PaedPalLit

A literature search for all those working with children with life-limiting conditions

Editors: Richard Hain, Anne Hunt, Sat Jassal, Angela Thompson
How to use PaedPalLit

PaedPalLit is a tool for keeping track of articles relevant to the care of children with life-limiting conditions, from a wide range of professional journals.

PaedPalLit is available in three formats:

- The **electronic version** is published on the ACT website ([www.act.org.uk](http://www.act.org.uk)) and can be freely accessed.

- This **paper format** is distributed free to ACT members. Details on becoming a member of ACT are on the inside back cover.

- A **searchable electronic version** can be delivered by email to ACT members, in Word or Acrobat formats.

*Comments and suggestions:* please let the Editorial Team have feedback on info@act.org.uk

Dr Richard Hain  
LATCH Senior Lecturer in Paediatric Palliative Care  
University of Wales College of Medicine

Dr Anne Hunt  
Nurse researcher in Paediatric Palliative Care  
RCN Institute, Oxford  
& Institute of Child Health, London.

Dr Sat Jassal  
Medical Director,  
Rainbows Children’s Hospice, Loughborough

Dr Angela Thompson  
Associate Specialist in Paediatrics  
Palliative Care Lead  
North Warwickshire Primary Care Trust
Table of contents

LETTER FROM THE EDITORS

INVITED PAPER. MODELS OF CHILD HEALTH CARE AND PAEDIATRIC PALLIATIVE CARE RESEARCH. H. SIDEN MD, MHSc

SELECTED ABSTRACTS

Parents experience of caring for a child with life-limiting or life-threatening illness
Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals.
Experiences of families in which a child has a prolonged terminal illness: modifying factors
Stress in families with medically fragile children
Parenting in a crisis: conceptualising mothers of children with cancer
Commentary

Symptom control and the care of children with cancer
The spectrum of neurologic disease in children with systemic cancer.
A typology of fatigue in children with cancer.
The school experience of the child with cancer
Palliative care and the child with cancer
Commentary

Miscellaneous
Itch: scratching more than the surface
The assessment and management of chronic pain in children
Observational visual analog scale in paediatric pain assessment: Useful tools or good riddance.
Supportive care: Palliative care in children, adolescents, and young adults – model of care, interventions, and cost of care: A retrospective review
An ecology of love: Aspects of music therapy in the paediatric oncology environment
The use of drugs beyond licence in palliative care and pain management

Other journal articles identified

Books
LETTER FROM THE EDITORS

In previous editions abstracts for inclusion in PaedPalLit have been identified by searches of online databases including Pubmed, Cinahl, and PsycINFO. The abstracts have subsequently been reproduced in the printed and online versions. We are in the process of resolving some issues around copyright and meanwhile are trying a new approach. In this edition of PaedPalLit, the editors have each selected a group of papers, provided an abstract of the paper and written a short commentary, either on the theme of the papers or on each individual article. We would be very pleased to hear from you on what most suits your needs so that we take this in to account in our deliberations as to how we should proceed with the ‘journal’. We would also be very happy to receive letters to the editors in relation to aspects of paediatric palliative care which may be reproduced in PaedPalLit.

Another new innovation is to include an invited paper. In this edition it is from Hal Siden. Hal is medical director of Canuck Place, the hospice for children in Vancouver. We very much appreciate his contribution. It is thought provoking and we hope that it may generate correspondence to the editors.
INVITED PAPER

Models of child health care and paediatric palliative care research
H. Siden, MD, MHSc

Paediatric Palliative care research faces a number of challenges. The challenges include difficulty in conducting clinical trials, small numbers, lack of funding, challenges to recruitment, paucity of assessment tools, and evaluating outcomes in a heterogeneous population. Some of these challenges are common to the broader field of paediatrics and others are common to palliative care research.

There is an additional obstacle that hinders our efforts both to undertake research and to develop clinical programs. That obstacle is a lack of clarity regarding the model or paradigm that encompasses paediatric palliative care. What do I mean by a model? Models, or alternatively paradigms, help us organize our thoughts about the world. I suggest that we have this obstacle because paediatric palliative care teams do not work with a single model; instead they operate with, and in-between, several distinct healthcare models. In addition, some of these are not dominant paradigms within healthcare thinking, and are thus challenged by the more predominant ones. If paediatric palliative care is able to establish itself in relation to these models, I suggest we will then see better opportunities for research, program development and policy formulation.

Models of Paediatric Health Care: A Framework

I will approach this topic by proposing an overall framework of models of paediatric healthcare, and then placing paediatric palliative care within this framework. Evidence for existence of these models comes from studying the general literature and grants. These models are characterized by their focus of interest, the kinds of questions they ask, and expectations around change and intervention. Much of the thinking regarding these models is informed by my perception of the different kinds of research underway. I do not use the term research in its most narrow sense of grant-funded, publishable science. A more accurate term, but less familiar, is inquiry. The term includes publishable science but extends from that all the way to the clinic or bedside, where practitioners ask themselves questions about the patient at hand. One finds evidence for clinical inquiry in the literature, by the nature of the kinds of questions researchers are trying to answer, and the stated relationship of that research to clinical care. For the purposes of this paper, however, I will stick to the more common term, research.

I wish to propose, that from my standpoint as a paediatrician, there are at least 4 active models currently in discourse. I label the 4 models as 1) the Well-Child model 2) the New Morbidities model 3) the Disease model and 4) the Chronic Condition model. Three of the 4 models are of relatively recent origin, while one is much older and much more powerful. I will have more to say about how the models interact with each other, and how patients (and clinicians) interact with the models.

The Well-Child Model

The Well-child Model is especially prominent in North American Paediatric and Family Medicine primary care literature. This model takes for granted that much of the mortality and morbidity present until the early twentieth century have been eliminated, and that the challenge is to consolidate gains through improved care of the healthy child. (It is acknowledged that problems of basic health remain in the developing world). In other words, how do we maximize the gains made by biomedical-psychological science in the 20th century? Examples of this work include research into anticipatory guidance, studies of breast feeding, efforts to improve auto safety, management of sleep disorders and colic. This paradigm explicitly adopts a “wellness” rather than an illness approach.

One of the contributions of this work has been to stimulate renewed thinking into basic physiologic processes that are still not well understood, such as infant state regulation, and how those concepts can be applied to help children and families.
The New Morbidities Model

A closely related model is the "New Morbidities" Model, taken from a term coined a decade ago. Like the Well-Child model, this paradigm recognizes that the traditional scourges of childhood, namely the major infectious diseases, have been contained. The new morbidities include diseases with large social and behavioural components, such as fetal alcohol syndrome, exposure to violence and obesity in adolescents. Conditions that intersect between paediatrics, psychiatry, and neurology, such as Attention Deficit Hyperactivity Disorder and complex learning disabilities fall into this category.

Unlike the Well-Child Model this is not a wellness paradigm at all. Instead it attempts to look at complex dis-abilities of children as a combination of bio-psycho-social factors. There are several salient descriptive features for this model. One is that the diseases or conditions are assumed to be driven by social forces, although there is interest in the biological components, such as genetic vulnerability in certain populations. Second, both researchers and clinicians must work in inter-disciplinary groups, as many of these conditions are closely identified with other social institutions, and have their greatest impact there: for example, ADHD and the school system. Finally, because they do not have a readily explainable biological mechanism, workers in the New Morbidities fields must discuss even the basic nosology and taxonomy.

