PaedPalLit Vol. 1 No. 2 (Jan 2001 – July 2002)

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INDEX

PaedPalLit Vol. 1 No. 2 (Jan 2001–July 2002)

The use of drugs beyond licence in palliative care and pain management (a position statement prepared on behalf of the Association for Palliative Medicine and the Pain Society); 2002 ........................................... 5
Combining informal care and work: supporting carers in the workplace ................................................................. 5
From adolescence through young adulthood: Psychosocial adjustment associated with long-term survival of HIV .................................................................................................................. 5
Use of Intranasal/oral midazolam in paediatric palliative care. ................................................................................. 6
Lessons learned from providing transition services to adolescents with special health care needs. .......... 6
"Euthanasia": a survey by the Swiss Association for Palliative Care. ................................................................. 6
Pain and leukemia: the stories of three children. ........................................................................................................ 6
Hospice care for the child with AIDS. .................................................................................................................. 6
Massage and aromatherapy massage: nursing art and science. .............................................................................. 7
Tender, loving care... Camp TLC, a wellness center where therapy means relaxation and mental healing for children ages 6-18 with life-shortening illnesses. .............................................................. 7
The medical futility debate: patient choice, physician obligation, and end-of-life care. ........................................... 7
Comfort/palliative care guidelines for neonatal practice: development and implementation in an academic medical center. ................................................................................................................ 8
Dealing with uncertainty: parental assessment of pain in their children with profound special needs. . . . . . 8
Creation of a neonatal end-of-life palliative care protocol. .................................................................................... 9
Pediatric palliative care. ................................................................................................................................. 9
Helping children understand death. .................................................................................................................. 9
Developing CCN Services. ............................................................................................................................... 9

The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12. ...................................................................................... 10
Family perspectives on the quality of pediatric palliative care. ............................................................................. 10
Bereavement support following sudden and unexpected death: guidelines for care. ........................................ 10
Financial effects for families after the death of a disabled or chronically ill child: a neglected dimension of bereavement. ............................................................................................................. 11
When a Child Dies: Money Matters. ................................................................................................................ 11
The role of the cystic fibrosis nurse specialist. .................................................................................................... 11
Keep the focus on the family. .......................................................................................................................... 11
Do Not Resuscitate orders and ethical decisions in a neonatal intensive care unit in a Muslim community.......................................................... 11
Preparation, information and liaison: conducting successful research in palliative care. .............................. 12

1
Addressing spirituality in pediatric hospice and palliative care. .............................................................. 12
Pediatric end-of-life care: lessons learned from parents. .................................................................................. 13
Symptom control in cancer patients: the clinical pharmacology and therapeutic role of suppositories and rectal suspensions. .................................................................................................................. 13
The 'family' context of HIV: A need for comprehensive health and social policies. ........................................... 13
Putting bereaved parents in the frame. ................................................................................................................ 14
How parents can help children bereaved after the death of a close family member. .................................... 14
Radiotherapy for metastases to the mandible in children. .................................................................................. 14
Presenting a case for involving children with a terminal illness in clinical trials. ........................................... 14
Legal aspects of consent 20: research/children/incapable adults. ...................................................................... 14
A philosophical discussion of end-of-life decision-making methods for incompetent patients. .................... 15
A model of palliative care for the adolescent with cancer. ............................................................................... 15
Nitrous oxide is not beneficial for breakthrough cancer pain. ......................................................................... 15
Coping strategies used in residential hospice settings: findings from a national study. .................................... 15
Defining effective clinician roles in end-of-life care. .......................................................................................... 16
Characteristics of deaths occurring in children's hospitals: implications for supportive care services. 16
Experiences in family bereavement. ................................................................................................................... 17
Communicative competence in the delivery of bad news. .................................................................................. 17
Pediatric palliative care: a family-centered model for critical care. ................................................................. 18
Contemporary issues in the care of sick children and their families. ............................................................... 18
A neonatal end-of-life palliative protocol—an evolving new standard of care? ............................................. 18
Young adults with cancer: the effect of the illness on parents and families. .................................................... 19
The view from a bridge. .................................................................................................................................... 19
Opioids in children; perhaps more is less. ........................................................................................................... 19
Medically fragile children: an integrative review of the literature and recommendations for future research. 19
Toward evidence-based practice. End-of-life care for neonates and infants: the experience and effects of a palliative care consultation service. .......................................................................................... 19
Life stories of families with a terminally ill child. .............................................................................................. 20
Issues in Islamic biomedical ethics: a primer for the pediatrician. .................................................................... 20
End of life care in HIV-infected children who died in hospital. ..................................................................... 20
Enhancing seamless care: a review. .................................................................................................................. 21
Psychosocial practice trends in pediatric oncology. .......................................................................................... 21
Pain management for the child with cancer in end-of-life care: APON position paper. .................................... 21
Determining the need for terminal care for children. ....................................................................................... 22
Paediatric respite care: a literature review from New Zealand. ...................................................................... 22
Stability of pain parameters and pain-related quality of life in adolescents with persistent pain: a three-year follow-up. ........................................................................................................................................ 22
Pediatric palliative care: the time has come. ...................................................................................................... 23
Should paediatric units have bereavement support posts? ............................................................................... 23
Cancer narratives of adolescents and young adults: A quantitative and qualitative analysis. ......................... 23
Pediatric palliative care: heartbreaking yet rewarding. ................................................................................... 23
Grandparents of children with developmental disabilities: perceptions, beliefs, and involvement in their care. ........................................................................................................................................... 23
Current research in children's conceptions of death: A critical review ............................................................ 24
Responding when a baby dies. ............................................................................................................................ 24
Supporting 'expert' parents-professional support and families caring for a child with complex health care needs in the community. ........................................................................................................ 24
Variables influencing end-of-life care in children and adolescents with cancer. ......................................... 25
Psychosocial intervention in the process of empowering families with children living with HIV/AIDS: A descriptive study. .................................................................25
Mothers' experience of social support following the death of a child. .................................................................25
Resuscitation policy in children’s hospices. .............................................................................................................26
Starting the quest to define optimal pediatric end-of-life care. .............................................................................26
Palliative care in the neonatal population. ...............................................................................................................26
'Enough is enough': qualitative findings on the impact of dexamethasone during reinduction/consolidation for paediatric acute lymphoblastic leukaemia. .........................................................26
End-of-life care for hematological malignancies: the 'technological imperative' and palliative care. ...........27
Nurses' experiences of caring for culturally and linguistically diverse families when their child dies. ....27
Serial assessment of mortality in the neonatal intensive care unit by algorithm and intuition: certainty, uncertainty, and informed consent. .................................................................27
Coping styles and locus of control as predictors for psychological adjustment of adolescents with a chronic illness. ........................................................................................................................................28
The risk assessment of bereavement in a palliative care setting. ...........................................................................28
Parental perspectives on end-of-life care in the pediatric intensive care unit. .....................................................28
Feasibility of a home care program in a pediatric hematology and oncology department. Results of the first year of activity at a single Institution. .................................................................................29
Respite care for children who have complex nursing needs. ..............................................................................29
Intergenerational differences and similarities in life-sustaining treatment attitudes and decision factors. ........................................................................................................................................29
Information that informs rather than alienates families with disabled children: developing a model of good practice. ......................................................................................................................................30
A scale to measure satisfaction of bereaved family receiving inpatient palliative care. ..................................30
Families of children with cancer: the impact on anxiety experienced by fathers. ...............................................31
Communicating about pupils in mainstream school with special health needs: the NHS perspective. ..........31
Paediatric palliative care management issues in late infantile Battens disease—A case report. .................31
Bereaved parents' use of individual, family, and community resources 4 to 60 months after a child's violent death. ........................................................................................................................................32
Variant Creutzfeldt-Jakob disease: costs borne by families. .................................................................................32
A metasynthesis: mothering other-than-normal children. ..................................................................................32
Barriers that delay children and young people who are dependent on mechanical ventilators from being discharged from hospital. .......................................................................................33
Children with a chronic and life-limiting condition: Teachers' perceptions and experiences regarding students' school integration. ........................................................................................................33
Between parent and child: negotiating cancer treatment in adolescents. .........................................................33
The emotional dimension of children's life-threatening illnesses. ......................................................................34
Adolescent coping with grief after the death of a loved one. .................................................................................34
Education and High Quality Community Care. ..................................................................................................34
The ethics and practicalities of consent in palliative care research: an overview. ............................................34
Bereavement support for couples following death of a baby: program development and 14-year exit analysis. ........................................................................................................................................35
Shoestrings and bricolage: some notes on researching the impact of a child's death on family relationships. ........................................................................................................................................35
New initiatives in end-of-life care. ........................................................................................................................35
A prospective, within-patient comparison between metal butterfly needles and Teflon cannulae in subcutaneous infusion of drugs to terminally ill hospice patients. ............................................35
Pediatric ethics, issues, & commentary. Pediatric palliative care: the time is now! ...........................................36
Clinical note. Gabapentin in phantom limb pain management in children and young adults: report of seven cases. ....................................................................................................................................36
The personal development of mothers of terminal cancer patients: how Japanese women change through the experience of caring for and losing their children to cancer. ........................................... 36
Manual handling and nursing children. .................................................................................. 36
Choosing continence products for children. ................................................................. 37
Surgical and anesthetic decisions for children with terminal illness .......................................................... 37
Therapeutic Work with Children in Pain. .......................................................... 37
"I learned that no death is routine": description of a death and bereavement seminar for pediatrics residents. .................................................................................................................................. 37
The use of standardized patients in pediatric residency training in palliative care: anatomy of a standardized patient case scenario. ..................................................... 38
The increasing need for pediatric palliative care ............................................................... 38
Children's hospices: organizational and staff issues. ...................................................... 38
Do not resuscitate (DNR) orders in a children’s unit prevalence ........................................ 38
Life-sustaining support: ethical, cultural, and spiritual conflicts. Part II: Staff support--a neonatal case study. ..................................................................................................................................... 39
Exploring idealism in palliative nursing care through reflective practice and action research. .............. 39
Taking the measure of a father's grief ................................................................. 40
Defining and determining quality in end-of-life care ........................................................ 40
Attachment and meaning-making in perinatal bereavement .................................................... 40
Spirituality in palliative care: opportunity or burden? ........................................................ 40
Corticosteroids in the palliative phase of paediatric brain tumours ................................................ 40
Drawings by dying and bereaved children ............................................................................. 41
The grieving process in children: Strategies for understanding, educating, and reconciling children's perceptions of death ................................................................. 41
Workforce planning and community children's nurses: it's all in the advertisements .................. 41
In their own words: The lived experience of pediatric liver transplantation ................................ 42
Caring for dying infants: experiences of neonatal intensive care nurses in Hong Kong. .................. 42
Development and testing of the parental coping strategy inventory (PCSI) with children with cancer in Taiwan ................................................................. 42
Health-related quality of life in pediatric patients with cancer. A structural equation approach with the Roy Adaptation Model. ................................................................. 43
Hospice Care for Children ................................................................................................. 43
Financial implications of the death of a child ................................................................. 43
Health care & spirituality: Listening, assessing, caring. Death, value and meaning series ................. 43
Handbook of crisis counseling, intervention, and prevention in the schools. 2nd edition. ................. 43
Helping bereaved children: A handbook for practitioners. 2nd edition ........................................ 44
Grief counseling and grief therapy: A handbook for the mental health practitioner. 3rd edition ............ 44
Living with childhood cancer: A practical guide to help families cope. .................................... 44
The use of drugs beyond licence in palliative care and pain management (a position statement prepared on behalf of the Association for Palliative Medicine and the Pain Society); 2002.


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Combining informal care and work: supporting carers in the workplace.

Arksey H.


The UK Government is concerned that women and men who care for disabled or sick relatives, or elderly people, and who also wish to take part in paid work should have increased opportunities to do so. However, many informal carers find combining work and care difficult; some may 'choose' to give up paid employment completely. The present paper draws on the findings from two projects to explore the extent to which the needs of employees with caring responsibilities are supported in the workplace. The two projects examined evidence from a study of informal carers assessed under the 1995 Carers Act, identified the difficulties which they face in their workplace and observed the strategies which they developed to help sustain the two roles. From this, a model of support for working carers was developed which includes leave policies, carer-friendly working arrangements, access to a (private) telephone, and supportive line managers and co-workers. This support model was tested on the employment policies of 13 employers to see how 'carer-friendly' they were. Most of the organisations studied were able to provide appropriate support for carers identified in the model. Questions were then raised about different aspects of carer-friendly working arrangements, including whether carers should receive any special treatment that is not available to their colleagues, the role of line managers, and the relationship between seniority and opportunities to combine work and care.


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From adolescence through young adulthood: Psychosocial adjustment associated with long-term survival of HIV

Battles HB, Wiener LS.


Examined psychosocial adjustment factors associated with long-term survival with pediatric HIV infection. Factors included problem behavior, social support and diagnosis disclosure. Problem behaviors were drug/alcohol use, psychiatric hospitalization, anxiety, depression, suicide ideation/attempt, sexual activity, pregnancy, and arrests. HIV-infected children and caregivers were interviewed and completed self-report measures 3 times, approximately 12 mo apart. Average age was 11.8 yrs at time 1; 38.9% contracted HIV perinatally, 34.7% through a hemophilia-related transfusion, and 26.4% through another type of transfusion. Results show that degree of disclosure was positively related to social support, self-competence, and decreased problem behavior, except in the case of public disclosure. Social support was significantly negatively correlated with problem behavior. Five yr follow-up data indicate that Ss aged 18 yrs and older were less likely to complete their education than were healthy peers, and those who lost a parent were more likely to have suffered from depression. It is concluded that social support and open diagnosis communication are essential, and that psychosocial needs are changing to more closely resemble the needs of the chronically rather than the terminally ill. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

URLJ: http://www.elsevier.com/inca/publications/store/5/0/5/7/6/5/

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Use of Intranasal/oral midazolam in paediatric palliative care.

