recruitment issues of involving parents of children that are receiving palliative or end-of-life care. Key elements, that may maximize completion of research and a more representative sample, are also discussed. These elements include obtaining the opinions on study design and interview script from experienced families and maximizing the partnership between health care professionals and the research team.

44: J Pediatr Oncol Nurs. 2007 Sep-Oct;24(5):246-54.

Creating a palliative and end-of-life program in a cure-oriented pediatric setting: the zig-zag method.
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Children living with and dying of advanced-stage cancer suffer physically, emotionally, and spiritually.Relief of their suffering requires comprehensive, compassionate palliative and end-of-life (EoL) care.However, an EoL care program might appear inconsistent with the mission of a pediatric oncology research center committed to seeking cures. Here the authors describe the methods used to achieve full institutional commitment to their EoL care program and those used to build the program's philosophical, research, and educational foundations after they received approval.The authors convened 10 focus groups to solicit staff perceptions of the hospital's current palliative and EoL care. They also completed baseline medical record reviews of 145 patient records to identify key EoL characteristics.The authors then crafted a vision statement and a strategic plan, implemented new research protocols,and established publication and funding trajectories.They conclude that establishing a state-of-the-art palliative and EoL program in a cure-oriented pediatric setting is achievable via consensus building and recruitment of diverse institutional resources.

45: J Child Neurol. 2007 Aug;22(8):1027-49.

Consensus statement for standard of care in spinal muscular atrophy.
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Spinal muscular atrophy is a neurodegenerative disease that requires multidisciplinary medical care. Recent progress in the understanding of molecular pathogenesis of spinal muscular atrophy and advances in medical technology have not been matched by similar developments in the care for spinal muscular atrophy patients. Variations in medical practice coupled with differences in family resources and values have resulted in variable clinical outcomes that are likely to compromise valid measure of treatment effects during clinical trials. The International Standard of Care Committee for Spinal Muscular Atrophy was formed in 2005, with a goal of establishing practice guidelines for clinical care of these patients. The 12 core committee members worked with more than 60 spinal muscular atrophy experts in the field through conference calls, e-mail communications, a Delphi survey, and 2 in-person meetings to achieve consensus on 5 care areas: diagnostic/new interventions, pulmonary, gastrointestinal/nutrition, orthopedics/rehabilitation, and palliative care. Consensus was achieved on several topics related to common medical problems in spinal muscular atrophy, diagnostic strategies, recommendations for assessment and monitoring, and therapeutic interventions in each care area. A consensus statement was drafted to address the 5 care areas according to 3 functional levels of the patients: nonsitter, sitter, and walker. The committee also identified several medical practices lacking consensus and warranting further investigation. It is the authors' intention that this document be used as a guideline, not as a practice standard for their care. A practice standard for spinal muscular atrophy is urgently needed to help with the multidisciplinary care of these patients.

46: MCN Am J Matern Child Nurs. 2007 Sep-Oct;32(5):298-302; quiz 303-4.

End-of-life nursing education consortium for pediatric palliative care (ELNEC-PPC).
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Pediatric nurses must often care for children with life-threatening illness. Although the child may be a neonate with multiple organ failure, a young adolescent diagnosed with HIV, or a 7-year-old child involved in a serious bicycle accident, pediatric nurses are an essential part of the interdisciplinary team that plans, organizes, implements, and manages the care of these children and their families. To date, more than 600 pediatric nurses have attended a national End-of-Life Nursing Education Consortium-Pediatric Palliative Care (ELNEC-PPC) training program. Many of these nurses have returned to their institutions dedicated to making a difference in the palliative care provided to children and their families. Because pediatric palliative care education is so important, many trainers have incorporated ELNEC-PPC into their nursing orientation, annual competencies, and undergraduate and graduate nursing education. They are developing standards of care and serve on key hospital/hospice committees, such as policy, education, clinical care, and ethics committees. This article showcases various activities of ELNEC-PPC trainers and demonstrates their commitment to improve pediatric palliative care not only in their institutions but also on local, state, national, and international levels.

47: J Dev Behav Pediatr. 2007 Oct;28(5):399-403.

Interactive music as a treatment for pain and stress in children during venipuncture: a randomized prospective study.

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OBJECTIVE: The experience of venipuncture is seen by children as one of the most fearful experiences during hospitalization. Children experience anxiety both before and during the procedure. Therefore, any intervention aiming to prevent or reduce distress should focus on the entire experience of the procedure, including waiting, actual preparation, and conclusion. This study was designed to determine whether the presence of musicians, who had attended specific training to work in medical settings, could reduce distress and pain in children undergoing blood tests. METHODS: Our sample population was composed of 108 unpremedicated children (4-13 years of age) undergoing blood tests. They were randomly assigned to a music group (n=54), in which the child underwent the procedure while interacting with the musicians in the presence of a parent or to a control group (n=54), in which only the parent provided support to the child during the procedure. The distress experienced by the child before, during and after the blood test was assessed with the Amended Form of the Observation Scale of Behavioral Distress, and pain experience with FACES scale (Wong Baker Scale) only after the venipuncture. RESULTS: Our results show that distress and pain intensity was significantly lower (p<.001; p<.05) in the music group compared with the control group before, during, and after blood sampling. CONCLUSIONS: This controlled study demonstrates that songs and music, performed by "professional" musicians, have a beneficial effect in reducing distress before, during, and after blood tests. This study shows, moreover, that the presence of musicians has a minor, but yet significant, effect on pain due to needle insertion.

48: Pediatr Rev. 2007 Aug;28(8):e46-56.

Pediatric palliative care.
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49: Pediatrics. 2007 Jul;120(1):244-5; author reply 245.

Pediatric palliative care.
Howell S.

50: Arch Pediatr Adolesc Med. 2007 Jun;161(6):597-602.

Pediatric patients receiving palliative care in Canada: results of a multicenter review.
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OBJECTIVES: To describe the patients who received care from the 8 dedicated pediatric palliative care programs in Canada in 2002 and to estimate the number of children who may have benefited but did not receive services from these programs. DESIGN: Retrospective review of medical records combined with a survey of each program. SETTING: Seven pediatric palliative care programs based in tertiary care settings and 1 freestanding children's hospice. PARTICIPANTS: The programs cared for 317 children during 2002, of whom 123 died during that year. An additional 32 children died by the end of 2003. MAIN EXPOSURE: Pediatric palliative care program. RESULTS: Nearly half (48.6%) of the patients were younger than 5 years, and almost half of these were younger than 1 year. Primary diagnoses were disorders of the nervous system (39.1%), malignancies (22.1%), and conditions arising in the perinatal period or congenital anomalies (22.1%). Most of the children (43.9%) died at home, with those centers reporting more comprehensive home care services having the highest percentage of home deaths. From a national perspective, between 5% and 12% of the children who could benefit from palliative care received services from 1 of these programs. CONCLUSIONS: Pediatric palliative care programs in Canada care for a diverse population of patients with a wide range of age and disease conditions. Only a small percentage of children who die, however, receive services from these dedicated programs.

51: J Pediatr (Rio J). 2007 May;83(2 Suppl):S109-16.

End-of-life care in children: the Brazilian and the international perspectives.

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OBJECTIVE: To analyze the medical practices and the end-of-life care provided to children admitted to pediatric intensive care units in different parts of the globe. SOURCES: Articles on end-of-life care published during the last 20 years were selected from the PubMed, MEDLINE and LILACS databases, with emphasis on studies of death in pediatric intensive care units in Brazil, Latin America, Europe and North America, using the following keywords: death, bioethics, pediatric intensive care, cardiopulmonary resuscitation and life support limitation. SUMMARY OF THE FINDINGS: Publications on life support limitation (LSL) are concentrated in North America and Europe. In North American pediatric intensive care units there is a greater incidence of LSL (approximately 60%) than in Europe or Latin America (30-40%). These differences appear to be related to cultural, religious, legal and economic factors. Over the last decade, LSL in Brazilian pediatric intensive care units has increased from 6 to 40%, with do not resuscitate orders as the most common method. Also of note is the low level of family participation in the decision-making process. A recent resolution adopted by the Federal Medical Council (Conselho Federal de Medicina) regulated LSL in our country, demystifying a certain apprehension of a legal nature. The authors present a proposal for a protocol to be followed in these cases. CONCLUSIONS: The adoption of LSL with children in the final phases of irreversible diseases has ethical, moral and legal support. In Brazil, these measures are still being adopted in a timid manner, demanding a change in behavior, especially in the involvement of families in the decision-making process.

52: Br J Cancer. 2007 Jun 18;96(12):1828-33. Epub 2007 May 22.

Transmucosal fentanyl vs intravenous morphine in doses proportional to basal opioid regimen for episodic-breakthrough pain.

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The use of supplemental doses of opioids is commonly suggested to manage breakthrough pain. A comparative study of intravenous morphine (IV-MO) and oral transmucosal fentanyl citrate (OTFC) given in doses proportional to the basal opioid regimen was performed in 25 cancer patients receiving stable opioid doses. For each episode, when it occurred and 15 and 30 min after the treatment, pain intensity and opioid-related symptoms were recorded. Fifty-three couples of breakthrough events, each treated with IV-MO and OTFC, were recorded. In episodes treated with IV-MO, pain intensity decreased from a mean of 6.9 to 3.3 and to 1.7 at T1 and T2, respectively. In episodes treated with OTFC, pain intensity decreased from a mean of 6.9 to 4.1 and to 2.4 at T1 and T2, respectively. Statistical differences between the two treatments were found at T1 (P=0.013), but not at T2 (P=0.059). Adverse effects were comparable and were not significantly related with the IV-MO and OTFC doses. Intravenous morphine and OTFC in doses proportional to the scheduled daily dose of opioids were both safe and effective, IV-MO having a shorter onset than OTFC. Future comparative studies with appropriate design should compare titration methods and proportional methods of OTFC dosing.

53: Lancet. 2007 May 12;369(9573):1576.

Improving end-of-life care for children.

[No authors listed]

54: Orphanet J Rare Dis. 2007 May 11;2:23.

Hypoplastic left heart syndrome.

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Hypoplastic left heart syndrome (HLHS) refers to the abnormal development of the left-sided cardiac structures, resulting in obstruction to blood flow from the left ventricular outflow tract. In addition, the syndrome includes underdevelopment of the left ventricle, aorta, and aortic arch, as well as mitral atresia or stenosis. HLHS has been reported to occur in approximately 0.016 to 0.036% of all live births. Newborn infants with the condition generally are born at full term and initially appear healthy. As the arterial duct closes, the systemic perfusion becomes decreased, resulting in hypoxemia, acidosis, and shock. Usually, no heart murmur, or a non-specific heart murmur, may be detected. The second heart sound is loud and single because of aortic atresia. Often the liver is enlarged secondary to congestive heart failure. The embryologic cause of the disease, as in the case of most congenital cardiac defects, is not fully known. The most useful diagnostic modality is the echocardiogram. The syndrome can be diagnosed by fetal echocardiography between 18 and 22 weeks of gestation. Differential diagnosis includes other left-sided obstructive lesions where the systemic circulation is dependent on ductal flow (critical aortic stenosis, coarctation of the aorta, interrupted aortic arch). Children with the syndrome require surgery as neonates, as they have duct-dependent systemic circulation. Currently, there are two major modalities, primary cardiac transplantation or a series of staged functionally univentricular palliations. The treatment chosen is dependent on the preference of the institution, its experience, and also preference. Although survival following initial surgical intervention has improved significantly over the last 20 years, significant mortality and morbidity are present for both surgical strategies. As a result pediatric cardiologists continue to be challenged by discussions with families regarding initial decision relative to treatment, and long-term prognosis as information on long-term survival and quality of life for those born with the syndrome is limited.

55: J Music Ther. 2007 Summer;44(2):139-55.

A project investigating music therapy referral trends within palliative care: an Australian perspective.

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The purpose of this project is to analyze music therapy (MT) referral trends from palliative care team members across nine Australian inpatient and community-based palliative care settings. For each referral 6 items were collected: referral source, reason and type; time from Palliative Care Program (PCP) admission to MT referral; time from MT referral to death/discharge; and profile of referred patient. Participants (196 female, 158 male) were referred ranging in age from 4-98 years and most were diagnosed with cancer (91%, n = 323). Nurses (47%, n = 167) referred most frequently to music therapy. The mean average time in days for all referrals from PCP admission to MT referral was 11.47 and then 5.19 days to time of death. Differences in length of time to referral ranged from 8.19 days (allied health staff) to 43.75 days (families). Forty-eight percent of referrals (48.5%, n = 172) were completed when the patient was rated at an Eastern Cooperative Oncology Group Performance (ECOG) of three. Sixty-nine percent (n = 244) were living with others at the time of referral and most were Australian born. Thirty-six percent (36.7%, n = 130) were referred for symptom-based reasons, and 24.5% (n = 87) for support and coping. Implications for service delivery of music therapy practice, interdisciplinary care and benchmarking of music therapy services shall be discussed.

56: J Music Ther. 2007 Summer;44(2):123-38.

The effects of orff-based music therapy and social work groups on childhood grief symptoms and behaviors.

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This study evaluated and compared the effects of Orff-based music therapy, social work, and wait-list control groups on behavioral problems and grief symptoms of bereaved school-aged children. Social work and music therapy sessions were provided weekly for one hour over an eight-week period. Participants (N = 26) attended three different public elementary schools, and each school was randomly assigned to one of the conditions. Pre and posttest measures consisted of the Behavior Rating Index for Children (BRIC) and the Bereavement Group Questionnaire for Parents and Guardians (BP). The BRIC measured behavioral distress and the BP measured grief symptoms prior to and following participation in the assigned conditions. Statistical analyses indicated that participants in the music therapy group significantly improved in the behaviors and grief symptoms, and those in the social work group experienced a significant reduction in their behavioral problems but not their grief symptoms. Participants in the wait-list control group made no significant improvements in either their grief symptoms or behavioral problems. A reduction in behavioral distress as measured by the BRIC and a reduction in grief symptoms as measured by the BP is the most desired outcome. This study supports the use of Orff-based music therapy interventions for bereaved children in a school-based grief program. Recommendations for future research are included.

