

Synopsis

International digest of children's palliative
care research abstracts

Editors: Dr Satbir Singh Jassal, Dr Angela Thompson,
Dr Linda Maynard, Sue Langley and Lizzie Chambers

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Synopsis, International digest of children's palliative care research abstracts
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Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

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SYNOPSIS

July 2015

SELECTED ABSTRACTS FROM OCTOBER 2014 – MARCH 2015

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Clinical and Ethical Decision Making

Askegard-Giesmann, J. R. and Kenney, B. D. (2015). "Controversies in nutritional support for critically ill children." Semin Pediatr Surg 24(1): 20-24.

Nutritional support for critically ill infants and children is of paramount importance and can greatly affect the outcome of these patients. The energy requirement of children is unique to their size, gestational age, and physiologic stress, and the treatment algorithms developed in adult intensive care units cannot easily be applied to pediatric patients. This article reviews some of the ongoing controversial topics of fluid, electrolyte, and nutritional support for critically ill pediatric patients focusing on glycemic control and dysnatremia. The use of enteral and parenteral nutrition as well as parenteral nutritional-associated cholestasis will also be discussed.

<http://www.ncbi.nlm.nih.gov/pubmed/25639806>

Barello, S., Graffigna, G. and Meyer, E. C. (2015). "Ethics and etiquette in neonatal intensive care: the value of parents' engagement in everyday ethics and recommendations for further advancing the field." JAMA Pediatr 169(2): 190.

<http://www.ncbi.nlm.nih.gov/pubmed/25642902>

Bartholdson, C., Lutzen, K., Blomgren, K. and Pergert, P. (2015). "Experiences of ethical issues when caring for children with cancer." Cancer Nurs 38(2): 125-132.

BACKGROUND: The treatment for pediatric cancer is often physically, socially, and psychologically demanding and often gives rise to ethical issues. OBJECTIVE: The purpose of this study was to describe healthcare professionals' experiences of ethical issues and ways to deal with these when caring for children with cancer. METHODS: A study-specific questionnaire was given to healthcare professionals at a pediatric hospital in Sweden. Qualitative content analysis was used to analyze answers to open-ended questions. The data were sorted into 2 domains based on the objective of the study. In the next step, the data in each domain were inductively coded, generating categories and subcategories. RESULTS: The main ethical issues included concerns of (1) infringing on autonomy, (2) deciding on treatment levels, and (3) conflicting perspectives that constituted a challenge to collaboration. Professionals desired teamwork and reflection to deal with ethical concerns, and they needed resources for dealing with ethics. IMPLICATIONS FOR PRACTICE: Interprofessional consideration needs to be improved. Forums and time for ethics reflections need to be offered to deal with ethical concerns in childhood cancer care. CONCLUSIONS: Experiences of ethical concerns and dealing with these in caring for children with cancer evoked strong feelings and moral perplexity among nursing staff. The study raises a challenging question: How can conflicting perspectives, lack of interprofessional consideration, and obstacles related to parents' involvement be "turned around," that is, contribute to a holistic perspective of ethics in cancer care of children?

<http://www.ncbi.nlm.nih.gov/pubmed/24945260>

Bartholdson, C., Lutzen, K., Blomgren, K. and Pergert, P. (2015). "Clarifying perspectives: Ethics case reflection sessions in childhood cancer care." Nurs Ethics.

BACKGROUND: Childhood cancer care involves many ethical concerns. Deciding on treatment levels and providing care that infringes on the child's growing autonomy are known ethical concerns that involve the whole professional team around the child's care. OBJECTIVES: The purpose of this study was to explore healthcare professionals' experiences of participating in ethics case reflection sessions in childhood cancer care. RESEARCH DESIGN: Data collection by observations, individual interviews, and individual encounters. Data analysis were conducted following grounded theory methodology. PARTICIPANTS AND RESEARCH CONTEXT: Healthcare professionals working at a publicly funded children's hospital in Sweden participated in ethics case reflection sessions in which ethical issues concerning clinical cases were reflected on. ETHICAL CONSIDERATIONS: The children's and their parents' integrity was preserved through measures taken to protect patient identity during ethics case reflection sessions. The study was approved by a regional ethical review board. FINDINGS: Consolidating care by clarifying perspectives emerged. Consolidating care entails striving for common care goals and creating a shared view of care and the ethical concern in the specific case. The inter-professional perspectives on the ethical aspects of care are clarified by the participants' articulated views on the case. Different approaches for deliberating ethics are used during the sessions including raising values and making sense, leading to unifying interactions. DISCUSSION: The findings indicate that ethical concerns could be eased by implementing ethics case reflection sessions. Conflicting perspectives can be turned into unifying interactions in the healthcare professional team with the common aim to achieve good pediatric care. CONCLUSION: Ethics case reflection sessions is valuable as it permits the discussion of values in healthcare-related issues in childhood cancer care. Clarifying perspectives, on the ethical concerns, enables healthcare professionals to reflect on the most reasonable and ethically defensible care for the child. A consolidated care approach would be valuable for both the child and the healthcare professionals because of the common care goals.

<http://www.ncbi.nlm.nih.gov/pubmed/25736273>

Boss, R. D., Hutton, N., Griffin, P. L., Wieczorek, B. H. and Donohue, P. K. (2015). "Novel legislation for pediatric advance directives: surveys and focus groups capture parent and clinician perspectives." Palliat Med 29(4): 346-353.

BACKGROUND: Legislative measures increasingly require consideration of pediatric inpatients for Medical Orders for Life-Sustaining Treatment. AIM: To explore pediatric clinicians' experiences with life-sustaining treatments prior to the Medical Orders for Life-Sustaining Treatment mandate and to describe clinician and family concerns and preferences regarding pediatric Medical Orders for Life-Sustaining Treatment. DESIGN: Clinician surveys and clinician and parent focus groups. SETTING/PARTICIPANTS: Pediatric clinicians and parents from one of Maryland's largest health systems. RESULTS: Of 96 survey respondents, 72% were physicians and 28% were nurse practitioners. A total of 73% of physicians and 34% of nurse practitioners felt able to lead discussions about limiting therapies "most" or "all" of the time.

A total of 75% of physicians and 37% of nurse practitioners led such a discussion in the prior year. A total of 55% of physicians and 96% of nurse practitioners had written no order to limit therapies in the past year. Only for children predicted to die within 30 days did >80% of clinicians agree that limitation discussions were warranted. A total of 100% of parent focus group participants, but 17% of physicians and 33% of nurse practitioners, thought that all pediatric inpatients warranted Medical Orders for Life-Sustaining Treatment discussions. Parents felt that universal Medical Orders for Life-Sustaining Treatment would decrease the stigma of limitation discussions. Participants believed that Medical Orders for Life-Sustaining Treatment would clarify decision making and increase utilization of palliative care. Medical Orders for Life-Sustaining Treatment communication skills training was recommended by all. CONCLUSION: A minority of clinicians, but all parents, support universal pediatric Medical Orders for Life-Sustaining Treatment. Immediately prior to the Medical Orders for Life-Sustaining Treatment mandate, many clinicians felt unprepared to lead limitation discussions, and few had written relevant orders in the prior year. Communication training is perceived essential to successful Medical Orders for Life-Sustaining Treatment conversations.

<http://www.ncbi.nlm.nih.gov/pubmed/25670471>

Chin, L. E., Loong, L. C., Ngen, C. C., Beng, T. S., Shireen, C., Kuan, W. S. and Shaw, R. (2014). "Pediatric palliative care: using miniature chairs to facilitate communication." *Am J Hosp Palliat Care* 31(8): 833-835.

Good communication is essential but sometimes challenging in pediatric palliative care. We describe 3 cases whereby miniature chairs made of various materials and colors were used successfully to encourage communication among pediatric patients, family, and health care professionals. This chair-inspired model may serve as a simple tool to facilitate complex discussions and to enable self-expression by children in the pediatric palliative care setting.

<http://www.ncbi.nlm.nih.gov/pubmed/24150973>

de Vos, M. A., Bos, A. P., Plotz, F. B., van Heerde, M., de Graaff, B. M., Tates, K., Truog, R. D. and Willems, D. L. (2015). "Talking with parents about end-of-life decisions for their children." *Pediatrics* 135(2): e465-476.

BACKGROUND AND OBJECTIVE: Retrospective studies show that most parents prefer to share in decisions to forgo life-sustaining treatment (LST) from their children. We do not yet know how physicians and parents communicate about these decisions and to what extent parents share in the decision-making process. METHODS: We conducted a prospective exploratory study in 2 Dutch University Medical Centers. RESULTS: Overall, 27 physicians participated, along with 37 parents of 19 children for whom a decision to withhold or withdraw LST was being considered. Forty-seven conversations were audio recorded, ranging from 1 to 8 meetings per patient. By means of a coding instrument we quantitatively and qualitatively analyzed physicians' and parents' communicative behaviors. On average, physicians spoke 67% of the time, parents 30%, and nurses 3%. All physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in 2 cases were parents asked to share in the decision-making. Despite their intense emotions, most parents made great effort

to actively participate in the conversation. They did this by asking for clarifications, offering their preferences, and reacting to the decision being proposed (mostly by expressing their assent). In the few cases where parents strongly preferred LST to be continued, the physicians either gave parents more time or revised the decision. CONCLUSIONS: We conclude that parents are able to handle a more active role than they are currently being given. Parents' greatest concern is that their child might suffer.

<http://www.ncbi.nlm.nih.gov/pubmed/24150973>

de Vos, M. A., Seeber, A. A., Gevers, S. K., Bos, A. P., Gevers, F. and Willems, D. L. (2015). "Parents who wish no further treatment for their child." *J Med Ethics* 41(2): 195-200.

BACKGROUND: In the ethical and clinical literature, cases of parents who want treatment for their child to be withdrawn against the views of the medical team have not received much attention. Yet resolution of such conflicts demands much effort of both the medical team and parents. OBJECTIVE: To discuss who can best protect a child's interests, which often becomes a central issue, putting considerable pressure on mutual trust and partnership. METHODS: We describe the case of a 3-year-old boy with acquired brain damage due to autoimmune-mediated encephalitis whose parents wanted to stop treatment. By comparing this case with relevant literature, we systematically explored the pros and cons of sharing end-of-life decisions with parents in cases where treatment is considered futile by parents and not (yet) by physicians. CONCLUSIONS: Sharing end-of-life decisions with parents is a more important duty for physicians than protecting parents from guilt or doubt. Moreover, a request from parents on behalf of their child to discontinue treatment is, and should be, hard to over-rule in cases with significant prognostic uncertainty and/or in cases with divergent opinions within the medical team.

<http://www.ncbi.nlm.nih.gov/pubmed/24917616>

Derrington, S. F. (2015). "Are we doing right by dying children?" *J Pediatr* 166(3): 524-525.

<http://www.ncbi.nlm.nih.gov/pubmed/25557965>

Dionne, J. M. and d'Agincourt-Canning, L. (2014). "Sustaining life or prolonging dying? Appropriate choice of conservative care for children in end-stage renal disease: an ethical framework." *Pediatr Nephrol*.

Due to technological advances, an increasing number of infants and children are surviving with multi-organ system dysfunction, and some are reaching end-stage renal disease (ESRD). Many have quite limited life expectancies and may not be eligible for kidney transplantation but families request dialysis as alternative. In developed countries where resources are available there is often uncertainty by the medical team as to what should be done. After encountering several of these scenarios, we developed an ethical decision-making framework for the appropriate choice of conservative care or renal replacement therapy in infants and children with ESRD. The framework is a practical tool to help determine if the burdens of di-

alysis would outweigh the benefits for a particular patient and family. It is based on the four topics approach of medical considerations, quality-of-life determinants, patient and family preferences and contextual features tailored to pediatric ESRD. In this article we discuss the basis of the criteria, provide a practical framework to guide these difficult conversations, and illustrate use of the framework with a case example. While further research is needed, through this approach we hope to reduce the moral distress of care providers and staff as well as potential conflict with the family in these complex decision-making situations.
<http://www.ncbi.nlm.nih.gov/pubmed/25330877>

Dussel, V., Orellana, L., Soto, N., Chen, K., Ullrich, C., Kang, T. I., Geyer, J. R., Feudtner, C. and Wolfe, J. (2015). "Feasibility of Conducting a Palliative Care Randomized Controlled Trial in Children with Advanced Cancer: Assessment of the PediQUEST Study." *J Pain Symptom Manage.*

CONTEXT: Pediatric palliative care randomized controlled trials (PPC-RCTs) are uncommon. OBJECTIVES: To evaluate the feasibility of conducting a PPC-RCT in pediatric cancer patients. METHODS: This was a cohort study embedded in the Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) Study (NCT01838564). This multicenter PPC-RCT evaluated an electronic patient-reported-outcomes system. Children ≥ 2 -years-old, with advanced cancer, and potentially eligible for the study were included. Outcomes measured were: pre-inclusion attrition: patients not approached, refusals; post-inclusion attrition: drop-out, elimination, death, and intermittent attrition (missing surveys) over nine months; child/teenager self-report rates; and reasons to enroll/participate. RESULTS: Over five years, of the 339 identified patients, 231 were eligible (in 22 we could not verify eligibility); 87774 eligible patients were not approached and 43 declined participation. Patients not approached were more likely to die or have brain tumors. We enrolled 104 patients. Average enrollment rate was one patient/site/month; shortening follow-up from nine to three months (with optional re-enrollment) increased recruitment by 20%. Eighty-seven patients completed the study (24 died) and 17 dropped out. Median intermittent attrition was 41% in the first 20 weeks of follow-up, and over 60% in the eight weeks preceding death. Child/teenager self-report was 94%. Helping others, low burden procedures, incentives, and staff attitude were frequent reasons to enroll/participate. CONCLUSION: A PPC-RCT in children with advanced cancer was feasible, post-inclusion retention adequate; many families participated for altruistic reasons. Strategies that may further PPC-RCT feasibility include: increasing target population through large multicenter studies, approaching sicker patients, preventing exclusion of certain patient groups, and improving data collection at end of life.
<http://www.ncbi.nlm.nih.gov/pubmed/25640275>

Fowler, A., Freiburger, D. and Moonan, M. (2015). "Palliative and end-of-life care in pediatric solid organ transplantation." *Pediatr Transplant* 19(1): 11-17.