Bentley R, Cope J, Jenney M, Hain RDW.

Archives of Disease in Childhood 2002;86(Suppl 1):A76.

AIMS: To reduce child's distress/anxiety without intramuscular/subcutaneous injections. To enable parents to have some control over relieving their child's symptoms. METHODS AND PATIENTS: Case presentations. The authors would like to present their experience in the use of intranasal Midazolam in 4 patients dying at home. Cases A, B, & C were aged 8 months, 2yrs, and 5yrs. Case D was a 24yr old, who had started treatment when aged 19yr, hence continued to have input from the paediatric service. In cases A, B, & C there was reluctance from parents for their children to receive extra injections for relief of symptoms. In case D it was the choice of the patient. DISCUSSION: Reasons for using Midazolam intranasally: To provide more immediate symptom relief so that parents can give medication without having to wait for CNS/GP to arrive. Symptoms treated were agitation of the child not responding to extra pain relief and in case D, extreme anxiety related to increased pain and imminent death. Experience of authors has shown this to be an effective route for the administration of Midazolam as uptake of the drug was more immediate than previous intramuscular/subcutaneous administration. CONCLUSION: Intranasal Midazolam is effective in treating anxiety/agitation quickly in dying children and therefore helps parents feel involved in their child's care during a very traumatic time.

Lessons learned from providing transition services to adolescents with special health care needs.

Betz CL, Redcay G.


This article provides insight and information about obstacles adolescents with special health care needs (ASHCNs) face as they progress to adulthood. Descriptions of these challenges are based upon clinical experiences in providing transition services to youth by the service coordinator seen through the Creating Healthy Futures transition clinic. These obstacles were classified as those related to health care, employment, education, independent living, social and recreational skills, and the service system. Information is also provided on the strategies project staff developed to assist youth in dealing with the challenges of the transition obstacles they faced.


"Euthanasia": a survey by the Swiss Association for Palliative Care.

Bittel N, Neuenschwander H, Stiefel F.


Since the Swiss Association for Palliative Care (SAPC) considers itself an important partner in the national debate on euthanasia, the Board decided to conduct a survey among its members. An anonymous questionnaire was sent to the 726 members of the SAPC, consisting of multiple choice questions on positions that might be adopted in different hypothetical scenarios and one open question about the rationale for the answers. The response rate achieved with one mailing was 55.6%. The proportions of the respondents who were opposed to different forms of euthanasia were, in ascending order: 56% opposed to physician-assisted suicide (PAS); 69% to direct active euthanasia (DAE); 75% to DAE for psychiatric patients; 84% to delegation of DAE in the case of incompetent patients; and 90% to life-terminating acts without explicit requests (LAWER). Almost 10% of the members reported personal experiences with PAS and different forms of DAE. The main decisional bases drawn on for the answers were ethical values and the clinical or personal experience of the respondents; however, the same categories of arguments were used both by those opposing and by those favouring DAE. There are important variations among the members of the SAPC in the debate on euthanasia. Individual autonomy seems to be an important underlying concept for the different positions; the categories of arguments cited by opponents and supporters of DAE did not differ.

Pain and leukemia: the stories of three children.
Bossert EA, Van Cleve L, Adlard K, Savedra M.


The stories of the pain experience of three children with acute leukemia during the first year after diagnosis are presented in this report. To provide a broad picture, children who represent various characteristics were selected: ages 6, 9, and 15 years; two male and one female; two Latino and one Caucasian; two English-speaking and one Spanish; two with acute lymphocytic leukemia and one with acute myelocytic leukemia. Consideration of the disease, procedures, treatment, and normal childhood pain experiences will provide the nurse who cares for these children guidance in knowing why and when pain may occur, which will lead to timely interventions for the pain.

Hospice care for the child with AIDS.
Buckingham RW, Meister EA.


Hospice care was established to provide palliative (i.e., noncurative) services for the dying and their families. The advent of the AIDS epidemic has posed a challenge to hospice care, particularly for the child dying of the disease, and has adapted to modified palliative services. Parents, with a child dying of AIDS, must deal with many issues of disclosing the disease status to the child, coping with the emotions of losing a child, and when and where to incorporate hospice services into the dying process. Optimizing home based hospice care involves; (1) Nutritional management, (2) Prevention of opportunistic infections, (3) Pain management, and (4) Protection of Non-HIV positive members of hospice care. For the dying, hospice strives to achieve a peaceful death and provide supportive intervention for the survivors. (PsycINFO Database Record (c) 2002 APA, all rights reserved)(journal abstract)

Massage and aromatherapy massage: nursing art and science.
Buckley J.


Tender, loving care... Camp TLC, a wellness center where therapy means relaxation and mental healing for children ages 6-18 with life-shortening illnesses.
Buford D.


The medical futility debate: patient choice, physician obligation, and end-of-life care.
Burt RA.


Physicians' use of the "medical futility" concept to override the treatment demands of patients or their family/surrogates is difficult to justify in principle. At the same time, patient demands for obviously futile treatments can conflict with
physicians' professional obligation to do no harm to their patients. There is no clear general principle available to resolve this conflict between patient self-determination and physician autonomy; extended negotiation between patient or family/surrogates and physicians provides the only prospect for satisfactory resolution. Though such negotiation will not invariably succeed in reaching agreement, the legal system should ensure that each side has some practical measure of independent authority and power to exert against the other in order to maximize the likelihood that the negotiating process will be seriously engaged.


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Comfort/palliative care guidelines for neonatal practice: development and implementation in an academic medical center.

Carter BS, Bhatia J.


OBJECTIVE: To report the multidisciplinary developmental process of a comfort care guideline for the neonatal intensive care unit (NICU) addressing palliative care measures in a tertiary academic medical center. The guideline was developed to be (1) practical, (2) family-centered, (3) respectful of the infant patient, and (4) educational. METHODS: A consensus-building process involving medical, nursing, administrative, and ancillary professional staff integral to the NICU and Obstetrics units using naturalistic inquiry. RESULTS: An approved hospital guideline was formulated and implemented over a 16-month period. It described candidates for comfort care, the locale for such care to be rendered, and the construct of essential services to the infant and family. Early reports attest to staff acceptance and it is currently incorporated into trainee education. CONCLUSION: Clinically practical guidelines, comprehensive in their scope of providing comfort care to newborns with life-limiting conditions, can be institutionally derived and locally implemented for both consistency in patient care and educational value for staff and trainees.


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Dealing with uncertainty: parental assessment of pain in their children with profound special needs.

Carter B, McArthur E, Cunliffe M.


Dealing with uncertainty: parental assessment of pain in their children with profound special needs Background. Despite advances in the assessment and management of children's pain, children with profound special needs are especially vulnerable to poor pain management. Their underpinning condition often severely compromises their ability to express pain through the usual verbal and behavioural routes. The lack of any appropriate framework for assessment results in a suboptimum and inaccurate approach to an important aspect of their care. Purpose. The purpose of the study was to explore the ways in which parents of children with profound special needs assess and manage their children's pain. METHODS. Qualitative case study design underpinned the study using guided interviews with the 15 parents/carers (of 12 children aged 5-16 years with profound special needs). Ethical approval. Ethics Committee approval was gained. Findings. A number of themes emerged from the data including learning to live with pain, dealing with uncertainty, expression of pain and making decisions. Conclusions. Parents felt that their child had learned to live with significant levels of chronic and acute pain. Assessment of pain was an uncertain and complex process requiring parents to draw on skills and knowledge developed over a number of years. Parents used different strategies for both the assessment and management of pain based on an intimate knowledge of their child's usual nonpain state. Even with a limited repertoire of behaviours available to them, children were able to express pain. Parents often felt isolated in relation to pain management and under-used as a resource by health professionals.


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**PaedPalLit Vol.1 No2 (Jan 2001-July 2002)**

**Creation of a neonatal end-of-life palliative care protocol.**

Catlin A, Carter B.


**OBJECTIVE:** To create a protocol delineating the needs of patients, families, and staff necessary to provide a pain-free, dignified, family-, and staff-supported death for newborns who cannot benefit from intensive, life-extending, technological support. **STUDY DESIGN:** Using Internet e-mail, a Delphi study with sequential questionnaires soliciting participant response, investigator analysis, and follow-up responses from participants was conducted to build a consensus document. Institutional review was granted and respondents gave consent. Recruitment was conducted at medical, ethics, nursing, and multidisciplinary organization meetings. Synthesis of 16 palliative care/end-of-life protocols developed by regional, institutional, and parent organizations was included. Participants from 93 locations in the US and 4 abroad gave feedback to 13 questions derived from clinical experience and the literature. The data underwent four rounds of analysis with 95% retention of the 101 participants over an 18-month period. **RESULTS/CONCLUSION:** Specific consensus-based recommendations are presented with a description of palliative care; categories of candidates; planning and education needed to begin palliative care services; relationships between community and tertiary centers; components of optimally supported neonatal death; family care, including cultural, spiritual, and practical needs; ventilator withdrawal, including pain and symptom management; recommendations when death does not occur after cessation of life-extending interventions; family follow-up care; and necessary ongoing staff support.


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**Pediatric palliative care.**

Chaffee S.

*Primary Care* 2001;28(2):365-90.

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.


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**Helping children understand death.**

Cole BV.


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**Developing CCN Services.**

Coley H, Partridge J.

*Paediatric Nursing* 2002;14(6).
The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12.


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.


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Family perspectives on the quality of pediatric palliative care.

Contro N, Larson J, Scofield S, Sourkes B, Cohen H.


BACKGROUND: As a prelude to establishing a Pediatric Palliative Care Program, we solicited information from families about their experiences and their suggestions for improving the quality of end-of-life care. Participants were English- and Spanish-speaking family members of deceased pediatric patients who received care at Lucile Salter Packard Children's Hospital, Stanford University Medical Center, Palo Alto, Calif. METHODS: Sixty-eight family members of 44 deceased children were interviewed regarding treatment, transition to palliative care, and bereavement follow-up. Four clinical social workers and one clinical psychologist reviewed the participants' responses and identified frequently occurring themes. RESULTS: Several areas of unsatisfactory interactions with staff were identified: confusing, inadequate, or uncaring communications regarding treatment or prognosis; preventable oversights in procedures or policies; failure to include or meet the needs of siblings and Spanish-speaking family members; and inconsistent bereavement follow-up. A discrepancy emerged between the high degree of pain described by the families and parents' perceptions that pain had been managed well. Community hospice programs are frequently poorly prepared to serve pediatric patients. CONCLUSIONS: There is a need to improve pediatric palliative care. Recurring themes in the family interviews suggest useful issues to consider in the development of a palliative care program.


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Bereavement support following sudden and unexpected death: guidelines for care.

Cook P, White DK, Ross Russell RI.

Archives of Disease in Childhood 2002;87(1):36-8.

Dealing with families who have suffered a sudden and unexpected death is a skill that may be needed by any paediatrician. Offering a bereavement follow up meeting to such families is part of accepted practice and is perceived to be of value in helping the family to come to terms with the loss. Unfortunately, there is very little guidance on the objectives for such a meeting, or the training required to help staff conduct such meetings. The nature of the work on a paediatric intensive care unit (PICU) means that staff have a greater experience of handling families in such a situation. We have reviewed our
experience over the past five years following up the families of 51 children who have died suddenly and unexpectedly in our regional PICU. In doing this we have identified five key elements that we suggest are essential to a successful follow up meeting, and have supported this with case studies as illustration.

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**Financial effects for families after the death of a disabled or chronically ill child: a neglected dimension of bereavement.**

Corden A, Sloper P, Sainsbury R.

*Child: Care, Health & Development* 2002;28(3):199-204.

AIM: To investigate the financial circumstances of families whose child had died after a long-term illness and the factors contributing to financial difficulties. RESEARCH METHODS: Qualitative exploration involved semi-structured interviews with a purposive sample of 16 families whose child had died in the last 2 years and who were in touch with a children's hospice. RESULTS: All parents were affected by loss of or reduction in social security benefits. This could result in an immediate drop in income of as much as 72%. Paying for funerals and headstones could be hard. Financial problems after the child's death often had origins in the period of care, when parents had reduced incomes but faced extra costs of care. Some families had got into debt. Re-engaging with employment could be a slow process, and it was not clear where professional responsibility lay in providing financial advice and support. Insensitive treatment by administrative agencies increased problems for parents. DISCUSSION: Findings provide further evidence of the financial impact for families of caring for severely disabled children. This study shows how this impact can extend far into the period after death. Findings indicate the need for financial advice and support to families both during the period of care and after bereavement.

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**When a Child Dies: Money Matters.**

Corden A, Sainsbury R, Sloper P.


The financial implications of a death are rarely discussed—indeed, in the case of a child's death, almost never. This article describes an exploratory study conducted in the United Kingdom in response to the belief of staff in a children's hospice that for many bereaved parents, the nature and extent of their financial problems were obstructing the effectiveness of support and help available to deal with emotional aspects of grief and loss. Findings from depth interviews with bereaved parents and staff in health and care services, and a questionnaire sent to all U.K. children's hospices, throw light on the reasons for and the impact of financial problems. Findings provide a number of pointers to ways of improving support for parents whose child dies. At the same time, findings provide strong arguments for including money in debate about dealing with death in contemporary society.

*Social Policy Research Unit. York*

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**The role of the cystic fibrosis nurse specialist.**

Cowland J.


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**Keep the focus on the family.**

Crawford DA.

*Journal of Child Health Care* 2002;6(2):133-46.

Children's nurses deal with the family on a daily basis. There are many theories about the family, and there is good supporting evidence focusing on the family as it interacts with healthcare professionals. Modern technology and the structure of today's society have influenced the way families function. This article considers some of the cornerstone
Do Not Resuscitate orders and ethical decisions in a neonatal intensive care unit in a Muslim community

da Costa DE, Ghazal H, Al Khusaiby S.