57: J Pediatr Psychol. 2007 Oct;32(9):1079-88. Epub 2007 Apr 2.

Patient-reported outcomes in end-of-life research in pediatric oncology.

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OBJECTIVE: The purpose of this review of published literature was to identify the number and focus of empirically based papers that included research methods used to directly solicit patient-reported outcomes

(PRO) from pediatric oncology patients at end of life. METHODS: Key terms including "pediatric or child and oncology or cancer and end of life or palliative or hospice or dying" were used with five data bases (PubMed, Ovid, Cochrane, PsycInfo & PsycArticles, and CINAHL) for English language literature published between January, 2001 and June, 2006. All retrieved documents were independently reviewed by a panel of six (nurses, physicians, and one psychologist) with backgrounds in pediatric oncology. RESULTS: Thirty-five publications were identified but nine (25.7%) were eliminated from the analysis as they did not meet inclusion criteria. Of the remaining 26, four (15.4%) included patient-reported outcomes, six (23.1%) included parent only-reported outcomes, and five (19.2%) included staff only-reported outcomes. Nine (34.6%) were retrospective medical record reviews. Two (7.7%) included parent and record review data or parent and physician reports. CONCLUSIONS: Empirically-based end-of-life publications in pediatric oncology are relatively few in number and nearly 85% of completed studies do not include PRO.

58: J Public Health Policy. 2007;28(1):26-7.

Special section: palliative care as a public health issue in the developing world.
Freeman P.

59: J Pain. 2007 Mar;8(3):187-207.

Transdermal fentanyl in childhood and adolescence: a comprehensive literature review.
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The recently introduced fentanyl transdermal therapeutic system (TTS) with a drug release rate of 12.5 microg/h matches the lower dosing requirements of cancer pain control in children. It is likely that fentanyl TTS will be used in pediatrics with increasing frequency. We compiled the published evidence on pediatric applications of this drug formulation to help physicians get the most benefit from its use. Within this systematic review, a total of 11 observational clinical or pharmacokinetic studies were identified. There are no pediatric randomized or controlled cohort studies. Pharmacokinetic studies poorly described time-concentration profiles after application. The time to reach steady-state serum drug concentrations seems to be longer, clearance (expressed as liters per kilogram per hour) higher, and elimination half-life shorter in children than in adults. There are no fundamental differences in effect or profile of adverse effects compared with adults. Fentanyl TTS may be associated with less constipation compared with morphine use. Frequently, pediatric patients need supplemental mechanical fixation of the fentanyl TTS by means of medical tape. Younger patients tend to have a higher fentanyl requirement when referenced to body weight. Both parents and medical professionals are satisfied with fentanyl TTS to a higher degree than with individual analgesic pretreatment regimens. Fentanyl TTS is a promising option for chronic pain control in children. An approximate conversion factor of 45 mg/day oral morphine to 12.5 microg/h fentanyl TTS is used for initial therapy dose estimation in children receiving long-term morphine therapy. This is conservatively low to avoid respiratory depression. Daily oral morphine equivalent dose should be at least 30 mg/d before fentanyl TTS therapy is started with 12.5 microg/h. Evidence for superiority of fentanyl TTS treatment above conventional opioid administration is both scarce and of low quality. PERSPECTIVE: The article gives a comprehensive overview of all pediatric data concerning the fentanyl TTS. Children may take longer to reach steady-state fentanyl serum concentrations than adults, and younger children may require higher doses referenced to body weight than older children or adults. Consequently, there is a need to provide sufficient medication in the phase of therapy initiation to prevent breakthrough pain. The 72-hour dosing schedule recommended by the manufacturers may not be applicable to children because of poor patch adhesiveness. The authors suggest to ensure firm fixation of the fentanyl TTS with additional medical tape if necessary and to change the fentanyl TTS after 48 hours. Transdermal fentanyl in children may exhibit fewer side effects when compared with other opioids, especially constipation. Randomized studies are urgently needed to definitively answer this question.

60: Palliat Med. 2007 Jan;21(1):15-22.

Patient demographics and centre description in European palliative care units.
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Patients in palliative care are elderly, frail and in decline with multisystem disease. These and other factors make palliative care research particularly challenging, and has been one of several reasons why relatively little systematic research has been performed. The European Association for Palliative Care (EAPC) is seeking to emphasise the importance of research. The present project is the first empirical multicentre study organised by the EAPC Research Network, with the aim of identifying the patient population using specialised palliative care, and identifying a network of palliative care services across Europe, able to participate in a multicentre collaboration for research. During a designated week in the autumn of 2000, data on patients were recorded from 143 centres. The survey was carried out by means of two questionnaires, one centre questionnaire and one patient questionnaire. Data were submitted on 3013 patients from 22 different European countries. Almost all patients had cancer (94%), while some had neurological disease (3%). The majority (75%) had been referred to a palliative care service during the six to seven months before the survey was performed. Very few patients had less than one week of expected survival (6%), the majority were expected to live one to six months, while as many as 16% were expected to live more than one year. The majority of the patients (27%) were fully ambulatory--the ability to walk independently without any assistance. The majority of the patients (60%) received care as an outpatient, either at a traditional clinic in an outpatient cancer hospital (12%), in home-care programs from a specialised advisory service (24%), or external nursing care (24%). The population of patients included in this survey was not a sample of dying patients. There were a substantial number of patients with an anticipated life expectancy of more than six months. The study demonstrated a considerable enthusiasm for research in the palliative care community across Europe. The heterogeneity of the sample is evident, and this will need careful consideration for future clinical trials. This calls for an international consensus on how to report on patient characteristics within palliative care research. This is necessary in order to be able to evaluate the representativity of the study population, as well as to compare data between studies. The range of services encountered in the survey highlights the need for the organisational and clinical standards for palliative care, which can be audited.

61: Home Healthc Nurse. 2007 Jan;25(1):45-51; quiz 52-3.

Improving care in the home for children with palliative care needs.
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62: J Palliat Care. 2006 Summer;22(2):99-104.

Future echoes in pediatric palliative care: becoming sensitive to language.
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As the specialty of pediatric palliative care emerges and develops, finding language to describe the complexity of "living while dying" is a challenge. Terms such as "life-limiting" and "life-threatening" are commonly used, but may not be sensitive enough to capture the experience of children and their families due to the restrictions and power at play in the history of the words "limit" and "threat". The search for the right words to use when speaking of children who are living while dying takes us to the language of metaphor and poetry that speaks to us in a different way, a way that encompasses not only the suffering, but also the dreams, hopes, and joys of children and families. Our preferred use of language also provides more than factual statements ever can, by speaking to the hearts and souls of health care providers who share precious moments with these families.

63: Chest. 2006 Dec;130(6):1879-86.

Recent advances in respiratory care for neuromuscular disease.
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The impact of ventilatory support on the natural history of neuromuscular disease (NMD) has become clearer over the last 2 decades as techniques have been more widely applied. Noninvasive ventilation (NIV) allows some patients with nonprogressive pathology to live to nearly normal life expectancy, extends survival by many years in patients with other conditions (eg, Duchenne muscular dystrophy), and in those patients with rapidly deteriorating disease (eg, amyotrophic lateral sclerosis) survival may be increased, but symptoms can be palliated even if mortality is not reduced. A growing number of children with NMD are surviving to adulthood with the aid of ventilatory support. The combination of NIV with cough-assist techniques decreases pulmonary morbidity and hospital admissions. Trials have confirmed that NIV works in part by enhancing chemosensitivity, and in patients with many different neuromuscular conditions the most effective time to introduce NIV is when symptomatic sleep-disordered breathing develops.

64: Paediatr Respir Rev. 2006 Dec;7(4):281-7. Epub 2006 Oct 16.

Palliative care and paediatric respiratory medicine.
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Progressive respiratory failure is a common modality of death in children with a terminal illness. The management of respiratory failure, and in particular symptoms of dyspnoea and musculoskeletal chest pain in children receiving palliative care, remains challenging. The emergence of palliative care paediatricians and the application of non-invasive ventilation to children with progressive respiratory failure are the two major advances in the care of children with respiratory complaints in the palliative care setting. This article outlines current approaches to palliative care in children with progressive respiratory symptoms.

65: Recent Results Cancer Res. 2006;168:73-9.

Children with cancer.
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Some specific aspects of communication in pediatric oncology will be outlined in this chapter. These include openness about the disease, which has become increasingly important. Furthermore, the law of double protection, a self-protective strategy used by children, parents, and hospital staff, will be sketched out. It is very striking that protection is often achieved through protection of the other. Several examples of this strategy will be presented. Finally, attention will be paid to communication about death in the palliative phase.

66: Paediatr Nurs. 2006 Sep;18(7):20-4.

Home-based palliative care for children: the case for funding.
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Paediatric palliative care services have grown up in response to local needs with the result that provision is patchy and in some areas non-existent. Funding for existing services comes from a variety of sources and in the case of teams funded in 2003 from The New Opportunities Fund, there is uncertainty about future provision as funding streams come to an end. This article illustrates how home-based palliative care achieves the objectives of the NHS Plan (DH 2000a) and makes the case for the continuation of paediatric palliative care teams already established through New Opportunities Fund (NOF) funding as these provide a ready made, quality service meeting the government agenda and addressing the needs of patients in a place and at a time to suit them.

67: Pain Res Manag. 2006 Autumn;11(3):163-71.

Ensuring pain relief for children at the end of life.
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Pain management in the context of pediatric palliative care can be challenging. The present article reviews, through a case-based presentation, the nonpharmacological and pharmacological methods used to ensure adequate pain control in children facing end of life. Details on the impressive range of opioid dosages required and routes of administration are highlighted from published literature and clinical experience. Where available, evidence-based recommendations are provided. Potential side effects of pain medication and barriers to good pain control are discussed. Novel analgesics and innovative delivery methods are presented as future tools enhancing pain relief at the end of life. Some challenges to ethically grounded research in this important context of care are reviewed.

68: Br J Nurs. 2006 Jul 27-Aug 9;15(14):764-8.

The potential of integrated multi-agency care pathways for children.
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In 2004, a Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-Threatening and Life-Limiting Conditions, funded by the Department of Health, was developed by a working party. It included the Association for Children with Life-Threatening or Terminal Conditions and their Families, the Royal College of Nursing and the Royal College of Paediatrics and Child Health. This article will identify the need for this framework and its potential to transform the delivery of palliative care services to overcome present inequalities based on condition and geography that currently beset children with these conditions and their families. It will show how the three stages of the pathway (diagnosis or recognition, living with a condition, and end of life and bereavement) follow the patient's journey and complement guidance set out in the Children's National Service Framework (2004) for multi-agency assessments, protocols and standards to ensure high-quality coordinated care and services. It concludes with the need to evaluate the effectiveness of pathways that may develop from this initiative through audit and research.

69: Paediatr Respir Rev. 2006;7 Suppl 1:S210-1. Epub 2006 Jun 5.

Spinal muscular atrophy type 1: what are the ethics and practicality of respiratory support?
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Spinal Muscular Atrophy Type I (SMA I) is the most severe form of SMA. It presents in infancy and without treatment death occurs by 2 years. Treatments in use address respiratory and nutritional issues but even with aggressive treatment death is still likely in childhood. Thus their use is not obligatory. However, pediatric respirologists must be willing and comfortable at presenting all treatment options, including the option of palliative care, to families and then supporting the family's choice. Whatever the chosen treatment regimen, decision making is difficult for families. Support and help must be provided from the time of presentation till death by a knowledgeable and compassionate team.

70: Child Adolesc Psychiatr Clin N Am. 2006 Jul;15(3):759-77.

Palliative medicine in neonatal and pediatric intensive care.
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Patients and families in NICU and PICU settings can be well served by fundamental palliative care approaches during curative and end-of-life care.A wide variety of patients are suitable for these services. Although barriers exist to implementing these teams within the ICU, the concepts remain sound,and models for successful integration of practices in these settings exist.

71: Child Adolesc Psychiatr Clin N Am. 2006 Jul;15(3):717-37.

Nursing interventions in pediatric palliative care.
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Caring for chronically ill children whose health is declining and thosechildren who are critically ill is stressful and can be overwhelming to bothhealthcare professionals and parents. Palliative care teams aim to providethe multidisciplinary and holistic support staff and families need. Families,nurses, and primary medical teams value the involvement of a pediatric pal-liative medicine team to improve the quality of living. The bedside nurse isa vital part of the support system and is ready and available to be presentwith the palliative care team to support families no matter what the circum-stances. Advocating for the patient; creating a culture of flexibility; antici-pating, identifying, and responding to the patient and family needs;fostering hope; and providing the support needed for the parents to makeinformed decisions, are keys to providing quality patient care. Nurses arein the position to positively influence each of these areas of patient care ina positive manner.

72: Child Adolesc Psychiatr Clin N Am. 2006 Jul;15(3):693-715.

Multidisciplinary care of the dying adolescent.
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The adolescent at the end of life poses a unique combination of challenges resulting from the collision of failing health with a developmental trajectory meant to lead to attainment of personal independence. Because virtually all spheres of the dying adolescent's life are affected, optimal palliative care for these young persons requires a multidisciplinary team whose members have a good understanding of their complementary roles and a shared commitment to providing well-coordinated care. Members of the team include the physician (to initiate and coordinate palliative care management); the nurse (to work collaboratively with the physician and adolescent, especially through effective patient advocacy); the psychologist (to assess and manage the patient's neurocognitive and emotional status); the social worker (to assess and optimize support networks); the chaplain (to support the adolescent's search for spiritual meaning); and the child life specialist (to facilitate effective communication in preparing for death). A crucial area for dying adolescents is medical decision making, where the full range of combined support is needed. By helping the young person continue to develop personal autonomy, the multidisciplinary team will enable even the dying adolescent to experience dignity and personal fulfillment.