End-of-life care is a component of palliative care and takes a holistic, individualized approach to patients, focusing on the assessment of quality of life and its maintenance until the end of life, and beyond, for the patient's family. Transplant teams do not always make timely referrals to palliative care teams due to various clinician and perceived family barriers, an impor-

tant one being the simultaneous, active care plan each patient would have alongside an end-of-life plan. Application of findings and further research specific to the pediatric solid organ population would be of significant benefit to guide transplant teams as to the most effective time to introduce end-of-life care, who to involve in ongoing discussions, and important ethical and cultural considerations to include in care planning. Attention must also be paid to clinician training and support in this challenging area of health care.

<http://www.ncbi.nlm.nih.gov/pubmed/25422076>

Furingsten, L., Sjogren, R. and Forsner, M. (2015). "Ethical challenges when caring for dying children." *Nurs Ethics* 22(2): 176-187.

BACKGROUND: Caring for dying children presents special challenges, according to the children themselves, their relatives and healthcare professionals. **OBJECTIVE:** The aim of this study was to describe caring as represented in healthcare workers' experiences of caring for dying children. **METHOD:** A phenomenological approach was chosen, in-depth interviews were carried out and data were analysed in four steps focusing on (a) open reading, (b) meaning units, (c) constituents and (d) essence. **ETHICAL CONSIDERATIONS:** Four nurses in a general acute paediatric care setting in Sweden participated after providing written informed consent. Voluntary participation and confidentiality were ensured, and the study was ethically approved. **FINDINGS:** The essence of caring for dying children was likened to a musically attuned composition, comprising five constituents: presence, self-knowledge, injustice in dying, own suffering and in need of others. Presence was found to be a prerequisite for caring when a child is dying. Self-knowledge and support from others can be of help when struggling with emotional pain and injustice. **DISCUSSION:** Caring for dying children has been found to be a delicate task for healthcare workers all over the world, and the ethical dimension is emphasized in international research. In this study, emotional pain and suffering accompanied caring, but an atmosphere in which it is possible to give and get support from colleagues and to have time to grieve and time to focus on the patient's needs may ease the burden, as can having time to process thoughts about life and death, and a possibility to grow in self-knowledge. **CONCLUSION:** Caring in ethically demanding situations may be facilitated through presence, atmosphere, self-knowledge and time. The challenge does not demand highly technological solutions; these assets are readily available, no matter where on earth. However, there is a need to further investigate these prerequisites for caring, particularly when a child is dying.

<http://www.ncbi.nlm.nih.gov/pubmed/24917270>

Horridge, K. A. (2014). "Advance Care Planning: practicalities, legalities, complexities and controversies." *Arch Dis Child*.

Increasing numbers, complexities and technology dependencies of children and young people with life-limiting conditions require paediatricians to be well prepared to meet their changing needs. Paediatric Advance Care Planning provides a framework for paediatricians, families and their multidisciplinary teams to consider, reflect and record the outcome of their conversations about what might happen in the future in order to optimise quality of clinical care and inform decision-making. For some children and young people this will include dis-

cussions about the possibility of death in childhood. This may be unexpected and sudden, in the context of an otherwise active management plan or may be expected and necessitate discussions about the process of dying and attention to symptoms. Decision-making about appropriate levels of intervention must take place within a legal and ethical framework, recognising that the UK Equality Act (2010) protects the rights of disabled children and young people and infants and children of all ages to the same high quality healthcare as anyone else.

<http://www.ncbi.nlm.nih.gov/pubmed/24917270>

Isaacs, D. (2015). "Ethics of paediatric end-of-life decision making and consent for publication." *J Med Ethics* 41(2): 201-202.

<http://www.ncbi.nlm.nih.gov/pubmed/24958335>

Kahveci, R., Ayhan, D., Doner, P., Cihan, F. G. and Koc, E. M. (2014). "Shared decision-making in pediatric intensive care units: a qualitative study with physicians, nurses and parents." *Indian J Pediatr* 81(12): 1287-1292.

OBJECTIVES: To understand how decisions are made in Intensive Care Unit (ICU) settings where critically-ill children require life-support decisions and what are the perceptions of health professionals and parents. METHODS: In this qualitative study, in-depth, semi-structured, face to face interviews with 8 doctors, 9 nurses and 6 parents of critically ill children were conducted. Interviews were digitally recorded and transcribed. The transcriptions were further analyzed following open coding and formation of themes. RESULTS: The themes were discussed in two major titles: perceived roles and emotions during the decision-making process. All nurses and patients agreed that the decision maker should be the physician. Nurses understood patients' emotions better and had a closer relation with the parents. Both doctors and nurses thought that parents could not have all responsibilities about treatment choices, because they do not have the required knowledge. Similarly parents were afraid to make a wrong decision, thus they wanted to leave this to the doctors. CONCLUSIONS: The present study revealed that shared-decision making is not well understood by health care professionals in Turkey. Doctor is the major decision-making authority and this is also accepted and preferred by the patients and nurses.

<http://www.ncbi.nlm.nih.gov/pubmed/24752630>

Kain, V. J. (2014). "Babies born dying: just bad karma? A discussion paper." *J Relig Health* 53(6): 1753-1758.

The paper examines the notion of being born dying and karma. Karma is a belief upheld by Buddhists and non-Buddhists: That is, karma follows people from their previous lives into their current lives. This raises a difficult question: Does karma mean that a baby's death is its own fault? While great peace can be found from a belief in karma, the notion of a baby's karma returning in some sort of retributive, universal justice can be de-emphasized and is considered "un-Buddhist." Having an understanding of karma is intrinsic to the spiritual care

for the dying baby, not only from the perspective of parents and families who have these beliefs, but also for reconciling one's own beliefs as a healthcare practitioner.

<http://www.ncbi.nlm.nih.gov/pubmed/24752630>

Khilnani, P. (2014). "Decision making for life sustaining therapies in pediatric intensive care: who should decide?" *Indian J Pediatr* 81(12): 1283-1284.

<http://www.ncbi.nlm.nih.gov/pubmed/25385076>

Robert, H. (2014). "The bereavement gap: grief, human dignity and legal personhood in the debate over Zoe's law." *J Law Med* 22(2): 319-334.

A Bill before the New South Wales Parliament attempted to re-frame harm to late-term fetuses as grievous bodily harm to the fetus itself rather than (under the existing law) grievous bodily harm to the mother. To achieve this, the Bill extended legal personhood to the fetus for a limited number of offences. The Bill was brought on behalf of Brodie Donegan, who lost her daughter Zoe at 32 weeks' gestation when Donegan was hit by a drug-affected driver. This article asks what the perspective of a grieving mother can bring to the debate, in terms of helping the criminal law accurately come to grips with the complexity of pregnancy and the specific harm of fetal loss. It assesses the likely impacts of a change to fetal personhood and suggests an alternative legislative approach which is less likely to result in an erosion of bodily autonomy for pregnant women.

<http://www.ncbi.nlm.nih.gov/pubmed/25385076>

Schechter, T. and Grant, R. (2015). "The complexity of consenting to clinical research in phase I pediatric cancer studies." *Paediatr Drugs* 17(1): 77-81.

The principal aim of phase I studies is to define the recommended dosing of drugs for phase II studies through assessment of drug pharmacokinetics and observation of the drug's toxicity profile. In the setting of pediatric oncology, the use of an experimental drug in phase I study is offered when prognosis is poor. Thus, phase I oncology studies are not given to patients with a primary purpose of an intent to cure. They may offer little to no treatment benefit and carry a potential toxic effect. They may offer other benefits such as improved quality of life and relief of pain, however. Three parties are involved in the informed consent process: the parents, patients, and physicians. Families report hope as the main cause for enrollment. Physicians focus on providing information so families can decide about participation. Physicians also try to maintain hope despite understanding the nature of the disease. This makes the informed consent complicated for all parties involved in the process. The purpose of this review is to discuss the aims of phase I studies in pediatric oncology and to convey the ethical challenges that patients, parents, and physicians are facing when discussing informed consent with potential study participants.

<http://www.ncbi.nlm.nih.gov/pubmed/25573671>

Thomas, S. M., Ford, P. J., Weise, K. L., Worley, S. and Kodish, E. (2015). "Not just little adults: a review of 102 paediatric ethics consultations." *Acta Paediatr.*

AIM: The American Academy of Pediatrics statement on institutional ethics committees highlights the importance of paediatric ethics consultation. However, little has been published on actual experience with ethics consultation in paediatrics. The objective of this study was to review and describe topics covered by a large retrospective sample of clinical ethics consultations in paediatric medicine. METHODS: We reviewed ethics consultations involving patients of <18 years of age from January 2005 to July 2013 at one institution. Descriptive statistics of the patient population, the reason for the ethics consultation and the consultant's perceived contribution to the case were generated. Subgroups of patients were compared based on demographic and clinical characteristics using Wilcoxon's rank sum tests, chi-square tests and logistic regression models. RESULTS: Most of the 102 eligible consultations originated from intensive care units and were requested by attending physicians. The most frequent topic leading to consultation was end-of-life issues. Both younger age and male sex were associated with consults for end-of-life issues ($p < 0.001$ and $p = 0.010$). CONCLUSION: This analysis provides important information describing the type of consults requested in paediatric medicine, which is necessary given the movement towards professionalising clinical ethics consultation. Further empirical research is needed on ethics consultation in paediatrics. <http://www.ncbi.nlm.nih.gov/pubmed/25611088>

Education, Research and Professional Issues

Amin, R., Vresk, L. and Cohen, E. (2015). "Nutritional and metabolic assessment for children receiving long-term ventilation at home: a call to action for clinicians?" J Pediatr 166(2): 228-229.

<http://www.ncbi.nlm.nih.gov/pubmed/25620508>

Andrews, W. W. (2015). "What is new in stillbirth?: important recent articles." Obstet Gynecol 125(1): 160-161.

This month we focus on current research in stillbirth. Dr. Andrews discusses five recent publications, and each is concluded with a "bottom line" that is the take-home message. The complete reference for each can be found in on this page, along with direct links to the abstracts.

<http://www.ncbi.nlm.nih.gov/pubmed/25560119>

Arzuaga, B. H. and Caldarelli, L. (2015). "Paediatric trainees and end-of-life care: a needs assessment for a formal educational intervention." Perspect Med Educ 4(1): 25-32.

BACKGROUND: Literature suggests a paucity of formal training in end-of-life care in contemporary American medical education. Similar to trainees in adult medicine, paediatric trainees are frequently involved in end-of-life cases. OBJECTIVE: To determine current experience and comfort levels among paediatric trainees when caring for dying patients with the hypothesis that more clinical experience alone would not improve comfort. METHODS: Paediatric residents, subspecialty fellows and programme directors at the University of Chicago completed a voluntary electronic needs assessment in June and July 2013. Ten question pairs determined frequency of experiencing various aspects of end-of-life care in clinical practice and comfort levels during these encounters. RESULTS: 118 respondents participated (63.8 % response rate): 66.4 % were female; 53 % had previous education in end-of-life care. The proportion of those with experience in end-of-life care increased through the third year of training, and remained at 1.0 thereafter. Conversely, positive comfort scores increased gradually throughout all six years of training to a maximum proportion of 0.45. Comfort in many specific aspects of care lagged behind experience. Previous education had a significant positive effect on comfort levels of most, but not all, aspects of care. 58 % or more of trainees desired further education on specific end-of-life topics. CONCLUSIONS: Paediatric trainees are often involved in end-of-life care but may not be comfortable in this role. More experience alone does not improve comfort levels; however, there is a positive correlation with comfort and previous education. Trainees had a strong interest in further education on a variety of end-of-life care topics.