AIMS: To evaluate the need for Do Not Resuscitate (DNR) orders in a tertiary referral centre for neonatal intensive care, the criteria used in making these decisions, and the applicability of the Muslim ethical stance among parents in an Islamic community. METHODS: A prospective evaluation of all DNR decisions in the neonatal intensive care unit at the Royal Hospital in Oman, over a one year period between November 1999 and October 2000. This included decision criteria, and parental responses and expectations. RESULTS: Of 659 admissions to the neonatal intensive care unit during this period, DNR orders were written in 39 (6%) instances. Most related to congenital malformations (24/39, 62%). In those in whom ventilation was commenced (19/39, 49%) withdrawal was not culturally acceptable and expressly permitted in only 11%. For those in whom ventilation was not commenced (20/39, 51%), 70% agreed not to put their child on the ventilator if they did require it. Presence of extended family support (grandparents) and clergy was extremely useful. CONCLUSIONS: Asking parents alone to be explicitly involved or take full responsibility for decisions involving life and death is not culturally or socially acceptable in this community. Presence of extended family, and indirectly sounding out and taking into account their wishes, is more appropriate after assessing the resources and support services available.


Preparation, information and liaison: conducting successful research in palliative care.

Daniels LE, Exley C.


Palliative care professionals are increasingly exposed to, and under pressure to participate in, research to promote evidence-based practice. This may pose challenges and tensions within normal working practices. This article draws on the results of a small qualitative study that explored the experiences of a group of specialist nurses at an independent hospice involved in palliative care research. By reflecting on their experiences and the difficulties they encountered, primarily with regard to obtaining informed consent from patients to take part in the research, this article explores issues relevant to practitioners and researchers when conducting palliative care research involving patients. It concludes by suggesting guidelines for conducting good quality research.


Addressing spirituality in pediatric hospice and palliative care.

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


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.


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**Pediatric end-of-life care: lessons learned from parents.**

Davies B, Connaughty S.


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**Symptom control in cancer patients: the clinical pharmacology and therapeutic role of suppositories and rectal suspensions**

Davis MP, Walsh D, LeGrand SB, Naughton M.

*Supportive Care in Cancer* 2002;10(2):117-38.

Rectally administered medications are essential in palliative medicine, particularly in the last days of life. They are underutilized. The pharmacology of rectally administered medications relates not only to the medication but also to the suppository base, additives, drug ionization, p K(a), absorptive surface of the rectum, and rectal health. The pharmacokinetics may differ from those of orally administered medications owing to reduced hepatic first-pass clearance. In this review the pharmacology of rectally administered palliative medications is reviewed and the use of individual drugs is outlined.


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**The 'family' context of HIV: A need for comprehensive health and social policies.**

DeMatteo D, Wells LM, Goldie RS, King SM.

*AIDS Care* 2002;14(2):261-278 URL:

Reports on the findings from a multi-site psychosocial study of 91 Canadian families with HIV-positive mothers. Qualitative analysis revealed a number of themes including a complex web of personal, health and family concerns; the needs of children; family finances; disclosure dilemmas; and social experiences and challenges. These themes reflect an intricate and dynamic picture of parental and family life for adults and children living with HIV. Nowhere in the literature do we see HIV framed as a 'family infection'. Yet with HIV several family members and multiple generations as well as single or both parents may be infected, highlighting the importance of 'family HIV' as a framework for health policy and program development. At issue is the problem that medical and other institutions view issues of surveillance, treatment and care through the lens of the infected individual, rather than being family focused. Often it is only in the context of identifying support, or barriers to support, for the medically diagnosed individual that biological or socially created families become a focus of concern. The failure to situate both chronic and life-threatening illnesses within the family setting has serious quality of life and planning consequences. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

http://www.tandf.co.uk/journals/carfax/0954012.html

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Putting bereaved parents in the frame.

Dent A.

Bereavement Care 2002;21(1):9-10.

How parents can help children bereaved after the death of a close family member.

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Radiotherapy for metastases to the mandible in children.

Deutsch M, Wollman MR.


PURPOSE: We present a retrospective review of all children treated since 1979 at our institution with radiotherapy for symptomatic metastases that involve the mandible. PATIENTS AND METHODS: Nine children were treated with 1 or more courses of radiotherapy for symptomatic metastases that involve the mandible. Six children had a neuroblastoma, 1 had angiosarcoma of the liver, 1 had adenocarcinoma of the rectum, and 1 had peripheral primitive neuroectodermal tumor (Ewing's sarcoma) of the spine. In 3 children, the mandible was the first bone involved by metastases. Seven children were treated with short intensive courses of radiotherapy consisting of 1 to 3 fractions to a total dose of 400 to 1,200 cGy. One child received 2,400 cGy in 6 fractions, and another child received 3,000 cGy in 10 fractions. Three children were treated with second courses of radiotherapy at 1, 2, and 5 months, respectively, from the initial course of radiotherapy. All children had received chemotherapy. RESULTS: All children died of disseminated disease at 5 to 59 months from their initial diagnosis, 5 to 29 months from the detection of metastases to bone, and only 6 days to 17 months (median, 2 months) from the first treatment of metastases to the mandible. CONCLUSIONS: The outlook for children with metastases that involve the mandible is very poor, and we recommend short intensive courses of radiotherapy consisting of 1 to 3 treatments to total doses of 400 to 1,200 cGy for palliation of pain.


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Presenting a case for involving children with a terminal illness in clinical trials.

Devine T.


Today's approaches to the treatment of childhood malignancies are the result of past clinical trials. In order to improve survival it is essential we continue to seek benefit from clinical trials. However, entry of terminally ill children into a phase I or phase II clinical trial, involving a novel, potentially therapeutic, agent is highly contentious. This article will argue in favour of a child's active and full participation in the decision to enter into a phase I or phase II clinical trial. A formal study of the role of children in clinical trials, especially phase I and phase II trials, is urgently required if standards of best practice are to be laid down and subsequently measured.


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Legal aspects of consent 20: research/children/incapable adults.

Dimond B.


James is 10 years old and is suffering from leukaemia. He has had a bone marrow transplant which at first appeared to succeed, but has now failed. The health authority has refused, in the best interests of James, to fund further chemotherapy and a second bone marrow transplant. However, the pioneer of a new treatment for leukaemia has offered to provide treatment for James without any cost to the family. The family is tempted by the possibility of James' life being saved. What is the law?

A philosophical discussion of end-of-life decision-making methods for incompetent patients.

Edwards D.


This article provides an analysis of decision-making methods that can be used with incompetent patients (patients who are unable to make decisions for themselves). It is intended as a general discussion of the relevant issues rather than an examination of legal or policy concerns. The advance directive principle (whereby a person leaves instructions for what to do if they become unable to make their own decisions) is discussed with reference to practical and philosophical issues. Substituted judgement (where surrogate decision makers make decisions that the patient who is incompetent would make if competent) is then discussed followed by the principle of best interests, which requires consideration beyond purely medical interests. The need to make patient-centred quality-of-life judgements as a component of best interests decisions is argued. Conclusions reached include the notion that the advance directive principle and the substituted judgement principle facilitate the concept of self-determination. The best interests principle helps to ensure that patients ending up in this vulnerable position are protected.


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A model of palliative care for the adolescent with cancer.

Edwards J.


Adolescents are a distinct group in paediatric and adult cancer and palliative care specialities. The process that is experienced by the patient and his/her family of the transition from health to living with a life-threatening illness and from a life-threatening to a life-limiting illness raises specific issues for service provision. The adolescent population presents with a wide variety of physical and emotional maturity that highlights the need for health professionals to be equipped with skills in adolescent care, cancer care and specialist palliative care. Due to the small number of patients who will require such a service in any one health district in the UK this is not usually realistic. This article discusses a model of care that promotes collaborative professional practice in a cancer centre between the paediatric department and adult specialist palliative care team that in turn extends a philosophy of care into cancer units and the community setting.

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Nitrous oxide is not beneficial for breakthrough cancer pain.

Enting RH, Oldenmenger WH, van der Rijt CC, Koper P, Lieverse J, Sillevis SP.


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Coping strategies used in residential hospice settings: findings from a national study.

Evans WM, Bibeau DL, Conley KM.


The purpose of this study was to explore professional caregivers' coping strategies for dealing with the deaths of patients in residential hospices in the United States. Using the Guide to the Nation's Hospices, 1996-97, purely residential hospices were identified and invited to participate in the study. Employees at each residential hospice were asked to complete the Ways of Coping Questionnaire. Results indicated that positive reappraisal coping was the most frequently used coping strategy. Employees dissatisfied with the coping experience reported greater use of confrontive coping, escape-avoidance coping, and accepting responsibility strategies. The findings suggest that in-service training related to coping strategies and environmental interventions may help in strengthening the coping responses of residential hospice staff.

Defining effective clinician roles in end-of-life care.

Farber SJ, Egnew TR, Herman-Bertsch JL.


OBJECTIVE: Our goal was to determine primary care clinician perceptions of what is important to the provision of quality end-of-life care. STUDY DESIGN: We used ethnography, a qualitative research method involving the use of open-ended semistructured interviews. POPULATION: We included 38 family practice residency faculty from 9 community residency programs of the Affiliated Family Practice Residency Network, Department of Family Medicine, University of Washington School of Medicine. OUTCOMES MEASURED: The roles described by interviewees when discussing their best practices while delivering end-of-life care were compiled. RESULTS: Primary care clinicians organize their delivery of quality end-of-life care predominantly through their relationships with patients and families. They play 3 roles when providing end-of-life care. As consultants, clinicians provide expert medical advice and treatment. As collaborators, they seek to understand the patient and family experience. Seasoned clinicians act as guides, using their personal intuitive knowledge of patient and family to facilitate everyone's growth when providing end-of-life care. CONCLUSIONS: Shifting clinician focus from skills and knowledge toward relationship, meaning, and roles provides new opportunities to improve end-of-life care for patients, families, and clinicians.


Feudtner C, Silveira MJ, Christakis DA.


OBJECTIVE: Little is known about factors that influence whether children with chronic conditions die at home. We sought to test whether deaths attributable to underlying complex chronic conditions (CCCs) were increasingly occurring at home and to determine what features were associated with home deaths. DESIGN: A retrospective case series was conducted of all deaths that occurred to children age 0 to 18 years in Washington state from 1980 to 1998 using death certificate data, augmented with 1990 US Census data regarding median household income by zip code in 1989, to determine the site of death. RESULTS: Of the 31 455 deaths identified in infants, children, and adults younger than 25 years, 52% occurred in the hospital, 17.2% occurred at home, 8.5% occurred in the emergency department or during transportation, 0.4% occurred in nursing homes, and 21.7% occurred at other sites. Among children who died as a result of some form of CCC (excluding injury, sudden infant death syndrome, and non-CCC medical conditions), the percentage of cases younger than 1 year who died at home rose slightly from 7.8% in 1980 to 11.6% in 1998, whereas the percentage of older children and young adults who had a CCC and died at home rose substantially from 21% in 1980 to 43% in 1998. Children who had lived in more affluent neighborhoods were more likely to have died at home. Using leukemia-related deaths as a benchmark, deaths as a result of congenital, genetic, neuromuscular, and metabolic conditions and other forms of cancer all were more likely to have occurred at home. Significant variation in the likelihood of home death, not explained by the individual attributes of the cases, also existed across the 39 counties in Washington state. CONCLUSIONS: Children who die with underlying CCCs increasingly do so at home. Age at death, specific condition, local area affluence, and the location of home all influence the likelihood of home death. These findings warrant additional study, as they have implications for how we envision pediatric palliative care, hospice, and other supportive services for the future.

http://www.pediatrics.org/cgi/content/full/109/4/656
http://www.pediatrics.org/cgi/content/abstract/109/4/656

Characteristics of deaths occurring in children's hospitals: implications for supportive care services.

Feudtner C, Christakis DA, Zimmerman FJ, Muldoon JH, Neff JM, Koepsell TD.

CONTEXT: End-of-life care is an important yet underdeveloped component of pediatric hospital services. OBJECTIVES: We sought 1) to describe the demographics of children who die in children's hospitals, 2) to describe the prevalence of complex chronic conditions (CCCs) among these cases, and 3) to test the hypotheses that cases with a greater number of CCC diagnoses experience longer periods both of mechanical ventilation and of hospitalization before death. Design and METHODS. We identified all deaths of patients 0 to 24 years old that occurred in the 60 hospitals contributing discharge data to the National Association of Children's Hospitals and Related Institutions data consortium for the years 1991, 1994, and 1997. We classified discharge diagnoses into 9 major categories of CCCs (cardiovascular, neuromuscular, malignancy, respiratory, renal, metabolic, gastrointestinal, hematologic/imunologic, and other congenital/genetic). RESULTS: Of the 13,761 deaths identified, 42% had been admitted between 0 and 28 days of life, 18% between 1 and 12 months, 25% between 1 and 9 years, and 15% between 10 and 24 years. Fifty-three percent were white, 20% were black, and 9% were Hispanic. The principal payer was listed as a governmental source for 42% and a private insurance company for 35%. Based on all the discharge diagnoses recorded for each case, 40% had no CCC diagnosis, 44% had diagnoses representing 1 major CCC category, 13% had diagnoses representing 2 CCC categories, and 4% had diagnoses representing 3 or more CCC categories. Among cases that had no CCC diagnoses, the principal diagnoses were related to prematurity and newborn disorders for 32% of these cases, injuries and poisoning for 26%, and an assortment of acute and infectious processes for the remaining 42%. Mechanical ventilation was provided to 66% of neonates, 40% of infants, 36% of children, and 36% of adolescents. Cases with CCCs were more likely than non-CCC cases to have been mechanically ventilated (52% vs 46%), and to have been ventilated longer (mean: 11.7 days for CCC cases vs 4.8 days for non-CCC cases). The median duration of hospitalization was 4 days, while the mean was 16.4 days. After adjustment for age, sex, year, and principal payer, compared with patients with no CCC diagnoses, those with 1 major CCC category had a significantly lower hazard of dying soon after admission (hazard ratio [HR]: 0.60; 95% confidence interval [CI]: 0.57-0.62), those with 2 CCC categories even lower (HR: 0.53; 95% CI: 0.50-0.57), and those with 3 or more CCC categories the lowest hazard of rapid death (HR: 0.51; 95% CI: 0.46-0.57). This trend of diminishing hazard of rapid death was significant across the 3 groups of children with 1 or more CCCs. CONCLUSIONS: Children's hospitals care for a substantial number of dying patients, who differ widely by age and medical conditions. Children who die in the hospital with CCCs are more likely to experience longer periods of mechanical ventilation and hospitalization before death.