The Disease Model

The Disease Model is the dominant model of modern Western health care. It is based upon illness within organ systems where it identifies aberrancies in underlying physiology and pathology. This is the realm of disease. This area of work is often "organ" based, such as the heart, the brain, the respiratory system, and the blood-forming organs. Other times, it is disease-based, for example infectious diseases. The model has in common powerful biological explanations for the inciting event, an understanding of the underlying normal and abnormal physiology, and ideas of where (or where not) to intervene.

This is the classic paradigm of medicine, and leads us to think about diagnosis, prognosis, cure or failure. Its impact on our thinking is head and shoulders above those of the other models.

There are examples within this paradigm where conditions or diseases are actually self-limited, but may require professionals’ intervention for accurate diagnosis, prognostic reassurance and symptom management. In other situations prevention of uncommon but untoward sequelae is important. For example, many episodes of otitis media are viral-induced and self-limited; one rationale for treatment is to cure the bacterial induced episodes and prevent progression to mastoiditis or meningitis.

The recent development of the varicella zoster vaccine is another example -- on the basis of significant morbidity and mortality, the chickenpox vaccine may not be a priority; however, the rare but devastating consequences and the costs to society were sufficient to warrant implementation.

Within this model I include conditions that are not self-limited, (and in fact may be fatal) except that we have developed powerful tools for treatment. This is the bread and butter of high-tech medicine; examples that we are all familiar with include prematurity, congenital heart disease and cancer.

Some of these conditions, once "cured" do not require much further attention -- pyelonephritis would be an example. Others, such as leukemia, can be cured, but attention is needed because of recurrence, or side effects of treatment. Other times attention is paid to late complications that we cannot fully prevent, such as coronary artery aneurysm in Kawasaki disease.

In summary, this model concentrates on organ-based illness, where there is some expectation of cure or resolution. A good outcome is usually achieved through skilful intervention, but sometimes through the natural course. Standard inquiry in this model looks at: better understanding of the pathophysiology, even at the molecular level; at improving outcomes with better therapy; with learning about late complications as our therapy improves. While much inquiry is biologically-based, more recently there has been increasing recognition of the social and personal aspects of the disease or treatment.
The Chronic Condition model

The fourth model describes the investigation and treatment of conditions that cannot be cured, are life long, and sometimes life-limiting. Some of the conditions can be managed well, even though they cannot be cured, with better understanding of the underlying biology and tools for intervention. Other conditions, for example severe neurological impairment with CNS Dysgenesis (so-called cerebral palsy) are sometimes even challenging to manage. It appears that there is a relationship between our understanding of the biology, our tools for intervention, how close we are to cure and the nature of inquiry. A comparative spectrum can be developed with the examples of cystic fibrosis, muscular dystrophy and severe neurologic impairment.

For these conditions there is not even a guarantee that we understand the basic underlying biology; therefore, research in this area covers a great deal of ground between basic biology and social science. Overall, there is great recognition in this group of the holistic nature of the conditions precisely because they are chronic, fixed and not amenable to curative interventions.

How does this model differ from the New Morbidities Model and the Disease Model? It can be distinguished from the New Morbidities group because of the strong biological component underlying these conditions. The pathophysiology often means that the Chronic Conditions may not be compatible with a normal life span or fully functional health. The model also differs from the Disease Model because the conditions are usually not single-organ based and are not “cured” or resolved. Admittedly there are close similarities and overlap with these other two models (which I will discuss below). But it should be realized that what this model really describes are *conditions* as opposed to *illnesses*. An illness represents disruption of a previous healthy state leading to cure, resolution or death. A condition is a description of a state. For example, severe neurological impairment (SNI, sometimes mislabelled “cerebral palsy”) is not an *illness* in the sense that it does not necessarily represent an acute or temporary derangement of the previously normal physiology. Instead, SNI is a *condition* with its own homeostasis. Thus, the child with cystic fibrosis, despite the deterioration of physiologic status, may experience being “well”, through participation in school, activities, friendships and describe periods of good “health”.

The Interaction Of The Models, The Patient And The Clinician

The models as described are not meant to be treated as rigid; they are flexible, and interact in several ways. First, the models should not be thought of as deduced from any inherent quality of the illness/condition or of the child. Instead, the model is a characteristic of the inquiry; that is the research, the literature and our thinking about it. An individual child, groups of children and diseases/conditions, will predominantly but not exclusively locate within one or another of the models.

Second, there can be transition and overlap (as one of my teachers used to say, you can have measles and a broken arm at the same time). A child may move between models, or a disease/condition can relocate itself entirely from one model to another. These phenomena occur in different patterns.

A child may “shift” if their health status changes. A simple example is when a previously healthy child (located in the Well Child model) develops an acute illness, and is seen through the lens of the Disease Model. Patients may move in the opposite direction; for example, corrective cardiac surgery may take a child from the Disease Model into the Well Child model. A transition we are familiar with in paediatric palliative care, but are still challenged to contend with, is the child whose transition is from the Disease Model (cure / resolution) to the Chronic Condition Model. Sometimes this particular transition occurs because of unanticipated results, for example, the child with cancer who does not achieve an “expected” cure. That child shifts from an expectation of disease treatment leading to cure into an expectation of management of symptoms with life-limitation and/or chronicity. Children may shift therefore because of the onset of disease, natural resolution, therapeutic intervention, or the failure of that intervention.

Alternatively, the entire underlying disease of condition can relocate its “home” model over time. When this happens, it may be the direct result of clinical research with better understanding of the biology and improved
treatment. For a childhood example, polio is now discussed in regards to its eradication through vaccination not as regards to treatment. One of our hopes is that a condition like cystic fibrosis will eventually shift from the chronic model to the curable disease model.

Since the models are not mutually exclusive and since the model is defined by its dominant inquiry, a child can be within two models at the same time – for example, the child with muscular dystrophy may have a learning disability requiring educational modifications. This lack of exclusivity means that perspective is also important-- parents, patient and different healthcare providers may all see the situation through the lens of different models, reminding us of the story of the 5 blind men and the elephant.

**Implications of the Models for Paediatric Palliative Care**

For physicians (and nurses) working in paediatric palliative care, one particular challenge for both our research and our program development is that we work between different models, especially the third and the fourth. The field of paediatric palliative care started with the failures within the Disease Model, notably in oncology, but soon begun to include conditions in the Chronic Conditions model, for example the neurodegenerative conditions.

So here we have several moving targets. One moving object is the clinician because he/she must work with patients potentially located in different models of inquiry. The second moving object may be the patient themselves as they move from a curative to a non-curative state, and therefore from one model to another. The third moving object may be the underlying disease or condition, which may drift or relocate, as we learn to intervene and change the natural course. Finally, a “fixed” obstacle as seen through this lens may be our colleagues, who see themselves as primarily residing within only one particular model. It is easy to recognize the obvious communication problem that ensues when clinicians speak from different understandings.