<http://www.ncbi.nlm.nih.gov/pubmed/25645998>

Balkin, E. M., Wolfe, J., Ziniel, S. I., Lang, P., Thiagarajan, R., Dillis, S., Fynn-Thompson, F. and Blume, E. D. (2015). "Physician and Parent Perceptions of Prognosis and End-of-Life Experience in Children with Advanced Heart Disease." J Palliat Med 18(4): 318-323.

BACKGROUND: Little is known about how physician and parent perspectives compare regarding the prognosis and end-of-life (EOL) experience of children with advanced heart disease (AHD). OBJECTIVE: The study's objective was to describe and compare parent and physician perceptions regarding prognosis and EOL experience in children with AHD. METHODS: This was a cross-sectional survey study of cardiologists and bereaved parents. Study subjects were parents and cardiologists of children with primary cardiac diagnoses who died in a tertiary care pediatric hospital between January 2007 and December 2009. Inclusion required both physician and parent to have completed surveys respective to the same patient. A total of 31 parent/physician pairs formed the analytic sample. Perceptions were measured of cardiologists and bereaved parents regarding the EOL experience of children with AHD. RESULTS: Nearly half of parents and physicians felt that patients suffered 'a great deal,' 'a lot,' or 'somewhat' at EOL, but there was no agreement between them. At diagnosis, parents more often expected complete repair and normal lifespan while the majority of physicians expected shortened lifespan without normal quality of life. Parents who expected complete repair with normal life were more likely to report 'a lot' of suffering at EOL (p=0.002). In 43% of cases, physicians reported that the parents were prepared for the way in which their child died, while the parents reported feeling unprepared. CONCLUSION: Both parents and physicians perceive suffering at EOL in patients who die of AHD. Moreover, parent expectations at diagnosis may influence perceptions of suffering at EOL. Physicians overestimate the degree of parent preparedness for their child's death.

<http://www.ncbi.nlm.nih.gov/pubmed/25493354>

Bansal, S. (2014). "Chronic myeloid leukemia in children, do we have all the answers?" South Asian J Cancer 3(4): 192.

<http://www.ncbi.nlm.nih.gov/pubmed/25422800>

Barczykowska, E., Szwed-Kolinska, M., Wrobel-Bania, A. and Slusarz, R. (2014). "The Use of Central Venous Lines in the Treatment of Chronically Ill Children." Adv Clin Exp Med 23(6): 1001-1009.

Treatment of chronic diseases in children is a special medical problem. Maintaining constant access to the central vascular system is necessary for long-term hemato-oncological and nephrological therapies as well as parenteral nutrition. Providing such access enables chemotherapeutic treatment, complete parenteral nutrition, long-term antibiotic therapy, hemodialysis, treatment of intensive care unit patients, monitoring blood pressure in the pulmonary artery and stimulation of heart rate in emergency situations as well as treatment of patients suffering from complications, especially when chances of access into peripheral veins are exhausted. Continuous access to the central vascular system is desirable in the treatment of chronically ill children. Insertion of a central venous catheter line eliminates the unnecessary pain and stress to a child patient accompanying injection into peripheral vessels. In order to

gain long-term and secure access to the central venous system, respecting the guidelines of the Center for Disease Control and Prevention contained in the updated 'Guidelines for the Prevention of Intravascular Catheter-Related Infections' is necessary.

<http://www.ncbi.nlm.nih.gov/pubmed/25618129>

Berger, J., Polivka, B., Smoot, E. A. and Owens, H. (2015). "Compassion Fatigue in Pediatric Nurses." J Pediatr Nurs.

Compassion fatigue in nursing has been shown to impact the quality of patient care and employee satisfaction and engagement. The aims of this study were to determine the prevalence and severity of compassion fatigue among pediatric nurses and variations in prevalence based on respondent demographics using a cross-sectional survey design. Nurses under 40 years of age, with 6-10 years of experience and/or working in a medical-surgical unit had significantly lower compassion satisfaction and higher levels of burnout. Secondary traumatic stress from caring for children with severe illness or injury or end of life was a key contributor to compassion fatigue.

<http://www.ncbi.nlm.nih.gov/pubmed/25800590>

Bloomer, M. J., O'Connor, M., Copnell, B. and Endacott, R. (2015). "Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: Nurses' emotional talk and sources of discomfort. A mixed methods study." Aust Crit Care 28(2): 87-92.

BACKGROUND: The majority of in-hospital deaths of children occur in paediatric and neonatal intensive care units. For nurses working in these settings, this can be a source of significant anxiety, discomfort and sense of failure. OBJECTIVES: The objectives of this study were to explore how NICU/PICU nurses care for families before and after death; to explore the nurses' perspectives on their preparedness/ability to provide family care; and to determine the emotional content of language used by nurse participants. METHODS: Focus group and individual interviews were conducted with 22 registered nurses from neonatal and paediatric intensive care units of two major metropolitan hospitals in Australia. All data were audio recorded and transcribed verbatim. Transcripts were then analysed thematically and using Linguistic Inquiry to examine emotional content. RESULTS: Four core themes were identified: preparing for death; communication challenges; the nurse-family relationship and resilience of nurses. Findings suggested that continuing to provide aggressive treatment to a dying child/infant whilst simultaneously caring for the family caused discomfort and frustration for nurses. Nurses sometimes delayed death to allow families to prepare, as evidenced in the Linguistic Inquiry analysis, which enabled differentiation between types of emotional talk such as anger talk, anxiety talk and sadness talk. PICU nurses had significantly more anxiety talk ($p=0.018$) than NICU nurses. CONCLUSION: This study provided rich insights into the experiences of nurses who are caring for dying children including the nurses' need to balance the often aggressive treatments with preparation of the family for the possibility of their child's death. There is some room for improvement in nurses' provision of anticipatory guidance, which encompasses effective and open communication, focussed on preparing families for the child's death.

<http://www.ncbi.nlm.nih.gov/pubmed/25659197>

Bogetz, J. F., Bogetz, A. L., Gabhart, J. M., Bergman, D. A., Blankenburg, R. L. and Rassbach, C. E. (2015). "Continuing education needs of pediatricians across diverse specialties caring for children with medical complexity." *Clin Pediatr (Phila)* 54(3): 222-227.

OBJECTIVE: Care for children with medical complexity (CMC) relies on pediatricians who often are ill equipped, but striving to provide high quality care. We performed a needs assessment of pediatricians across diverse subspecialties at a tertiary academic US children's hospital about their continuing education needs regarding the care of CMC. METHODS: Eighteen pediatricians from diverse subspecialties were asked to complete an online anonymous open-ended survey. Data were analyzed using modified grounded theory. RESULTS: The response rate was 89% (n = 16). Of participants, 31.2% (n = 5) were general pediatricians, 18.7% (n = 3) were hospitalists, and 50% (n = 8) were pediatric subspecialists. Pediatricians recognized the need for skills in care coordination, giving bad news, working in interprofessional teams, and setting goals of care with patients. CONCLUSIONS: Practicing pediatricians need skills to improve care for CMC. Strategically incorporating basic palliative care education may fill an important training need across diverse pediatric specialties.

<http://www.ncbi.nlm.nih.gov/pubmed/25561699>

Bradford, N., Herbert, A., Mott, C., Armfield, N., Young, J. and Smith, A. (2014). "Components and principles of a pediatric palliative care consultation: results of a Delphi study." *J Palliat Med* 17(11): 1206-1213.

BACKGROUND: Pediatric palliative care is a distinct specialty that requires input from pediatric and palliative medicine specialists to provide comprehensive high-quality care. Consultations undertaken early in a child's illness trajectory, when end-of-life care is not anticipated to be required, enables relationships to be established and may enhance the quality of care provided. OBJECTIVE: To define optimal components of an early pediatric palliative care consultation. DESIGN: Consensus of an expert group was sought in a five-round Delphi study. SETTING/PARTICIPANTS: Based on the literature and existing standards for specialist palliative care, components of an early pediatric palliative care consultation were derived. In rounds 2 and 3, experts from around Australia participated in online surveys to review and prioritize the components and principles. Consensus of survey items was determined by defined criteria. A flowchart was developed in the fourth round and the final round involved review and refinement of the flowchart by the expert group. RESULTS: Nineteen experts participated and prioritized 34 components and principles in the first survey round, and 36 statements in the second survey round. There was consensus from all participants that the first priority of a consultation was to establish rapport with the family, and examples of how to achieve this were defined. Other components of a consultation included: establishing the family's understanding of palliative care; symptom management; an emergency plan; discussion of choices for location of care, and a management plan. Components considered suitable to defer to later consultations, or appropriate to address if initiated by family members, included: spiritual or religious issues; discussion around resuscitation and life-sustaining therapies; end-of-life care; and the dying process. CONCLUSION: We have provided the first published framework from expert consensus that defines the components and principles of an early pediatric palliative care consultation. This framework will provide guidance for clinical practice as well as being useful for education and research in this area.

<http://www.ncbi.nlm.nih.gov/pubmed/25006759>

Branch, C. and Klinkenberg, D. (2015). "Compassion Fatigue Among Pediatric Health-care Providers." MCN Am J Matern Child Nurs.

Background: Compassion fatigue is a term used to describe the unique stressors affecting people in caregiving professions. Purpose: For nurses and other direct care providers, the impact of compassion fatigue may result in stress-related symptoms, job dissatisfaction, decreased productivity, decreased patient satisfaction scores, safety issues, and job turnover. Those who care for seriously ill children and their families are at increased risk for compassion fatigue. Constant exposure to children who are suffering, in combination with work place stressors and personal issues, may contribute to the development of compassion fatigue. Methods: The Professional Quality of Life Scale Version 5 was used to determine the risk for compassion fatigue among 296 direct care providers at St. Louis Children's Hospital. Results: Compassion satisfaction, burnout, and secondary traumatic stress scores did not differ by age, work category, level of education, or work experience. There were, however, significant differences in scores as a function of nursing unit. Nurses who work in the pediatric intensive care unit may be a priority group targeted for immediate intervention. Clinical Implications: Results demonstrated the risk for compassion fatigue and provided data necessary to support development of a compassion fatigue program for direct care providers.

<http://www.ncbi.nlm.nih.gov/pubmed/25594692>

Butler, A., Hall, H., Willetts, G. and Copnell, B. (2015). "Parents' experiences of health-care provider actions when their child dies: an integrative review of the literature." J Spec Pediatr Nurs 20(1): 5-20.

PURPOSE: To review, critique and synthesise current research studies that examine parental perceptions of healthcare provider actions during and after the death of a child. CONCLUSIONS: Five main themes were synthesised from the literature: staff attitudes and affect; follow-up care and ongoing contact; communication; attending to the parents; and continuity of care. PRACTICE IMPLICATIONS: This review helps to identify important aspects of paediatric end-of-life care as recognised by parents, with the intention of placing the family at the centre of any future end-of-life care education or policy/protocol development.

<http://www.ncbi.nlm.nih.gov/pubmed/25443391>

Cavinder, C. (2014). "The relationship between providing neonatal palliative care and nurses' moral distress: an integrative review." Adv Neonatal Care 14(5): 322-328.

Moral distress has been identified in multiple clinical settings especially in critical care areas. The neonatal intensive care unit (NICU) has frequent situations in which moral distress may occur including providing palliative care. The purpose of this integrative review was to determine the relationship between the provision of palliative care in a NICU and nurses' moral distress. The evidence reviewed supports that moral distress does occur with the provision of neonatal palliative care. An interdisciplinary care team, an established protocol, and educational interventions may decrease moral distress in nurses providing end-of-life care to infants in the NICU.

<http://www.ncbi.nlm.nih.gov/pubmed/25022749>

Colville, G., Dalia, C., Brierley, J., Abbas, K., Morgan, H. and Perkins-Porras, L. (2015). "Burnout and traumatic stress in staff working in paediatric intensive care: associations with resilience and coping strategies." *Intensive Care Med* 41(2): 364-365.

<http://www.ncbi.nlm.nih.gov/pubmed/25403756>

Cortezzo, D. E., Sanders, M. R., Brownell, E. A. and Moss, K. (2014). "End-of-Life Care in the Neonatal Intensive Care Unit: Experiences of Staff and Parents." *Am J Perinatol*.