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Experiences in family bereavement.

Fletcher PN.

*Family & Community Health* 2002;25(1):57-70.

These case studies illustrate the stories of two families grieving the losses of their children. Some 42,000 infants and children die yearly in the United States, but there is a dearth of research for professionals to draw on when considering the family as the context for grieving the loss of a child. These narratives illustrate the identity crisis the family as whole goes through after the death of a child—the sense of parental duty, the need for communication, and the goal of reunification of the family unit. These stories also provide direction for further research with bereaved families.

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Communicative competence in the delivery of bad news.

Gillotti C, Thompson T, McNeilis K.

*Social Science and Medicine* 2002;54(7):1011-23.

Grounded in the Cegala and Waldron (Communication Studies 43 (1992) 105) model of communicative competence, the present study applied the McNeilis (Health Communication 13 (2001) 5) provider-patient coding scheme to video tapes of 3rd year medical students delivering bad news to a standardized patient. The goal of the study was to understand the specific communicative moves that are associated with perceptions of competence during bad news delivery. The coding scheme assesses Content, Acknowledgment Tokens, Interruptions, Alignment, and Function of the message. Naive observers also evaluated the tapes on several items, assessing empathy and communicative effectiveness. Nonmedical talk was the most common type of content, followed by discussion of the current health problem. Neither acknowledgment tokens nor interruptions were frequent. The most common function of a message was a closed question, followed by explanations, assertions, and open questions. Summing across the functions indicated that information giving was the most common behavior. The perceivers' data showed fairly neutral assessments of the medical students—they were generally not evaluated very positively, although they were not disliked. Regression analyses indicated numerous specific communicative behaviors.
that were associated with judgments of competence. Statements falling into the Nonspecific Content category were associated with more positive perceptions, while relational statements, moderately closed questions, solicited answers, expansions, restatements, assertions, explanations, open questions, bracketing, and small talk as well as information verifying, seeking, and giving (summed functions) led to more negative perceptions. The results indicate that the delivery of bad news requires communicative moves that differ from other kinds of medical communication. Depending on the results of future analyses of this topic health are providers may be well advised to focus little of their communication information seeking, giving, or verifying during the initial lab news delivery consultation, but rather to save most communication information for a follow-up scheduled shortly afterwards.


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Pediatric palliative care: a family-centered model for critical care.
Gilmer MJ.


Melanie's case and the associated concerns are not unique. Children with life-threatening conditions and their families and communities may benefit from a family-centered model of pediatric palliative care. Benefits from its implementation are not just at the end of life, but throughout the course of therapy. Compassion coupled with a holistic approach incorporating humane and family-centered care is essential in meeting physical, mental, and spiritual needs. An interdisciplinary and collaborative model of pediatric palliative care involves the work of many, including nurses, physicians, social workers, chaplains, child life specialists, pharmacists, ethicists, bereavement counselors, ancillary staff, volunteers, and families themselves. They must incorporate key elements of the model, including clinical services, education and training, support services, and research that address physical, mental, and spiritual needs of families, children, and communities faced with life-threatening conditions.


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Contemporary issues in the care of sick children and their families.
Glasper EA.


This article considers the response of children's nurses to contemporary change in the management of sick children and their families throughout the last decade. In recognizing the rich and diverse history of children's nursing the impact of those factors which have led to the development of operational strategies to manage children's services will be considered. The quest, not always successful, to coordinate care as a seamless web of services to children and their families will be investigated, as will the role dimensions encompassed by specialist children's nurses and their interface with interprofessional colleagues. A range of nurse-led services in a variety of contemporary child health settings will be explored.


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A neonatal end-of-life palliative protocol--an evolving new standard of care?
Glicken AD, Merenstein GB.


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Young adults with cancer: the effect of the illness on parents and families.
Grinyer A, Thomas C.

This article is based on the findings from a qualitative study involving a collection of narratives written by the parents of young adults with cancer. It examines the effects of the illness on parents and family and illustrates that young people aged 18-25 years face particular difficulties when diagnosed with a life-threatening illness. The article focuses on how these difficulties are experienced by the parents of young adults who are attempting to maintain 'normality' and perhaps also manage newly established sexual relationships. The article considers the problems for parents, e.g. the ownership of medical information when the young adult is of age but dependent on his/her parents, the effect on siblings and the financial implications of the illness for the family. A gap in the knowledge of professionals and families relating to these effects may result in families believing that the acute problems they face are caused by their particular family dynamics rather than the life-stage of their young adult children.


The view from a bridge.
Hain RDW.
*European Journal of Palliative Care* 2002;9(2):75-77.

Opioids in children; perhaps more is less.
Hain RDW.

Medically fragile children: an integrative review of the literature and recommendations for future research.
Harrigan RC, Ratliffe C, Patrinos ME, Tse A.

The literature related to medically fragile children (MFC) is analyzed, and a model is generated to improve quality of care and cost effectiveness. The sources of stress for families include home care professionals, respite care, financial concerns, and limited community resources. Children cared for in hospitals often experience less than desirable quality outcomes. Community-based pediatric extended care facilities may be a means of reducing family stress, improving physiologic and developmental outcomes, and reducing cost. Case management may significantly reduce parental stress and improve the quality of life for these children. Additional systematic study of care options for MFC is essential.


Hayman LL.
Life stories of families with a terminally ill child.

Hechter S, Poggenpoel M, Myburgh C.

Curationis 2001;24(2):54-61.

Family units with a terminally ill child have a tendency to withdraw and this isolation may lead to problems in their mental health. A tendency with psychologists, clergy and helpers from other professions is to act as ideal experts on the lives of saddened people. From painful personal experience, this does not seem to enable acquiescence. Therefore, the aim of research on families with terminally ill children, was to explore and describe their lives and to develop an approach to facilitate their families to obtain acquiescence. In this article however, attention will be given to the life-world of families with terminally ill children. The research consists of two phases. In phase one the experiences of four families with terminally ill children are explored and described by means of phenomenological, unstructured, in-depth interviews. In phase two an acquiescence approach, which was designed for educational psychologists to facilitate families with terminally ill children to achieve acquiescence, is described. This approach is based on results from phase one. This article focuses on phase one. In this phase four families were interviewed individually, in the privacy of their homes. The interviews were audiotaped, and were transcribed for the purpose of data gathering. The data was analysed according to Tesch's method and a literature control was performed to verify the results. Guba's model for the validity of qualitative research was used. Five recurrent themes were identified: 1. Families are able to choose their reactions to the crises of having a terminally ill child. 2. When there is a terminally ill child in the family, the family's values change. 3. Acceptance of the circumstances with a terminally ill child, makes life easier. 4. As families with a terminally ill child learn to live every moment to the full, their quality of life improves. 5. As people learn to accept support, their quality of life with a terminally ill child improves. The research indicated that families with terminally ill children are explored and described by means of phenomenological, unstructured, in-depth interviews. In phase two an acquiescence approach, which was designed for educational psychologists to facilitate families with terminally ill children to achieve acquiescence, is described. This approach is based on results from phase one. This article focuses on phase one. In this phase four families were interviewed individually, in the privacy of their homes. The interviews were audiotaped, and were transcribed for the purpose of data gathering. The data was analysed according to Tesch's method and a literature control was performed to verify the results. Guba's model for the validity of qualitative research was used. 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Acceptance of the circumstances with a terminally ill child, makes life easier. 4. As families with a terminally ill child learn to live every moment to the full, their quality of life improves. 5. As people learn to accept support, their quality of life with a terminally ill child improves. The research indicated that families with terminally ill children are explored and described by means of phenomenological, unstructured, in-depth interviews.

Issues in Islamic biomedical ethics: a primer for the pediatrician.

Hedayat KM, Pirzadeh R.


The United States is becoming increasingly pluralistic. Pediatricians must become familiar with the factors that affect the emotional, physical, and spiritual health of their patients that are outside the kin of the traditionally dominant value system. Although many articles have addressed the cultural and ethnic factors, very few have considered the impact of religion. Islam, as the largest and fastest-growing religion in the world, has adherent throughout the world, including the United States, with 50% of US Muslims being indigenous converts. Islam presents a complete moral, ethical, and medical framework that, while it sometimes concurs, at times diverges or even conflicts with the US secular ethical framework. This article introduces the pediatrician to the Islamic principles of ethics within the field of pediatric care and child-rearing. It demonstrates how these principles may impact outpatient and inpatient care. Special attention is also given to adolescent and end-of-life issues.

End of life care in HIV-infected children who died in hospital.

Henley LD.


Evaluated terminal care among hospitalized children who died of HIV/AIDS at a public children's hospital in Cape Town, South Africa. The design was a retrospective chart review of the terminal hospitalization. The main outcome measures included: documentation of do not resuscitate (DNR) orders and comfort care plans, intensity of diagnostic and therapeutic
Interventions in last 24 hrs of life, and presence of pain and distress in last 48 hrs of life. The results are based on the review of 165 out of 167 in-patient deaths. Of those, 79% of patients died in general wards. Median age and length of stay were 4 mo and 6 days respectively. A total of 84% of patients had a DNR order. Only 44% of patients had a comfort care plan. Pain and distress in the last 48 hrs was documented in 55% of patients who died in the general wards. Respiratory symptomatology and painful skin conditions accounted for most discomfort. Half the patients with pain and distress, including 16 with a comfort care plan, received no analgesia. The lower rate of comfort care plans suggests doctors had difficulty making the transition from curative to palliative care. Many comfort care plans were incoherent and included interventions unlikely to promote patients' comfort. The need for reforms is discussed. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

URL: http://www.blackwellpublishers.co.uk/asp/journal.asp?ref=1471-8731

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Enhancing seamless care: a review.
Heywood J.
Paediatric Nursing 2002;14(5).

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Psychosocial practice trends in pediatric oncology.
Hicks MD, Lavender R.

Children with cancer are now living longer lives. As a result, the focus on care has shifted to include psychosocial components to help promote healthy adjustment to the diagnosis of cancer. In addition, the focus extends to the systems that encompass the patient and family. This ranges from cultural needs to comfort care and how the medical team and institutions address these issues. Through well-defined psychosocial practices, children and families are better prepared to cope with cancer and become well-adjusted survivors. However, regardless of the eventual outcome of the disease, providing psychosocial services can add to the quality of life. Many common practices have emerged over the last 25 years, and many more will continue to arise as outcome studies continue to address the impact of psychosocial services and interventions. This report explores some current trends and common psychosocial practices in working with children with cancer and their families. Copyright 2001 by Association of Pediatric Oncology Nurses (43 ref)

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Pain management for the child with cancer in end-of-life care: APON position paper.
Hooke C, Hellsten MB, Stutzer C, Forte K.

Although there have been major advances in the treatment of childhood cancer with an overall survival rate of more than 70%, cancer continues to be the leading cause of death in children resulting from disease. In 1998, 2,500 children in the United States died of cancer-related causes. Each year cancer kills more children than asthma, diabetes, cystic fibrosis, congenital anomalies, and acquired immunodeficiency syndrome combined. The Association of Pediatric Oncology Nurses (APON) is the leading professional organization for nurses caring for children and adolescents with cancer and their families. The highest standards of nursing practice are achieved through education, research, certification, advocacy, and affiliation. It is the position of APON that pain in the child dying of cancer can be effectively managed. This can be accomplished by making the prevention and alleviation of pain a primary goal, partnering with the patient and parents, and aggressively using appropriate pharmacologic and non-pharmacologic interventions. The pediatric oncology nurse has an essential role in the child's pain management at the end of life through nursing assessment, identifying expected outcomes, and performing and evaluating interventions.

Determining the need for terminal care for children.
Horrocks S, Somerset M, Salisbury C.
*European Journal of Palliative Care* 2002;9((2)):78-79.

Paediatric respite care: a literature review from New Zealand.
Horsburgh M, Trenholme A, Huckle T.

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.


OBJECTIVE: Many juveniles with chronic pain of no known organic cause recover. Because adolescents whose pain persists may have chronic pain as adults, a subsample of 42 adolescents from a prevalence study in which continuation of their pain was observed throughout the study period was investigated quantitatively and qualitatively. All mothers (n = 42) completed a questionnaire on the impact of the adolescent's pain on the family. The authors tested the hypothesis that pain parameters, pain-related quality of life, and impact of pain on the family would deteriorate over time. DESIGN: Three-year follow-up questionnaires, diaries, and interviews were used. SETTING: The study was conducted in the general population in the Rotterdam area. PARTICIPANTS: Adolescents (aged 12-18 years) who indicated chronic pain in our previous prevalence study and in a diary and questionnaire each year of the 3-year follow-up were included in the study. RESULTS: The most prevalent pains were limb pain and headache. The pain intensity was mild (33 mm on a visual analog scale), very frequent (72% of all diary entries), and associated with relatively poor functional status and poor psychological and somatic functioning. The pain parameters, pain-related quality of life, and impact of pain on the family (i.e., restrictions in social life and problems in dealing with the stress of the adolescent's pain) remained surprisingly stable across the assessments. The interviews showed that pain had become part of the daily life of several adolescents, who structured their activities and sleeping hours to prevent aggravation of pain. In particular, adolescents with headache reported problems with cognitive activities, whereas those with limb pain and back pain reported problems with physical activities. CONCLUSIONS: For adolescents with persistent pain with no known organic cause, intensity and frequency of pain, quality of life, and impact of pain on the family did not change. Generally, they seemed to cope quite well with their pain. In view of these results, further studies should involve follow-up of adolescents with persistent pain into adulthood to establish the determinants of their pain and to find out whether they maintain their adaptive ways of living with their pain.