73: Child Adolesc Psychiatr Clin N Am. 2006 Jul;15(3):683-91.

Cognitive-behavioral interventions for physical symptom management in pediatric palliative medicine.

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The alleviation of symptoms, with the ultimate intention of improvement of quality of life, is a fundamental component of pediatric palliative medi-cine. Psychological factors can exacerbate physical symptoms or influence the perception of symptoms in children with advanced disease. Cognitive-behavioral interventions have yielded positive outcomes for the management of symptoms across various disease populations. There is a paucity of evidence specific to the application of these interventions in pediatric palliation, although evidence-based treatments developed through investigation of other disease populations can be applied in pediatric palliation. Children tend to be receptive to these noninvasive interventions, which can decrease fear and anxiety, increase self-efficacy and sense of control, and improve overall coping. Continued investigation into the use of these interventions in pediatric palliation is encouraged.

74: Child Adolesc Psychiatr Clin N Am. 2006 Jul;15(3):575-84, vii.

From cure to palliation: managing the transition.

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When a child is diagnosed with a life-threatening or life-limiting condition, their physical and affective world is immediately changed, regardless of the outcome of treatment. Pediatric care providers are in a unique position to offer hope to children and families even when cure is not possible. This hope focuses not only on cure, but incorporates the understanding that quality of life is not commensurate with length of life and that compassionate care can be provided in all stages of treatment.

75: Pediatrics. 2006 Jun;117(6):e1179-86.

Symptoms in children/young people with progressive malignant disease: United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses Forum survey.

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AIM: The purpose of this study was to survey symptoms in children/young people with progressive cancer and identify which are the most important and which are the most difficult to treat effectively. PATIENTS AND METHODS: This was a questionnaire survey of 22 United Kingdom Children's Cancer Study Group centers. Data were collected by clinical nurse specialists in pediatric oncology regarding children/young people between 0 and 20 years of age, using 2 questionnaires. The first collected demographic details and the second data about the occurrence and perceived impact of symptoms. RESULTS: There were 185 children/young people from 20 centers registered in the study, aged 4 months to 19 years (mean: 8.7 years), who received palliative care for a median of 34 days (range: 0-354 days). Data were analyzed for 164 children/young people who died during the study. Between referral to palliative care and death, there were significant increases in the number of symptoms reported and children/young people experiencing pain (70.6% vs 91.5%). Symptoms included some that often go unrecognized in children/young people, for example, anorexia, weight loss, and weakness. The nature of the underlying malignancy significantly influenced the prevalence of some symptoms. There were significant differences between the symptoms associated with central nervous system tumors and other groups. Pain other than headache occurred more commonly in children with solid tumors (98.4%) than in others (87%). Neurologic symptoms, including headache, were universal among those with central nervous system tumors. CONCLUSION: This study documents the frequency of symptoms and contrasts the experiences of children/young people with different groups of malignant disease. With access to skilled symptom control, pain can be effectively treated in most children/young people. Some other symptoms often remain intractable. The study highlights the need for further research to establish the effectiveness of therapeutic interventions for symptom control and their impact on the quality of life for children/young people dying from cancer.

76: Paediatr Nurs. 2006 May;18(4):41-5.

Palliative care for children: a public health initiative.

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This article draws parallels between the work of a children's palliative care team and the health promoting/prevention focus of public health. From the primary prevention role in supporting decisions about screening for genetic disorders to advocacy for adequate respite, the palliative care team makes a significant but largely unrecognised contribution to community health. Reframing the palliative care service in this way may help organisations responsible for commissioning and delivering services to more clearly see the essential benefits to the wider community of such services and to locate them within their planning priorities.

77: Clin Med. 2006 Mar-Apr;6(2):148-50.

Psychological distress in patients with advanced cancer.
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78: J Soc Integr Oncol. 2006 Spring;4(2):75-8.

Music therapy in pediatric oncology: a review of the literature.
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The review of literature provides an overview of both qualitative and quantitative research studies in the area of pediatric oncology music therapy. A total of 12 studies were reviewed. Eight used qualitative and four used quantitative research methods. All articles were published in peer-reviewed journals. This review summarizes the use of music therapy in treating the physical, emotional , social, and developmental needs of children undergoing curative and palliative treatment for cancer.

79: J Perinatol. 2006 May;26 Suppl 1:S24-6; discussion S31-3.

Palliative care in the fetus and newborn.
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The changing environment in neonatology and perinatology has led to the examination of issues surrounding palliative care. Newborn palliative care should be considered in three general areas: (1) Neonates at the limits of viability. As advances in technology and outcomes become available, it is the responsibility of the health-care community and society to reach a consensus regarding the limits of viability. (2) Neonates with lethal congenital anomalies. When appropriate, and diagnosis and prognosis are certain, why should a family be deprived the opportunity to choose palliative care for the unborn child? (3) Neonates not responsive to aggressive medical management where continuing therapy may prolong suffering and postpone death. The question 'Are you doing for the neonate or to the neonate?' should be asked. These complex issues, along with best interest issues, site, mode and timing of delivery, and the development of palliative care are the subject of this manuscript.

80: Pediatr Nurs. 2006 Jan-Feb;32(1):95.

Providing pediatric palliative care through a pediatric supportive care team.
Locke L.

81: Int Anesthesiol Clin. 2006 Winter;44(1):95-107.

Integration of pain services into pediatric oncology.
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82: Int J Palliat Nurs. 2006 Jan;12(1):27-33.

Emotion work in the palliative nursing care of children and young people.
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The nurse's role in supporting and caring for children and young people with life-limiting illness/conditions and their families requires specialist expertise. This domain can be one of the most emotionally challenging areas of practice. The concept of time, and how long practitioners are involved with individual children and their families may sometimes be underestimated. Emotion work is defined as the work involved in managing feelings in both self and others (Hochschild, 1983). The sense of community within the clinical setting can facilitate the nurse to care and maintain professional boundaries.

83: Int J Palliat Nurs. 2006 Jan;12(1):16-9.

The art of healing and knowing in cancer and palliative care.

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This article examines the role of artwork in cancer and palliative care. The literature review focuses on both children and adults. One case scenario focuses on a child's reaction to his mother's illness showing his distress through painting. Artwork from children are included in the text to help demonstrate some feelings and reactions to illness. Some themes, which emerged from examination of the artwork, were isolation, anger, and lack of hope. Carers became overtly aware of the distress people were experiencing through artwork. Art depicted graphically what people were feeling and can, therefore, be considered a valuable tool in the communication process. It is useful especially when individuals are unable to express their feelings verbally. Recommendations focus on how artwork may be implemented in hospice and hospital settings and on how the environment may be made safe psychologically. The importance of the art process rather than on artistic skill is discussed. The potential for developing creativity at the end of life, when self-esteem may be low is explored.

84: Anesthesiol Clin. 2006 Mar;24(1):145-61, ix.

Palliative care and pediatrics.

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This article reviews the unique challenges of pediatric palliative medicine. These challenges originate from the specific epidemiology of pediatric diseases for which palliative care is indicated and the necessity to provide child-focused, family-oriented, relationship-centered medical care. The emphasis of the ultimate aims of pediatric palliative care is to care for the body, mind, and spirit, to enhance quality of life, and to minimize suffering.

85: Curr Opin Pediatr. 2006 Feb;18(1):10-4.

Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis.

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PURPOSE OF REVIEW: Pediatric palliative care, with its emphasis on symptom management and quality of life, is an important aspect of care of children with life-threatening illnesses. We review recent publications with implications for care of these children. RECENT FINDINGS: Invasive and life-sustaining measures continue to be part of care for many children with life-threatening illnesses, even at the end of life. While these measures may seem reasonable when recovery is possible, they may not fit with a family's preferences for end-of-life care. One possible cause of the prevalence of invasive measures in children at the end of life is that complex illness trajectories in children make it difficult to predict the timing of death. Inadequate communication by clinicians can also lead to poor preparation for the end-of-life period. Early integration of palliative care allows for improved symptom management, parental adjustment, and preparation for the end-of-life care period. Families who have the opportunity to prepare for the end-of-life period, including learning what to expect, are more likely to feel that their care has been of high quality. Bereaved parents also recognize the value of talking about death with their children. SUMMARY: Early integration of palliative care can allow children and families to make decisions about care that fit with their values, and should become a standard of care for all children with life-threatening illnesses.

86: J Palliat Med. 2006 Feb;9(1):163-81.

Palliative care for infants, children, adolescents, and their families.

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87: Int Anesthesiol Clin. 2006 Winter;44(1):109-18.

The evolution of pediatric palliative medicine and its integration with anesthesia.

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88: Eur J Pain. 2006 Oct;10(7):587-95. Epub 2005 Oct 21.

Paediatric cancer pain management using the WHO analgesic ladder--results of a prospective analysis from 2265 treatment days during a quality improvement study.

Zernikow B, **Smale H**, **Michel E**, **Hasan C**, **Jorch N**, **Andler W**.
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OBJECTIVE: To collect data on pain management in paediatric oncology with respect to the WHO ladder approach. SETTING, DESIGN, PATIENTS AND METHODS: Eight German tertiary care paediatric oncology centres prospectively documented all their in-patient pain treatment courses from June 1999 to December 2000. Pain was scored using a 1-6 faces scale. RESULTS: Two hundred and twenty four patients (median age, 9 years; range 0.2-32.1) were enrolled. Three hundred and thirty three pain episodes comprising a total of 2265 treatment days were documented. Pain was mostly therapy associated. The most frequently administered non-opioid analgesics were dipyrone and paracetamol. On WHO step 2, tramadol was almost the only opioid used. During tramadol monotherapy average daily pain scores were lower than with a combination of tramadol and non-opioid analgesics. On WHO step 3, morphine was at least part of the analgesic regimen on most treatment days. Strong opioids were combined with a non-opioid analgesic on 41% of the treatment days. The mean intravenous morphine equivalence dose was 0.034 mg/kg/h. During opioid and non-opioid combination therapy, adverse effects were more frequent, and average pain scored higher than on opioid monotherapy. CONCLUSIONS: WHO-guidelines were closely followed in Germany and seem to provide effective analgesia for children with cancer pain. In our patient group there is no evidence that a combination of an opioid with a non-opioid is more effective than opioid therapy alone in in-patient paediatric oncology pain treatment.

89: Contemp Nurse. 2005 Dec;20(2):193-200.

Evaluation of a nurse education workshop on children's grief.

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This paper provides an overview of the development and evaluation of an educational program to increase the knowledge of hospice and paediatric nurses who support grieving children and improve their attitudes toward death and bereavement. The specific target groups for the project included nurses providing care through community-based hospice services and inpatient palliative care units, as well as nurses providing inpatient and community-based care at a children's teaching hospital. Fifty-nine nurses from hospice, community and inpatient settings participated in three workshops. Results indicated that the workshop produced a sustained improvement in bereavement knowledge among the nurses and an improvement in their attitudes toward death and bereavement.

90: J Pain Symptom Manage. 2005 Dec;30(6):528-35.

Factors predicting home death for terminally ill cancer patients receiving hospital-based home care: the Lyon comprehensive cancer center experience.

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This study aimed to determine factors favoring home death for cancer patients in a context of coordinated home care. A retrospective study was conducted among patients followed up by the home care coordinating unit of the cancer center of Lyon. The main endpoint was place of death. Univariate analysis included general characteristics (age, gender, rural or urban residence, disease), Karnofsky Index (KI), type of care at referral (chemotherapy, palliative care, or other supportive care), and coordinating medical oncologist (MCO) home visits. Significant factors were used in a logistic regression analysis. Of 250 patients, 90 (36%) had home death. Low KI and MCO home visit were correlated with home death (odds ratio, respectively, 2.1 and 3.1). These results indicate that health care support favors home death. A hospital-based home care unit is effective for bridging the gap between community and hospital. MCO home visits offer concrete support to health care professionals, patients, and relatives.

91: J Palliat Med. 2005 Dec;8(6):1089-90.

"Virtual" pediatric palliative care: a novel concept for small pediatric programs.

Joshi DD.

92: J Palliat Care. 2005 Autumn;21(3):165-72.

Issues in pediatric palliative care: understanding families.
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While family-centred care has always been part of the rhetoric of hospice and palliative care, few models have been developed that successfully integrate care of the caregivers into the overall schema. Systematic analyses of interventions have failed to produce any demonstrable benefit to families arising from the modern practice of palliative care. This alarming finding constitutes the greatest challenge for the 21st century. Pediatric palliative care may have much to teach in its approach to family care. Family-focused grief therapy is one model, used with both adolescent and adult families, that has promise for the field. The time has surely arrived for palliative medicine to focus on family-based research.

93: J Clin Oncol. 2005 Dec 20;23(36):9055-7. Epub 2005 Nov 28.

Pediatric palliative care: relationships matter and so does pain control.
Solomon MZ, **Browning D**.

94: Anesthesiol Clin North America. 2005 Dec;23(4):837-56, xi.

Palliative care in pediatrics.
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Palliative care for children is not about dying; rather, it is about helping children and families to live to their fullest and to restore wholeness while facing complex medical conditions. Family centered pediatric palliative care is the art and science of improving quality of life and attending to suffering for children with life-threatening conditions; the basic principles are presented and discussed in this article.

95: J Palliat Med. 2005;8 Suppl 1:S70-8.