Objective The aim of the study is to determine the perceptions of end-of-life care practices and experience with infants who have died in the NICU among neonatologists, advanced practitioners, nurses, and parents, and also to determine perceived areas for improvement and the perceived value of a palliative care team. **Study Design** This descriptive, exploratory cross-sectional study using surveys consisting of 7-point Likert scales and free response comments was sent to all neonatologists (n = 14), advanced practitioners (n = 40), and nurses (n = 184) at Connecticut Children's Medical Center's neonatal intensive care units (NICUs) in April 2013 and to all parents whose infants died in these NICUs from July 1, 2011, to December 31, 2012 (n = 28). **Results** The response rates were 64.3% for physicians; 50.0% for practitioners; 40.8% for nurses; and 30.4% for parents. Most providers reported they feel comfortable delivering end-of-life care. Bereavement support, debriefing/closure conferences, and education did not occur routinely. Families stressed the importance of memory making and bereavement/follow-up. Consistent themes of free responses include modalities for improving end-of-life care, inconsistency of care delivery among providers, and the importance of memory making and follow-up. **Conclusion** End-of-life experiences in the NICU were perceived as variable and end-of-life practices were, at times, perceived as inconsistent among providers. There are areas for improvement, and participants reported that a formalized palliative care team could help. Families desire memory making, follow-up, and bereavement support.

<http://www.ncbi.nlm.nih.gov/pubmed/25519196>

Crocker, J. C., Beecham, E., Kelly, P., Dinsdale, A. P., Hemsley, J., Jones, L. and Bluebond-Langner, M. (2015). "Inviting parents to take part in paediatric palliative care research: A mixed-methods examination of selection bias." *Palliat Med* 29(3): 231-240.

BACKGROUND: Recruitment to paediatric palliative care research is challenging, with high rates of non-invitation of eligible families by clinicians. The impact on sample characteristics is unknown. **AIM:** To investigate, using mixed methods, non-invitation of eligible families and ensuing selection bias in an interview study about parents' experiences of advance care planning (ACP). **DESIGN:** We examined differences between eligible families invited and not invited to participate by clinicians using (1) field notes of discussions with clinicians during the invitation phase and (2) anonymised information from the service's clinical database. **SETTING:** Families were eligible for the ACP study if their child was receiving care from a UK-based tertiary palliative care service (Group A; N = 519) or had died 6-10 months previously having received care from the service (Group B; N = 73). **RESULTS:** Rates of non-invitation to

the ACP study were high. A total of 28 (5.4%) Group A families and 21 (28.8%) Group B families ($p < 0.0005$) were invited. Family-clinician relationship appeared to be a key factor associated qualitatively with invitation in both groups. In Group A, out-of-hours contact with family was statistically associated with invitation (adjusted odds ratio 5.46 (95% confidence interval 2.13-14.00); $p < 0.0005$). Qualitative findings also indicated that clinicians' perceptions of families' wellbeing, circumstances, characteristics, engagement with clinicians and anticipated reaction to invitation influenced invitation. CONCLUSION: We found evidence of selective invitation practices that could bias research findings. Non-invitation and selection bias should be considered, assessed and reported in palliative care studies.

<http://www.ncbi.nlm.nih.gov/pubmed/25519146>

Dallara, A., Meret, A. and Saroyan, J. (2014). "Mapping the literature: palliative care within adult and child neurology." *J Child Neurol* 29(12): 1728-1738.

Objectives of this review were to examine definitions and background of palliative care, as well as address whether there is an increased need for palliative care education among neurologists. The review also explores what literature exists regarding palliative care within general neurology and child neurology. A literature review was conducted examining use of palliative care within child neurology. More than 100 articles and textbooks were retrieved and reviewed. Expert guidelines stress the importance of expertise in palliative care among neurologists. Subspecialties written about in child neurology include that of peripheral nervous system disorders, neurodegenerative diseases, and metabolic disorders. Adult and child neurology patients have a great need for improved palliative care services, as they frequently develop cumulative physical and cognitive disabilities over time and cope with decreasing quality of life before reaching the terminal stage of their illness.

<http://www.ncbi.nlm.nih.gov/pubmed/24717986>

dos Santos, R. A. and Moreira, M. C. (2014). "Resilience and death: the nursing professional in the care of children and adolescents with life-limiting illnesses." *Cien Saude Colet* 19(12): 4869-4878.

The purpose of this article is to analyze the resilience of the nursing staff in providing care for children and adolescents with chronic diseases, including coping with their deaths. The participants of this qualitative research were nursing professionals working in the pediatric ward of a hospital in the city of Rio de Janeiro, Brazil. The data collection was obtained by applying the resilience scale, by returning the scales in groups, and by semi-structured interviews. The relationship between professional resilience and coping with the process of children and adolescent's deaths stood out in the analysis based on data obtained from group and individual interviews. The care given to children and adolescents with life-limiting illnesses triggers resilience-related answers concerning alternatives that oscillate between individual reactions (religious and psychological support), and the search for an incipient collective support based on personal relationships. This study points out that this subject must be strategically handled to train this professional, who must be able to rely on support from the collective environment, presumed within the professional health care training and in the management of humanization at the hospital.

<http://www.ncbi.nlm.nih.gov/pubmed/25388195>

Edwards, S., Davis, A. M., Bruce, A., Mousa, H., Lyman, B., Cocjin, J., Dean, K., Ernst, L., Almadhoun, O. and Hyman, P. (2015). "Caring for Tube-Fed Children: A Review of Management, Tube Weaning, and Emotional Considerations." JPEN J Parenter Enteral Nutr.

Enteral nutrition is the practice of delivering nutrition to the gut either orally or through a tube or other device. Many children are reliant on enteral feedings to either supplement their nutrition or as a complete source of their nutrition. Managing children on tube feedings requires a team of providers to work through such dilemmas as feeding schedules, weaning from tube feeding, sensory implications of tube feeding, treatment of pain or nausea associated with eating, oral-motor issues, and behavioral issues in the child and family. The purpose of the current review is to summarize the multidisciplinary aspects of enteral feeding. The multidisciplinary team consists of a variable combination of an occupational therapist, speech-language pathologist, gastroenterologist, psychologist, nurse, pharmacist, and dietitian. Children who have minimal oral feeding experience and are fed via a nasogastric or gastrostomy tube often develop oral aversions. Limited data support that children with feeding disorders are more likely to have sensory impairment and that early life pain experiences contribute to feeding refusal. There are inpatient and outpatient programs for weaning patients from tube feeding to eating. The parent-child interaction is an important part of the assessment and treatment of the tube-fed child. This review also points out many information gaps, including data on feeding schedules, blenderized tube feedings, the best methods for weaning children off enteral feedings, the efficacy of chronic pain medications with tube-fed children, and, finally, the necessity of the assessment of parental stress among all parents of children who are tube fed.

<http://www.ncbi.nlm.nih.gov/pubmed/25791833>

Frommelt, M. A. (2014). "Challenges and controversies in fetal diagnosis and treatment: hypoplastic left heart syndrome." Clin Perinatol 41(4): 787-798.

Today, almost 70% of babies with hypoplastic left heart syndrome (HLHS) will survive into adulthood, although significant long-term morbidity and mortality still exists. Prenatal diagnosis of HLHS is increasingly common, allowing improved counseling, and the potential for fetal intervention if indicated. Exciting progress continues to be made in the area of fetal diagnosis and intervention, specifically catheter intervention for intact atrial septum or severe aortic stenosis. Pediatric cardiologists should be keenly aware of the flaws of staged palliation for the treatment of HLHS, and need to keep abreast of the emerging data regarding fetal diagnosis and intervention.

<http://www.ncbi.nlm.nih.gov/pubmed/25459774>

Granek, L., Barrera, M., Scheinemann, K. and Bartels, U. (2015). "When a child dies: pediatric oncologists' follow-up practices with families after the death of their child." Psychooncology.

OBJECTIVES: Follow-up practices with bereaved families are considered a part of good medical care, yet little is known about pediatric oncologists' protocol with families when their patients die. The objective of this study was to examine follow-up practices employed by pediatric oncologists after patient death using an in-depth qualitative analysis. **METHODS:** The Grounded Theory method of data collection and analysis was used. Twenty-one pediatric oncologists at two Canadian pediatric hospitals were interviewed about their follow-up practices with bereaved families after patients died. Line-by-line coding was used to establish codes and themes, and constant comparison was used to establish relationships among emerging codes and themes. **RESULTS:** Pediatric oncologists actively engage in follow-up practices that include making phone calls, sending an email or condolence card, attending funerals or visitations, having long-term and short-term meetings with parents, and attending hospital or departmental memorials for the deceased child. Attending funerals or visitations was less frequent and varied widely across pediatric oncologists. Reasons for not participating in bereavement follow-up practices included logistical, emotional, and practical considerations. **CONCLUSIONS:** While the majority of pediatric oncologists at two Canadian centers engage in some follow-up practices with bereaved families, these practices are complex and challenging because of the emotional nature of these interactions. Medical institutions should provide both structured time for this follow-up work with families, as well as medical education and financial and emotional support to pediatric oncologists who continue caring for these families long after their child has died. Copyright (c) 2015 John Wiley & Sons, Ltd.

<http://www.ncbi.nlm.nih.gov/pubmed/25707675>

Granek, L., Bartels, U., Barrera, M. and Scheinmann, K. (2015). "Challenges faced by pediatric oncology fellows when patients die during their training." *J Oncol Pract* 11(2): e182-189.

PURPOSE: Given the paucity of research on the experience of pediatric oncology fellows regarding patient death, the purpose of this study was to explore the specific challenges that pediatric oncology fellows face when patients die during their training. **METHODS:** Six pediatric oncology fellows at two academic cancer centers in Ontario, Canada, were interviewed about their experiences with patient death during their fellowship training. The grounded theory method of data collection and data analysis was used. Line-by-line coding was used to establish themes, and constant comparison was used to establish relationships among emerging codes and themes. **RESULTS:** Fellows reported structural challenges that included ward duty and lack of follow-up opportunities with bereaved families. Personal challenges included feelings of vulnerability as a result of being a trainee, inexperience with patient death, and feeling alone with one's reactions to patient death. Relational challenges included duration of relationships with families and with supervising staff and perceived lack of modeling on how to cope with patient deaths. **CONCLUSION:** Structural changes to the fellowship model can be made in order to enhance support with patient death, including informing fellows of all patient deaths and incorporating fellows into follow-up practices with bereaved families. Moreover, integrating fellows' debriefing (facilitated by grief counselors) after a patient death into fellow training, as well as greater involvement with palliative care physicians, can lessen feelings of isolation and help fellows learn effective strategies for dealing with patient deaths from experienced palliative care physicians.

<http://www.ncbi.nlm.nih.gov/pubmed/25784578>

Granek, L., Bartels, U., Scheinemann, K. and Barrera, M. (2015). "Challenging patient deaths in pediatric oncology." Support Care Cancer.

PURPOSE: Pediatric oncologists look after patients and their families for extended periods of time when they are diagnosed and treated for cancer. Twenty percent of these children will die while under their care. The purpose of this study was to explore what makes patient deaths challenging for pediatric oncologists. **METHODS:** Twenty-one Canadian pediatric oncologists were interviewed about their experiences with patient death and were probed about the factors that make patient deaths particularly challenging. Data were analyzed using the grounded theory method. **RESULTS:** Challenging factors pertaining to patient death were categorized into three main domains. Relational factors included dealing with families perceived as challenging; identifying with parents; and having long-term relationships and special connections with patients and their caregivers. The second domain captured the process of death and dying and included death after curative treatment was stopped; death caused by complications; and unexpected deaths. The third domain encompassed patient factors that included suffering of the child, and the sense that no child should die. **CONCLUSIONS:** The types of relationships pediatric oncologists have with patients and caregivers, and the process by which children die affects pediatric oncologists' perceived level of difficulty in coping with the death. The findings point to the complexity of working with children where parents are included in the decision-making processes around a child's treatment. Implementation of structured review opportunities around patient death and associated decision-making within a multidisciplinary healthcare team may alleviate some of the emotional burden associated with patient deaths.

<http://www.ncbi.nlm.nih.gov/pubmed/25586526>

Granek, L., Bartels, U., Scheinemann, K., Labrecque, M. and Barrera, M. (2015). "Grief reactions and impact of patient death on pediatric oncologists." Pediatr Blood Cancer 62(1): 134-142.

BACKGROUND: To examine pediatric oncologists' grief reactions to patient death, and the impact patient death has on their personal and professional lives. **PROCEDURE:** The grounded theory method was used. Data was collected between March 2012 and July 2012 at two academic centres in Canada. Twenty-one out of 34 eligible pediatric oncologists at different stages of their career were recruited and interviewed about their experiences with patient death. Inclusion criteria were: being able to speak English and having had a patient die in their care. The participants formed three groups of oncologists at different stages of career including: fellows, junior oncologists, and senior oncologists who varied in subspecialties, gender, and ethnicities. **RESULTS:** Pediatric oncologists reported a range of reactions to patient death including sadness, crying, sleep loss, exhaustion, feeling physically ill, and a sense of personal loss. They also reported self-questioning, guilt, feelings of failure and helplessness. The impact of these deaths had personal consequences that ranged from irritability at home, feeling disconnected from family members and friends, and becoming more desensitized towards death, to gaining a greater and more appreciative perspective on life. Professional impacts included concern about turnover or burnout at work and improving holistic care as a result of patient deaths. **CONCLUSIONS:** Grief over patient death and the

emotional labour involved in these losses are a robust part of the pediatric oncology workplace and have major impacts on pediatric oncologist's personal and professional lives. Interventions that focus on how to help pediatric oncologists deal with these reactions are needed.