In some ways, I don't think that the challenge of research for paediatric palliative care is because we work in a "particularly difficult" arena. While we may complain about study recruitment, randomization and ethics, is it really any harder than any other areas of paediatrics? (I am always amazed that researchers can find parents and children willing to enter even the simplest randomized clinical trial.) I think one of our biggest challenges is defining our work in relationship to models where the patients, families, and sometimes the conditions themselves are shifting all of the time - defining that work for ourselves, for the programs and funders, and then for research.

This conceptual work regarding models of child health care is still in its early stages. The next steps will be to refine these models/paradigms; test them for fit; determine whether there are additional or different models; better describe our work as between and within different models; and finally define the specific kinds of research questions (and inherent clinical questions) that are compatible with these models.

**SELECTED ABSTRACTS**

*The following four papers examine the experiences of parents caring for a child with a life-threatening or life-limiting condition.*

**Stresses and coping strategies of mothers living with a child with cystic fibrosis:** implications for nursing professionals.

Hodgkinson, R. and Lester, H.


**SETTING. UK. Children with Cystic Fibrosis (CF).** AIMS. To explore the current stresses and coping
strategies of mothers of children with cystic fibrosis and to identify roles and strategies that nurses could extend or adapt to support them and the families generally. METHODS. Semi-structured interviews with 17 mothers of children with cystic fibrosis. Data analysed using Framework Analysis, a method based on Grounded Theory where theories are developed from the data. FINDINGS. Three themes were identified in relation to maternal stress 1) feelings of being in the middle in terms of decision making 2) the burden of responsibility and 3) coming to terms with a personal change in identity. The most commonly used coping strategy was seeking support from others. Relationships with health professionals in secondary care were generally positive, however relationships with primary care health professionals appeared to be more limited. Here some mothers described how the roles were reversed and they felt it was their responsibility to educate and inform the primary care professionals about CF. Nurses often were the first people mothers turned to when they had concerns and were also key interpreters of medical information. Strategies which encourage relationships between health professionals and parents are - acknowledging the parents’ effort, recognising the burden of responsibility they carry and holding hope for the family. CONCLUSIONS. Nurses in primary and secondary care have a role as holders of hope, bridge builders between medical and nonmedical worlds and in providing continuity of care for families. To optimize care, there is a need to look beyond the care of the child to the needs of the mother and to recognise and foster their individuality.

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

SETTING. Canada, children with neurodegenerative life-threatening illness (NLTI). AIMS. To investigate the experience of families when a child with NLTI is dying at home – in particular, to describe families’ perceptions of the factors that influence their ability to care for their child, and the intervening conditions that facilitate or restrain them. METHODS. Grounded Theory. Observation of and interviews with 29 members of 8 families with 10 sick children. FINDINGS. Families moved through a process of ‘navigating uncharted territory’ as they lived with their dying child. The strategies that families used to manage this phenomenon were influenced by four intervening conditions that reflected the broader structural context of the phenomenon, namely, relationships with healthcare providers, availability of information, gender differences, and communication between parents. Each condition facilitated or constrained the strategies that families were able to use. CONCLUSIONS. The study reinforces the need to relate to families as partners in care, neither to control or to abandon them.

Stress in families with medically fragile children
Ratliffe, C. E., Harrigan, R. C., Haley, J., Tse, A., Olson, T.

SETTING. USA. Medically fragile children. AIMS. To identify the causes of stress for families of medically fragile children. METHODS. A literature search of Medline and Cinahl for data-based papers related to medical fragility, technology dependence, families and stress and a search of the reference lists of retrieved papers. Themes from retrieved papers were recorded in a data-collection table and constant comparative analysis used to generate a model of unifying themes. FINDINGS. 24 relevant papers were retrieved. Four core themes were identified under which most of the stressors identified in the literature could be grouped. These were role conflict, financial burden, care burden, and independence. These were in turn arranged as a matrix in which the family, the child, the care professional, and health care system interact dynamically with the four core themes.
Parenting in a crisis: conceptualising mothers of children with cancer
Young, B., Dixon-Woods, M., Findlay, M., Heney, D.

SETTING. UK, Children with cancer. AIMS. Drawing on writings from the sociology of care-giving, motherhood and childhood, this study aims to investigate the experience of mothers living with a child with cancer and in so doing to contribute to the literature on the experience of being a parent of a sick child.

METHODS. Semi-structured interviews with 20 mothers of children aged from 4 to 17 years who had a confirmed diagnosis of leukaemia, malignant tumour or brain tumour. Data analysis was based on the constant comparison method of Glaser and Strauss (Grounded Theory).

FINDINGS. The authors suggest that mothers, although not ill themselves, experience many of the consequences of chronic illness. Biographical disruption begins for them when they first notice something wrong with their child, and intensifies with diagnosis, altering their sense of self and their social identity. The diagnosis brings with it a set of new responsibilities and role expectations, including an obligation of 'proximity'-being physically close to their child at all times to provide 'comfort' and 'keep-watch'. For mothers, caring evokes an intense emotional interdependence with their sick child, and involves a range of technical tasks and emotional work, including acting as 'brokers' of information for their child and managing their co-operation with treatment. Managing these obligations was achieved at high cost to the mothers themselves, and resulted in severe role strain by compromising their ability to function in other roles, including their role as the mother of their other children. Against the backdrop of a severe and life-threatening illness, everyday concerns about their child's diet or appropriate discipline take on a new significance and carry a heightened potential for generating conflict and distress for mothers. In presenting their accounts, mothers draw on prevailing cultural discourses about motherhood, childhood and cancer, and these clearly influence the context in which they care for their child, and shape their reflexive constructions of their experiences.

CONCLUSIONS. Caring for a child with cancer had many adverse implications for the quality of life of the women studied. Mothers of a child with cancer warrant study in their own right, and such study benefits from interpretative perspectives. The authors emphasise the importance of supporting mothers in ways that enable them to fulful their role as parents of a child in crisis.

COMMENTARY
Each of these four papers explores parents' (mainly mothers') experiences of caring for a child with a life-limiting or life-threatening conditions. The three original studies come from different settings but use similar qualitative methodology (Grounded Theory) to explore the issues, whilst Ratcliffe and colleagues attempt, not altogether successfully perhaps, to conduct a form of meta-analysis of previous qualitative research in the area. Unifying themes across the studies include

- Personal – parents experience of a change in their identity, role conflicts, effect on relationships within the family, loss of independence and reduction in quality of life.
- Burden of care – the responsibility and tasks of caring.
- Interactions with professionals - the ways in which actions of professionals can assist or impede the mechanisms parents use to manage their new role.