Key factors affecting dying children and their families.
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The death of a child alters the life and health of others immediately and for the rest of their lives. How a child dies influences parents' abilities to continue their role functions as well as siblings' abilities to make and maintain friendships, and may be the basis for health care providers' decisions to exit direct care roles. Thus, facilitating a "good death"-an obvious care priority for all involved with the dying child-ought also to be a priority for the health of bereaved families and affected health care providers. Making this a care priority is complicated by a serious lack of data, as details of the last hours or weeks of a dying child or adolescent's life are largely unknown. The purpose of this paper is to identify key factors that affect the course of dying children and adolescents and that of their bereaved survivors, and to link those key factors to needed research that could produce clinically relevant findings to improve the care of these patients. Key factors described here include suffering (physical, psychological, and spiritual), communication, decision making, prognostic ambiguities, ability of the seriously ill child to give assent to research participation, and educational preparation of health care providers to give competent end-of-life care.

96: Cochrane Database Syst Rev. 2005 Oct 19;(4):CD004598.

Local anesthetic sympathetic blockade for complex regional pain syndrome.
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BACKGROUND: Local anesthetic blockade of the sympathetic chain is widely used to treat reflex sympathetic dystrophy (RSD) and causalgia. These two pain syndromes are now conceptualized as variants of a single entity: complex regional pain syndrome (CRPS). A recent meta-analysis of the topic has been published. However, this study only evaluated studies in English language and therefore it could have overlooked some randomized controlled trials. OBJECTIVES: This systematic review had three objectives: to determine the likelihood of pain alleviation after sympathetic blockade with local anesthetics in the patient with CRPS; to assess how long any benefit persists; and to evaluate the incidence of adverse effects of the procedure. SEARCH STRATEGY: We searched the Cochrane Pain, Palliative and Supportive Care Register, the Cochrane Central Register of Controlled Trials, MEDLINE, EMBASE, LILACS, and conference abstracts of the World Congresses of the International Association for the Study of Pain. Bibliographies from retrieved articles were also searched for additional studies. SELECTION CRITERIA: We considered for inclusion randomized controlled trials that evaluated the effect of sympathetic blockade with local anesthetics in children or in adult patients to treat RSD, causalgia, or CRPS. DATA COLLECTION AND ANALYSIS: The outcomes of interest were the number of patients who obtained at least 50% of pain relief shortly after sympathetic blockade (30 minutes to 2 hours) and 48 hours or later. We also assessed the presence of adverse effects in each treatment arm. A random effects model was used to combine the studies. MAIN RESULTS: Two small randomized double blind cross over studies that evaluated 23 subjects were found. The combined effect of the two trials produced a relative risk (RR) to achieve at least 50% of pain relief 30 minutes to 2 hours after the sympathetic blockade of 1.17 (95% CI 0.80-1.72). It was not possible to determine the effect of sympathetic blockade on long-term pain relief because the authors of the two studies evaluated different outcomes. AUTHORS' CONCLUSIONS: This systematic review revealed the scarcity of published evidence to support the use of local anesthetic sympathetic blockade as the 'gold standard' treatment for CRPS. The two randomized studies that met inclusion criteria had very small sample sizes, therefore, no conclusion concerning the effectiveness of this procedure could be drawn. There is a need to conduct randomized controlled trials to address the value of sympathetic blockade with local anesthetic for the treatment of CRPS.

97: Palliat Med. 2005 Sep;19(6):477-84.

Pain and pain treatments in European palliative care units. A cross sectional survey from the European Association for Palliative Care Research Network.

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The Research Network of the European Association for Palliative Care (EAPC) performed a survey of 3030 cancer patients from 143 palliative care centres in 21 European countries. The survey addressed pain intensity and the use of non-opioid analgesics, adjuvant analgesics and opioids. Patients were treated with analgesics corresponding to the WHO pain ladder step I (n = 855), step II (n = 509) and step III (n = 1589). The investigators assessed 32% of the patients as having moderate or severe pain. In general there were small differences between pain intensities across different countries. Cancer primary sites and the presence of metastasis had only minor influences on pain intensity. The most frequently used non-opioid analgesics were NSAIDs (26%) and paracetamol (23%). Adjuvant analgesics or co-analgesics used by >1% of the patients were corticosteroids (39%), tricylic antidepressants (11%), gabapentin (5%), bisphosphonates (4%), clonazepam (2%), carbamazepine (4%) and phenytoin (2%). The use of non-opioid analgesics and co-analgesics varied widely between countries. Opioids administered for mild to moderate pain were codeine (8%), tramadol (8%), dextropropoxyphene (5%) and dihydrocodeine (2%). Morphine was the most frequently used opioid for moderate to severe pain (oral normal release morphine: 21%; oral sustained-release morphine: 19%; i.v. or s.c. morphine: 10%). Other opioids for moderate to severe pain were transdermal fentanyl (14%), oxycodone (4%), methadone (2%), diamorphine (2%) and hydromorphone (1%). We observed large variations in the use of opioids across countries. Finally, we observed that only a minority of the patients who used morphine needed very high doses.

98: J Pediatr Nurs. 2005 Oct;20(5):326-34.

The initiative for pediatric palliative care: an interdisciplinary educational approach for healthcare professionals.

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There is growing empirical evidence that the U.S. healthcare system fails to meet the needs of children with life-threatening conditions and their families. The confluence of several recent developments has created a critical window of opportunity for improving clinical practice and institutional effectiveness in pediatric palliative care. This article presents an innovative, comprehensive approach to pediatric palliative care education that was developed by the Initiative for Pediatric Palliative Care, a consortium of seven academic children's hospitals, Education Development Center, the National Association of Children's Hospitals and Related Institutions, the New York Academy of Medicine, the Society of Pediatric Nursing, and the Association of Medical School Pediatric Department Chairs. The approach is based on needs assessment research with clinicians and parents and reflects a commitment to culturally respectful, family-centered care of children with life-threatening conditions. The pedagogy combines principles of adult education, includes families as teachers, and integrates affective and cognitive dimensions to enhance learning.

99: J Pediatr Nurs. 2005 Oct;20(5):311-25.

A framework for integrated pediatric palliative care: being with dying.
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Recent studies highlight the need for an integrated model for palliative and end-of-life pediatric care. About 55,000 children die each year in the United States and, on any given day, about 8,600 children could benefit from care that acknowledges their limited life expectancy and severity of illness. Two case studies of children illustrate different approaches-one that aggressively applies all possible technologies to maximize chances of survival and another that focuses on the patient's overall quality of life and on healing rather than curing. The cases highlight characteristics of an integrated model of palliative care to address clinical, moral, and ethical uncertainties. This model integrates being with doing, provides for developing attunement and presence as capacities for being with children and their parents, and addresses challenges in the healthcare environment. Strategies for integrating palliative care into pediatric practice include listening, fostering respect for the child and parents across the organization, nurturing collaborative connections, managing uncertainty, tolerating ambiguity, making peace with conflict, and committing to self-care. Every pediatric nurse can play a role in making the vision of palliative care a reality integrated into the fabric of pediatric practice.

100: Pediatr Ann. 2005 Jul;34(7):546-52.

Developing an interdisciplinary palliative care plan for the patient with muscular dystrophy.
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The care of children with MD presents many complex issues. An interdisciplinary team, focused on patient and family outcome, that incorporates palliative care initiatives can best outline and meet the goals of family-centered care. The early introduction of a palliative team allows for a relationship of trust to develop, serving as the foundation for the many interventions necessary to fill the gaps in care that arise during the care of a child with a chronic, life-threatening illness such as MD.

101: Pediatr Nurs. 2005 May-Jun;31(3):195-200.

Providing pediatric palliative care through a pediatric supportive care team.
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We expect children to live to adulthood; however, children do die. Some die from diseases they are born with, others from accidents or illnesses. The devastating effects associated with the death of a child can be lessened by providing palliative, hospice, and bereavement care. At St. John Hospital (SJH) in Detroit, MI, the services that provide care for children chartered the Pediatric Palliative Care Committee. The committee brought together staff from the inpatient pediatric unit, cancer center, home care, and hospice care services within the St. John Health System. Utilizing established staff and services, this group began to provide care for children with potentially life limiting illnesses in a coordinated, multidisciplinary team approach. The positive outcomes of this approach include an overall increase in patient and family satisfaction with care, a decrease in the number of emergency room visits and inpatient hospital stays, and an increase in patient and family informed decision making and goal setting. Positive outcomes for the staff include support in caring for children with life limiting illnesses and an increase in satisfaction with the care they provide.

102: J Pain Symptom Manage. 2005 Jul;30(1):1-3.

Ketamine use for reduction of opioid tolerance in a 5-year-old girl with end-stage abdominal neuroblastoma.
Anghelescu DL, **Oakes LL**.

103: J Perinatol. 2005 Sep;25(9):563-8.

A paradigm of integrative care: healing with curing throughout life, "being with" and "doing to".
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We are presenting an integrative paradigm of care. We will review the basis for its evolution from prior series and parallel models. In this paradigm, healing and palliation (when indicated) are introduced in parallel with curative measures as soon as any diagnosis, especially a critical one, is made. Frequently palliative measures address patient symptoms, such as pain, anxiety, delirium, or depression, and are geared towards comfort care at the end of life. Our view of healing care is that it actively addresses the cognitive, emotional and spiritual needs of the patient and family, and includes the elements of palliative care as a complement.

Because a loss is often experienced in many conditions, even in the absence of death, bereavement is represented in our model as an ongoing, continual process throughout a disease process. While we will be drawing mainly from experiences with children, the proposed model is applicable to all ages. In order to implement this model most effectively, it will be important to shift from our mindset of "doing to" to one that includes "being with" our patients and their families. The uniqueness of this paradigm, in contrast to other models, is its comprehensiveness and universality. It is appropriate for patients of any age, at any stage of their disease or illness, regardless of the severity or duration of their condition.

104: Int J Palliat Nurs. 2005 Jun;11(6):294-8.

The palliative care nurse's role in supporting the adolescent child of a dying patient.

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The aim of this article was to critically evaluate the author's role as a hospital-based palliative care nurse in supporting the adolescent child of a dying parent. The approach taken and the resources that were available have been reflected upon. The article explores whether it was possible to adapt the theory of bereavement support for those working with adults within the constraints of a busy acute hospital. It was found that although there were limitations to the amount of support the author could give within her role, there remains a window of opportunity for all healthcare professionals within this field to support parents in preparing their children for bereavement.

105: Int J Palliat Nurs. 2005 Jun;11(6):292-3.

A global children's hospice and palliative care website.

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106: Int J Palliat Nurs. 2005 Jun;11(6):278-83.

Palliative care management of a child with juvenile onset Huntington's disease.

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This is a case report of the palliative care management of a 13-year-old girl who died of juvenile onset Huntington's disease in a children's hospice in the southeast of England. It outlines her disease progression and describes the care that she received. In particular, the medications and other measures used to control her symptoms during her last 10 days are discussed. The article also explores some of the ethical difficulties of caring for children dying from degenerative disorders. Although juvenile onset Huntington's disease is an extremely rare condition, the issues around terminal care management are very similar to those for any neuro-degenerative disorder, whether in an adult or child. A number of children's hospices have opened in the last 10-15 years in the UK. They accept children with a wide range of life-limiting conditions and have become experts in offering respite care and symptom control to these children and their families. They are chosen increasingly as the place of death for such children.

107: Curr Pain Headache Rep. 2005 Aug;9(4):249-55.

Issues and challenges in palliative care for children with cancer.

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Although the majority of children with cancer are cured of their illness, the children who die from their disease or complications require special care at the end of life. We present special issues and challenges unique to pediatric palliative care and suggest ways in which we can face these issues and address the challenges. The care must be family centered and balance the needs of the health-care system, the child, and the family. The way in which the care is delivered, the services provided, and the place in which that care is given are not carved into a simple protocol. Quality of life is an important concept that is often overlooked. Educational initiatives for patients, families, health-care providers, and third-party payers are essential. Reimbursement for palliative care services presents a large barrier to provision of appropriate services to all children and families in need. Hypothesis-driven research must be developed to help us learn more about how best to deliver end-of-life care to children and their families.

108: Pediatr Nurs. 2005 Mar-Apr;31(2):77, 86.

Challenging the assumptions for better pediatric palliative care.
Feeg VD.

109: Paediatr Drugs. 2005;7(1):1-9.

Strong opioids in pediatric palliative medicine.
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The management of pain in the palliative care of children is somewhat different from that in adults. It also differs in approach from the management of other types of acute and chronic pain in childhood. Whereas once opioids were thought to be highly dangerous drugs, unsuitable for use in children, they have now taken their place as the mainstay for provision of good analgesia to manage moderate-to-severe pain in both malignant and non-malignant life-limiting conditions. There are relatively little clinical or laboratory data regarding opioids specifically in children. However, much of what has been published regarding the management of pain in palliative medicine in adults can be extrapolated. On saying that, early research in children does suggest some significant differences in opioid pharmacokinetics, particularly with respect to morphine clearance, which seems to be faster in adults. Thus, the use of opioids in pediatric palliative care presents some unique challenges. Confident and rational use of opioids by pediatricians, illustrated by the WHO guidelines, is essential for the adequate management of pain complicating the palliative phase in children with life-limiting conditions.

110: Am J Hosp Palliat Care. 2005 Jan-Feb;22(1):26-31.