<http://www.ncbi.nlm.nih.gov/pubmed/25214471>

Harrison, J., Evan, E., Hughes, A., Yazdani, S., Federman, M. and Harrison, R. (2014). "Understanding communication among health care professionals regarding death and dying in pediatrics." *Palliat Support Care* 12(5): 387-392.

OBJECTIVE: Effective communication regarding death and dying in pediatrics is a vital component of any quality palliative care service. The goal of the current study is to understand communication among health care professionals regarding death and dying in children. The three hypotheses tested were: (1) hospital staff (physicians of all disciplines, nurses, and psychosocial clinicians) that utilize consultation services are more comfortable communicating about death and dying than those who do not use such services, (2) different disciplines of health care providers demonstrate varying levels of comfort communicating about a range of areas pertaining to death and dying, and (3) health care staff that have had some type of formal training in death and dying are more comfortable communicating about these issues. METHODS: A primary analysis of a survey conducted in a tertiary care teaching children's hospital. RESULTS: Health care professionals who felt comfortable discussing options for end of life care with colleagues also felt more comfortable: initiating a discussion regarding a child's impending death with his/her family ($r = 0.42$), discussing options for terminal care with a family ($r = 0.58$), discussing death with families from a variety of ethnic/cultural backgrounds ($r = 0.51$), guiding parents in developmentally age-appropriate discussions of death with their children ($r = 0.43$), identifying and seeking advice from a professional role model regarding management concerns ($r = 0.40$), or interacting with a family following the death of a child ($r = 0.51$). Among all three disciplines, physicians were more likely to initiate discussions with regards to a child's impending death ($F = 13.07$; $p = 0.007$). Health care professionals that received formal grief and bereavement training were more comfortable discussing death. Significance of the results: The results demonstrated that consultation practices are associated with a higher level of comfort in discussing death and dying in pediatrics.

<http://www.ncbi.nlm.nih.gov/pubmed/23916065>

Hendricks-Ferguson, V. L., Akard, T. F., Madden, J. R., Peters-Herron, A. and Levy, R. (2015). "Contributions of advanced practice nurses with a DNP degree during palliative and end-of-life care of children with cancer." *J Pediatr Oncol Nurs* 32(1): 32-39.

The doctorate in nursing practice (DNP) degree is recommended as the terminal degree for advanced practice nurses by 2015. Improvement in the quality of palliative and end-of-life care for children with cancer is recognized as a health care priority. The purpose of this article is to describe: (a) how the American Association of Colleges of Nursing's 8 core elements and competencies can be used by DNP-advanced practice nurses in pediatric oncology settings and (b) the DNP-advanced practice nurses' leadership role to advocate translation of evidence in the care of pediatric oncology patients and to promote interdisciplinary collaboration to improve health care outcomes for pediatric oncology patients.

<http://www.ncbi.nlm.nih.gov/pubmed/25416517>

Hendricks-Ferguson, V. L., Kane, J. R., Pradhan, K. R., Shih, C. S., Gauvain, K. M., Baker, J. N. and Haase, J. E. (2015). "Evaluation of Physician and Nurse Dyad Training Procedures to Deliver a Palliative and End-of-Life Communication Intervention to Parents of Children with a Brain Tumor." J Pediatr Oncol Nurs.

When a child's prognosis is poor, physicians and nurses (MDs/RNs) often struggle with initiating discussions about palliative and end-of-life care (PC/EOL) early in the course of illness trajectory. We describe evaluation of training procedures used to prepare MD/RN dyads to deliver an intervention entitled: Communication Plan: Early Through End of Life (COMPLETE) intervention. Our training was delivered to 5 pediatric neuro-oncologists and 8 pediatric nurses by a team of expert consultants (i.e., in medical ethics, communication, and PC/EOL) and parent advisors. Although half of the group received training in a 1-day program and half in a 2-day program, content for all participants included 4 modules: family assessment, goal-directed treatment planning, anticipatory guidance, and staff communication and follow-up. Evaluations included dichotomous ratings and qualitative comments on content, reflection, and skills practice for each module. Positive aspects of our training included parent advisers' insights, emphasis on hope and non-abandonment messages, written materials to facilitate PC/EOL communication, and an MD/RN dyad approach. Lessons learned and challenges related to our training procedures will be described. Overall, the MDs and RNs reported that our PC/EOL communication-training procedures were helpful and useful. Future investigators should carefully plan training procedures for PC/EOL communication interventions.

<http://www.ncbi.nlm.nih.gov/pubmed/25623029>

Hendricks-Ferguson, V. L., Sawin, K. J., Montgomery, K., Dupree, C., Phillips-Salimi, C. R., Carr, B. and Haase, J. E. (2015). "Novice Nurses' Experiences With Palliative and End-of-Life Communication." J Pediatr Oncol Nurs.

Health care providers recognize that delivery of effective communication with family members of children with life-threatening illnesses is essential to palliative and end-of-life care (PC/EOL). Parents value the presence of nurses during PC/EOL of their dying child. It is vital that nurses, regardless of their years of work experience, are competent and feel comfortable engaging family members of dying children in PC/EOL discussions. This qualitative-descriptive study used focus groups to explore the PC/EOL communication perspectives of 14 novice pediatric oncology nurses (eg, with less than 1 year of experience). Audio-taped focus group discussions were reviewed to develop the following 6 theme categories: (a) Sacred Trust to Care for the Child and Family, (b) An Elephant in the Room, (c) Struggling with Emotional Unknowns, (d) Kaleidoscope of Death: Patterns and Complexity, (e) Training Wheels for Connectedness: Critical Mentors during PC/EOL of Children, and (f) Being Present with an Open Heart: Ways to Maintain Hope and Minimize Emotional Distress. To date, this is the first study to focus on PC/EOL communication perspectives of novice pediatric oncology nurses.

<http://www.ncbi.nlm.nih.gov/pubmed/25556105>

Henry, M. and Sung, L. (2015). "Supportive care in pediatric oncology: oncologic emergencies and management of fever and neutropenia." Pediatr Clin North Am 62(1): 27-46.

Advancements in the care of children with cancer have, in part, been achieved through improvements in supportive care. Situations that require prompt care can occur at the time of presentation as well as during treatment. This article discusses the approach to children with fever and neutropenia, a complication encountered daily by care providers, as well as oncologic emergencies that can be seen at the time of a child's initial diagnosis: hyperleukocytosis, tumor lysis syndrome, superior vena cava syndrome, and spinal cord compression.
<http://www.ncbi.nlm.nih.gov/pubmed/25435110>

Howes, C. (2015). "Caring until the end: a systematic literature review exploring Paediatric Intensive Care Unit end-of-life care." Nurs Crit Care 20(1): 41-51.

AIMS AND OBJECTIVES: A systematic review of the literature focusing on the provision of end-of-life care (EOLC) on Paediatric Intensive Care Units (PICUs) and the options available to children and families within contemporary clinical practice. BACKGROUND: The death of a child is recognized as a uniquely traumatic experience for a parent. The care delivered to a child and family surrounding death can have a lasting effect on the grieving process. The majority of paediatric deaths occur within PICUs, often as a result of withdrawing or withholding treatment. Withdrawal of intensive care is becoming more common within UK PICUs, and this review will focus on the options available when a child's on-going treatment is deemed to be futile. SEARCH STRATEGIES: Literature published from 2002 to 2013 was obtained from a range of sources and critically reviewed. Cormack's (2000) framework for systematic literature review was utilized to critically review literature before analysis and synthesis of the literature was undertaken within the qualitative approach. INCLUSION/EXCLUSION CRITERIA: Each article focused on issues surrounding the topic area, excluded adult and neonatal intensive care and was published in English. CONCLUSIONS: Eight papers met the inclusion criteria and were suitable for review (highlighting difficulties in reviewing a small, complex subject area). Key themes identified included family views, staff views, decision-making, medico-legal issues and resources. RELEVANCE TO CLINICAL PRACTICE: Although the number of relevant articles is limited, a wide range of challenges facing children, parents and staff are highlighted, whilst generally supporting the facilitation of transferring children to their homes or hospice for withdrawal of intensive care and continuing EOLC. Further research is required, particularly regarding long-term implications, legal issues and the effectiveness of clinical protocols.
<http://www.ncbi.nlm.nih.gov/pubmed/25378129>

Hunter, J. P., Stinson, J., Campbell, F., Stevens, B., Wagner, S. J., Simmons, B., White, M. and van Wyk, M. (2015). "A novel pain interprofessional education strategy for trainees: assessing impact on interprofessional competencies and pediatric pain knowledge." Pain Res Manag 20(1): e12-20.

BACKGROUND: Health care trainee students lack knowledge and skills for the comprehensive clinical assessment and management of pain. Moreover, most teaching has been limited to classroom settings within each profession. OBJECTIVES: To develop and evaluate the feasibility

ity and preliminary outcomes of the 'Pain-Interprofessional Education (IPE) Placement', a five-week pain IPE implemented in the clinical setting. The utility (content validity, readability, internal consistency and practical considerations) of the outcome measures was also evaluated. METHODS: A convenience sample of 21 trainees from eight professions was recruited over three Pain-IPE Placement cycles. Pre- and postcurriculum assessment included: pain knowledge (Pediatric Pain Knowledge and Attitudes Survey), IPE attitudes (Interdisciplinary Education Perception Scale [IEPS]) and IPE competencies (Interprofessional Care Core Competencies Global Rating Scales [IPC-GRS]), and qualitative feedback on process acceptability. RESULTS: Recruitment and retention met expectations. Qualitative feedback was excellent. IPE measures (IEPS and IPC-GRS) exhibited satisfactory utility. Postcurriculum scores improved significantly: IEPS, $P < 0.05$; IPC-GRS constructs, $P < 0.01$; and competencies, $P < 0.001$. However, the Pediatric Pain Knowledge and Attitudes Survey exhibited poor utility in professions without formal pharmacology training. Scores improved in the remaining professions ($n=14$; $P < 0.01$). DISCUSSION: There was significant improvement in educational outcomes. The IEPS and IPC-GRS are useful measures of IPE-related learning. At more advanced training levels, a single pain-knowledge questionnaire may not accurately reflect learning across diverse professions. CONCLUSION: The Pain-IPE Placement is a successful collaborative learning model within a clinical context that successfully changed interprofessional competencies. The present study represents a first step at defining and assessing change in interprofessional competencies gained from Pain-IPE.

<http://www.ncbi.nlm.nih.gov/pubmed/25144859>

Klick, J. C., Friebert, S., Hutton, N., Osenga, K., Pituch, K. J., Vesel, T., Weidner, N., Block, S. D. and Morrison, L. J. (2014). "Developing competencies for pediatric hospice and palliative medicine." *Pediatrics* 134(6): e1670-1677.

In 2006, hospice and palliative medicine (HPM) became an officially recognized subspecialty. This designation helped initiate the Accreditation Council of Graduate Medical Education Outcomes Project in HPM. As part of this process, a group of expert clinician-educators in HPM defined the initial competency-based outcomes for HPM fellows (General HPM Competencies). Concurrently, these experts recognized and acknowledged that additional expertise in pediatric HPM would ensure that the competencies for pediatric HPM were optimally represented. To fill this gap, a group of pediatric HPM experts used a product development method to define specific Pediatric HPM Competencies. This article describes the development process. With the ongoing evolution of HPM, these competencies will evolve. As part of the Next Accreditation System, the Accreditation Council of Graduate Medical Education uses milestones as a framework to better define competency-based, measurable outcomes for trainees. Currently, there are no milestones specific to HPM, although the field is designing curricular milestones with multispecialty involvement, including pediatrics. These competencies are the conceptual framework for the pediatric content in the HPM milestones. They are specific to the pediatric HPM subspecialist and should be integrated into the training of pediatric HPM subspecialists. They will serve a foundational role in HPM and should inform a wide range of emerging innovations, including the next evolution of HPM Competencies, development of HPM curricular milestones, and training of adult HPM and other pediatric subspecialists. They may also inform pediatric HPM outcome measures, as well as standards of practice and performance for pediatric HPM interdisciplinary teams.

<http://www.ncbi.nlm.nih.gov/pubmed/25404726>

Lala, M. M. and Merchant, R. H. (2014). "After 3 decades of paediatric HIV/AIDS - Where do we stand?" Indian J Med Res 140(6): 704-706.