Young et al., (2002), from a sociology background, are critical of the more commonly used psychological models which tends to view the dis-stress experienced by parents in this situation as pathological. They cite Sloper (2000). Another example might be Mastroymnopoulou et al., (1997) who found that a high percentage of mothers scored above the cut-off on the General Health Questionnaire (GHQ), a widely used scale for identifying psychiatric disorder in the community. The scores for mothers were higher than for the fathers in their study and higher than women in the general population. The authors suggest that being a woman in itself is significantly predictive of adjustment difficulties. However, in drawing these conclusions it would be important to consider, as Mastroymnopoulou and co-authors themselves suggest, whether the scale being used equally accesses the forms of difficulties that both mothers and fathers might have. Rather than see the responses as pathological, Young et al (2002) suggest these are the normal responses of parents to their abnormal and painful situation. It could be necessary, therefore, to set revised norms on measurement scales such as the GHQ for parents undergoing such life altering experiences.

Steele (as did Mastroymnopoulou et al) found that fathers did describe different experiences from mothers
and responded differently. But such responses need to be viewed within a context in which societal and individual expectations leads individuals to take on different roles and responsibilities in the family and in society more generally. It has been noted that although this can lead to discomfort, as described by both Steele (2002) and Mastrovannopoulou et al (1997), it can also be adaptive. Whilst one parent is feeling particularly vulnerable the other may be able to adapt and continue to function in their role as caregiver or as family provider. Authors of the studies reviewed here urge health care professionals to recognize and foster the individuality of parents, not to abandon or attempt to control them but to support them in their parenting roles. Further research in to how fathers experience living with a life-limited child is needed. The papers by Steel (2002) and Young et al., (2002) are particularly recommended. (AH).

References cited:

-------------------

The following four articles look at symptom control and care of children with cancer.

The Spectrum of Neurologic Disease in Children with Systemic Cancer.
Antunes NL.
Paediatric Neurology 2001; 25(3): 227-235

SETTING. USA. Children with systemic cancer requiring neurologic consultations (requested by paediatric department). AIMS. To determine the spectrum of neurologic disease in children with systemic cancer. METHODS. Prospective data collation by means of existing computer database. Data was collected re main complaints (up to three), diagnoses (up to three), neuroradiologic investigations, cancer status, aetiology and demographic information. Patients attended Memorial Sloan-Kettering Cancer Centre, New York (528 consultations, 372 patients). Data gathered at neurologic consultation by author (paediatric neurologist with specialist training in neuro-oncology). FINDINGS. Headache (18.3%) was the most common complaint, then altered mental status (8.4%) and back pain (7.1%). Migraine was the commonest form of headache. Of those with recent onset headache, 31.2% had abnormal neurological examination.10.9% of those with normal neurologic examination had CNS infections or space occupying lesions. In this study, none of those with a headache of chronic nature (present for 3 months or longer) had structural lesions.52.1% of those with back pain had metastatic disease, as did 41.7% of those with neck pain. Structural disease accounted for 33.3% of altered mental status and 41.3% of seizures. 25.2% suffered symptoms as a direct result of effects of the cancer on the nervous system, 27.7% were iatrogenic in aetiology (29.5% due to chemotherapy, 41.8% due to other medications, especially opioids). Headache was twice as common in children with leukaemia and lymphoma as those with solid cancers, but back pain was rare in haematological malignancies but common in solid tumours. Chronic headaches were common in children in remission. Neuroradiologic studies were abnormal in many cases, with 63% of magnetic resonance imaging being diagnostic. CONCLUSIONS. Neurologic complications are common in children with cancer. Headaches appear twice as frequent as back and neck pain. A normal neurologic examination does not exclude significant intracranial pathology, and neuroradiologic study, preferably MRI should be carried out in any child undergoing treatment for cancer who presents with a headache of unknown aetiology. A child in remission who has a chronic headache, is unlikely to have structural disease. Neck or back pain was a very serious symptom in this series of patients, more than half having metastatic disease. Headaches, seizures and altered mentation are more common in haematological malignancies, but focal weakness is more common in solid tumours. Children with cancer suffer from complex neurologic symptoms which benefit from assessment by a paediatric neurologist with a thorough knowledge of paediatric cancer, including its effects and complications.
A Typology of Fatigue in Children with Cancer.
Davies B, Whitsett SF, Bruce A, McCarthy P.
Journal of Pediatric Oncology Nursing 2002; 19(1):12-21

SETTING: USA and Canada. Children with cancer. Oncology departments of two regional children’s hospitals. AIMS. To produce a detailed description of fatigue in children with cancer, fatigue being poorly and only recently described in the literature. METHODS: Children aged 5 to 15 with leukaemia or lymphoma were recruited through notices in the inpatient and outpatient units of the oncology departments of two regional children’s hospitals. All were interviewed within 36 months of diagnosis, by individuals trained in interviewing techniques. Children and parents were interviewed separately. FINDINGS: Energy was a core concept in the descriptions of fatigue. A process of losing and restoring energy was described, both as a sudden plummet and a gradual decline, often being unpredictable, and leaving the child feeling ‘drained’. A typology of fatigue comprising of typical tiredness, treatment fatigue, and shutdown fatigue, was identified. ‘Typical tiredness’ was an expected response to events or circumstances, involving the use of energy. It was short lived, responded to relaxation or sleep, had a predictable trajectory, was understandable, and consequently did not cause anxiety. Treatment fatigue was often initiated by hospitalisation, chemotherapy, radiotherapy, and surgery, and was exacerbated by noise, interrupted sleep etc so that the ‘never ending tiredness’ was not fully restored by sleep or rest. The children identified heavy mental demands of having people constantly around. Shutdown fatigue was differentiated in its intensity, duration, and immobilising effects, being described as sustained or profound energy loss. Children entered a ‘hibernating phase’ in an attempt to conserve energy. Participants developed different strategies for the different typologies of fatigue, aimed at replenishing, conserving and preserving energy, and variables which increased or inhibited the strategies were identified. CONCLUSIONS. Children in this study experienced fatigue as unpredictable, bothersome and sometimes frightening. Identification of the type of fatigue experienced appears to help establish which strategies would be most likely to be effective in managing the symptoms, and has implications for clinical practice.

The School Experience of the Child with Cancer
Vance YH, Eiser C

SETTING: UK. Children with cancer. AIMS: To summarise what is known about the school experience of the child with cancer, in terms of how it affects school attendance, classroom behaviour, social relationships, and how effective intervention programmes are in promoting school attendance and adjustment. METHODS: Database search from Jan 1981 to March 2000 of Web of Science, Psyclit, Medline, Cinahl and BIDS. Papers in English, focusing on children aged 5-18 years at all stages of cancer treatment and their school experience were included. FINDINGS: 42 papers were identified, 18 addressing issues of absence, 19 the child’s behaviour, 11 the child’s social relationships, and 13 reported results of intervention programmes. School absence was identified as a big problem at all stages of the children’s illness, including the phase after completion of treatment. Absence is greatest in the year after diagnosis and then gradually decreases with time. Children with cancer have more absences than those with chronic conditions; those with solid tumours have more absences than those with leukaemia; those who relapse miss more school than those in remission. Although absences decline with time, they remain a problem long past the original diagnosis. In terms of effect upon classroom behaviour, authors generally reported children with cancer as no different from peers in willingness to attend school, or in age-inappropriate behaviours, but were considered to have less energy, and had more difficulty concentrating and completing tasks. In terms of affect upon social relationships, teachers were generally asked to assign children to one of three roles as if acting as a casting director of a play. The roles were sociability-leadership, aggressive-disruptive, and sensitive-isolated. Children treated for malignancies were more often chosen for roles involving sensitive-isolated behaviours. Assessment of intervention programmes successes at improving
school attendance and behaviour suggested that classmates may benefit from short intervention sessions, looking at causes and treatments of cancer, and teachers become more confident in dealing with school re-entry when they are informed about childhood cancer. CONCLUSIONS: Whilst school absence for children treated for cancer decreases with time, it remains a concern for many survivors. The evidence regarding behaviour problems in school is variable, but children with cancer are generally regarded as more sensitive and isolated than peers. Although many children with cancer return to school successfully, some are at special risk, and future research to distinguish between children who differ in vulnerability, would be useful, to aid focus upon support for those in special need.