End-of-life care: perspectives of family members of deceased patients.
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This study was undertaken to determine the opinions of family members of deceased patients regarding end-of-life care. This multisite cross-sectional survey was administered to 969 volunteer participants during 1997 to 2000. Eligible participants included immediate family members of deceased patients at five local institutions in a regional health system. Among 969 respondents, most (84.4 percent) indicated that the care for their family member was excellent. Reasons cited for satisfaction included overall care (40.2 percent), staff effort (23.2 percent), and communication (16.4 percent). Reasons cited for dissatisfaction included perceived incompetence (9.7 percent), perceived uncaring attitude (8.4 percent), and perceived understaffing (3.7 percent). Respondents were more satisfied with communication from nursing staff (88 percent) than physicians' communication (78 percent, $p < 0.001$, Bowker's test). Respondents indicated higher overall satisfaction with nursing (90 percent) and pastoral care (87 percent), than with physician care (81 percent, $p < 0.001$ and $p = 0.006$, Bowker's test). A unique survey instrument can be used to measure family perceptions and opinions regarding end-of-life care.

111: J Pain Symptom Manage. 2005 Feb;29(2):185-92.

HIV/AIDS symptom management in Southern Africa.
Sukati NA, **Mndebele SC**, **Makoa ET**, **Ramukumba TS**, **Makoae LN**, **Seboni NM**, **Human S**, **Holzemer WL**.
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We describe self-reported strategies used by persons living with HIV/AIDS in Botswana, Lesotho, South Africa, and Swaziland to manage common HIV-related symptoms. A questionnaire asked participants to list three to six symptoms they had recently experienced, the care strategies they had used to make them better, where they had learned the strategy, and to rate the perceived effectiveness of the strategy. Data were collected in 2002 from 743 persons. The self-care management strategies were coded into eight categories: medications, complementary treatments, self-comforting, changing diet, seeking help, exercise, spiritual care, and daily thoughts/activities. Overall, participants reported medications as the most frequently occurring management strategy and the most effective. A very small inventory of behavioral strategies was available to participants to help them manage their HIV-related symptoms.

112: J Pain Symptom Manage. 2005 Feb;29(2):156-64.

Status quo of palliative care in pediatric oncology-a nationwide survey in Germany.
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Cancer is the leading cause of death among the pediatric population with life-limiting conditions. The provision of palliative care at home and on the children's cancer unit has not been surveyed previously on a national scale. A survey of 71 (of 73) German pediatric oncology units (response rate 97%) provided information on the timing of breaking bad news, place of death, orchestrating palliative care at home and on the ward, integration of services and staff, funding of palliative care, bereavement services for siblings and parents, educational needs, level of self-satisfaction, and designated integrated palliative care services for children with cancer. More than 60% of children with malignancies died as inpatients in 2000, fewer than 40% at home. Twenty-nine pediatric cancer departments were able to provide comprehensive medical palliative home care, and nine units incorporate a designated palliative care team or person. Only half of the departments provide bereavement services for siblings. Many health professionals working on pediatric cancer units in Germany provide palliative home care in their free time without any payment. They predominantly use their private vehicles and often are unclear about the legal background and insurance arrangements covering their provision of care. The data suggest an important need for education about palliative and end-of-life care. The majority of children dying from cancer in Germany do not have access to comprehensive palliative care services at home. Our study highlights the necessity of incorporating the palliative paradigm into the care of children with cancer. Barriers to its implementation must be identified and overcome.

113: Contemp Nurse. 2004 Dec-2005 Jan;18(1-2):34-45.

Fathers struggling for relevance in the care of their terminally ill child.

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Children with terminal illness receive substantial amounts of care from their parents within their home, a palliative care facility or general hospital. Whilst there is a long history of research exploring child and family experiences and coping styles within these settings, the focus has not been on fathers' participation in care-giving. This phenomenon can be explained by traditional sex-role socialisations whereby men are ostensibly conditioned as breadwinners and mothers remain embedded as the primary carers for children, particularly when illness arises. Nevertheless, nurses report that men do provide direct care-giving or seek to be more involved in caring for their child. This literature review offers opportunities for health professionals to reflect on the significance of gender in parenting the terminally ill child and to develop empathy for men experiencing difficulties in their role as care-givers. As there is little literature available on this topic, this paper portrays men's experiences and importantly the barriers they encounter in meeting their desire to care. The approach provides a suitable basis for developing a research agenda to promote competencies and relevance for fathers in their role as care-giver.

114: Palliat Med. 2004 Oct;18(7):654-62.

Cancer pain management in children.

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Unrelieved pain may have a major impact on the care of children with cancer. The type and severity of pain experienced by children with cancer varies from acute, procedure-related pain to progressive chronic pain associated with the progression of the disease or sequelae of treatment. Drugs are the mainstay of treatment. Regular pain assessments combined with appropriate analgesic administration at regular dosing intervals, adjunctive drug therapy for control of adverse effects and associated symptoms, and nonpharmacological interventions are recommended. Although standard dosing of opioids adequately treats most cancer pain in children, more complex treatment is required by a significant group. Strategies to improve analgesia include the use of epidural or intrathecal infusions of a combination of opioids and other adjuvants, or other regional anaesthesia techniques. Procedure- and treatment-related pain is an even greater problem than cancer pain. Recommendations have been published with regard to the monitoring and personnel required when children are sedated which aim to set the standard of care and minimize both physical discomfort or pain and negative psychological responses, by providing analgesia; and to maximize the potential for amnesia; and to control behaviour.

115: Pediatr Res. 2004 Dec;56(6):831-41. Epub 2004 Nov 5.

Evolving therapeutic strategies for Duchenne muscular dystrophy: targeting downstream events.

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Duchenne muscular dystrophy (DMD) is a progressive, lethal, muscle wasting disease that affects 1 of 3500 boys born worldwide. The disease results from mutation of the dystrophin gene that encodes a cytoskeletal protein associated with the muscle cell membrane. Although gene therapy will likely provide the cure for DMD, it remains on the distant horizon, emphasizing the need for more rapid development of palliative treatments that build on improved understanding of the complex pathology of dystrophin deficiency. In this review, we have focused on therapeutic strategies that target downstream events in the pathologic progression of DMD. Much of this work has been developed initially using the dystrophin-deficient mdx mouse to explore basic features of the pathophysiology of dystrophin deficiency and to test potential therapeutic interventions to slow, reverse, or compensate for functional losses that occur in muscular dystrophy. In some cases, the initial findings in the mdx model have led to clinical treatments for DMD boys that have produced improvements in muscle function and quality of life. Many of these investigations have concerned interventions that can affect protein balance in muscle, by inhibiting specific proteases implicated in the DMD pathology, or by providing anabolic factors or depleting catabolic factors that can contribute to muscle wasting. Other investigations have exploited the use of anti-inflammatory agents that can reduce the contribution of leukocytes to promoting secondary damage to dystrophic muscle. A third general strategy is designed to increase the regenerative capacity of dystrophic muscle and thereby help retain functional muscle mass. Each of these general approaches to slowing the pathology of dystrophin deficiency has yielded encouragement and suggests that targeting downstream events in dystrophinopathy can yield worthwhile, functional improvements in DMD.

116: Neurosurg Clin N Am. 2004 Oct;15(4):511-27.

Management of pain associated with spinal tumor.

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Metastatic spinal disease is common in cancer patients, and it is a frequent source of pain and disability. Expert management of the patient's pain and neurologic dysfunction is required. Neurosurgical advances have afforded the patient the opportunity to have improved symptom management and improved quality-of-life outcomes. Patients and their families are best served by the provision of supportive care by specialty pain medicine and palliative care services (especially neurology based) working with the primary neurosurgical team in an integrated model.

117: J Palliat Care. 2004 Summer;20(2):105-12.

What are the key components of quality perinatal and pediatric end-of-life care? A literature review.

Widger KA, **Wilkins K**.

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118: J Clin Oncol. 2004 Feb 1;22(3):563-6.

The Day One Talk.

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119: J Natl Cancer Inst Monogr. 2004;(32):144-9.

Palliative care in children with cancer: which child and when?

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At a time of increasing interest in palliative care in pediatrics, pediatric oncology programs may be failing to deliver adequate palliation to children with cancer. In a recent study, parents of children who died on a pediatric oncology service reported that despite treatment at the end of life, their children's suffering was not adequately relieved and that parents were more likely than caregivers to recognize their children's suffering. Why do pediatric oncologists fail? First, death in children from cancer is a rare event. Second, few prospective trials in the field of pediatric palliative care describe and quantify symptoms during cure-directed care or at the end of life. This leads to a lack of evidence-based practice and forces the clinician to use personal experience and trial-by-error medical care. Third, pediatric oncologists and those charged with developing pediatric palliative care programs must deal with the different physiologic and developmental stages encountered while caring for infants, children, and adolescents. Fourth, education is needed for pediatric oncology caregivers in many areas of palliative care. Finally, reimbursement issues surround the palliative care field and are a major hindrance in developing effective integrated palliative care teams. These factors have also made it difficult to perform palliative care research in children. When discussing palliative care in children with cancer, where few die but many suffer, a paradigm shift must occur that does not equate palliative care with end-of-life care. A model on how we might make the transition from symptom control that we should offer to every patient to end-of-life care is discussed.

120: J Natl Cancer Inst Monogr. 2004;(32):105-11.

Treatment of depression in cancer.
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Depression occurs in about 15% of the general population and is at least two to three times more common in patients with cancer. Depression is often difficult to diagnose in these patients because of the complexity and constraints of cancer care, patient and family reluctance to acknowledge distress, and the presence of multiple other symptoms. Both antidepressants and psychotherapy are effective in treating depression in patients with cancer, much like in patients with other significant medical problems. Precise assessments of the benefits of treating depression in these patients are important in weighing them against the costs and potential adverse effects. Such estimates are limited by a paucity of randomized, placebo-controlled trials and methodological problems in the existing studies that reflect some of the clinical difficulties in case-finding, treatment, and follow-up of patients with cancer. The existing body of research about depression in cancer patients is extremely limited in terms of the number of studies published and the number of total patients reported over the last 30 years. Moreover, these limited data may not generalize well because of high rates of patient dropout and the very limited enrollment of children, adolescents, older adults, and minority groups. There is an emerging trend toward simplifying the assessment of depression in outpatient cancer care settings and studying depression therapies in cohorts of patients with cancer other than those with fully characterized depressive disorders.

121: N Engl J Med. 2004 Jul 15;351(3):301-2; author reply 301-2.

Pediatric palliative care.

Gothelf D, **Cohen IJ**.

122: Br J Cancer. 2004 Aug 2;91(3):441-6.

Interstitial photodynamic therapy as salvage treatment for recurrent head and neck cancer.
Lou PJ, **Jäger HR**, **Jones L**, **Theodossy T**, **Bown SG**, **Hopper C**.
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Interstitial photodynamic therapy (IPDT) is a technique for applying photodynamic therapy (PDT) to internal tumours using light delivered via fibres inserted percutaneously. This phase I-II study assessed the safety and efficacy of IPDT for patients with persistent or recurrent head and neck cancer unsuitable for further treatment with surgery, radiotherapy or chemotherapy, recruited for 'last hope' salvage treatment. Patients were sensitised with 0.15 mg kg(-1) mTHPC (meso-tetrahydroxyphenyl chlorin) 4 days prior to light delivery from fibres inserted directly into the target tumour (20 J per site at 652 nm) under image guidance. In all, 45 patients were treated. Nine achieved a complete response. Five are alive and free of disease 10-60 months later. Symptomatic relief (mainly for bleeding, pain or tumour debulking) was achieved in a further 24. The median survival (Kaplan-Meier) was 16 months for the 33 responders, but only 2 months for the 12 nonresponders. The only serious complication was a carotid blow out 2 weeks after PDT. No loss of function was detected in nerves encased by treated tumours. Interstitial photodynamic therapy provides worthwhile palliation with few complications and occasional long-term survivors for otherwise untreatable advanced head and neck cancers. It is a treatment option worth adding to those available to integrated head and neck oncology teams.

123: Arch Pediatr Adolesc Med. 2004 Jul;158(7):615-9.

Dying young: cues from the courts.
Hartman RG.
School of Medicine and Center for Bioethics and Health Law, University of Pittsburgh, Pittsburgh, PA, USA. hartmanr+@pitt.edu

124: Curr Pain Headache Rep. 2004 Aug;8(4):281-3.

Integrating palliative care in pediatrics.
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An integrated palliative care plan with goals of therapy that change throughout a child's illness will reflect an individualized, child-centered, and family-centered approach to care. This care plan will act as a foundation to assist and guide all providers, from the primary pediatrician to the subspecialty surgeon, in providing interventions that will most benefit a child and add life to the child's years.

125: Br J Nurs. 2004 May 27-Jun 9;13(10):594-6.

The challenge of transitional care for young people with life-limiting illness.
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Centre for Child Health, School of Health Science, University of Wales, Swansea, Wales, UK.

Transitional care for young people with life-limiting illness is a particularly complex issue. The process of moving from paediatric to adult services is often fraught and poorly planned. As a result, this can add to the distress experienced by the young people and their families. The ideal would be to have a dedicated service for young adults that bridges the gap in care. The continued slow growth of community children's nursing services, however, highlights the constraints in developing services for a relatively small percentage of the population. Healthcare professionals must recognize the specialist needs of this patient group, and develop strategies to ensure that young people receive the care to which they are entitled.

126: Arch Pediatr Adolesc Med. 2004 Jun;158(6):590-1.

Parental grief and palliative care require attention.
Sandler I, **Kennedy C**, **Shapiro E**.

127: Eur J Oncol Nurs. 2004 Jun;8(2):138-47.