**Pediatric palliative care: the time has come.**

Hutton N.

*Archives of Pediatric and Adolescent Medicine 2002;156(1):9-10.*


Should paediatric units have bereavement support posts?

Jennings P.

*Archives of Disease in Childhood 2002;87(1):40-2.*

Eight bereavement support posts in paediatrics and maternity were established using the experience of the Child Bereavement Trust (CBT). Evaluation showed that staff welcomed the informal support and teaching for themselves, as well as support for families; 67% of staff who returned questionnaires felt care for bereaved families had improved as a result of the posts. Many felt that there had been a positive effect on staff retention and stress levels.

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**Cancer narratives of adolescents and young adults: A quantitative and qualitative analysis.**

Kameny RR, Bearison DJ.

*Children's Health Care 2002;31(2):143-173.*

Themes and linguistic structures in the narratives of adolescents and young adults with cancer were investigated, focusing on 3 broad narrative domains: medical, personal, and social. As a basis for the themes and structures explored, some of the pediatric research conducted in the areas of psychological well-being, relationships with others, coping, and control is reviewed, and methodological limitations are discussed. The 27 participants (ages 13-21 yrs) came from a variety of socioeconomic and ethnic backgrounds, with various forms of childhood cancer and at various stages of treatment. Themes and linguistic structures were measured against narrative domain, time in treatment, age, and gender. Participants made more negative than positive physical assessments, women made more self statements, control issues occurred more in medical domains, distancing occurred more in personal domains, and coping statements increased with age. Pediatric psychologists should encourage patients to discuss negative physical implications, gaining control despite uncertainties; and male patients may need more support for talking about thoughts and emotions. Facilitating discussion among peers with cancer can also be beneficial. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

**URL:** http://www.erlbaum.com/Journals/journals/CHC/chc.htm

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**Pediatric palliative care: heartbreaking yet rewarding.**

Kastner B.

*Nursing matters 2002;13(2).*

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**Grandparents of children with developmental disabilities: perceptions, beliefs, and involvement in their care.**

Katz S, Kessel L.


This exploratory study evaluated the perceptions and beliefs of grandparents regarding their grandchild with a developmental disability and their involvement in his/her care and the impact of the child's disability on their lives and on their relationship between them. The sample included 16 grandparents of children with a severe developmental disability.
ranging in age from 5-10 who were studying in a special school. Data was collected by using semistructured interviews in the home of the grandparents. The findings indicated that grandparents’ involvement and satisfaction with their role were a function of their attitudes towards disabilities in children in general and their relationship with their adult children, as well as their own life experiences. Their involvement with their grandchild with developmental disability served to strengthen the relationship between the grandparents. An important implication of the study is that professionals should plan interventions to support and encourage grandparents to be more involved in the care of the child with developmental disability.


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**Current research in children's conceptions of death: A critical review.**

Kenyon BL.


Reviews literature published since the early 1980s concerning how children come to understand death, development of the death concept, and relevant contributing factors. Discussed are the effects of age, cognitive development, type of object inquired about, culture, religious beliefs, SES, experience with death, and emotional factors on the development of the understanding of death. Results show that by age 10 yrs most Ss have mastered the components of irreversibility, universality, non-functionality, personal mortality, and causality. However, acquisition of individual components appears to be differentially affected by several factors. Cognitive development, verbal ability, and cultural and religious experiences appear to influence the acquisition of abstract components such as universality. Direct experience appears to affect the acquisition of physically based components, such as non-functionality and irreversibility. The components appear to have different developmental trajectories. Emotional factors appear to play a significant role in how Ss respond to questions about death and might be highly influential in the development of their understanding of death. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

URL: http://baywood.com/search/PreviewJournal.asp?qsRecord=22

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**Responding when a baby dies.**

Kenyon S.


The aim of this article is to highlight some of the unique challenges relating to handling children, such as: their stage of physical and cognitive development, their position in relation to the carer's centre of gravity, their level of comprehension and their ability to communicate.


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**Supporting ‘expert’ parents-professional support and families caring for a child with complex health care needs in the community.**

Kirk S, Glendinning C.


In the United Kingdom a new group of children with intensive and complex health care needs are now being cared for at home as a result of medical advances and government policies emphasising the community as the arena for care. This has led their parents to become involved in providing care of a highly technical and intensive nature that would previously have been considered to be the domain of professionals. In-depth qualitative interviews were conducted with parents and professionals to discover parents' and professionals' experiences of receiving and providing support in a context where parents rather than professionals are the expert caregivers. This paper describes the elements of professional 'support' that were particularly valued by parents and concludes with a discussion of the implications for professional education and roles.
Variables influencing end-of-life care in children and adolescents with cancer.
Klopfenstein KJ, Hutchison C, Clark C, Young D, Ruymann FB.


BACKGROUND: The purpose of this study was to describe the variables influencing end-of-life care in children and adolescents dying of cancer. MATERIALS AND METHODS: Records of 146 children with cancer who died at Children's Hospital were reviewed for demographics, diagnosis, location of death, withdrawal of life support, use of "do not resuscitate" (DNR) orders, and the length of time that those orders were in effect. RESULTS: Ninety-five patients were evaluated. Fifty-nine died of progressive disease and 36 deaths were therapy-related. Sixty-four percent of disease-related deaths occurred at home with support from home care or hospice. Only 10% of all patients died while receiving maximal aggressive support in the intensive care unit. Age, diagnosis (solid tumor vs. leukemia), cause of death, length of last hospital admission, and the duration of DNR orders had a significant correlation with the place of death and referral to and use of hospice. Thirty-five percent of all patients had hospice support. CONCLUSIONS: Most children who die of cancer die because of progressive disease at home with hospice support. Do not resuscitate orders were written for most patients who died. End-of-life decisions are influenced by patient diagnosis, cause of death, and age.

Psychosocial intervention in the process of empowering families with children living with HIV/AIDS: A descriptive study.
Kmita G, Baranska M, Niemiec T.


The notion of 'family empowerment' is of crucial importance in any kind of psychosocial intervention directed to families with children living with HIV/AIDS. The goal is to restore self-efficacy and self-esteem, encourage positive coping and help family members make their own choices. Two settings for psychosocial intervention in Poland are described: an outpatient clinic within a larger medical institution and a therapeutic camp for families with children. Different psychotherapeutic and counselling strategies and approaches are briefly presented. Preliminary results based on work with families with children infected and/or affected by HIV/AIDS are described. The conclusion is that interventions that involve different settings seem to be most effective, especially for the most vulnerable families. The important issue is also collaboration between different service providers and NGOs. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

Mothers' experience of social support following the death of a child.
Laakso H, Paunonen-Ilmonen M.


1. This study aimed at analysing the grief and coping of mothers whose child had died under the age of 7 years. The paper describes the social support received as experienced by mothers. 2. Data were collected using a survey (n=91) and interviews (n=50) with mothers who had lost their child at least 1 year previously. The questionnaire contained questions concerning background characteristics, the Hogan Grief Reaction Checklist and open-ended questions. Survey data were analysed using a two-way analysis of variance, Wilcoxon test, cross-tabulation and content analysis. Interview data were analysed using inductive content analysis. 3. Findings showed that the spouse, children, grandparents, next of kin, friends and colleagues were the main sources of support. 4. Support consisted of emotional support, informational and instrumental support, and consolation and caring. Informational support consisted of advice and guidance from the mother's own mother or fellow sufferers. Instrumental support consisted of assistance with practical issues. Negative support manifested itself in unwarranted interference by relatives in the family's affairs or breaking up of friendships. 5. Mothers expected professional
practitioners to provide honest information about the dying child's illness and practical arrangements after the child's death, and to keep up hope as long as the child was alive. 6. The care facility was also expected to maintain contact with the family after the child's death.


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Resuscitation policy in children's hospices.

Leung MA, Cuddeford LM.

Archives of Disease in Childhood 2002;86(Suppl 1):A76.

AIMS: The aim of this study was to ascertain the presence or absence of resuscitation policies in Children's Hospices on mainland UK. METHODS: The Heads of Care at a total of twenty-three children's hospices were contacted by letter, and information on their resuscitation policy requested. RESULTS: There were responses from seventeen hospices. Thirteen of these were written replies and four were telephone calls to the lead nurse of the investigating hospice. Salient points from the discussion were noted. A written policy was in place in nine of the seventeen hospices, including written documentation of parents' wishes. Resuscitation was actively discussed by twelve of the seventeen respondents. In seven of the respondents a discussion covering resuscitation policy occurred at each visit. None of the respondents indicated whether the child's views was sought. Seven hospices were examining their policy at the time of the study. A number of replies highlighted the difficult ethical and practical issues raised when discussing resuscitation of children in the hospice setting. CONCLUSIONS: This preliminary study suggests there are wide national differences in resuscitation policy in children's hospices. There is a need for a more detailed study examining resuscitation practices in the Children's Hospice setting. Guidelines are required to ensure minimum standards.

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Starting the quest to define optimal pediatric end-of-life care.

Levetown M.


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Palliative care in the neonatal population.

Maginnes E.


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'Enough is enough': qualitative findings on the impact of dexamethasone during reinduction/consolidation for paediatric acute lymphoblastic leukaemia.

McGrath P, Pitcher L.

Supportive Care in Cancer 2002;10(2):146-55.

The results of a longitudinal study conducted with children undergoing treatment for acute lymphoblastic leukaemia (ALL) and their families in Brisbane, Australia, indicate that the emotional impact of one of the protocol drugs, dexamethasone, is acutely distressing. The findings presented cover the second interviews with the parents and children of the first 11 ALL families to have completed the re-consolidation stage of treatment. The results indicate that the negative impact of this drug is particularly severe during the reconsolidation stage, when families are exhausted with coping with the intensity of treatment. Thus, the administration of dexamethasone is a critical point in the pathway of care for children with ALL. The emotional consequences of the drug are profoundly disturbing, not only for the child, but for the whole family. The findings indicate that the period when dexamethasone is being administered is an important time for providing families with emotional support and information about likely sequelae of treatment. Because of guilt and self-doubt parents will not necessarily seek help, even if it is greatly needed. Recommendations are provided as to possible ways of reducing the distressing impact of the administration of this pharmaceutical intervention.
End-of-life care for hematological malignancies: the 'technological imperative' and palliative care.

McGrath P.


Recent research indicates that hospice/palliative care practices have not yet been integrated into the care of patients with hematological malignancies. As research in relation to palliative care and hematological malignancies is in its infancy, many of the end-of-life care practices with these diagnostic groups are based on unexamined ideas. The findings presented in this article, which are taken from recent post-doctoral research on hematological malignancies and palliative care, make a contribution to documenting information on what is happening to patients and their families in this area. In particular, the findings provide insights on issues associated with the patient and carer awareness that the patient is dying, understanding of prognosis, and the desire to die at home. Such insights are placed in the context of descriptions of the patients' experience with treatment during the terminal stage.

Nurses' experiences of caring for culturally and linguistically diverse families when their child dies.

McKinley D, Blackford J.


Nurses experience the care of a dying child and their family as a challenging but distressing event. In a paediatric intensive care unit (PICU), Melbourne, Australia, nurses expressed a concern that they may not be providing the most appropriate care when a cultural disparity exists between nurses and families experiencing the death of their child. A critically informed study was undertaken with six PICU nurses to explore their experiences of caring for a culturally and linguistically diverse family whose child had died. Three consecutive focus group interviews were conducted with the nurses to identify issues in this area of their nursing practice and to contemplate how their practice might be changed. The focus of this paper is on one particular finding of the study about the nurses' use of controlling practices to ensure families conformed to the established routines and values of the PICU staff.

Serial assessment of mortality in the neonatal intensive care unit by algorithm and intuition: certainty, uncertainty, and informed consent.


OBJECTIVES: Does predictive power for outcomes of neonatal intensive care unit (NICU) patients get better with time? Or does it get worse? We determined the predictive power of Score for Neonatal Acute Physiology (SNAP) scores and clinical intuitions as a function of day of life (DOL) for newborn infants admitted to our NICU. METHODS: We identified 369 infants admitted to our NICU during 1996-1997 who required mechanical ventilation. We calculated SNAP scores on DOL 1, 3, 4, 5, 7, 10, 14, 21, 28, and weekly thereafter until either death or extubation. We also asked nurses, residents, fellows, and attendings on each day of mechanical ventilation: "Do you think this child is going to live to go home to their family, or die before hospital discharge?" RESULTS: Two thousand twenty-eight SNAP scores were calculated for 285 infants. On DOL 1, SNAP for nonsurvivors (24 +/- 8.7 [standard deviation]) was significantly higher than SNAP for survivors (13 +/- 4.9 vs 10.0 +/- 4.8). On each NICU day, at all ranges of SNAP scores, there were at least as many infants who would ultimately survive as would die. Consequently, the positive predictive value of any SNAP value for subsequent mortality was <0.5 on all NICU days. Prediction profiles were obtained for 230 ventilated infants reflecting over 11 000 intuitions obtained on
2867 patient days. One hundred fifty-seven (81%) of 192 survivor profiles displayed consistent accurate prediction profiles—-at least 90% of their NICU ventilation days were characterized by 100% prediction of survival. Twenty-five (13%) of 192 surviving infants survived somewhat unexpectedly; that is, after at least 1 day characterized by at least 1 estimate of “death.” Thirty-three (60%) of the 55 nonsurvivors died before DOL 10. Eighty-two percent of the prediction profiles for these early dying infants were homogeneous, dismal, and accurate. Twenty-two (40%) of the 55 nonsurvivors died after DOL 10. Seventeen (78%) of these 22 late-dying infants were predicted to live by many observers on many hospital days. Sixty-one (30%) of 230 profiled patients had at least 1 NICU day characterized by at least 1 prediction of death; 26/61 (43%) of these patients were incorrectly predicted; that is, they survived. Seventeen infants who were predicted to die during but survived nonetheless were assessed neurologically at 1 year. Fourteen (82%) of these 17 were not neurologically normal—8 were clearly abnormal, 1 suspicious, and 5 had died. CONCLUSIONS: If absolute certainty about mortality is the only criterion that can justify a decision to withhold or withdraw life-sustaining treatment in the NICU, these data would make such decisions difficult on the first day of life, and increasingly problematic thereafter. However, if we acknowledge that medicine is inevitably an inexact science and that clinical predictions can never be perfect, we can ask the more interesting question of whether good but less-than-perfect predictions of imprecise but ethically relevant clinical outcomes can still be useful. We think that they can—and that they must.

http://www.pediatrics.org/cgi/content/full/109/5/878
http://www.pediatrics.org/cgi/content/abstract/109/5/878

Coping styles and locus of control as predictors for psychological adjustment of adolescents with a chronic illness.