Palliative Care and the Child With Cancer
Collins JJ
Hematology and Oncology Clinics of North America 2002;16:657-670

SETTING. Australia. AIMS: To address the core psychosocial and physical issues in the palliative care of children with cancer. METHODS. Literature review. FINDINGS. There is an increasing awareness that palliative care should be integrated into the care of any child with cancer, irrespective of their geographical location. Many children experience substantial physical suffering in the last month of life. Barriers to the integration of palliative care were identified as lack of formal courses in paediatric palliative care, trial and error learning in caring for dying children, lack of strong role models, and lack of access to pain and palliative care services. Communication with the dying child and parents is acknowledged to be difficult, but essential as part of the therapeutic relationship throughout the disease process. Parental grief is often stronger than that for individuals with another relationship to the deceased, and sibling grief is significant. With respect to the disease process, children with cancer are highly symptomatic, ranging from 49.7% with lack of energy, to 6.3% with problems with urination. Pain relief is acknowledged to be that in keeping with the WHO pain ladder approach, with route of administration as simple and safe as possible. CONCLUSIONS: The palliative care paradigm should be incorporated into the care of children with cancer, irrespective of geographical location, and the identified barriers to its achievement must be overcome.

COMMENTARY
These four articles bring a swift reminder of the work that still has to be done within the field of paediatric palliative care to improve the day to day lives of children treated for cancer. We recognise the tremendous improvements that have been achieved in survival rates in many cancers, but these four articles each highlight some of the issues around morbidity and the difficulties experienced in attempting to reintegrate into life in general, which deserve our ongoing acknowledgement and attention. Antunes article based upon prospective data collection describes the potential for complex neurological symptoms, with debilitating headache as the most likely symptom. He acknowledges that any experienced neurologist will recognise the presence of chemotherapy induced neurological symptoms, and hence not refer on these children, and that the incidence of neurologic symptoms may therefore be greater than his study suggests. Davies structured interviews led to the description of differing types of fatigue experienced during and post treatment, and strategies to improve these situations. Fatigue was common, and a ‘bothersome’ symptom, affecting life substantially. Vance and Eiser’s article based upon a literature search concurs with the difficulties experienced by children with cancer when attempting to reintegrate into their ‘normal lives’. In particular, they identify that the children are no less willing to attend school than their peers, but experience barriers to do so, for example, in experiencing less energy, and being less able to concentrate. Collins reviews the literature and concludes that a palliative care approach should be made available to any child with a diagnosis of cancer, to support psychosocial and physical symptom control. Collins emphasises that children with cancer are highly symptomatic and that the most prevalent symptom is lack of energy. Throughout these four articles there is therefore a strong theme of symptom control issues with fatigue being one of the commonest symptoms experienced by children being treated for cancer. It is interesting that all articles express this concern surrounding fatigue, and yet the paediatric literature has only recently begun to acknowledge this and to consider ways of addressing it. Collins suggests that a range of issues identified to support palliative care provision to children with cancer will only be more fully addressed when we improve training and availability of palliative care services. If we accept the conclusions of these
four sets of authors, then we will be challenged to continue to address them at several levels, including that of the clinical consultation level with the individual child, service provision level regarding palliative care services availability within any given area, and the training of the staff involved in the care of children with cancer from the time of diagnosis onwards. The articles by Antunes and Davies in particular would be well worth digesting, and would be likely to inform and shape clinical practice. (AT).

-----------------------------

MISCELLANEOUS

Do children with non-malignant life-threatening conditions receive effective palliative care?
A pragmatic evaluation of a local service.
Horrocks, S., Somerset, M., Salisbury, C.

AIM. The aim of this study was to evaluate a highly innovative service for children with non-malignant life-limiting conditions based in the West of England. METHODS. Questionnaires were given to the carers of children at the time of referral to the service, and again six months later. The questionnaires assess various aspects of their satisfaction and were compared. At the same time, there was a postal survey of health professionals and a review of records held by nursing and psychology services. RESULTS. There were twenty-nine families recruited and as might be expected the range of palliative care needs that were recorded was extremely wide. There were three main indices: information needs, nursing care needs and distress rating. The first two were significantly improved, but perhaps surprisingly distress rating was only slightly reduced after involvement of the lifetime service. The perception was that equipment and respite needs were not improved by involvement of the service. Despite this, satisfaction was expressed by most families. CONCLUSIONS. The evaluation indicated improvements needed to be made in three areas. They were respite care (especially the amount available), the need for a twenty-four hour service and the need for even better communications.

COMMENTARY
The Lifetime Service is well known in the United Kingdom for its innovative approach to supporting children particularly with non-malignant life-limiting conditions. The service is based in the statutory sector and delivers high quality respite care in the home. This includes attention to physical needs but is unusual in also having a psychologist on the staff so that these needs can also be met professionally.

This particular survey is a very honest and robust evaluation. Although at first sight they may appear to be less than a ringing endorsement for the service, on closer examination the results should be extremely encouraging. This is a group of children whose every day needs have received relatively little attention. The Lifetime Service has succeeded in drawing attention to their needs, and has designed a service to meet them. This study suggests they have done that successfully but have been able to identify areas that particularly need improvement. Perhaps even more importantly they have published these results in an international journal of high reputation, drawing attention not only to the needs of these children but to the potential for addressing them in a rational and evidence based manner. If I have a criticism it is that there were no measures of satisfaction from the patients themselves. We know that practical difficulties often make this impossible but it would have been interesting to have some views about how they felt about the service and whether it had improved their lives. (RH)

-----------------------------

Itch: scratching more than the surface

AIM. This is an educational review of the literature attaining to the pathophysiology and treatment of
pruritus. METHODS: Educational and literature review. CONCLUSION. Itch is a very great deal more complicated than we realised and there are many different possible approaches to managing it, none of which is entirely satisfactory at present.

COMMENTARY
This is very much Twycross and his team doing what they do best. They have taken a complex and almost incomprehensible subject and made it understandable. They have performed a thorough review of the published literature, encompassing the basic science and the clinical trial and drawing it all together in a logical sequence. This is one of those articles one should photocopy and if necessary laminate to ensure it remains legible for the next decade before it becomes outdated. The only danger with such authoritative summaries is that they can conceal genuine lacunae in available knowledge. I would have appreciated a final paragraph mentioning some of these and perhaps directing a proportion of its readers into areas of research that might clarify them. (RH)

-------------------

The Assessment and Management of Chronic Pain in Children
Chambliss, C. R., Heggen, J., Copelan, D.N., Pettignano R
_Paediatric Drugs_ 2002; 4 (11): 737-46

AIM. Educational Review. METHOD. Summary of literature relating to pharmacological management of chronic pain, and application to paediatric population. CONCLUSION. Useful overview of the subject.