Evaluation of educational programmes for paediatric cancer nursing in England.
Sanderson L, **Long T**, **Hale C**.
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The results of part of a larger study to evaluate educational provision for paediatric oncology and palliative care nursing in England are presented here. Mapping of cancer care provision, based upon the English National Board 240 programme, was undertaken by analysis of relevant curriculum documents. Prescribed programme outcomes were reviewed against expected course outcomes proposed by the European Oncology Nursing Society. Particular attention was also paid to expected processes of assessment of clinical practice, consideration of adolescent patients, and opportunities for shared learning. Widespread compliance with the European Oncology Nursing Society standard was found, with only two of the 19 areas substantially neglected. These related to the prevention and early detection of cancer (less relevant in paediatric cancer than for adults), and understanding the principles of cancer clinical trials (probably due to lack of explicit statement in curriculum documents rather than actual failure to address the topic). A range of prescribed assessment practices were noted, but the degree to which direct observation was involved was variable, and indirect measures appeared to predominate. There was little specific recognition of adolescence as a discrete topic to be addressed in the programmes. Shared learning tended to be introduced for logistical reasons of small class numbers rather than for any perceived intrinsic value.

128: Am J Nurs. 2004 Apr;104(4):54-63; quiz 63-4.

Ethics and palliative care in pediatrics.
Rushton CH.
School of Nursing, Phoebe R. Berman Bioethics Institute, Johns Hopkins University, Baltimore, MD, USA. crushton@son.jhmi.edu

129: Int J Palliat Nurs. 2004 Apr;10(4):197-200.

Palliative care for children in the Republic of Belarus.
Costello J, **Gorchakova A**.
School of Nursing Midwifery and Health Visiting, The University of Manchester, Gateway House, Piccadilly South, Manchester, M60 7LP, UK. john.costello@man.ac.uk

130: Child Care Health Dev. 2004 May;30(3):195-9.

Supporting children with complex health care needs and their families - an overview of the research agenda.
Emond A, **Eaton N**.

131: Child Care Health Dev. 2004 May;30(3):193-4.

Children with complex health care needs - supporting the child and family in the community.
Craft A.

132: Child Care Health Dev. 2004 May;30(3):191-2.

Children with complex health care needs: supporting the child and family in the community.
Lenton S, **Franck L**, **Salt A**.

133: N Engl J Med. 2004 Apr 22;350(17):1752-62.

Pediatric palliative care.
Himelstein BP, **Hilden JM**, **Boldt AM**, **Weissman D**.
Pediatric Palliative Care Program, Children's Hospital of Wisconsin, Milwaukee, USA. bhimelstein@chw.org

134: J Trop Pediatr. 2003 Dec;49(6):324-5.

Palliative care for children.
Simkiss D.

135: Neurosurg Focus. 2003 Nov 15;15(5):E12.

Surgical management of metastatic spinal neoplasms.
Vrionis FD, **Small J**.
H. Lee Moffitt Cancer Center and Research Institute, Neuro-Oncology Program, and Department of Neurosurgery, University of South Florida College of Medicine and Florida Orthopedic Institute, Tampa, Florida, USA. vrionif@moffit.usf.edu

OBJECT: In this study the authors retrospectively review outcomes in patients treated for metastases to the spine. Surgery for metastatic tumors to the spine remains an important part of the treatment armamentarium. Maximum tumor resection with a minimum number of complications is one of the goals of surgery. Current surgical procedures include tumor resection and spinal stabilization for optimal results. METHODS: The records of 96 patients who underwent surgery for a metastatic spine tumor at the authors' institution were reviewed. Spinal instrumentation was used in the majority of patients. Ambulatory status was maintained in 91% and pain improved in 94% of patients. Complications included infection (5.2%), cerebrospinal fluid leak (2%), and delayed hardware failure (3.1%). The mortality rate was 4.1%; the main cause was due to tumor progression. CONCLUSIONS: Surgery is indicated in a select group of patients with metastatic tumors to the spine. A multidisciplinary approach is recommended for patient selection and complication avoidance. Surgical options, including approach, type of reconstruction and extent of resection (including en bloc spondylectomy) need to be addressed for optimal outcomes.

136: Pediatr Nurs. 2003 Sep-Oct;29(5):383-4.

Lactation suppression: forgotten aspect of care for the mother of a dying child.
Moore DB, **Catlin A**.
NICU, Alta Bates Summit Medical Center, Berkeley, CA, USA.

137: Postgrad Med J. 2003 Oct;79(936):566-8.

Terminal care in paediatrics: where we are now.
Hutchinson F, **King N**, **Hain RD**.
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As in adults, palliative care in children is a comprehensive multidisciplinary approach to care that seeks to enhance the life of children and families living with life limiting conditions. It involves a holistic approach embracing symptom management, psychosocial/spiritual care, and bereavement support.

138: Cochrane Database Syst Rev. 2003;(4):CD003868.

Oral morphine for cancer pain.
Wiffen PJ, **Edwards JE**, **Barden J**, **McQuay HJ**.
Cochrane Pain, Palliative and Supportive Care CRG, Pain Research Unit, Churchill Hospital, Old Road, Headington, Oxford, UK, OX3 7LJ.

BACKGROUND: Morphine has been used to relieve pain for many years. Oral morphine in either immediate release or sustained release form remains the analgesic of choice for moderate or severe cancer pain. OBJECTIVES: To determine the efficacy of oral morphine in relieving cancer pain. To assess the incidence and severity of adverse effects. SEARCH STRATEGY: The following databases were searched: The Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Library, Issue 4, 2002; the trials register of the Cochrane Pain, Palliative and Supportive Care group (February 2002); MEDLINE 1966 to December 2002; EMBASE 1988 to December 2002; and the Oxford Pain Relief database 1950 to 1994. SELECTION CRITERIA: Published randomised controlled trials (full reports) reporting on the analgesic effect of oral morphine in adults and children with cancer pain. Any comparator trials were considered. Trials with fewer than 10 subjects were excluded. DATA COLLECTION AND ANALYSIS: One reviewer extracted data, and the findings were checked by two other reviewers. There were insufficient comparable data for meta-analysis to be undertaken, or to produce numbers-needed-to-treat (NNT) for the analgesic effect. MAIN RESULTS: Forty five studies (3061 subjects) met the inclusion criteria. Fourteen studies compared oral sustained release morphine (MSR) preparations with immediate release morphine (MIR). Eight studies compared MSR and MSR in different strengths. Nine studies compared MSR with other opioids. Five studies compared MIR with other opioids. Two studies compared oral MSR with rectal MSR. One study was found comparing each of the following: MSR tablet with MSR suspension; MSR with MSR at different dose frequencies; MSR with non-opioids; MIR with non-opioids; oral morphine with epidural morphine; and MIR with MIR by a different route of administration.Morphine was shown to be an effective analgesic. Pain relief did not differ between MSR and MIR. Sustained release versions of morphine were effective for 12 or 24 hour dosing depending on the formulation. Adverse effects were common but only 4% of patients discontinued treatment because of intolerable adverse effects. REVIEWER'S CONCLUSIONS: The randomised trial literature for morphine is small given the importance of this medicine. Most trials recruited fewer than 100 participants, and did not provide appropriate data for meta-analysis. Trial design was frequently based on titration of morphine or comparator to achieve adequate analgesia, then crossing subjects over in crossover design studies. It is not clear if these trials are sufficiently powered to detect any clinical differences between formulations or comparator drugs.

139: J Pain Symptom Manage. 2003 Oct;26(4):889.

Re: High dose opioids in pediatric palliative care.
Lidstone V.

140: BMJ. 2003 Jul 26;327(7408):223.

In search of a good death: Palliative care is also remit of intensivists.
Rashid A, **Ferguson M**.

141: BMJ. 2003 Jul 26;327(7408):222-3.

In search of a good death: Can children with life threatening illness and their families experience a good death?
Beaune L, **Newman C**.

142: J Pain Symptom Manage. 2003 May;25(5):397-9.

High dose opioids in pediatric palliative care.
Siden H, **Nalewajek**.

143: Palliat Med. 2003 Apr;17(3):229-31.

Training in paediatric palliative medicine.
Hain R, **Goldman A**.

144: Pain Manag Nurs. 2003 Mar;4(1):31-9.

A study of the effectiveness of a pain management education booklet for parents of children having cardiac surgery.
Huth MM, **Broome ME**, **Mussatto KA**, **Morgan SW**.
Jane B. Pettit Pain and Palliative Pain Center, Children's Hospital of Wisconsin, Milwaukee 53201-1997, USA.

Parents need education about pain so they can support their hospitalized child and manage their child's pain at home. The purpose of this study was to examine the effectiveness of a pain booklet on parental pain support to children experiencing postoperative pain. A randomized, repeated measures, experimental design using a pain education booklet and a standard care comparison group was used to study parents of 51 children (3 to 16 years of age) having cardiac surgery. Measurement techniques used to assess differences in parental pain management included: attitudes about pain medication, child and parent pain ratings (Oucher), opioids used, recovery, satisfaction, and comfort in communication. Results indicate that children do report moderate levels of pain postoperatively. Parents who were exposed to the pain assessment and management for parents education booklet preoperatively significantly increased their knowledge and attitudes toward pain medication scores from pre- to post-test, whereas those in the control group remained stable. Post-test scores were not significantly different between groups. Child and parent pain ratings were significantly and positively correlated. Practice implications include the use of an educational booklet about pain with parents before surgery to increase their knowledge about and attitudes toward pain management. Additionally, a parent may provide an alternative pain report when a child is unable to or unwilling to self-report their pain. Copyright 2003 by the American Society of Pain Management Nurses.

145: N Z Med J. 2003 Mar 14;116(1170):U370.

Palliative home care and cost savings: encouraging results from Italy.
Di Cosimo S, **Pistillucci G**, **Ferretti G**, **Cicchetti A**, **Leggio M**, **Silvestris N**, **Moro C**, **Mandala M**, **Curigliano G**, **Battigaglia B**, **Di Chio G**, **Cirignotta S**, **D'Aprile M**.

146: Arch Pediatr Adolesc Med. 2003 Feb;157(2):207-8; author reply 208.

Palliative program considerations.
Nitschke R.

147: Med Pediatr Oncol. 2003 Feb;40(2):136.

Strontium-89 for palliation of bone pain.
Gompakis N, **Triantafyllou P**, **Sidi B**, **Koliouskas ED**, **Salem N**, **Pistevou K**.

148: Med Pediatr Oncol. 2003 Jan;40(1):72.

Palliative and terminal care for dying children.
Kurashima AY, **de Camargo B**.

149: J Pain Symptom Manage. 2002 Oct;24(4):437-46.

A phase I study on the feasibility and acceptability of an acupuncture/hypnosis intervention for chronic pediatric pain.
Zeltzer LK, **Tsao JC**, **Stelling C**, **Powers M**, **Levy S**, **Waterhouse M**.
UCLA Pediatric Pain Program, Department of Pediatrics, #22-464 MDCC, UCLA School of Medicine, 10833 Le Conte Avenue, Los Angeles, CA 90095-1752, USA.

The purpose of the present study was to conduct a Phase I investigation examining the feasibility and acceptability of a complementary and alternative medicine (CAM) package combining acupuncture and hypnosis for chronic pediatric pain. Thirty-three sequentially referred children (21 girls) aged 6-18 years were offered 6 weekly sessions consisting of individually tailored acupuncture treatment together with a 20-minute hypnosis session (conducted while the needles were in place). Parent and child ratings of pain and pain-related interferences in functioning, as well as child ratings of anxiety and depression, were obtained at pre- and post-treatment. The treatment was highly acceptable (only 2 patients refused; > or = 90% completed treatment) and there were no adverse effects. Both parents and children reported significant improvements in children's pain and interference following treatment. Children's anticipatory anxiety declined significantly across treatment sessions. Our results support the feasibility and acceptability of a combined acupuncture/hypnosis intervention for chronic pediatric pain.

150: Arch Pediatr. 2002 Nov;9(11):1173-8.

[Treatment of non-painful symptoms in terminally ill children]
Duval M, Wood C.

Service d'hémato-oncologie pédiatrique, hôpital Sainte-Justine, 3175, chemin de la Côte-Sainte-Catherine, Montréal, QC, Canada, H3T 1C5. michel.duval@umontreal.ca

The care of children at the end of life is gradually improving. Nevertheless, more than half suffer from intractable symptoms before dying. Although pain has been the subject of clinical research, evidence-based data are almost completely lacking for other symptoms, highlighting the need for clinical research in palliative care. We review the available evidence on fatigue, anorexia, dyspnea, respiratory secretions, cough, constipation, mouth dryness, urinary obstruction, terminal convulsions and gasping. When evidence is lacking, we offer our empiric approach. Short duration benzodiazepines have become an important component of treatment that should remain simple, while providing the dying child the comfort needed to experience the highest quality relationships with those around him.

151: Nurs Forum. 2002 Oct-Dec;37(4):24-31.

Critique of transcultural practices in end-of-life clinical nursing practice.
Mitchell AM, Gale DD, Matzo ML, McDonald MC, Gadmer N.

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TOPIC: Transcultural nursing practices for terminally ill patients. PURPOSE: To examine several criticisms of transcultural nursing theory in end-of-life care. SOURCES: Published literature and interviews with nurses. CONCLUSIONS: Nurses often encounter barriers that impede their ability to provide ideal end-of-life care.

152: Pediatr Clin North Am. 2002 Oct;49(5):1043-62.

Caring for children with advanced cancer integrating palliative care.
Wolfe J, Friebert S, Hilden J.

Children's Hospital and Dana-Farber Cancer Institute, Boston, MA 02115, USA.

The care of children with advanced cancer is multifaceted. Treatment should focus on continued efforts to control the underlying illness whenever possible. At the same time, children and their families should have access to interdisciplinary care aimed at promoting optimal physical, psychological and spiritual wellbeing. Open and compassionate communication can best facilitate meeting the goals of these children and families. However, there remain significant barriers to achieving optimal care related to lack of formal education, reimbursement issues and the emotional impact of caring for a dying child. Future research efforts should focus on ways to enhance communication, symptom management and quality of life for children with advanced cancer and their families. As efforts to break down barriers and create the evidence base continue, we conclude as follows: this is a most rewarding part of the practice of medicine. A kind word and caring attitude are remembered for decades.