Meijer SA, Sinnema G, Bijstra JO, Mellenbergh GJ, Wolters WH.

Social Science and Medicine 2002;54(9):1453-61.

This study examines the way coping styles and locus of control contribute to the prediction of psychosocial adjustment in adolescents with a chronic illness. Psychosocial adjustment of 84 adolescents aged 13-16 years with a chronic illness was assessed with measures of social adjustment, global self-esteem and behavior problems. Linear regressions were performed with demographic factors (age and gender) and stress-processing factors (coping style and locus of control) as predictor variables. Results indicated that coping styles were related to most aspects of social adjustment. The coping styles 'seeking social support' and 'confrontation' were important predictors for positive social adjustment; the coping style 'depression' was a predictor for poor adjustment, viz, low social self-esteem and high social anxiety. Avoidance and locus of control were not strongly associated with psychosocial adjustment. Clinical implications of these findings were discussed in terms of preventive interventions for adolescents with a chronic illness.


The risk assessment of bereavement in a palliative care setting.


An effective bereavement risk assessment document used in a palliative care setting was identified which could ensure bereavement support for those in need, be it a family or carer group. The nursing team were used as assessors with a system to indicate carers' and relatives' immediate need following the death of a patient. The aim of this bereavement risk assessment system was to lessen the possible long-term effects of unresolved grief for family and carers of patients who died within a hospice setting. The assessment document is a useful education tool for nurses, allied support professionals and bereavement support volunteers in their work with grief and loss.

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Parental perspectives on end-of-life care in the pediatric intensive care unit.

Meyer EC, Burns JP, Griffith JL, Truog RD.
OBJECTIVE: To identify priorities for quality end-of-life care from the parents' perspective. DESIGN: Anonymous, self-administered questionnaire. SETTING: Three pediatric intensive care units in Boston. PARTICIPANTS: Parents of children who had died after withdrawal of life support. MEASUREMENT AND MAIN RESULTS: Parents' views of the adequacy of pain management, decision making, and social support during and after the death of their child were measured with the Parental Perspectives Questionnaire. Of 96 eligible households, 56 (58%) responded. In 90% of cases, physicians initiated discussion of withdrawal of life support, although nearly half of parents had considered it independently. Among decision-making factors, parents rated the quality of life, likelihood of improvement, and perception of their child's pain as most important. Twenty percent of parents disagreed that their children were comfortable in their final days. Fifty-five percent of parents felt that they had little to no control during their child's final days, and nearly a quarter reported that, if able, they would have made decisions differently. There were significant differences (p < .001) between the involvement of family, friends, and staff members at the time of death and greater agreement (p < .01) about the decision to withdraw support between parents and staff members than with other family members. CONCLUSIONS: Parents place the highest priorities on quality of life, likelihood of improvement, and perception of their child's pain when considering withdrawal of life support. Parents make such decisions and garner psychosocial support in the context of a social network that changes over time and includes healthcare professionals, family, and friends.

Feasibility of a home care program in a pediatric hematology and oncology department. Results of the first year of activity at a single Institution.


BACKGROUND AND OBJECTIVES. Giannina Gaslini Children's Hospital (GGCH) is a tertiary care hospital with an average of 100 new cancer diagnoses made each year. In April 2000, following preliminary analysis of the potential benefits, and the results of a questionnaire filled in by the parents attending the out-patient clinic, a Home Care (HC) program was started. DESIGN AND METHODS. Children in stable, non-critical, clinical conditions requiring i.v. therapy, parenteral nutrition, transfusional support, blood examinations, and central venous catheter use training management, as well as terminally ill children needing palliative and support therapy were considered eligible for the program. RESULTS. After one year of activity, 45 children, aged 1 month-19 years (median 3 years), requiring i.v. therapy and blood tests in 32 cases, central venous catheter use training in 5, and palliative care in 8, were treated at home. The median duration of assistance for each child was 19 days (range 1-172). An average of 4 patients per week were assisted for a total of 1,364 days. A total of 881 accesses at home replaced 551 and 330 out-patient and in-patient days of hospitalization, respectively. The average cost per patient given home care (2,936 E, range 150-20,700) resulted to be significantly lower than the average cost per patient hospitalized to undergo the same procedures (9,785E, range 350-96,750). INTERPRETATION AND CONCLUSIONS. The opportunity to reduce the frequency and duration of hospitalization represents an incalculable advantage for these children and their families. This report shows that home care is a feasible kind of assistance for children suffering from cancer, and reduces costs as well.

Respite care for children who have complex nursing needs.

Miller S. Paediatric Nursing 2002;14(5).

Intergenerational differences and similarities in life-sustaining treatment attitudes and decision factors.

Mills TL, Wilmoth JM.
A cross-sectional sample of members of 3-generation families was used to evaluate life-sustaining medical treatment attitudes and end-of-life decision factors for oneself and for parents. The selection criteria for Ss included the presence of a grandfather aged 55+ yrs (G1s); an adult child and his or her spouse, if available (G2s); and a grandchild aged 16+ yrs (G3s). Nine decision factors were examined: level of pain, age, mental capacity, time to live, financial strain, family burden, doctor recommendations, family opinion, and type of treatment. Results show that the older generation (G1) perceived mental capacity, family burden, and pain as the most important considerations. Among the middle generation (G2), family burden was not an important factor, but the type of life-sustaining treatment was important. The youngest generation (G3) was similar to the other two generations in that mental capacity and pain were important, but a smaller percentage of the G3s considered this important. Overall, there was consensus across generations about the right to die and the right of families to make end-of-life decisions.

Information that informs rather than alienates families with disabled children: developing a model of good practice.

Mitchell W, Sloper P.

Health & Social Care in the Community 2002;10(2):74-81.

The importance to families with disabled children of relevant and accessible information about services has been illustrated in numerous studies and was re-emphasised by the Department of Health's 'quality protects' initiative. Indeed, the provision of information and the importance of keeping families informed is frequently viewed as a significant factor within both the concept of empowerment and the facilitation of enabling and participatory processes for service users and their families. However, although there has been considerable research highlighting parents' information needs, there has been significantly less exploration of how parents would actually like to receive this information. This paper seeks to bridge this knowledge gap and also discusses the empowering potential of user-friendly information. Drawing upon data collected from focus group discussions with parents caring for children with a range of disabilities or chronic illnesses, this paper explores how the families of service users would like to receive information. In particular, it examines the criteria by which parents judge the quality of information and their ideas as to what constitutes good practice, especially in terms of how information is presented, its content and the way it is delivered. Using these ideas and criteria, the paper begins to develop a model of good information practice that is both three-dimensional and personally interactive. Indeed, parents' desire for a combination of personal guidance and good-quality information, whether in the form of in-depth booklets or shorter directories, is viewed as being of paramount importance and, furthermore, as having an important empowering potential.

A scale to measure satisfaction of bereaved family receiving inpatient palliative care.

Morita T, Chihara S, Kashiwagi T.

Palliative Medicine 2002;16(2):141-50.

Although satisfaction is an important outcome of medical care, there are no validated tools to quantify family satisfaction with hospital-based palliative care. In this nationwide postal survey, an instrument to measure informal carer satisfaction with an inpatient palliative care service was validated. A 60-item questionnaire was mailed to 1344 bereaved people who had lost their family members at 50 palliative care units in Japan, and 850 responses were analysed (response rate = 64%). The reliability, construct validity, and convergent validity of the scale were examined after the responses were randomly divided into two groups: a training set used in the development phase (n = 500) and a testing set used in the validation phase (n = 350). The number of scale items was reduced from 50 to 34 through psychometric techniques in the development phase. In the testing sample, the overall Cronbach's coefficient alpha for the final 34-item scale was 0.98. A factor analysis revealed that the scale consisted of seven subcategories: Nursing Care, Facility, Information, Availability, Family Care, Cost, and Symptom Palliation. The total score of the scale was significantly correlated with the degree of global satisfaction of the bereaved (Spearman's rho = 0.78). In conclusion, this 34-item scale, the Satisfaction Scale for Family Members Receiving Inpatient Palliative Care (Sat-Fam-IPC), has acceptable psychometric properties and would be a useful tool to measure carer satisfaction with an inpatient palliative care service.

Families of children with cancer: the impact on anxiety experienced by fathers.

Mu PF, Ma FC, Hwang B, Chao YM.


By using the contextual model of family stress, this study examined fathers' family stress experience when caring for a child receiving cancer treatments. A descriptive correlational study was designed to examine the relationships between fathers' uncertainty, sense of mastery, and anxiety. Eighty fathers were recruited from two teaching hospitals in Taiwan. A pilot study was conducted to establish the reliability and validity of the Chinese language version of the above instruments. These instruments showed an acceptable internal consistency and satisfactory construct validity. Results showed that fathers' level of education had a significant effect on paternal anxiety. Uncertainty and fathers' education level equal to or higher than university are good predictors of paternal anxiety, which explain 25% of the variance. The results provide insight into the paternal experience of family stress and suggest ways to improve family-centered nursing interventions and thereby establish better family well-being.


Communicating about pupils in mainstream school with special health needs: the NHS perspective.

Mukherjee S, Lightfoot J, Sloper P.


AIM: To add to previous research carried out with young people, parents and teachers, by investigating health staff's perspectives on the difficulties, and possibilities for, achieving good communication with school staff with regard to children in mainstream school with a chronic illness or physical disability. RESEARCH DESIGN AND METHODS: A qualitative research study was carried out in one NHS Trust. Twenty semi-structured interviews were carried out with a purposive sample of health staff to cover the spectrum of professionals who have responsibility for meeting the needs of children with a chronic illness or physical disability in mainstream schools (paediatricians, school doctors, school nurses, specialist nurses, health visitors, GPs, speech and language therapists, paediatric occupational therapists, paediatric physiotherapists, clinical psychologists and psychiatrists). RESULTS: The extent to which health professionals communicated with school staff, and the way in which they went about it, varied widely. Communication was facilitated by joint meetings, shared documentation, and local policy development. Sources of difficulty in communication between health and education staff were: the parent as a conduit of information; the practical difficulties of arranging meetings; and lack of knowledge about other professionals' roles. The ethos of the school with regard to health matters, and the flow of information within health services, also had an impact on the communication process. Participants' recommendations focused on two key issues: clarification of the roles of health and education staff with regard to this group of pupils; and how information should flow from health to school staff. DISCUSSION: Many of the findings parallel the previous research with teachers, indicating agreement between professionals from different agencies about aspects of the communication process which are problematic and require attention. The findings suggest that improving communication requires both joint work between health and education staff, and improvements to practice within each agency.


Paediatric palliative care management issues in late infantile Battens disease—A case report.

Murphy K, Thom V.

Archives of Disease in Childhood 2002;86(Suppl 1):A76.

Background: Batten’s disease is an extremely rare condition with autosomal recessive inheritance and is a progressive neurodegenerative condition with no known treatment. AIMS: To discuss the difficulty in identifying the terminal phase of...
METHOD: A case report of a child now aged 9 years who was diagnosed with late infantile Battens disease when he was 4 years old.

RESULTS: This boy was admitted to hospital in status epilepticus, he was transferred to PICU when therapy caused respiratory depression. Artificial ventilation was deemed inappropriate and he was transferred to Martin House for terminal care in May 1999. Seizure control was poor and he had frequent apnoeic attacks. While potentially a terminal situation a decision was made to treat his seizures actively. Seizure control was finally achieved with subcutaneous infusions of midazolam and phenobarbitone, gastrostomy administered chlormethiazole and fosphenytoin injections and also by alteration of background anticonvulsant therapy. Subsequent admissions highlighted further dilemmas regarding the degree of intervention for recurrent haematemesis, buttock abscess and pyrexia of unknown origin.

CONCLUSION: This case study illustrates the difficulties in the identification of the terminal phase and in the assessment of the degree of intervention required in children with chronic life limiting illness.

Bereaved parents' use of individual, family, and community resources 4 to 60 months after a child's violent death.

Murphy SA, Johnson LC, Lohan J, Tapper VJ.

Family & Community Health 2002;25(1):71-82.

We recruited a community-based sample of 261 parents bereaved by the violent deaths of their 12- to 28-year-old children. Parents were observed over time, and data were collected from several sources. The findings showed that of six individual, family, and community resources examined, none of the resources seemed to improve parents' outcomes either 1 or 5 years later. Implications of the findings are discussed.

Variant Creutzfeldt-Jakob disease: costs borne by families.

Myles S, Douglas MJ, Ward HJ, Campbell H, Will RG.

Health and Social Care in the Community 2002;10(2):91-8.