<http://www.ncbi.nlm.nih.gov/pubmed/25758566>

MacDermott, C. and Keenan, P. M. (2014). "Grief experiences of nurses in Ireland who have cared for children with an intellectual disability who have died." Int J Palliat Nurs 20(12): 584-590.

BACKGROUND: The personal grief experience of nurses who have cared for children with an intellectual disability who have died is little understood. METHOD: This descriptive qualitative study was initiated to ascertain nurses' knowledge and personal experience of grief and how this is managed. Semi-structured interview was the method used to collect data from eight nurses who had cared for a child with an intellectual disability who had died. A pragmatic approach to qualitative data analysis was adopted. RESULTS: Of the eight main themes identified, the four most prevalent are discussed in detail: grief, relationship with the child, end of life, and support. The findings demonstrate that nurses have a good understanding of grief, but the way they experience and manage it varies. CONCLUSION: The study suggests that nurses who have cared for children with an intellectual disability who have died may experience disenfranchised grief. Nurses seek support from a variety of sources. Organisational support is important for nurses following the death of a child for whom they have provided care.

<http://www.ncbi.nlm.nih.gov/pubmed/25526287>

Mandac, C. and Battista, V. (2014). "Contributions of palliative care to pediatric patient care." Semin Oncol Nurs 30(4): 212-226.

OBJECTIVES: To provide an overview of pediatric palliative care (PPC) as it relates to children and families living with oncologic disease. DATA SOURCES: Journal articles, clinical research reports, clinical guidelines, and national statistics. CONCLUSION: As new treatment protocols become available, the need for simultaneous supportive PPC, including adequate pain and symptom management, is evident. Further research and PPC program development is necessary for adherence to the current recommendation that PPC should be initiated at the time of diagnosis and continue throughout the course of a child's disease. IMPLICATIONS FOR NURSING PRACTICE: Palliative care nursing holds a specific role in the pediatric oncology setting. Registered nurses and advanced practice nurses should be adequately trained in PPC because they are in an optimal role to contribute to interdisciplinary PPC for pediatric oncology patients and their families.

<http://www.ncbi.nlm.nih.gov/pubmed/25361873>

Meisenhelder, J. B. and Gibson, L. E. (2015). "Caring for the bereaved parent: Guidelines for practice." J Am Assoc Nurse Pract.

PURPOSE: The purpose of this research review was to create practical guidelines for the primary care practitioner in comforting, counseling, and educating bereaved parents and their significant supporters. DATA SOURCES: The authors used an extensive review of the litera-

ture for original research reports of bereaved parents' self-identified needs for comfort from their friends, family, and healthcare practitioners. Insight gained from the authors' clinical work with bereaved parents added further understanding. CONCLUSIONS: Parents express strong preferences and needs regarding support from both social relationships and health-care personnel. Specific guidelines were created for use by both friends/family members and health professionals. IMPLICATIONS FOR PRACTICE: Nurse practitioners have an important role in supporting bereaved parents, and educating their friends and family on the most helpful behaviors during this painful time.

<http://www.ncbi.nlm.nih.gov/pubmed/25721824>

Mitchell, S. and Dale, J. (2015). "Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff." *Palliat Med* 29(4): 371-379.

BACKGROUND: The majority of children and young people who die in the United Kingdom have pre-existing life-limiting illness. Currently, most such deaths occur in hospital, most frequently within the intensive care environment. AIM: To explore the experiences of senior medical and nursing staff regarding the challenges associated with Advance Care Planning in relation to children and young people with life-limiting illnesses in the Paediatric Intensive Care Unit environment and opportunities for improvement. DESIGN: Qualitative one-to-one, semi-structured interviews were conducted with Paediatric Intensive Care Unit consultants and senior nurses, to gain rich, contextual data. Thematic content analysis was carried out. SETTING/PARTICIPANTS: UK tertiary referral centre Paediatric Intensive Care Unit. Eight Paediatric Intensive Care Unit consultants and six senior nurses participated. FINDINGS: Four main themes emerged: recognition of an illness as 'life-limiting'; Advance Care Planning as a multi-disciplinary, structured process; the value of Advance Care Planning and adverse consequences of inadequate Advance Care Planning. Potential benefits of Advance Care Planning include providing the opportunity to make decisions regarding end-of-life care in a timely fashion and in partnership with patients, where possible, and their families. Barriers to the process include the recognition of the life-limiting nature of an illness and gaining consensus of medical opinion. Organisational improvements towards earlier recognition of life-limiting illness and subsequent Advance Care Planning were recommended, including education and training, as well as the need for wider societal debate. CONCLUSIONS: Advance Care Planning for children and young people with life-limiting conditions has the potential to improve care for patients and their families, providing the opportunity to make decisions based on clear information at an appropriate time, and avoid potentially harmful intensive clinical interventions at the end of life.

<http://www.ncbi.nlm.nih.gov/pubmed/25721360>

Price, J., Janicki, J. S., McKee, H., Nurse, S. and Gray, E. (2014). "Perspectives of an international education initiative in children's palliative care." *Int J Palliat Nurs* 20(11): 542-548.

Education is viewed as central to improving future palliative care for children and families across all countries. International education initiatives will ensure practitioners are aware of global health issues and can provide culturally sensitive care. Creative and innovative means

of meeting such directives are required to achieve meaningful student learning. This paper focuses on one innovation, a children's palliative care workshop using case studies as a teaching method, with nursing students from the USA and nursing and midwifery students from the UK. Key learning points arising from student evaluation were recorded under three main themes, these were: differences across countries, similarities across countries, and making learning fun and memorable. Findings indicated that this joint learning activity was viewed positively by all students and has enabled them to learn with and from each other, potentially impacting on their future practice.

<http://www.ncbi.nlm.nih.gov/pubmed/25426881>

Reed, S., Kassis, K., Nagel, R., Verbeck, N., Mahan, J. D. and Shell, R. (2015). "Breaking bad news is a teachable skill in pediatric residents: A feasibility study of an educational intervention." *Patient Educ Couns* 98(6): 748-752.

OBJECTIVE: Patients and physicians identify communication of bad news as a skill in need of improvement. Our objectives were to measure change in performance of first-year pediatric residents in the delivery of bad news after an educational intervention and to measure if changes in performance were sustained over time. **METHODS:** Communication skills of 29 residents were assessed via videotaped standardized patient (SP) encounters at 3 time points: baseline, immediately post-intervention, and 3 months post-intervention. Educational intervention used was the previously published "GRIEV_ING Death Notification Protocol." **RESULTS:** The intraclass correlation coefficient demonstrated substantial inter-rater agreement with the assessment tool. Performance scores significantly improved from baseline to immediate post-intervention. Performance at 3 months post-intervention showed no change in two subscales and small improvement in one subscale. **CONCLUSIONS:** We concluded that breaking bad news is a complex and teachable skill that can be developed in pediatric residents. Improvement was sustained over time, indicating the utility of this educational intervention. **PRACTICE IMPLICATIONS:** This study brings attention to the need for improved communication training, and the feasibility of an education intervention in a large training program. Further work in development of comprehensive communication curricula is necessary in pediatric graduate medical education programs.

<http://www.ncbi.nlm.nih.gov/pubmed/25775928>

Samsel, C. and Lechner, B. E. (2014). "End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative." *J Perinatol*.

Objective:We hypothesized that the implementation of a neonatal palliative care initiative will result in improved markers of end-of-life care.**Study design:**A retrospective and prospective chart review of neonatal intensive care unit deaths was performed for 24 months before, 16 months during and 24 months after the implementation of palliative care provider education and practice guidelines (n=106). Ancillary care, redirection of care, palliative medication usage and outcome meetings in the last 48 h of life and basic demographic data were compared between epochs. Parametric and nonparametric analysis was performed.**Result:**There was an increase in redirection of care and palliative medication usage and a decrease in variability of use of end-of-life interventions (P=0.012, 0.022 and <0.001).**Conclusion:**The implementation of a neonatal palliative care initiative was associated with increases in palliative

interventions for neonates in their final 48 h of life, suggesting that such an initiative may enhance end-of-life care. *Journal of Perinatology* advance online publication, 23 October 2014; doi:10.1038/jp.2014.189.

<http://www.ncbi.nlm.nih.gov/pubmed/25341197>

Scott, A. M. and Caughlin, J. P. (2015). "Communication nonaccommodation in family conversations about end-of-life health decisions." *Health Commun* 30(2): 144-153.

Furthering our understanding of how communication can improve end-of-life decision making requires a shift in focus from whether people talk to how people talk about end-of-life health decisions. This study used communication accommodation theory to examine the extent to which communication nonaccommodation distinguished more from less successful end-of-life conversations among family members. We analyzed elicited conversations about end-of-life health decisions from 121 older parent/adult child dyads using outside ratings of communication over- and underaccommodation and self-reported conversational outcomes. Results of multilevel linear modeling revealed that outside ratings of underaccommodation predicted self-reported and partner-reported uncertainty, and ratings of overaccommodation predicted self-reported decision-making efficacy and change in concordance accuracy. We discuss the methodological, theoretical, and practical implications of these findings.

<http://www.ncbi.nlm.nih.gov/pubmed/25470439>

Setou, N., Sakaguchi, Y., Kurokawa, K. and Takada, S. (2015). "Effectiveness of professional training in bereavement care: Survey of Japanese pediatricians supporting families who have lost a child." *Pediatr Int*.

BACKGROUND: The aim of this study was to assess the effectiveness of professional training in bereavement care. **METHOD:** We mailed a questionnaire to 554 Japanese pediatricians. It asked about demographic characteristics, personal support experiences, professional training, psychological distress, recognition of high risk after a child's death, and eight items relating to awareness in bereavement care. We divided the subjects into two groups based on the presence or absence of professional training and compared them on the basis of each item (chi² test), and conducted logistic regression analysis. **RESULTS:** Of the 239 respondents, 193 (80.8%) had performed bereavement care. The final number included in the analysis was 175, after excluding responses with missing data. A total of 46 respondents (26.3%) had attended bereavement care training. The subjects who had had training were more likely to recognize those at high risk for poor psychological recovery, have information about support groups, have a desire to study bereavement care, and understand the necessity of cooperation with mental health specialists. **CONCLUSION:** Many pediatricians had personally provided support for the bereaved. On logistic analysis, it was considered that four factors (recognition of high risk for poor recovery, information about support, desire to study, and cooperation with professionals) were significantly associated with the professional training. There were no significant differences, however, in psychological distress, helplessness, and fatigue. Training programs related to stress management must be improved for pediatricians who feel high levels of psychological distress.

<http://www.ncbi.nlm.nih.gov/pubmed/25728462>

Szurhaj, W., Lamblin, M. D., Kaminska, A. and Sediri, H. (2015). "EEG guidelines in the diagnosis of brain death." Neurophysiol Clin 45(1): 97-104.

In France, for the determination and diagnostic validation of brain death the law requires either two EEG recordings separated by a 4-hour observation period, both showing electrocerebral inactivity; or cerebral angiography examination. Since EEG is available in most hospitals and clinics, it is often used in this indication, at the patient's bedside, especially in the context of organ donation. However, very precise methodology must be followed. The last French guidelines date back to 1989, before the development of digital EEG recording. We present the new guidelines from the Societe de Neurophysiologie Clinique de Langue Francaise. Electrocerebral inactivity may be confirmed when a 30-minute good quality EEG recording shows complete electrocerebral silence, defined as no cerebral activity greater than 2uV, having first ruled out the possible influence of sedative drugs, metabolic disorders or hypothermia. In the presence of sedative drugs, CT brain angiography will be the gold standard test for this diagnosis. In the newborn, the utmost caution is indicated since electrocerebral inactivity can be observed in the absence of cerebral death. In the infant, the criterion for the observation period to be respected between both EEG recordings needs to be more clearly refined.

<http://www.ncbi.nlm.nih.gov/pubmed/25687591>

Ten Cate, K. and van de Vathorst, S. (2015). "Dutch pediatricians' views on the use of neuromuscular blockers for dying neonates: a qualitative study." J Perinatol.

Objective: To assess Dutch pediatricians' views on neuromuscular blockers for dying neonates. Study design: Qualitative study involving in-depth interviews with 10 Dutch pediatricians working with severely ill neonates. Data were analyzed using appropriate qualitative research techniques. Result: Participants explained their view on neuromuscular blockers for neonates with a protracted dying process. Major themes were the interpretation of gasping, the role of (the suffering of) the parents, the need for judicial review and legislation's impact on the care participants provide for dying neonates. Conclusion: The interviews show no consensus between pediatricians and provide insights into the points of disagreement. Interviews also suggest friction between the convictions of pediatricians and legislation, which seems to have an undesirable impact on Dutch care for dying neonates and their parents. This study raises important questions for pediatricians worldwide to reflect upon, such as: 'what constitutes 'dying well'?' and 'what role should the parents' perspective play?'. Journal of Perinatology advance online publication, 22 January 2015; doi:10.1038/jp.2014.238.