153: N Z Med J. 2002 Oct 11;115(1163):U195.

Caring for children who are dying.
MacLeod R.

154: Pediatr Nurs. 2002 Sep-Oct;28(5):487-90.

Mindfulness meditation in pediatric clinical practice.
Ott MJ.

Pain and Palliative Care Program, Zakim Center for Integrated Therapies, Dana-Farber Cancer Institute, Boston, MA, USA.

Complementary therapies are used in addition to conventional treatments; alternative therapies are generally used instead of conventional treatments. In the Five Domains of complementary and alternative therapies, patient education and cognitive-behavioral approaches are listed as mainstream interventions. Meditation is listed within the mind-body domain as a complementary intervention used to facilitate the mind's ability to affect bodily functions and symptoms.

155: Int J Palliat Nurs. 2002 Sep;8(9):418-34.

Experiences of families in which a child has a prolonged terminal illness: modifying factors.
Steele RG.

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A significant proportion of children requiring palliative care have neurodegenerative life-threatening illnesses (NLTIs). While most of their care is provided at home by their families over many years, there is a paucity of research examining families' experiences when a child with an NLTI is dying at home. In this grounded theory study, data were collected from eight families through observations and audiotaped interviews. Families moved through a process of 'navigating uncharted territory' as they lived with their dying child. The strategies that families used to manage this phenomenon were influenced by four intervening conditions that reflected the broader structural context of the phenomenon; relationships with healthcare providers, availability of information, gender differences, and communication between parents. Each condition facilitated or constrained the strategies that families were able to use. Implications for research, education and practice are discussed.

156: Eur J Cancer. 2002 Sep;38(14):1900-7; discussion 1908-10.

Palliative care in paediatric oncology.
Beardsmore S, **Fitzmaurice N**.
Paediatric Macmillan Nursing Service, The Birmingham Children's Hospital NHS Trust, Birmingham, UK.

157: Hematol Oncol Clin North Am. 2002 Jun;16(3):657-70.

Palliative care and the child with cancer.
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There is a growing awareness and a WHO directive that the palliative care paradigm should be incorporated into the care of all children with cancer, irrespective of geographic location. The barriers to pediatric palliative care identified by pediatric oncologists [3] are lack of formal courses in pediatric palliative care, a high reliance on trial-and-error learning, lack of strong role models, and lack of access to a pain and palliative care service. These barriers must be overcome.

158: Hematol Oncol Clin North Am. 2002 Jun;16(3):543-55.

The use of methadone for cancer pain.
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Methadone is not a new analgesic drug [69]. Several studies have demonstrated that methadone is a valid alternative to morphine, hydromorphone, and fentanyl for the treatment of cancer-related pain, and extensive reviews on the subject have been published in recent years [10,23,25,64,70,71]. Most people involved in pain therapy, however, are not well informed about the properties of methadone. The authors believe that the low cost of methadone paradoxically contributes to the limited knowledge of its characteristics and to the restricted therapeutic use of this drug. The low cost of methadone means there is little financial incentive for pharmaceutical companies to invest in research or to disseminate scientific information. Unfortunately, the lack of scientific information from pharmaceutical companies frequently results in a lack of knowledge on the part of physicians. Unless the existing approach changes, both culturally and politically, ignorance about methadone will persist among medical experts. The low cost of methadone, rather than being an advantage, will result in the limited exploitation of an effective drug.

159: Palliat Med. 2002 Mar;16(2):79-80.

Children's hospices: organizational and staff issues.
Sheldon F, **Speck P**.

160: Soins Pediatr Pueric. 2002 Jun;(206):24-6.

[Pediatric palliative care and the family environment]
Bass HP.
L'université Paris V-Sorbonne, service d'oncologie et d'hématologie pédiatrique du professeur Guy Leverger, Hôpital d'enfants Armand-Trousseau (AP-HP), Paris (75).

161: Oncologist. 2002;7(3):251-8.

When does the responsibility of our care end: bereavement.
Penson RT, **Green KM**, **Chabner BA**, **Lynch TJ Jr**.

Department of Medicine, Division of Hematology-Oncology, Massachusetts General Hospital, Boston, Massachusetts, USA. rpenson@partners.org

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital, founded the Kenneth B. Schwartz Center. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, support to caregivers, and sustenance to the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers, and gain insight and support from fellow staff members. Two vignettes are presented of a caregiver's response to the death of a patient, contrasting the extremes of involved compassion for the family and fractured relationships. Grief for loss is an inevitable part of life and a common part of cancer care. Support of the bereaved may be one of the hardest tasks for cancer care professionals, who are confronted with the limits of modern medicine. There is a responsibility to provide grieving families with support and care; care that goes beyond the death. A compassionate response helps both those who suffer and those who care. Complicated and uncomplicated bereavement, grief reactions, resources for bereavement counseling, and the role of condolence letters are reviewed.

162: J Palliat Care. 2002 Spring;18(1):59-67.

Addressing spirituality in pediatric hospice and palliative care.

Davies B, **Brenner P**, **Orloff S**, **Sumner L**, **Worden W**.

Department of Family Health Care Nursing, School of Nursing, University of California, San Francisco, California, USA.

Hospice and palliative care principles mandate clinicIans to provide "total" care to patients and their families. Such care incorporates not only physical, emotional, and psychosocial care, but spiritual care as well. Even though considerable attention has been directed to spiritual issues for adult patients in hospice and palliative care, spirituality in pediatric palliative care has been virtually neglected. The need for guidelines to assess spirituality in this population was identified as a priority issue by members of a subcommittee of the Children's International Project on Children's Palliative/Hospice Services, created under the auspices of the National Hospice Organization. Committee members, based on their clinical, research, and personal experiences, identified several aspects relevant to spirituality in general, and to spirituality in pediatric palliative care in particular, and developed guidelines for clinicians in pediatric palliative care. The purpose of this paper is to share the results of this committee's work and, in particular, to present their guidelines for addressing spiritual issues in children and families in pediatric hospice and palliative care.

163: Palliat Med. 2002 Mar;16(2):99-105.

Paediatric respite care: a literature review from New Zealand.

Horsburgh M, **Trenholme A**, **Huckle T**.

Division of Nursing, University of Auckland, PO Box 92019, Auckland, New Zealand. m.horsburgh@auckland.ac.nz This paper reviews relevant international and New Zealand literature, policy documents and reports on respite provision for children who are dying and their families. The literature describes why respite care for children is necessary, and evaluates present respite services in accord with recent reports and literature. The service provisions needed for dying children and their families are explored, including suggestions for the improvement of services and future research. The literature reveals that, although respite care for terminally ill children and their families is necessary, service provisions are uncoordinated, not always culturally sensitive and very limited for children and their families. Improvement in paediatric respite services is necessary and research needs to be conducted in this area to facilitate the development of more appropriate respite services for children and their families.

164: J Pain Symptom Manage. 2002 Jan;23(1):10-6.

The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12.

Collins JJ, **Devine TD**, **Dick GS**, **Johnson EA**, **Kilham HA**, **Pinkerton CR**, **Stevens MM**, **Thaler HT**, **Portenoy RK**.

Pain and Palliative Care Service, The Children's Hospital at Westmead, Sydney, New South Wales 2145, Australia. Few studies have attempted to describe the experience of symptoms in young children with cancer. This is due, in part, to the lack of validated symptom assessment scales for this patient population. The objective of this study was to evaluate the reliability and validity of a revised Memorial Symptom Assessment Scale (MSAS) in patients aged 7-12 as an instrument for the assessment of symptoms in young children with cancer. The MSAS (7-12) was administered to 149 children (inpatients and outpatients) who were undergoing treatment at either the Royal Marsden NHS Trust, London, United Kingdom or The Children's Hospital at

Westmead, Sydney, Australia. Validity was evaluated by comparison with the medical record, parental report, and concurrent assessment on visual analogue scales for selected symptoms. The data provide evidence of the reliability and validity of MSAS (7-12) and demonstrate that children with cancer as young as 7 years can report clinically relevant and consistent information about their symptom experience. Young children with cancer experience multiple symptoms. Approximately one-third had experienced lethargy and/or pain and/or insomnia during the 48 hours prior to the completion of MSAS (7-12). The completion rate for MSAS (7-12) was high and the majority of children completed the instrument in a short period of time and with little difficulty. The instrument appears to be age appropriate and may be helpful to older children unable to independently complete MSAS (10-18). Systematic symptom assessment may be useful in future epidemiological studies of symptoms and in cancer chemotherapy drug trials.

165: Arch Pediatr Adolesc Med. 2002 Jan;156(1):9-10.

Pediatric palliative care: the time has come.
Hutton N.

166: J Child Adolesc Psychiatr Nurs. 2001 Jan-Mar;14(1):5-6.

Helping children understand death.
Cole BV.

167: BMJ. 2001 Jan 27;322(7280):234.

Recent advances in palliative care. Importance of palliative care for children is being increasingly recognised.
Goldman A.

168: Adolesc Med. 2001 Feb;12(1):23-34.

Palliated congenital heart disease.
Hagler DJ.
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The group of patients with palliated complex forms of congenital heart disease presents a challenging and difficult management problem during the adolescent years. In patients not considered to be candidates for more fully palliated procedures that separate the circulations, a bidirectional caval pulmonary shunt, often associated with a systemic to pulmonary shunt, may provide significant palliation for several more decades. However, there remain a significant number of patients who, after some years, may develop increasing problems associated with myocardial failure and the development of serious atrial arrhythmias. Interventional cardiac catheterization combined with newer surgical techniques may return many of these patients to more satisfactory hemodynamic states. However, some patients during their adolescent years may eventually require cardiac transplantation for the long-term management of their complex congenital cardiac defects.

169: Eur J Pain. 2001;5 Suppl A:37-41.

Cancer pain management in children.
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The World Health Organization document Cancer Pain Relief and Palliative Care in Children (WHO, 1998) advocates the global application of the principles of pain management and palliative care for children with cancer. The principles of pain management include the application of the WHO analgesic ladder, appropriate opioid dose escalation, the use of adjuvant analgesics, and the use of non-pharmacological methods of pain control. These principles of pain management should be incorporated into the treatment protocols of all children with cancer, acknowledging that treatment options may be limited for some children. Copyright 2001 European Federation of Chapters of the International Association for the Study of Pain.

170: Clin Exp Rheumatol. 2001 Nov-Dec;19(6):617-20.

Diagnosis and treatment of amplified musculoskeletal pain in children.
Sherry DD.

171: Int J Palliat Nurs. 2001 Jul;7(7):317-21.

A practical approach to nutritional support for patients with advanced cancer.
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Palliative care can last from a few days to months and, in some cases, years. Consequently the nutritional needs of palliative care patients also vary, as does the extent to which nutrition intervention is pursued. Anorexia and cachexia are common side-effects of advanced cancer. They are characterized by physical depletion of the patients and an emotional drain on them, their families and carers. Pulling together the practical aspects of nutrition support and the emotional and social significance of food requires a skillful practitioner; an experienced dietitian can be a valued member of the palliative care team. This article examines the role of nutrition support in the palliative care setting, focusing upon practical advice including food modification, the use of oral supplements and enteral feeding.

172: Int J Palliat Nurs. 2001 May;7(5):248-54.

Staff stress in the children's hospice: causes, effects and coping strategies.
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Although there are an increasing number of hospices opening around the country, the concept of the children's hospice is still relatively new. Although stress involved in giving palliative care to adults has been examined quite extensively, very little work has been done on the impact of caring for children in the hospice setting. This article is a literature review, examining the causes and effects of staff stress in the children's hospice, as well as the factors that enable staff to cope with working in this environment. It concludes that the main causes of stress are often related to conflicts within the staff group, communication problems and role conflict. Poor relationships with the child's family as well as the inability to relieve distressing symptoms the child may be experiencing have also been identified as common sources of stress. Teamwork, good communication and the home-like atmosphere of the hospice all contribute to enabling staff to deal with work stress. Staff support groups may be beneficial, but need to be run well, by someone experienced in leading such groups. Additionally, stress can be reduced by providing staff with the appropriate training and education and by encouraging them to take some responsibility for preventing and relieving stress themselves.

173: Arch Pediatr. 2001 Nov;8(11):1178-80.

[How and when to decide to stop curative treatment? Pediatric oncology experience]
Raimondo G, **Hartmann O**.

174: Arch Pediatr. 2001 Nov;8(11):1175-7.

[The return to home for children at the end of life]
Bercovitz A, **Limagne MP**, **Sentilhes Monkam A**.

175: Nurs Clin North Am. 2001 Dec;36(4):779-94, vii-viii.

Managing pain at the end of life.
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There are many threats to a calm and peaceful passing, but none more distressing than unrelenting pain. Pain exists not only in the physical realm, but also in the psychological, social and spiritual senses. Discussion of barriers and responsibilities are important to assure that pain is appropriately treated. Effective pain treatment relies on communication among patients, families, and care providers. Nurses are a central force in this communication and must act as leaders and advocates in planning care and relieving pain in dying patients.

176: Am J Hosp Palliat Care. 2001 Nov-Dec;18(6):411-6.

The use of transdermal fentanyl in pediatric oncology palliative care.
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Transdermal fentanyl offers a noninvasive approach to the management of patients with opioid dependent and stable, chronic cancer pain. The transdermal delivery system offers distinct advantages where oral administration of opioids is difficult as a consequence of progressive disease and in patients whose compliance with oral medications is poor. Thirteen patients ranging in age from three years and nine months to 18 years and seven months were treated with transdermal fentanyl for between six hours and 112 days. All had previously been receiving oral morphine prior to the commencement of fentanyl and were transferred to fentanyl because of oral opioid side effects and poor oral compliance. Fentanyl was well tolerated and provided effective pain relief for 11 of 13 patients. Overall, patients and parents experienced satisfaction with fentanyl, both in terms of pain relief and improvement in quality of life.