COMMENTARY
The review starts with the traditional castigation of those who inadequately recognise, report or treat pain in children. There are sections on pathophysiology, assessment and management of pain. Management includes opioid and non-opioid approaches and even a section on complementary and herbal therapies.

The title suggests a much more comprehensive approach to this complex subject than the review actually provides. This is partly explained by the journal in which it appears (Pediatric Drugs) but could be misleading. There is no attempt to acknowledge the multi-dimensional nature of chronic pain in assessing or managing it. This is a very uni-dimensional approach, even when discussing complementary therapies.

The review of medications contributes little that is new to most people in the field. A useful table with doses of some of the important medications is included on the second page but otherwise the drugs are dealt with in a superficial manner. There are also some important omissions. There is no mention, for example, of ketamine and the only anticonvulsant that is mentioned is gabapentin. Oddly for an article that deals with chronic pain, clonidine does receive a mention since it ‘produces effective analgesia in surgical and burn patients, reduces postoperative vomiting, reduces the stress response to surgical trauma and attenuates symptoms of opioid withdrawal’. None of these seems relevant to chronic pain. In summary, I found this a disappointing review. The topic is dealt with in only one dimension (which is perhaps reasonable) and superficially (which is not). (RH)

-------------------

Observational Visual Analog Scale in Paediatric Pain Assessment: Useful Tools or Good Riddance.
Van Dijk, Monique Ph.D

SETTING. Netherlands. Literature Review. AIMS. To assess the reliability, validity and cut-off points for visual Analog Scales (VAS) when used as an observational tool in assessing paediatric pain. METHODS. Literature review of publications that reported quantity of information on reliability and validity of the VAS (obs) collected and then all the references were checked for available relevant data. Further searches were done in PubMed and Psychlit every two-months to check for new publications. The current criteria was
applied to judge the value of correlation coefficients. **FINDINGS.** The available psychometric data concerning the observational VAS was limited. The estimated inter-rate of reliability from nine studies range from 0.36 to 0.91. Concurrent validity range from 0.42 to 0.86 and the correlation between self-report and observational was variable with a range of 0.23 to 0.83. **CONCLUSIONS.** The authors concluded that further psychometric testing was needed on intraobserver reliability, responsiveness and optimal cut-off points, further research is required to choose between observer VAS and other behavioral pain instruments.

**COMMENTARY**
This paper requires considerable concentration to read but provides a very important insight into the use of pain assessment tools and the strengths and weaknesses of the VAS in assessments tool. It notably found that parent’s ratings were more strongly related to children’s self-report than those of nurses. Interestingly though it noted that parents and physicians tend to over report pain in the chronic pain situation. This is obviously of interest when one considers premature neonates and severely cognitively handicapped children currently may be assessed on the VAS observational scale. The other significant point that comes out from this study concerns the lack of knowledge or understanding of cut-off points for the VAS scale i.e. at which point pain itself becomes acceptable or unacceptable and this is obviously much more of a problem in pre-verbal children and cognitively handicapped children. (SJ).

---

**Supportive care: Palliative care in children, adolescents, and young adults – model of care, interventions, and cost of care: A retrospective review**

Belasco JB, Danz P, Drill A, Schmid W, Burkey E

*Journal of Palliative Care, 16, 4, p39*

**SETTING.** United States. Retrospective Study. **AIMS.** To describe a model of care that has provided palliative care to children, adolescents and young adults dying of progressive chronic diseases and to retrospectively review the medical interventions provided and the cost analysis of care. **METHODS.** Discussion of the model and execution of the programme of healthcare during the years 1988 to 1992. Documentation of therapies delivered at home as the acuity of care escalated for the dying child near the end of life, and the incidence of death at home as successful outcome parameters. Discussion of the cost/charges of care comparing an individual’s inpatient care to home care during the years 1995 to 1996.

**FINDINGS.**
1. Many children and young adults require active medical intervention in order to be at home to live as well as possible with terminal disease.
2. Anticipated life expectancy is very imprecise in the young.
3. Pain is the main common symptom across the spectrum of paediatric disease.
4. There are forms of suffering other than pain in the dying young.
5. Positive outcome with this approach may be: more time living at home and more deaths at home.
6. There is a significant decrease cost of care at home, even for technology-dependent children and adolescents.
7. The care of the dying child is often complex, especially in the oncology population, and requires a multidisciplinary coordinated approach to care.

**COMMENTARY**
This is a very interesting paper that looks at the American model of healthcare, specifically concepts of terminal and palliative needs as being six months leading up to death. Its main population base is oncological, with only a small proportion of the children cared for having HIV or other conditions. Many of the children seem to continue to have medical intervention up to the point of death. They have shown how successful the team approach can be to the care of the child at home and that this can in itself be very cost effective, which is of relevance not just to the United States, but also to other countries where cost benefits have to be continually evaluated. There was a very interesting section in this paper on symptom control, the frequency of symptoms and the medications used to control them. It is interesting to note the frequency of symptoms associated with sleep disorder, anxiety and depression. (SJ)
An ecology of love: Aspects of music therapy in the Paediatric oncology environment
Aasgaard T
*Journal of Palliative Care, 17,3, p177*

**SETTING.** Norway. Case Reports. **AIMS.** To explore how music therapy can assist patients and relatives in the process of making friendships and love audible in a child cancer ward. **METHOD.** Four short patient histories are presented describing how texts are made into songs and then performed. Another two histories dealing with musical communication with dying children and their parents. **FINDINGS.** The author has indicated that the musical interventions may involve more than palliation, as the musical activities could make it possible for the sick child to expand from being just a patient into playing if only for a moment, a more active social role. **CONCLUSIONS.** The process of artistic interplay in and outside the sick room influences various relationships in the child’s social environment.

**COMMENTARY**
This is a very moving paper describing the four case histories, in all of whom music therapy has played a considerable part, allowing the child to express thoughts and emotions with family and carers. It does endeavor to show that music therapy, although not a form of treatment in a medical sense can form an accompaniment that can be directed to facilitate changes in the individual or a specific environment, and that this interplay between individual health and environment can improve quality of life and death. (SJ)

-------------------

The use of drugs beyond licence in palliative care and pain management
Bennett M, Simpson K
*Palliative Medicine 2002: Issue 16: Pages 367 – 368*

**SETTING.** U.K. Editorial

**COMMENTARY.** This editorial although based around the use of drugs in adults and produced by an association of Palliative Medicine and the Pain Society, describes the use of unlicensed and off-label drugs in the adult palliative care world with some mention of similar paediatric clinical practice in the U.K. and Europe with increasing concern regarding the use of unlicensed and off-label drugs in paediatrics. It does make a very solid case and supports the need for this practice to continue and lists ten recommendations that if followed would allow such practices to continue safely. There is no reason why the same recommendations could not be used within the paediatric environment. (SJ)

-------------------

PaedPalLit Vol2 No1 (April 2003)
-Page 17 -
JOURNAL ARTICLES

Improving palliative care for children and their families.
*Journal of Psychosocial Nursing & Mental Health Services* 2002;40(10):12.