The objectives of this study were: (1) to estimate the costs borne by families caring for patients with variant Creutzfeldt-Jakob disease (vCJD); (2) to contextualise results to recent policy initiatives, and (3) to consider the methodological problems of estimating costs of care. Semi-structured interviews and a follow-up postal questionnaire, eliciting costs to families both before and after the patient's death, were carried out. Participants included 19 families of patients with vCJD. Cost profiles were constructed, detailing key time and financial costs associated with their relative's illness and death accruing to families. Main outcome measures included total, median and ranges of relevant cost elements. Sensitivity analyses, comparing high and low cost estimates, were undertaken. The total time cost to families before patient's death ranged between 605 and 9230 hours (median 2006 hours). Applying low cost estimates, families incurred between pound2616 and pound39 588 (median pound14 481) in forgone earnings and between pound2699 and pound18 558 (median pound8049) in marginal sundry costs before the patient's death. The value of care provided by families ranged between pound0 and pound87 303 (median pound9652) at low cost estimates. Many families continued to incur costs after the patient's death, with low cost estimates per week ranging between pound0 and pound176 (median pound29). Costs to families associated with vCJD were substantial and greatly exceeded benefit entitlements. These costs were high even if patients received care in hospital, varied as the illness progressed and continued after patients' deaths. The National Carers Strategy does not consider fully the needs of some groups of carers or the full range or magnitude of potential costs to families associated with caring.

A metasynthesis: mothering other-than-normal children.

Nelson AM.


The author used Noblit and Hare's 1988 comparative method of synthesizing qualitative studies to address the need for collective knowledge development related to mothering other-than-normal children. Twelve studies were included in a metasynthesis for a total sample of 79. The nature of the child's disability, demographics, and methodology used varied widely. Initially, 13 common themes were extracted using reciprocal translation. Further analysis revealed 4 steps common
to the mothering experience under which themes were categorized. Suggestions for application to practice include keeping in mind qualities of a supportive health professional from the mothers' perspective, encouraging mothers to challenge societal definitions of normalcy, and recognizing the significance of hope in fueling maternal caregiving.


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Barriers that delay children and young people who are dependent on mechanical ventilators from being discharged from hospital.

Noyes J.


A qualitative study of user perspectives published previously by the author found that children and young people who are dependent on ventilators spend many months and in some cases years in hospital when they no longer had a medical need or wanted to be there. This second paper is drawn from the same qualitative study and reports on the barriers that the children and young people who are dependent on ventilators, and their parents, described as important factors in preventing their discharge from hospital. Six issues were identified as significant barriers that prevented the children and young people from being discharged. These were: the attitudes of professionals; the lack of joint commissioning and accounting responsibility; general poor management both within the health service and in collaborating with other services; complex social issues; housing problems; and a general lack of auditing and outcome measures. The generalizability of the findings is unknown. However, recommendations are made in relation to the need to establish joint commissioning and accounting responsibility for care and services, and to establish outcome measures to monitor the effectiveness and appropriateness of the care and services provided.


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Children with a chronic and life-limiting condition: Teachers' perceptions and experiences regarding students' school integration.

Papadatou D, Metallinou O, Hatzichristou C, Pavlidi L.


The purpose of this study was to explore the perceptions and experiences of Greek teachers regarding the school integration of students with a chronic and life-limiting condition. This national survey comprised a representative sample of 1,792 educators. Of the sample, 19% (n=340) had at least a child with a serious disease in their classroom throughout their career and were faced with increased academic difficulties and few changes in the child's behavior. Affected by their student's health problem, educators systematically avoided discussing the illness experience with the child and classmates. They tended to become more lenient in their grading, less expectant of high academic performance, and more supportive of the ill child. To facilitate the student's school integration, Greek educators, who felt unprepared to handle such situations, requested training, a closer cooperation with mental health professionals, and ongoing support to effectively handle the experience of a serious illness within their classroom. (PsycINFO Database Record (c) 2002 APA, all rights reserved).

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Between parent and child: negotiating cancer treatment in adolescents.


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. Cancer in adolescents presents an extra dynamic of psychosocial complexity. The case of a 19-year-
old woman with acute myelocytic leukemia is discussed. Her disease was refractory to allogeneic transplantation, and she
died with severe graft-versus-host disease. Ms. P and her mother established very different relationships with the team
which supported them through the transitions in her care, and Ms. P was able to die at home, with hospice care. The
personal connection with the team enabled a degree of positive adjustment through the nightmare of loss. The epidemiology
of cancer in adolescents and paradigms of care are reviewed. Psychosocial aspects of adolescence, opportunities for
personal growth and support, and the challenge of end-of-life care are discussed.

http://theoncologist.alphamedpress.org/cgi/content/full/7/2/154
http://theoncologist.alphamedpress.org/cgi/content/abstract/7/2/154

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**The emotional dimension of children's life-threatening illnesses.**

Quinlan T.

*Positive Health* 2001;71:9-11.

The impact of a child's serious illness affects the entire family.

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**Adolescent coping with grief after the death of a loved one.**

Rask K, M. K, M. PI.


Described adolescent coping after the death of a loved one. Data were obtained by 2 self-report questionnaires filled in by
14-16-yr-old pupils in 2 secondary schools in Finland. The sample consisted of 89 adolescents who had each experienced
the death of a loved one. The instrument used in the study was developed by N. S. Hogan and L. DeSantis. This article
reports the responses to 2 open-ended questions. The data were analyzed using content analysis. The most important factors
that helped adolescents cope with grief were self-help and support from parents, relatives and friends. However, the official
social support system was not experienced as very helpful. No one reported help, for example, from school health services.
According to the adolescents, fear of death, a sense of loneliness and intrusive thoughts were factors that hindered coping
with grief. Some respondents felt that parents or friends were an additional burden on them. The results are discussed in
terms of identifying the different impact of social support, the importance of self-help and professional help. Knowledge of
factors that have an effect on adolescent coping with bereavement is important for families, effective nursing practice,
school health services and parents. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

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**Education and High Quality Community Care.**

Ream E.


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**The ethics and practicalities of consent in palliative care research: an overview.**

Rees E.


In order to ensure that further developments and improvements are made in palliative care, research is essential. Palliative
care is no different from other specialities in that it needs a scientific foundation on which to base its practice. Research in
palliative care is particularly difficult, however, because of the population under study. Research in palliative care presents a
'minefield' of ethical issues. One of the major issues is how to obtain informed consent from patients. This article discusses
the practical and ethical issues surrounding consent for quantitative research in palliative care, and offers some guidance to
health professionals considering the issue with patients.

Bereavement support for couples following death of a baby: program development and 14-year exit analysis.
Reilly-Smorawski B, Armstrong AV, Catlin EA.


Program development, implementation, and a 14-year exit analysis of a bereavement support program for couples whose baby died in the Neonatal Intensive Care Unit (NICU) is presented. A closed, hospital-based, time-limited (12 weeks) format was used. Team leadership was used and 54% of bereaved NICU parents participated. Each group was structured with a 2-week introductory period, open format grief-focused weekly discussions, evaluation in Week 11, and summary session with termination in Week 12. The exit analysis details program strengths, weaknesses, and recommendations. Bereavement support groups are one part of what we contend should be a comprehensive bereavement program, organized to care for families prior to, during, and after a baby's death. A sensitive, spiritually aware, supportive environment should be maintained throughout with relationship building as a cornerstone of the program.


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Shoestrings and bricolage: some notes on researching the impact of a child's death on family relationships.
Riches G, Dawson P.


An earlier version of this paper appeared as the appendix to our recent book, *An Intimate Loneliness: Supporting Bereaved Parents and Children* (G. Riches & P. Dawson, 2000). In it, we attempt to offer a brief history of the processes we have gone through in taking a simple research question, developing it into a practical proposal, experiencing how it shifted as we explored it, accounting for the changes that our broader reading imposed on our perceptions of what we were doing, and, finally, how the data itself and our efforts to understand it, resulted in a set of broad theoretical propositions rather than any tight conclusions.


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New initiatives in end-of-life care.
Rollins JA.


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A prospective, within-patient comparison between metal butterfly needles and Teflon cannulae in subcutaneous infusion of drugs to terminally ill hospice patients.
Ross JR, Saunders Y, Cochrane M, Zeppetella G.


We performed a prospective study of hospice in-patients requiring a syringe driver (SD), to determine the site duration and tolerability of metal butterfly needles compared to Teflon cannulae. Using patients as their own control, prescribed medications were divided equally between two SDs (Graseby MS16a), for delivery over 24 h. A butterfly infusion (Flosafer,
(25 gauge) was connected to one SD and a Teflon cannula (Abbocath-T, 24 gauge), to the second. These were inserted subcutaneously (s.c.) on opposite sides of the body at comparable sites; oedematous, broken or painful sites were excluded. SD sites were examined at 4-hourly intervals. The study was terminated when both devices had required resiting. Needle and cannula times were compared using the Wilcoxon signed rank test. Thirty patients entered the study, 13 males and 17 females, mean age (standard deviation): 70 (11) years. Thirteen patients completed the study. Nine patients died and eight patients discontinued the study before both needle and cannula had been resited. All 30 patients are included in the analysis. The time from insertion to resiting of the cannula was significantly longer than the needle: P < 0.0002, median (range) 93.5 (22.8-263.5) h versus 42.8 (7.5-162.3) h, respectively. The cost of the needle versus cannula is 1.93 Pounds versus 2.51 Pounds, respectively. Teflon cannulae have a median life span twice that of metal butterfly needles and are a cost-effective alternative for administration of medications by s.c. infusion in terminally ill patients.


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Pediatric ethics, issues, & commentary. Pediatric palliative care: the time is now!
Rushton CH, Catlin AJ.

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Rusy LM, Troshynski TJ, Weisman SJ.

Seven children and young adults with phantom limb pain (PLP) were treated with gabapentin. PLP resolved in six patients within two months. One patient still had symptoms to a lesser degree. Mean follow up time was 1.74 years. Gabapentin may be a useful adjunct to pain management in patients with PLP symptoms. (17 ref)

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The personal development of mothers of terminal cancer patients: how Japanese women change through the experience of caring for and losing their children to cancer.
Saiki-Craighill S.

The author interviewed 57 mothers who had lost children to cancer about their experiences concerning their children's illness and death. These mothers became their children's main caretakers because they felt responsible and unable to count on others. They maintained emotional stability while interacting with their children and worked to protect their children from mistakes made by health care professionals. These experiences made many mothers tougher. After their children died, they had to form a different kind of relationship to their children to overcome their grief. This process compelled the mothers to reconsider issues concerning life and death and changed their fundamental values.


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Manual handling and nursing children.
Sales R, Utting J.
Paediatric Nursing 2002;14(2):36-42; quiz 43.

The aim of this article is to highlight some of the unique challenges relating to handling children, such as: their stage of physical and cognitive development, their position in relation to the carer's centre of gravity, their level of comprehension and their ability to communicate.

Choosing continence products for children.

Sanders C.


A wide variety of continence products are available, and the range is changing constantly. Selecting products for children with continence difficulties requires sound knowledge, thorough assessment, regular review, and involvement of the child and family. This article provides some guidance on the products available and how to make an informed choice.


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Surgical and anesthetic decisions for children with terminal illness.

Santos KG, Fallat ME.


Terminal conditions such as congenital anomalies and cancer are a significant source of infant and childhood mortality. Many terminally ill children are considered for operative procedures each year. These procedures may be palliative or elective, and the prognosis and natural course of the terminal illness play a significant role in determining the appropriateness of the surgical procedure. Providing anesthesia to a terminally ill patient is a complex task requiring an appropriate balance between adequate anesthesia and hemodynamic normality. Some children with a terminal condition will have a standing "Do-Not-Resuscitate" order that should not necessarily be reversed. Surgeons, anesthesiologists, and family members must consider a number of factors when determining the appropriateness of an operation for a dying patient, including the rights of the child.


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Therapeutic Work with Children in Pain.

Savis C.

*Paediatric Nursing* 2002;14(5).

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"I learned that no death is routine": description of a death and bereavement seminar for pediatrics residents.

Serwint JR, Rutherford LE, Hutton N, Rowe PC, Barker S, Adamo G.


The American Academy of Pediatrics' statement on palliative care for children emphasizes the need to identify and address barriers to effective palliative care. The authors describe a seminar for pediatrics residents on death and bereavement that addresses these issues. The day-long seminar for second-year residents has been offered annually since 1996. The seminar is conducted offsite so that residents can concentrate without distraction. The seminar uses an intense and comprehensive multidisciplinary approach to accomplish seven goals: (1) to have residents gain expertise in talking with parents about the death of their child; (2) to have residents practice and experience how it feels to be in emotionally charged situations; (3) to train residents to become more knowledgeable concerning autopsy and organ donation, and to learn strategies to approach
these topics with a child's parents; (4) to have residents gain an understanding of the role of the ministry for families who
are grieving; (5) to provide residents with multidisciplinary strategies to support a family after a child has died; (6) to help
residents gain insight into the impact of death on their own emotions and the importance of addressing their own emotions
to cope with stress and potential burnout; (?) and to help residents better understand the parents’ perceptions of the medical
care providers and their dying child. In their evaluation comments, the residents report value from a seminar designed to
help them address issues of patient death and bereavement. This type of educational intervention should be considered for
the curriculum by other residency programs.

http://www.academicmedicine.org/cgi/content/full/77/4/278
http://www.academicmedicine.org/cgi/content/abstract/77/4/278

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The use of standardized patients in pediatric residency training in palliative care: anatomy of a
standardized patient case scenario.

Serwint JR.


The use of standardized patients (SPs) is an emerging strategy in palliative care education. We have used this strategy to
provide pediatric residents with a structured educational experience focused on effectively communicating bad news and
concurrently understanding the emotions that they and the parents may experience. This article describes the importance of
and process for realistic SP case development explicitly designed to address predetermined educational goals and objectives.
Topics addressed include the types of potential SPs that can be utilized, their potential strengths and weaknesses, training
issues which include giving constructive feedback, implementation strategies for the case scenarios and evaluation
strategies.


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The increasing need for pediatric palliative care.

Shah R, Ting T, Taylor P, Glover J.


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Children's hospices: organizational and staff issues.

Sheldon F, Speck P.

Palliative Medicine 2002;16(2):79-80.