<http://www.ncbi.nlm.nih.gov/pubmed/25611792>

Wilkinson, D., de Crespigny, L. and Xafis, V. (2014). "Ethical language and decision-making for prenatally diagnosed lethal malformations." Semin Fetal Neonatal Med 19(5): 306-311.

In clinical practice, and in the medical literature, severe congenital malformations such as trisomy 18, anencephaly, and renal agenesis are frequently referred to as 'lethal' or as 'incompatible with life'. However, there is no agreement about a definition of lethal malforma-

tions, nor which conditions should be included in this category. Review of outcomes for malformations commonly designated 'lethal' reveals that prolonged survival is possible, even if rare. This article analyses the concept of lethal malformations and compares it to the problematic concept of 'futility'. We recommend avoiding the term 'lethal' and suggest that counseling should focus on salient prognostic features instead. For conditions with a high chance of early death or profound impairment in survivors despite treatment, perinatal and neonatal palliative care would be ethical. However, active obstetric and neonatal management, if desired, may also sometimes be appropriate.

<http://www.ncbi.nlm.nih.gov/pubmed/25200733>

Wong, L. C. and Behr, E. R. (2014). "Sudden unexplained death in infants and children: the role of undiagnosed inherited cardiac conditions." *Europace* 16(12): 1706-1713.

Sudden unexplained death in childhood is a traumatic event for both the immediate family and medical professionals. This is termed sudden unexplained or arrhythmic death syndrome (SUDS/SADS) for children over 1 year of age while sudden unexplained death in infancy or sudden infant death syndrome (SUDI/SIDS) refers to unexplained deaths in the first year of life. There is increasing evidence for the role of undiagnosed inherited cardiac conditions, particularly channelopathies, as the cause of these deaths. This has far-reaching implications for the family regarding the potential risk to other family members and future pregnancies, providing a challenge not only in the counselling but also in the structured assessment and management of immediate relatives. This review will discuss the cardiac risk involved in sudden unexplained deaths of infants and children, the role of molecular autopsy, family cardiological screening, current management strategies, and future directions in this area.

<http://www.ncbi.nlm.nih.gov/pubmed/24585884>

Wool, C. (2015). "Clinician perspectives of barriers in perinatal palliative care." *MCN Am J Matern Child Nurs* 40(1): 44-50.

PURPOSE: Perinatal palliative care (PPC) is a developing model of care aimed at providing supportive services to families anticipating fetal or neonatal demise. This study measured barriers physicians and advance practice nurses report in providing and referring patients to PPC. **STUDY DESIGN AND METHODS:** A cross-sectional survey design using the Perinatal Palliative Care Perceptions and Barriers Scale (c) was administered using a Web-based tool. Recruitment was completed via email and flyer invitations and list serves. Physicians (n = 66) and advance practice nurses (n = 146) participated. T-test and Mann-Whitney U were used to examine differences in clinician-reported barriers to PPC. **RESULTS:** Physicians and nurses differ significantly in the barriers they report. Nurses expressed more obstacles at the health-care systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians are more confident in their ability to counsel patients than nurses. Members of both disciplines express similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. They also report a lack of societal support and understanding about PPC. **CLINICAL IMPLICATIONS:** Cultivating an environment of collaboration and interdisciplinary communication can benefit both caregivers and patients. Nurses have an opportunity to lead and promote PPC endeavors through par-

ticipating in advantageous partnerships and research. Both disciplines may benefit from interventions directed at increasing their comfort in caring for patients in a palliative setting through targeted education and supportive staff services.

<http://www.ncbi.nlm.nih.gov/pubmed/25503834>

Younge, N., Smith, P. B., Goldberg, R. N., Brandon, D. H., Simmons, C., Cotten, C. M. and Bidegain, M. (2014). "Impact of a palliative care program on end-of-life care in a neonatal intensive care unit." J Perinatol.

Objective :Evaluate changes in end-of-life care following initiation of a palliative care program in a neonatal intensive care unit. Study design: Retrospective study comparing infant deaths before and after implementation of a Palliative Care Program comprised of medication guidelines, an individualized order set, a nursing care plan and staff education. Result :Eighty-two infants died before (Era 1) and 68 infants died after implementation of the program (Era 2). Morphine use was similar (88% vs 81%; P =0.17), whereas benzodiazepines use increased in Era 2 (26% vs 43%; P=0.03). Withdrawal of life support (73% vs 63%; P=0.17) and do-not-resuscitate orders (46% vs 53%; P=0.42) were similar. Do-not-resuscitate orders and family meetings were more frequent among Era 2 infants with activated palliative care orders (n=21) compared with infants without activated orders (n=47). Conclusion: End-of-life family meetings and benzodiazepine use increased following implementation of our program, likely reflecting adherence to guidelines and improved communication. Journal of Perinatology advance online publication, 23 October 2014; doi:10.1038/jp.2014.193.

<http://www.ncbi.nlm.nih.gov/pubmed/25341195>

Epidemiology and pathology

(2014). "Earlier screening for life-threatening conditions in babies." **Community Pract** 87(10): 5.

<http://www.ncbi.nlm.nih.gov/pubmed/25619056>

Abu-Ouf, N. M. and Jan, M. M. (2015). "Metabolic syndrome in the survivors of childhood acute lymphoblastic leukaemia." Obes Res Clin Pract 9(2): 114-124.

Metabolic syndrome is a common complication encountered in children surviving acute lymphoblastic leukaemia (ALL). Affected patients develop obesity, insulin resistance, hypertension, and hyperlipidemia. Metabolic syndrome is a consequence of multiple factors, particularly hormonal imbalance induced by various ALL treatments. This review aims to evaluate the risk factors and mechanisms leading to the development of metabolic syndrome. Further research is needed to improve our understanding of the mechanisms leading to insulin resistance and the associated endothelial and adipose tissue dysfunction. Future studies should also examine other possible contributing factors, such as environmental and genetic factors. Understanding these factors will help in guiding modifications of the current ALL treatment protocols in order to prevent the development of this syndrome and hence improve the quality of life of ALL survivors. Until this is achieved, clinicians should continue to identify patients at risk early and use a therapeutic approach that combines dietary restrictions and enhanced physical activity.

<http://www.ncbi.nlm.nih.gov/pubmed/25081809>

Alfelali, M. and Khandaker, G. (2014). "Infectious causes of sudden infant death syndrome." Paediatr Respir Rev 15(4): 307-311.

Investigators have long suspected the role of infection in sudden infant death syndrome (SIDS). Evidence of infectious associations with SIDS is accentuated through the presence of markers of infection and inflammation on autopsy of SIDS infants and isolates of some bacteria and viruses. Several observational studies have looked into the relation between seasonality and incidence of SIDS, which often showed a winter peak. These all may suggest an infectious aetiology of SIDS. In this review we have summarised the current literature on infectious aetiologies of SIDS by looking at viral, bacterial, genetic and environmental factors which are believed to be associated with SIDS.

<http://www.ncbi.nlm.nih.gov/pubmed/25441371>

Alicandro, G., Frova, L., Di Fraia, G. and Colombo, C. (2015). "Cystic fibrosis mortality trend in Italy from 1970 to 2011." J Cyst Fibros 14(2): 267-274.

BACKGROUND: Survival in cystic fibrosis (CF) has progressively improved and the female-gender disadvantage first described many years ago remains controversial. OBJECTIVES: To describe the mortality trend due to CF in Italy over the last decades; to verify the female-

mortality disadvantage; to compare the comorbidities reported in death certificates of CF patients with those of the general population. METHODS: Mortality data were extracted from the database of underlying cause of death (1970-2011) and multiple causes of death (2003-2011) of the Italian National Institute of Statistics. Age-standardized mortality ratio (SMR) was calculated to compare the mortality between genders. The association between CF and other contributing causes of death was verified by calculating the age- and gender-adjusted proportional mortality ratio (PMR). RESULTS: During the study period, 1947 death certificates reported CF as the underlying cause of death. Mortality rate due to CF decreased in newborns and children and by the end of the 1990s also in adolescents and young adults. Adult mortality started to increase in the early 1990s. Over the whole period an excess in mortality was observed in young CF females (1-29 years). The multiple causes of death database included 531 certificates with CF listed as cause of death. Pneumonia, chronic lower respiratory diseases, pulmonary heart disease and diseases of pulmonary circulation, aspergillosis, sepsis, renal failure, diabetes, malnutrition and amyloidosis were more frequently reported in CF death certificates compared to those of the general population (PMR>1). CONCLUSIONS: This mortality trend provides evidence of a consistent improvement in survival, although the excess female-mortality persists despite aggressive treatment of CF lung disease. Several extra-pulmonary conditions associated with CF contributed to the morbidity leading to death. <http://www.ncbi.nlm.nih.gov/pubmed/25151032>

Ammann, R. A., Laws, H. J., Schrey, D., Ehlert, K., Moser, O., Dilloo, D., Bode, U., Wawer, A., Schrauder, A., Cario, G., Laengler, A., Graf, N., Furtwangler, R. and Simon, A. (2015). "Bloodstream infection in paediatric cancer centres-leukaemia and relapsed malignancies are independent risk factors." *Eur J Pediatr* 174(5): 675-686.

In a prospective multicentre study of bloodstream infection (BSI) from November 01, 2007 to July 31, 2010, seven paediatric cancer centres (PCC) from Germany and one from Switzerland included 770 paediatric cancer patients (58 % males; median age 8.3 years, interquartile range (IQR) 3.8-14.8 years) comprising 153,193 individual days of surveillance (in- and outpatient days during intensive treatment). Broviac catheters were used in 63 % of all patients and Ports in 20 %. One hundred forty-two patients (18 %; 95 % CI 16 to 21 %) experienced at least one BSI (179 BSIs in total; bacteraemia 70 %, bacterial sepsis 27 %, candidaemia 2 %). In 57 %, the BSI occurred in inpatients, in 79 % after conventional chemotherapy. Only 56 % of the patients showed neutropenia at BSI onset. Eventually, patients with acute lymphoblastic leukaemia (ALL) or acute myeloblastic leukaemia (AML), relapsed malignancy and patients with a Broviac faced an increased risk of BSI in the multivariate analysis. Relapsed malignancy (16 %) was an independent risk factor for all BSI and for Gram-positive BSI. CONCLUSION: This study confirms relapsed malignancy as an independent risk factor for BSIs in paediatric cancer patients. On a unit level, data on BSIs in this high-risk population derived from prospective surveillance are not only mandatory to decide on empiric antimicrobial treatment but also beneficial in planning and evaluating preventive bundles. WHAT IS KNOWN: * Paediatric cancer patients face an increased risk of nosocomial bloodstream infections (BSIs). * In most cases, these BSIs are associated with the use of a long-term central venous catheter (Broviac, Port), severe and prolonged immunosuppression (e.g. neutropenia) and other chemotherapy-induced alterations of host defence mechanisms (e.g. mucositis). What is New: * This study is the first multicentre study confirming relapsed malignancy as an independent risk factor for BSIs in paediatric cancer patients. * It describes the epidemiology of nosoco-

mial BSI in paediatric cancer patients mainly outside the stem cell transplantation setting during conventional intensive therapy and argues for prospective surveillance programmes to target and evaluate preventive bundle interventions.

<http://www.ncbi.nlm.nih.gov/pubmed/25804192>

Andrade, A., Yau, I. and Moharir, M. (2015). "Current concepts in pediatric stroke." Indian J Pediatr 82(2): 179-188.

Stroke is a relatively rare but rather significant cause of short- and long-term morbidity and mortality in children. It can be divided into three categories: arterial ischemic stroke (AIS), hemorrhagic stroke (HS) and cerebral sinovenous thrombosis (CSVT). This review focuses on AIS. The etiologies of pediatric AIS are diverse and different from those in adult stroke, chief among these being congenital heart disease, vasculopathies, hematological disorders and prothrombotic states. Additional factors might be related to the age group, ethnicity and geographic factors. Early recognition enables initiation of prompt therapy thereby reducing risk of further recurrence and complications.

<http://www.ncbi.nlm.nih.gov/pubmed/25804192>

Arnautovic, A., Billups, C., Broniscer, A., Gajjar, A., Boop, F. and Qaddoumi, I. (2015). "Delayed diagnosis of childhood low-grade glioma: causes, consequences, and potential solutions." Childs Nerv Syst.