------------------

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

------------------

An ecology of love: aspects of music therapy in the pediatric oncology environment.
Aasgaard T.
*Journal of Palliative Care* 2001;17(3):177-81.

------------------

Update in palliative medicine and end-of-life care.
Abrahm JL.

------------------

Teaching children to understand death and grieving.
Abras M-A.

------------------

The spectrum of neurologic disease in children with systemic cancer.
Antunes NL.

------------------

Childhood bereavement: What school psychologists need to know.
Ayyash-Abdo H.

------------------

Spinal muscular atrophy type 1: management and outcomes.
Bach JR, Baird JS, Plosky D, Navado J, Weaver B.

------------------

When children die: a seminar series for pediatric residents.

------------------

Creutzfeldt-Jakob disease: extending palliative care nursing knowledge.
Bailey B, Aranda S, Quinn K, Kean H.
Palliative care in paediatric oncology.
Beardsmore S, Fitzmaurice N.

Supportive care: palliative care in children, adolescents, and young adults--model of care, interventions, and cost of care: a retrospective review.
Belasco JB, Danz P, Drill A, Schmid W, Burkey E.

Using anti-muscarinic drugs in the management of death rattle: evidence-based guidelines for palliative care.
Bennett M, Lucas V, Brennan M, Hughes A, O'Donnell V, Wee B.

The use of drugs beyond licence in palliative care and pain management.
Bennett M, Simpson K.

Drug therapy - Analgesics for the treatment of pain in children.
Berde CB, Sethna NF.
<Go to ISI>://000178332900009

Intranasal fentanyl reduces acute pain in children in the emergency department: a safety and efficacy study.
Borland ML, Jacobs I, Geelhoed G.

Pediatric heart transplantation.
Boucek Jr RJ, Boucek MM.

Campbell ML.

Creation of a neonatal end-of-life palliative care protocol.
Catlin A, Carter B.
Depression in children with cancer.
Cavusoglu H.

-------------------
The assessment and management of chronic pain in children.
Chambliss CR, Heggen J, Copelan DN, Pettignano R.

-------------------
Gastrointestinal problems in the handicapped child.
Chong SK.

-------------------
Adolescent grief: "It never really hit me...until it actually happened".
Christ GH, Siegel K, Christ AE.

-------------------
A child-focused intervention for coping with procedural pain: are parent and nurse coaches necessary?
Cohen LL, Bernard RS, Greco LA, McClellan CB.

-------------------
Nebulized morphine as a treatment for dyspnea in a child with cystic fibrosis.
Cohen SP, Dudson TC.

-------------------
Palliative care and the child with cancer.
Collins JJ.

-------------------
Assessing dependency in a community hospice service.
Conisbee E.
Paediatric Nursing 2002;14(3):30-1.

-------------------
The changing face of terminal care for AIDS.
Cox S, Pickhaver K.

-------------------
A weekend camp for bereaved siblings.
Creed J, Ruffin JE, Ward M.
Studying communication about end-of-life care during the ICU family conference: development of a framework.

Diana, Princess of Wales Children's Community Team: an evaluation of a multi-professional service for children with life-limiting illnesses.
Danvers L, Freshwater D, Cheater F, Wilson A.

The wisdom of children.
Davies B.

A typology of fatigue in children with cancer.
Davies B, Whitsett SF, Bruce A, McCarthy P.

Providing nursing care in a children's hospice.
Day A.

Exploring documentation of end-of-life care of children with cancer.
De Graves SD, Aranda S.

The use of fentanyl and alfentanil sprays for episodic pain.
Duncan A.

Pain in hospitalized pediatric patients: how are we doing?
Ellis JA, O'Connor BV, Cappelli M, Goodman JT, Blouin R, Reid CW.

Examining the comfort of the unconscious patient.
Fullarton A, al e. ????
Management of HIV in resource-poor countries, with a focus on sub-Saharan Africa.
Harries AD.

Hypnosis treatment of sleeping problems in children experiencing loss.
Hawkins P, Polemikos N.

Information needs of young people with cystic fibrosis.

Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals.
Hodgkinson R, Lester H.

Horrocks S, Somerset M, Salisbury C.

What is it like being a sibling of a child with cancer?
Johnson B.

Children's understanding of death.
Karns JT.

When the child's illness is life threatening: impact on the parents.
Katz S.

Feeding tubes in palliative care.
Keely P.
**Fever and neutropenia in children with solid tumors is similar in severity and outcome to that in children with leukemia.**
Kocak U, Rolston KV, Mullen CA.
*Supportive Care in Cancer* 2002;10(1):58-64.

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

**Optimism and psychosocial functioning in caring for children with Battens and other neurological diseases.**
Labbe EE, Lopez I, Murphy L, O'Brien C.

**Paediatrics: part 7: palliative care of the dying child.**
Lambert P.

**Starting the quest to define optimal pediatric end-of-life care. [Editorial].**
Levetown MMD.

**Parents’ perceptions of adolescent sibling grief responses after an adolescent or young adult child’s sudden, violent death.**
Lohan JA, Murphy SA.

**Hereditary cancers in children and ethical and psychosocial implications.**
MacDonald DJ, Lessick M.

**Noninvasive ventilation in cystic fibrosis patients with acute or chronic respiratory failure.**
Madden BP, Kariyawasam H, Siddiqi AJ, Machin A, Pryor JA, Hodson ME.

**Rituals of the hospital palliative care team.**
Mallet D, Soyer S, Herbaut A, Danel M, Parent K.
*European Journal of Palliative Care* 2002;9(6):244-250.
Continuous lidocaine infusion for the relief of refractory malignant pain in a terminally ill pediatric cancer patient.
Massey GV, Pedigo S, Dunn NL, Grossman NJ, Russell EC.

-------------------
Qualitative findings on the experience of end-of-life care for hematological malignancies.
McGrath P.

-------------------
Caring for medically fragile children in the home: an alternative theoretical approach.
Mentro AM, Steward DK.
Research and Theory in Nursing Practice 2002;16(3):161-77.

-------------------
Walking the moral tightrope: respecting and protecting children in health-related research.
Miller PB, Kenny NP.

-------------------
Disability in children from different ethnic populations.

-------------------
Mu PF, Ma FC, Ku SM, Shu HQ, Hwang B, Kuo BL.

-------------------
[Extensive experience in supporting dying children].
Mundle DR.

-------------------
The aftermath of the violent death of a child: An integration of the assessments of parents' mental distress and PTSD during the first 5 years of bereavement.
Murphy SA, Johnson LC, Lohan J.

-------------------
A concept analysis of social support as experienced by siblings of children with cancer.
Murray JS.
Quality of life in terminally ill cancer patients.
Mystakidou K, Parpa E, Tsilika E, Georgaki S, Mavromati A, Vlahos L.