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Do not resuscitate (DNR) orders in a children’s unit prevalence.

Sivapiya R, Larcher V, Hird M, Burrows N.

Archives of Disease in Childhood 2002;86(Suppl 1):A76.

AIMS: To determine i) the number of children with Do Not Resuscitate (DNR) orders at the time of death ii) the recorded
process of decision making. METHODS: Retrospective case note review of all children dying between April 1999 to
March 2000. RESULTS: Hospital records of 36 of 58 patients were available: 13 were neonates (<28 days), 8 infants (<1yr),
3 children (1-11 yrs) and 6 adolescents (>11 yrs). Using RCPCH criteria, decisions to discuss changing aims of treatment
were based on: brain stem death in 5, “no chance” in 17, “no purpose” in 13 and “unbearable” in 1. DNR orders were
written in 30 (by consultant in 21 and SpR in 9), reviewed 48 hourly in 6, but only once in 21, and more likely to be written
about neonates than children. Written evidence of families' agreement to DNR was noted in 25, with understanding of
the child's condition in 24. Multidisciplinary meetings were held in 13 and the involvement of advocates and social workers recorded in 8 and 9 respectively. CONCLUSIONS: DNR orders were written for most children in whom records were located. Review of notes suggested that documentation might not be sufficient for UK human rights legislation.

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Life-sustaining support: ethical, cultural, and spiritual conflicts. Part II: Staff support--a neonatal case study.

Stutts A, Schloemann J.


As medical knowledge and technology continue to increase, so will the ability to provide life-sustaining support to patients who otherwise would not survive. Along with these advances comes the responsibility of not only meeting the clinical needs of our patients, but also of understanding how the family's culture and spirituality will affect their perception of the situation and their decision-making process. As the U.S. continues to become a more culturally diverse society, health care professionals will need to make changes in their practice to meet the psychosocial needs of their patients and respect their treatment decisions. Part I of this series (April 2002) discussed how the cultural and spiritual belief systems of Baby S's family affected their decision-making processes and also their ability to cope with the impending death of their infant. The development of a culturally competent health care team can help bridge the gap between culturally diverse individuals. This article addresses the following questions: 1. What legal alternatives are available to the staff to protect the patient from suffering associated with the continuation of futile life-sustaining support? 2. What conflicts might the staff experience as a result of the continuation of futile life-sustaining support? 3. What efforts can be made to support members of the staff? 4. What can be done to prepare others in the health care professions to deal more effectively with ethical/cultural issues?


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Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease.

Tak YR, McCubbin M.


Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease Background. Congenital heart disease (CHD) is now estimated to be the second most prevalent chronic illness. A child's chronic illness may have effects that have pervasive consequences for family life. Recently, attention has focused on resiliency variables, especially social support and coping strategy, regulating the impact of stress. In the resiliency model of family stress, adjustment and adaptation, social support is viewed as one of the primary moderators or mediators between stress and wellbeing. Aims. The purpose of this study was to explore the relationships of family stress, perceived social support, and coping and determine the resiliency factor associated with coping by families who have a child with chronic illness. Design. In a secondary analysis of a large longitudinal study, the sample consisted of 92 families who had a child under age 12 who was newly diagnosed with CHD within the last 3-4 months. Findings. Results from regression analysis revealed that perceived social support operated as a resiliency factor between family stress and both parental and family coping. Child and family characteristics appeared to be the important predictors of perceived social support and parental coping. Although perceived social support appeared to be an important predictor of parental and family coping, neither the moderating nor mediating model was supported in full but partial causal relations were confirmed. Conclusions. Findings provided evidence for the theoretical and empirical significance of perceived social support as a predictor of family coping. Further, these findings suggest that perceived social support is a factor influencing the resiliency of relatively high-risk groups of families who have a child with chronic illness.


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Exploring idealism in palliative nursing care through reflective practice and action research.

Taking the measure of a father's grief.

Thompson GL.


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Defining and determining quality in end-of-life care.

Thompson G, McClement S.


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Attachment and meaning-making in perinatal bereavement.

Uren TH, Wastell CA.


The study examined the psychological impact of perinatal bereavement on 108 women, from a dual attachment and meaning-making perspective, both descriptively and predictively. The study hypothesized that grief acuity is a function of both attachment security (operationalized by A. Antonovsky's 1979 Sense of Coherence [SOC] scale), and the ongoing search for meaning. Controlling for time post-loss, psychological distress and intrusive thoughts; sense of coherence and search for meaning significantly predicted current grief acuity. The findings supported the conceptualization of grief as an interpretive phenomenon, elicited by the loss of a primary attachment figure, thereby shattering core life purposes, and implicating the need to reinstate meaning.

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Spirituality in palliative care: opportunity or burden?

Walter T.


The article questions an assumption in palliative care literature, namely that all patients have a spiritual dimension and that all staff can offer spiritual care. The article identifies spirituality as a particular kind of discourse. In late-modern Anglophone societies, this discourse arises from the experience of a particular generation and a particular segment of the population, namely those moving beyond formal religion; this segment is probably better represented among caring professionals than among dying patients. A four-fold typology of patients' approaches to religion/spirituality is developed, indicating the potential of differentiating between actual patients, rather than presuming a universal 'search for meaning'. This alternative approach may enhance opportunities for team working and reduce the likelihood of any one member of staff feeling spiritual care to be an unwelcome burden.


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Corticosteroids in the palliative phase of paediatric brain tumours.

Watterson G, Goldman A, Michalski A.

*Archives of Disease in Childhood* 2002;86(Suppl 1):A76.

INTRODUCTION: Brain tumours are the second commonest childhood tumours. Long term survival is only 50% so effective palliative care is important. AIM: To assess the benefit and risks of corticosteroids in symptom management in children with progressive brain tumours. METHOD: A case note review of medical and nurse specialist notes, looking at
the use of steroids in palliative care of children who died between 1998 and 2001, attending Great Ormond Street Neuro-Surgery Unit. RESULTS: 60 children died, aged 8 months to 16 years (median 6 years). Complete information was collected for 47 (78%). 33 (70%) received steroids as symptom management and all received analgesics and anti-emetics. 19 (57%) children received a prolonged course of steroids (Dexamethasone), range 5 to 90 day (median 29 days). 14 (42%) children received a short course of steroids, 7 were travelling on holiday. 14 (42%) children had documented relief mainly of headache, vomiting and irritability. However cranial nerve palsies, dysarthria and limb weakness, did not respond as well. 10 (33%) experienced a range of adverse effects; most commonly weight gain, increased appetite and moodiness. All children with adverse effects had a prolonged course. CONCLUSIONS: 1: There was no systematic approach in prescribing the drug. 2: Symptom relief occurred in just under half of the children, and there was a suggestion that ataxia, dysarthria and limb weakness did not respond as well as headache, vomiting and irritability. It was unclear how long the improvement lasted. 3: Side effects occurred in a third of the patients, all of whom had received a prolonged course of steroids. Prospective assessment is required in order to produce guidelines for the use of corticosteroids in the terminal stages of brain tumours.

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Drawings by dying and bereaved children.

Wells T.

*Paediatric Nursing* 2001;13(4):30-1.

Artist and staff nurse Tricia Wellings makes the case for considering children's drawings as a communication tool, but warns of the practical and ethical implications for nurses.

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Willis CA.


Just like adults, children of all ages need time and understanding in order to process the concept of death and dying. This process is much different for children than it is for adults. There are 4 components relative to children's understanding of death: (a) the irreversibility factor, (b) finality, (c) inevitability, and (d) causality. These 4 components relate directly to the developmental level of the child at the time the death occurs. Knowing how children's concept of death is constructed provides parents and caregivers important information and helps them respond more sensitively to what children might feel and experience. This article provides an overview of how children understand death, concrete strategies for talking to children about death, and suggestions for teachers about how to help children through grief and mourning. (PsycINFO Database Record (c) 2002 APA, all rights reserved)(journal abstract)

URL: [http://www.wkap.nl/journalhome.htm/1082-3301](http://www.wkap.nl/journalhome.htm/1082-3301)

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Workforce planning and community children's nurses: it's all in the advertisements.

Winter AM, Teare J.

*Journal of Child Health Care* 2002;6(2):84-95.

This paper outlines a study exploring job advertisements for community children's nurses (CCNs). A post-structural approach was taken to illuminate the development of community children's nursing services (CCNS) and the profile of characteristics, skills and caseload within a workforce-planning context. An analysis of 100 advertisements looked at title, skills, caseload, qualifications and evolving roles. The analysis comprised an initial quantitative descriptive account of data, followed by further analysis of the text using thematic analysis and coding. The skills identified were compared to those identified by Proctor et al. (1999). The most commonly occurring skills were interpersonal (35%), multi-professional team working (33%), clinical (28%), management (18%) and leadership (16%). The analysis was limited, but provides a unique insight into employers' perceived needs in providing CCN services, evolving titles and roles and could inform practitioners, contribute to service evaluation, future service provision and workforce planning.

In their own words: The lived experience of pediatric liver transplantation.

Wise BV.


Examined the experience of pediatric liver transplantation from the child's perspective as a transplant recipient, using a phenomenological approach. For nine 7-15 yr olds (at least 1 yr post-transplant), experiences were examined from the period prior to transplantation, through surgery, and beyond. Results of in-depth conversations (in homes or outpatient settings) show that the children faced many challenges, including surviving a life-threatening illness while accomplishing normal developmental tasks. The predominant theme was striving for normalcy in their lives. The success of transplantation was seen more in the children's ability to balance reality and illusion than in measuring liver function. Implications for health care practice are discussed. (PsycINFO Database Record (c) 2002 APA, all rights reserved)

Caring for dying infants: experiences of neonatal intensive care nurses in Hong Kong.

Yam BM, Rossiter JC, Cheung KY.


Ten registered nurses working in a neonatal intensive care unit in Hong Kong were interviewed to explore their experiences of caring for infants whose disease is not responsive to curative treatment, their perceptions of palliative care, and factors influencing their care. Eight categories emerged from the content analysis of the interviews: disbelieving; feeling ambivalent and helpless; protecting emotional self; providing optimal physical care to the infant; providing emotional support to the family; expressing empathy; lack of knowledge and counselling skills; and conflicting values in care. The subtle cultural upbringing and socialization in nurse training and workplace environment also contributed to their moral distress. Hospital and nurse administrators should consider different ways of facilitating palliative care in their acute care settings. For example, by culture-specific death education, peer support groups, bereavement teams, modification of departmental policies, and a supportive work environment. Future research could include the identification of family needs and coping as well as ethical decision-making among nurses.


Development and testing of the parental coping strategy inventory (PCSI) with children with cancer in Taiwan.

Yeh CH.


RATIONALE: This study describes the development and psychometric testing of the parental coping strategy inventory (PCSI). METHODS: The PCSI was developed on the basis of previous qualitative study on the Taiwanese parental adaptation process, when caring for children with cancer. In order to develop the measure of parental coping strategy inventory (PCSI), relevant parameters or items for the assessment subscales were then identified and tested in a three-stage process: item development, content validity testing and reliability testing. The PCSI consisted of 48 items in 12 scales after item selection, and the internal consistency of the scales were acceptable. In order to test the psychometric characteristics of the PCSI, data were collected from 183 mothers with children with cancer. RESULTS: Confirmatory factor analysis supported a good overall model fit of the construct validity of PCSI. In order to test the generalizability of the factor structure, mothers with children with epilepsy were used. The factorial validity of PCSI was supported from the population of those mothers with children with epilepsy. CONCLUSIONS: This version of the PCSI was developed with an explicit prior conceptual model based on grounded qualitative study findings. The PCSI is a specified coping behaviour measure with the conceptual framework that adaptation problems can be solved through specific coping strategies. It can be administered in 20 minutes and is the first documented measure of the adaptation process administered directly to Taiwanese parents. It demonstrates acceptable psychometric properties and could be used as a quick screening instrument in evaluating parental problems when caring for children with cancer as well as chronic illness (such as epilepsy, as tested).
could also be used as a predictor of parental adaptation outcome. This report presents preliminary data on the initial instrument development and psychometric properties of PCSI.


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Health-related quality of life in pediatric patients with cancer. A structural equation approach with the Roy Adaptation Model.

Yeh CH.


The purpose of this study was to test the Roy Adaptation Model-based theory of health-related quality of life in Taiwanese children with cancer. The environmental stimuli included severity of illness, age, gender, communication with others, and understanding of the illness. The severity of the illness was considered as a latent variable construct, including the stage of illness, laboratory values, and number of hospitalizations. Biopsychosocial responses, that is health-related quality of life, was hypothesized as a latent variable that consisted of (1) physical function, (2) psychologic function, (3) peer/school function, (4) treatment/disease symptoms, and (5) cognition functions. In total, 102 children with cancer participated in the study. Structural equation modeling was used to examine 2 Roy Adaptation Model-based theory propositions. The findings showed that the construct of severity of illness demonstrated excellent fit with the stage of illness, laboratory values, and total number of hospitalizations. Second, the health-related quality of life also demonstrated good construct validity with 5 domains. Third, this study supported the Roy Adaptation Model-based theory proposition that environmental stimuli influenced biopsychosocial responses.


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BOOKS AND REPORTS

Hospice Care for Children.

Armstrong-Dailey A, Zardock S, editors.


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Financial implications of the death of a child.

Corden A, R. S, SP.


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Health care & spirituality: Listening, assessing, caring. Death, value and meaning series.

Gilbert RB, editor.


Includes chapter by Dominica, F. The terminally ill pediatric patient.

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Handbook of crisis counseling, intervention, and prevention in the schools. 2nd edition.
Sandoval J.


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**Helping bereaved children: A handbook for practitioners. 2nd edition.**

Webb NB.


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**Grief counseling and grief therapy: A handbook for the mental health practitioner. 3rd edition.**

Worden JW.


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**Living with childhood cancer: A practical guide to help families cope.**

Woznick LA, Goodheart CD.


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