177: Palliat Med. 2001 Sep;15(5):405-12.

Transdermal fentanyl for pain relief in a paediatric palliative care population.
Hunt A, **Goldman A**, **Devine T**, **Phillips M**; **FEN-GBR-14 Study Group**.
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This multicentre, observational study examined the efficacy of the therapeutic transdermal fentanyl system (TTS-fentanyl) in children requiring opioids for pain in life-threatening disease. Forty-one children receiving oral morphine (median dose 60 mg/day) transferred to transdermal fentanyl (median dose 25 micrograms/h according with the manufacturer's dose conversion guidelines). Twenty-six children completed the 15-day treatment phase, seven died due to disease progression and eight were withdrawn because of adverse events, inadequate analgesia or a change to parenteral opioids. After 15 days, the median fentanyl dose was 75 micrograms/h (range 25-250). No serious adverse events were attributed to fentanyl. There was a trend toward improved side-effects and convenience with fentanyl. Twenty-three of 26 parents (three missing) and 25 of 26 investigators considered transdermal fentanyl to be better than previous treatment. For all records available (at 15 days or on withdrawal if earlier), 75% (27/36) reported that fentanyl treatment was 'good' or 'very good'. The findings suggest that transdermal fentanyl is both effective and acceptable for children and their families.

178: Clin J Pain. 2001 Sep;17(3):229-35.

Effectiveness of virtual reality-based pain control with multiple treatments.
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OBJECTIVE: The current study explored whether immersive virtual reality continues to reduce pain (via distraction) with repeated use. SETTING: The study was conducted in a burn care unit at a regional trauma center. PATIENTS: Seven patients aged 9-32 years (mean age of 21.9 years; average of 23.7% total body surface area burned [range, 3-60%]) performed range-of-motion exercises of their injured extremity under an occupational therapist's direction on at least 3 separate days each. INTERVENTION: For each physical therapy session, each patient spent equal amounts of time in virtual reality and in the control condition (no distraction). The mean duration of physical therapy in virtual reality was 3.5, 4.9, and 6.4 minutes for the first, second, and third session, respectively. Condition order was randomized and counter-balanced. OUTCOME MEASURES: For each of the three physical therapy sessions, five visual analog pain scores for each treatment condition served as the dependent variables. RESULTS: Pain ratings were statistically lower when patients were in virtual reality, and the magnitude of pain reduction did not diminish with repeated use of virtual reality. The results of this study may be examined in more detail at www.vrpain.com. CONCLUSIONS: Although the small sample size limits generalizability. results provide converging preliminary evidence that virtual reality can function as a strong nonpharmacological pain reduction technique for burn patients during physical therapy. Results suggest that virtual reality does not diminish in analgesic effectiveness with three (and possibly more) uses. Virtual reality may also have analgesic potential for other painful procedures or pain populations. Practical implications are discussed.

179: Prim Care. 2001 Jun;28(2):415-25.

Grief and bereavement.
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Grief and bereavement are frequent concerns of primary care physicians. This article outlines grief in terminally ill patients and discusses interventions. Also included in this article is a review of the process of anticipatory grief and mourning and a discussion on normal and complicated grief. A portion of this article also covers grief in children and discusses interventions for grieving children.

180: Prim Care. 2001 Jun;28(2):365-90.

Pediatric palliative care.

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This article presents a model of integrated palliative care for children with life-limiting illnesses, with emphasis on collaboration of care over time among family, primary care providers, and several other groups of providers. Some of the unique aspects of caring for children related to normal developmental changes and the family unit are considered. Issues related to pain and to specific diseases are also reviewed.

181: Am J Hosp Palliat Care. 2001 May-Jun;18(3):161-9.

Alleviating the suffering of seriously ill children.

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Modern medicine has largely focused on the physical aspects of disease, aggressively attacking the illness, often at the expense of caring for pain and suffering. Medical interventions based solely on the diagnosis and treatment of disease limit the medical care of the severely ill child. Such an approach is particularly detrimental when caring for the terminally ill. Successful care of children with chronic, life-threatening, or terminal illnesses requires a comprehensive assessment of their physical, psychological, and spiritual needs as well as a process of collaboration between members of the multiple disciplines involved in the care of the patient and the family unit as a whole. Supportive/palliative care serves as a bridge between a scientific (disease-oriented) and humanistic (person-oriented) approach to patient care. Bridging this gap early in the course of life-threatening illness is essential for successful palliative intervention to relieve suffering and improve the quality of life for the child and his or her family. A model that introduces supportive, palliative, and hospice services into the mainstream of medical therapy is emphasized as a standard for the care of all children with significant chronic, life-threatening, or terminal illness. This article expands on a previous paper published in the American Journal of Hospice & Palliative Care (Kane JR, Barber RG, Jordan M, et al.: Supportive/palliative care of children suffering from life-threatening and terminal illness. May/June 2000; 17(3): 165-172).

182: Best Pract Res Clin Obstet Gynaecol. 2001 Apr;15(2):323-31.

Palliative care with pregnant women.

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When a pregnant woman has been declared dead because of brain death or cerebral death and a permanent vegetative state, the life and wellbeing of her fetus become a matter of crucial consideration. The possible options are an immediate caesarean section, continuation of efforts to maintain the organ functions of the woman to allow her fetus to mature, or discontinuation of the woman's somatic organ support. The decisions depend on the viability of the fetus, the probable health status of the fetus, any wish expressed by the mother and the commitment of her next of kin. Maintaining the pregnancy in order for the fetus to become more mature requires counselling of the woman's partner or family members. Immediate recourse of caesarean section should be withheld if the fetus is too immature or has a probable poor health status. Terminally ill pregnant women may require treatments which are potentially harmful to their fetus. Medical abortion early in pregnancy or premature delivery later in pregnancy are the usually recommended options. When the fetus is viable although extremely premature, delivery should not be imposed on a woman concerned with the risk of leaving a possibly handicapped child after her death.

183: Paediatr Drugs. 2001;3(4):273-84.

Patient-controlled analgesia: an appropriate method of pain control in children.

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Patient-controlled analgesia (PCA) is an analgesic technique originally used in adults but now with an established role in paediatric practice. It is well tolerated in children as young as 5 years and has uses in postoperative pain as well as burns, oncology and palliative care. The use of background infusions is more frequent in children and improves efficacy; however, it may increase the occurrence of adverse effects such as nausea and respiratory depression. Monitoring involves measurement of respiratory rate, level of sedation and oxygen saturation. Efficacy is assessed by self-reporting, visual analogue scales, faces pain scales and usage patterns. This is optimally performed both at rest and on movement. The selection of opioid used in PCA is perhaps less critical than the appropriate selection of parameters such as bolus dose, lockout and background infusion rate. Moreover, opioid choice may be based on adverse effect profile rather than efficacy.The concept

of PCA continues to be developed in children, with patient-controlled epidural analgesia, subcutaneous PCA and intranasal PCA being recent extensions of the method. There may also be a role for patient-controlled sedation. PCA, when used with adequate monitoring, is a well tolerated technique with high patient and staff acceptance. It can now be regarded as a standard for the delivery of postoperative analgesia in children aged >5 years.

184: Hematol Oncol Clin North Am. 2001 Feb;15(1):163-205.

Salvage therapy for refractory or relapsed acute lymphocytic leukemia.
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Department of Leukemia, University of Texas M. D. Anderson Cancer Center, Houston, Texas, USA. The overall prognosis for patients with relapsed or refractory adult ALL remains poor. Further insight into the biology of ALL is required, and novel therapeutic agents are needed to counter mechanisms of resistance. A palliative approach to the management of multiply relapsed or refractory ALL should be supplanted by enrollment into clinic trials to promote drug discovery. Monitoring of minimal residual disease may allow an earlier intervention before overt clinical relapse and improve outcome; prospective studies are needed. Attainment of a second or later CR should be followed by allogeneic BMT when feasible owing to the paucity of long-term survivors with salvage chemotherapy alone.

185: Int J Palliat Nurs. 2000 Jul-Aug;6(7):346-51.

Paediatric palliative care: a lack of research-based evidence.
Cooley C, **Adeodu S**, **Aldred H**, **Beesley S**, **Leung A**, **Thacker L**.
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Providing the best possible care for the child and family is paramount to health professionals working in paediatric palliative care. However, there is little research which enables practitioners to question their current practice. There are concerns about conducting research on children receiving palliative care at such a sensitive time for the child and his/her family. These concerns must be considered against the growing demand for clear standards and guidelines for practice within health care. According to the Department of Health (DoH) there is no place within the modern healthcare system for the adoption of unproven theories or outdated care (DoH, 1998). While no-one would question the dedication and care being delivered to children and their families by well-trained staff, the lack of research is a cause for concern. A group of students undertaking a degree module in paediatric palliative care identified the lack of literature and research in this area and have undertaken a review of the available literature.

186: Am J Hosp Palliat Care. 2000 Sep-Oct;17(5):294-5.

Palliative care for children: is it really needed?
Liben S.

187: Am J Hosp Palliat Care. 2000 May-Jun;17(3):165-72.

Supportive/palliative care of children suffering from life-threatening and terminal illness.
Kane JR, **Barber RG**, **Jordan M**, **Tichenor KT**, **Camp K**.
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188: J Palliat Care. 2000 Oct;16 Suppl:S45-52.

Decision making and end-of-life care in critically ill children.
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OBJECTIVES: 1) To comment on the medical literature on decision making regarding end-of-life therapy, 2) to analyze the data on disagreement about such therapy, including palliative care, and withholding and withdrawal practices for critically ill children in the pediatric intensive care unit (PICU), and 3) to make some general recommendations. Data sources and study selection: All papers published in peer-reviewed journals, and all chapters on end-of-life therapy, or on conflict between parents and caregivers about end-of-life decisions in the PICU were retrieved. RESULTS: We found three case series, three systematic descriptive studies, two qualitative studies, four surveys, and many legal opinions, editorials, reviews, guidelines, and book chapters. The main determinants of end-of-life decisions are the child's age, premorbid cognitive condition and functional status, pain or discomfort, probability of survival, and quality of life. Risk factors in persistent conflict between parents and caregivers about end-of-life care include a grave underlying condition or an unexpected and severe event. CONCLUSION: Making decisions about end-of-life care is a frequent event in the PICU. Children may need both intensive care and palliative care concurrently at different stages of their illness. Disagreements are more likely to be resolved if the root cause of the conflict is better understood.

189: Indian Pediatr. 2000 Oct;37(10):1047-50.

Education of physician on end of life care: Indian perspective.
Dey SK.

190: Support Care Cancer. 2000 Sep;8(5):385-97.

Psychostimulants in supportive care.
Homsi J, **Walsh D**, **Nelson KA**.
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Psychostimulant medications have been used clinically and investigated in psychiatric populations, the medically ill, cancer patients and healthy people. This article discusses the pharmacology of dextroamphetamine, methylphenidate, pemoline (and other psychostimulants such as caffeine and ephedrine), their use in general medicine and cancer care, side effects, and abuse potential. Therapeutic use in children is addressed only insofar as it illustrates facets of their use in adults.

191: Soc Sci Med. 2000 Sep;51(6):917-30.

Changing patterns of death and dying.
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This paper reviews changing patterns of mortality worldwide, paying particular attention to differences between developed and developing countries and the consequences of demographic and epidemiological transitions. These involve gains in life expectancy and a shift from infectious to degenerative conditions as causes of death. Reversals to these transitions in certain Eastern European and African countries, due respectively to the social disorganisation accompanying the collapse of communism and to AIDS is described. The implications of changing population structures for the experience of old age and dying are explored and gender and socio-economic differences within countries is highlighted. The current state of knowledge about differences in the dying trajectories of different causes of death is summarised and gaps in this knowledge identified. The availability of lay health care in the community at different points in the demographic transition is described, and the problems and dilemmas of formal health care provision for dying people in both developed and developing countries outlined, including an analysis of the reasons for public support for euthanasia in some Western countries. In particular, the appropriateness of models of specialist palliative care outside the cultures in which such care originally developed is questioned. Finally, there is discussion of the extent to which medical and scientific measures erode traditional religious consolations for the problems involved in dying and bereavement.

192: N Engl J Med. 2000 Jun 29;342(26):1998; author reply 1998-9.

Symptoms and suffering at the end of life in children with cancer.
Goldman A.

193: N Engl J Med. 2000 Jun 29;342(26):1997; author reply 1998-9.

Symptoms and suffering at the end of life in children with cancer.
Sandoval C.

194: Pediatr Clin North Am. 2000 Jun;47(3):711-46.

Pain and symptom control in terminally ill children.
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The management of pain in terminally ill pediatric patients has incalculable benefits to patients, their families, and physicians and nurses. A therapeutic management plan is dependent on a thorough understanding of the causes of pain in these patients, on pain assessment, and on the myriad drugs and drug strategies that are essential in pain treatment. Aggressive symptom control of treatment-related side effects can ensure successful implementation of such a plan.

195: J Palliat Care. 2000 Spring;16(1):35-8.

Music therapy in palliative care for hospitalized children and adolescents.
Daveson BA, **Kennelly J**.
Royal Children's Hospital Foundation/ABC Learning Centres, Brisbane, Australia.

196: Med Pediatr Oncol. 2000 Apr;34(4):271-3.

Regarding guidelines for assistance to terminally ill children with cancer: report of the SIOP working committee on psychosocial issues in pediatric oncology.
Nitschke R.

197: N Engl J Med. 2000 Feb 3;342(5):347-8.

Care of children who are dying of cancer.
Morgan ER, **Murphy SB**.