-------------------

Physical compatibility and in vivo evaluation of drug mixtures for subcutaneous infusion to cancer patients in palliative care.
Negro S, Azuara ML, Sanchez Y, Reyes R, Barcia E.
Supportive Care in Cancer 2002;10(1):65-70.

-------------------

Saying goodbye to Elizabeth.
Nisbet A.

-------------------

Mindfulness meditation in pediatric clinical practice.
Ott MJ.

-------------------

Greek nurse and physician grief as a result of caring for children dying of cancer.
Papadatou D, Bellali T, Papazoglou I, Petraki D.

-------------------

Grief: lessons from the past, visions for the future.
Parkes CM.

-------------------

Pendleton SM, Cavalli KS, Pargament KI, Nasr SZ.

-------------------

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

-------------------

End of life in pediatric oncology: how clinical practice leads to research.
Pritchard M, Davies B.

-------------------
Reflections on the use of sedation in terminal care.
Radbruch L.

-------------------

Stress in families with medically fragile children.
Ratliffe CE, Harrigan RC, Haley J, Tse A, Olson T.

-------------------

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

-------------------

ART is the heART: a palette of possibilities for hospice care.
Rollins JA, Riccio LL.

-------------------

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.

-------------------

Letting go of grief: Bereavement groups for children in the school setting.
Samide LL, Stockton R.
*Journal for Specialists in Group Work* 2002;27(2):192-204.

-------------------

Withdrawal of nutritional support in the terminally ill.
Schwarte AM.

-------------------

Increased risk of chronic hepatitis in children with cancer.
Sevinir B, Meral A, Gunay U, Ozkan T, Ozuysal S, Sinititas M.

-------------------

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

-------------------

Epidemiology of cancer in adolescents.
Stiller C.
*Medical and Pediatric Oncology* 2002;39(3):149-55.
Suffer the children: an examination of psychosocial issues in children and adolescents with terminal illness.
Stillion JM, Papadatou D.

Life expectancy in cerebral palsy.
Strauss D, Shavelle R.
Archives of Disease in Childhood 2001;85(5):442.

Adrenal functions in children with adrenoleukodystrophy.
Supornsilchai V, Wacharasindhu S, Desudchit T.

The relationship between individual differences in repressive styles and grief reaction, coping behaviors, and onset of pathological grief, anxiety, and mood disorders after child loss.

Clinical and research measures of grief: a reconsideration.
Tomita T, Kitamura T.

Physical functioning in female caregivers of children with physical disabilities compared with female caregivers of children with a chronic medical condition.

Itch: scratching more than the surface.

Observational visual analog scale in pediatric pain assessment: useful tool or good riddance?
van Dijk M, Koot HM, Saad HH, Tibboel D, Passchier J.

The school experience of the child with cancer.
Vance YH, Eiser C.
PaedPalLit Vol2 No1 (April 2003)
-Page 28-

Important aspects of care and assistance for children 0-7 years of age being treated for cancer. Parent and nurse perceptions.
Von Essen L, Enskar K, Haglund K, Hedstrom M, Skolin I.
Supportive Care in Cancer 2002;10(8):601-12.

-------------------
Impact of parental involvement in life-support decisions: A qualitative analysis of parents' adjustment following their critically ill child's death.
Votta E, Franche R, Sim D, Mitchell B, Frewen T, Maan C.

-------------------
Exploring multi-agency working in services to disabled children with complex healthcare needs and their families.
Watson D, Townsley R, Abbott D.

-------------------
The care of my child with cancer: a new instrument to measure caregiving demand in parents of children with cancer.

-------------------
Death education: what should student children's nurses be taught?
Whittle M.

-------------------
Time to go home: assisting families to take their child home following a planned hospital or hospice death.
Whittle M, Cutts S.

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

-------------------
Father's grief when a disabled child dies.
Wood JD, Milo E.
Death Studies 2001;25(8):635-661.

-------------------
The development of terminal care in Budapest.
Wright M, Clark D.
Gender differences of parental distress in children with cancer.
Yeh CH.

-------------------

Young B, Dixon-Woods M, Findlay M, Heney D.

-------------------

A phase I study on the feasibility and acceptability of an acupuncture/hypnosis intervention for chronic pediatric pain.

-------------------

Mourning parents: Considering safeguards and their relation to health.
Znoj HJ, Keller D.
URLJ: www.tandf.co.uk/journals/tf/07481187.html

-------------------

[Reaching a team consensus in pediatric oncology when treatment proves ineffective].
Zucker JM.
Archives de Pediatrie 2002;9 Suppl 1:55s-59s.

-------------------
BOOKS

In the Presence of Grief: Helping family members resolve death, dying, and bereavement issues.
Becvar DS.

-------------------

From Grief to Glory: spiritual journeys of mourning parents
Bruce, James W.

-------------------

Parenting through Crisis: Helping Kids in Times of Loss, Grief and Change.
Coloroso, B.

-------------------

Care of the Dying Child
Farrell M.

-------------------

Losing Malcolm: A Mother’s Journey through Grief.
Henderson, C.

-------------------

Hindmarch C.

-------------------

Longing for My Child: Reflections for Parents and Siblings After a Child’s Death
Lafser C.

-------------------

Lehmann-Norquist L.

-------------------

Lehmann-Norquist L.

-------------------

Men Coping with Grief.
Lund, Dale A. (Editor).
Death, value and meaning series.

-------------------
Help Your Marriage Survive the Death of a Child
Rosenblatt PC.

-------------------
A Child’s Grief
Stokes JA, Crossley D.

-------------------
Handbook of Bereavement Research: Consequences, Coping, and Care
Stroebe MS, Hansson RO, Henk S.

-------------------
What Forever Means After the Death of a Child
Talbot K.

-------------------
Approaches to Needs Assessment in Children's Services.
Ward H, Rose W. (Editors).

-------------------
When all the friends have gone: A guide for aftercare providers.
Weeks OD, Johnson C, (Editors).
Death, value, and meaning series.

-------------------
Children and Grief. When a parent dies
Worden, W.J.
What is ACT

ACT is the Association for Children with Life-threatening and Terminal Conditions and their Families. It is a registered charity seeking to influence, coordinate and promote the provision of the best possible care and support for all children with life-threatening or terminal conditions and their families.

Membership of ACT

ACT is an umbrella organisation representing the needs of children with life-threatening or terminal conditions and their families. It has a large and active membership of different professionals, organisations and parents from all over the world, all having a common concern for these children.

We welcome applications for membership from any individual or group who shares ACT’s mission:

To facilitate provision of the best possible care for children and young people with life-threatening conditions and their families by representing their needs, promoting good models of practice, providing information and education, and encouraging research.

Membership of ACT provides an opportunity for all those who share these aims to join together as a collective voice on behalf of children and families.

For a membership application form please visit us online at www.act.org.uk or contact:

ACT
Orchard House
Orchard Lane
Bristol  BS1 5DT
Tel:  UK:  0117 922 1556  International:  00 44 117 922 1556
Fax:  UK:  0117 930 4707  International:  00 44 117 930 4707
info@act.org.uk

www.act.org.uk