PURPOSE: Diagnosis of childhood brain tumors is delayed more than diagnosis of other pediatric cancers. However, the contribution of the most common pediatric brain tumors, low-grade gliomas (LGG), to this delay has never been investigated. METHODS: We retrospectively reviewed cases of childhood LGG diagnosed from January 1995 through December 2005 at our institution. The pre-diagnosis symptom interval (PSI) was conservatively calculated, and its association with race, sex, age, tumor site, tumor grade, and outcome measures (survival, disease progression, shunt use, seizures, extent of resection) was analyzed. Cases of neurofibromatosis type 1 were reported separately. RESULTS: The 258 children had a median follow-up of 11.1 years, and 226 (88 %) remained alive. Greater pre-diagnosis symptom interval (PSI) was significantly associated with grade I (vs. grade II) tumors ($p = 0.03$) and age >10 years at diagnosis ($p = 0.03$). Half of the 16 spinal tumors had a PSI > 6 months. PSI was significantly associated with progression ($p = 0.02$) in grade I tumors ($n = 195$) and in grade I tumors outside the posterior fossa ($n = 134$, $p = 0.03$). Among children with grade I tumors, median PSI was longer in those who had seizures (10.3 months) than in those who did not (2.5 months) ($p = 0.09$). CONCLUSIONS: Delayed diagnosis of childhood LGG allows tumor progression. To reduce time to diagnosis, medical curricula should emphasize inclusion of LGG in the differential diagnosis of CNS neoplasm.

<http://www.ncbi.nlm.nih.gov/pubmed/25742877>

Awano, T., Kim, J. K. and Monani, U. R. (2014). "Spinal muscular atrophy: journeying from bench to bedside." Neurotherapeutics 11(4): 786-795.

Spinal muscular atrophy (SMA) is a frequently fatal neuromuscular disorder and the most common inherited cause of infant mortality. SMA results from reduced levels of the survival of motor neuron (SMN) protein. Although the disease was first described more than a cen-

tury ago, a precise understanding of its genetics was not obtained until the SMA genes were cloned in 1995. This was followed in rapid succession by experiments that assigned a role to the SMN protein in the proper splicing of genes, novel animal models of the disease, and the eventual use of the models in the pre clinical development of rational therapies for SMA. These successes have led the scientific and clinical communities to the cusp of what are expected to be the first truly promising treatments for the human disorder. Yet, important questions remain, not the least of which is how SMN paucity triggers a predominantly neuromuscular phenotype. Here we review how our understanding of the disease has evolved since the SMA genes were identified. We begin with a brief description of the genetics of SMA and the proposed roles of the SMN protein. We follow with an examination of how the genetics of the disease was exploited to develop genetically faithful animal models, and highlight the insights gained from their analysis. We end with a discussion of ongoing debates, future challenges, and the most promising treatments to have emerged from our current knowledge of the disease.

<http://www.ncbi.nlm.nih.gov/pubmed/24990202>

Bansal, S., Kebede, T., Dean, N. P. and Carpenter, J. L. (2014). "Predictors of acute symptomatic seizures after intracranial hemorrhage in infants." *Pediatr Crit Care Med* 15(8): 750-755.

OBJECTIVE: To determine the prevalence of acute symptomatic seizures in infants with supratentorial intracranial hemorrhage, to identify potential risk factors, and to determine the effect of acute seizures on long-term morbidity and mortality. **DESIGN:** Children less than 24 months with intracranial hemorrhage were identified from a neurocritical care database. All patients who received seizure prophylaxis beginning at admission were included in the study. Risk factors studied were gender, etiology, location of hemorrhage, seizure(s) on presentation, and the presence of parenchymal injury. Acute clinical and electrographic seizures were identified from hospital medical records. Subsequent development of late seizures was determined based on clinical information from patients' latest follow-up. **SETTING AND PATIENTS:** Patients with idiopathic neonatal intracranial hemorrhage, premature infants, and those with prior history of seizures were excluded from analysis. Seventy-two infants met inclusion criteria. **INTERVENTIONS:** None. **MEASUREMENTS AND MAIN RESULTS:** Forty percent of infants had acute symptomatic seizures. The prevalence was similar regardless of whether etiology of hemorrhage was traumatic or nontraumatic. Seizures on presentation and parenchymal injury were independent risk factors of acute seizures ($p = 0.001$ and $p = 0.006$, respectively). Younger children and women were also at higher risk ($p < 0.05$). Twenty percent had electrographic-only seizures, and those with parenchymal injury trended toward an increased risk ($p < 0.1$). Acute seizures were not predictive of mortality, but nearly twice as many patients with acute seizures developed late seizures when compared with those without. Electrographic seizures and parenchymal injury were also predictive of development of late seizures ($p < 0.001$ and $p = 0.013$, respectively). **CONCLUSIONS:** Despite seizure prophylaxis, infants with supratentorial intracranial hemorrhage are at high risk for acute symptomatic seizures. This is regardless of the etiology of hemorrhage. Younger patients, women, patients with parenchymal injury, and patients presenting with seizure are most likely to develop acute seizures. Although the benefits of seizure prophylaxis have not been studied in

this specific population, these results suggest that it is an important component of acute care following intracranial hemorrhage.

<http://www.ncbi.nlm.nih.gov/pubmed/25280143>

Barr, R. D. (2015). "Clinical implications of malnutrition in children with cancer." Support Care Cancer.

<http://www.ncbi.nlm.nih.gov/pubmed/25763754>

Bendavid, E. (2014). "Changes in child mortality over time across the wealth gradient in less-developed countries." Pediatrics 134(6): e1551-1559.

BACKGROUND: It is unknown whether inequalities in under-5 mortality by wealth in low- and middle-income countries (LMICs) are growing or declining. METHODS: All Demographic and Health Surveys conducted between 2002 and 2012 were used to measure under-5 mortality trends in 3 wealth tertiles. Two approaches were used to estimate changes in under-5 mortality: within-survey changes from all 54 countries, and between-survey changes for 29 countries with repeated survey waves. The principal outcome measures include annual decline in mortality, and the ratio of mortality between the poorest and least-poor wealth tertiles. RESULTS: Mortality information in 85 surveys from 929 224 households and 1 267 167 women living in 54 countries was used. In the subset of 29 countries with repeat surveys, mortality declined annually by 4.36, 3.36, and 2.06 deaths per 1000 live births among the poorest, middle, and least-poor tertiles, respectively (P = .031 for difference). The mortality ratio declined from 1.68 to 1.48 during the study period (P = .006 for trend). In the complete set of 85 surveys, the mortality ratio declined in 64 surveys (from 2.11 to 1.55), and increased in 21 surveys (from 1.58 to 1.88). Multivariate analyses suggest that convergence was associated with good governance (P <= .03 for 4 governance indicators: government effectiveness, rule of law, regulatory quality, and control of corruption). CONCLUSIONS: Overall, under-5 mortality in low- and middle-income countries has decreased faster among the poorest compared with the least poor between 1995 and 2012, but progress in some countries has lagged, especially with poor governance.

<http://www.ncbi.nlm.nih.gov/pubmed/25384496>

Boelens, J. J., Orchard, P. J. and Wynn, R. F. (2014). "Transplantation in inborn errors of metabolism: current considerations and future perspectives." Br J Haematol 167(3): 293-303.

Inborn errors of metabolism (IEM) comprise an assorted group of inherited diseases, some of which are due to disordered lysosomal or peroxisomal function and some of which might be improved following haemopoietic cell transplantation (HCT). In these disorders, the onset in infancy or early childhood is typically accompanied by rapid deterioration, resulting in early death in the more severe phenotypes. Timely diagnosis and immediate referral to an IEM specialist are essential steps in optimal management. Treatment recommendations are based on the diagnosis, its phenotype, rate of progression, prior extent of disease, family values and expectations and the risks and benefits associated with available therapies, including

HCT. International collaborative efforts are of utmost importance in determining outcomes of therapy for these rare diseases, and have improved those outcomes significantly over recent decades. This discussion focuses on HCT in IEM, providing an international perspective on progress, limitations, and future directions.

<http://www.ncbi.nlm.nih.gov/pubmed/25074667>

Camperlengo, L., Shapiro-Mendoza, C. K. and Gibbs, F. (2014). "Improving sudden unexplained infant death investigation practices: an evaluation of the Centers for Disease Control and Prevention's SUID Investigation Training Academies." Am J Forensic Med Pathol 35(4): 278-282.

Lack of thorough sudden unexplained infant death investigations (SUIDIs) has hindered accurate cause-of-death determination, infant mortality surveillance, and prevention strategies. To standardize SUIDI practices, the Centers for Disease Control and Prevention created a reporting form, guidelines, training curriculum, and SUIDI Training Academies using a train-the-trainer format. The training goal was to train teams of five in each state, who would reach an additional 1250 participants. The aim of this study is to evaluate the SUIDI Training Academies by determining professional characteristics of participants, assessing the level of confidence in infant death investigation components, enumerating the number of secondary trainings, and discussing recommendations for future trainings. To evaluate the training and the success of the train-the-trainer strategy, we used training evaluations, participant lists, and Web-based training logs to assess participant knowledge, skills, perceptions, and characteristics and number of secondary trainings. We trained 270 trainers at 5 SUIDI Training Academies. Greater than 96% of respondents reported confidence in case investigation skills and reported that hands-on laboratory sessions facilitated the practice of new skills. Academy trainers have trained greater than 23,000 medicolegal professionals, exceeding the training goal. This evaluation allowed us to identify opportunities to improve future SUIDI trainings.

<http://www.ncbi.nlm.nih.gov/pubmed/25330248>

Cooper, S. L. and Brown, P. A. (2015). "Treatment of pediatric acute lymphoblastic leukemia." Pediatr Clin North Am 62(1): 61-73.

Acute lymphoblastic leukemia (ALL) is the most common pediatric oncologic diagnosis, and advances in its treatment have led to progressive improvements in survival. The 4 main components of therapy are remission induction, consolidation, maintenance, and central nervous system-directed therapy, and usually last 2 to 3 years. Treatment intensity based on risk-based stratification is the cornerstone of treatment. Patients with features of more favorable disease are spared the more toxic effects of chemotherapy, whereas more aggressive regimens are reserved for those with higher-risk disease. Prognosis of relapsed pediatric ALL depends primarily on duration of remission and site of relapse.

<http://www.ncbi.nlm.nih.gov/pubmed/25435112>

de Blank, P. M., Ostrom, Q. T., Rouse, C., Wolinsky, Y., Kruchko, C., Salcido, J. and Barnholtz-Sloan, J. S. (2015). "Years of life lived with disease and years of potential life lost in children who die of cancer in the United States, 2009." Cancer Med.

Incidence and survival rates are commonly reported statistics, but these may fail to capture the full impact of childhood cancers. We describe the years of potential life lost (YPLL) and years of life lived with disease (YLLD) in children and adolescents who died of cancer in the United States to estimate the impact of childhood cancer in the United States in 2009. We examined mortality data in 2009 among children and adolescents <20 years old in both the National Vital Statistics System (NVSS) and the Surveillance, Epidemiology, and End Results (SEER) datasets. YPLL and YLLD were calculated for all deaths due to cancer. Histology-specific YPLL and YLLD of central nervous system (CNS) tumors, leukemia, and lymphoma were estimated using SEER. There were 2233 deaths and 153,390.4 YPLL due to neoplasm in 2009. CNS tumors were the largest cause of YPLL (31%) among deaths due to cancer and were the cause of 1.4% of YPLL due to all causes. For specific histologies, the greatest mean YPLL per death was due to atypical teratoid/rhabdoid tumor (78.0 years lost). The histology with the highest mean YLLD per death in children and adolescents who died of cancer was primitive neuroectodermal tumor (4.6 years lived). CNS tumors are the most common solid malignancy in individuals <20 years old and have the highest YPLL cost of all cancers. This offers the first histology-specific description of YPLL in children and adolescents and proposes a new measure of cancer impact, YLLD, in individuals who die of their disease. YPLL and YLLD complement traditional indicators of mortality and help place CNS tumors in the context of other childhood malignancies.

<http://www.ncbi.nlm.nih.gov/pubmed/25627000>

Feldman, A. G. and Mack, C. L. (2015). "Biliary Atresia: Clinical Lessons Learned." J Pediatr Gastroenterol Nutr.

Biliary atresia is a rare disease of unclear etiology, where obstruction of the biliary tree causes severe cholestasis leading to cirrhosis and ultimate death if left untreated. Biliary atresia is the leading cause of neonatal cholestasis and the most frequent indication for pediatric liver transplantation. Any infant with persistent jaundice beyond 2 weeks of life needs to be evaluated for biliary atresia with fractionation of the bilirubin into a conjugated and unconjugated portion. Early performance of a hepatoportoenterostomy in the first 45 days of life to restore bile flow and lessen further damage to the liver is thought to optimize outcome. Despite surgery, progressive liver scarring occurs and 80% of patients with biliary atresia will require liver transplantation during childhood.

<http://www.ncbi.nlm.nih.gov/pubmed/25658057>

Finn, D., Collins, A., Murphy, B. P. and Dempsey, E. M. (2014). "Mode of neonatal death in an Irish maternity centre." Eur J Pediatr 173(11): 1505-1509.

Modes of neonatal dying vary among maternity centres, both within and between countries. There have been few reports concerning mode of dying from countries with low rates of termination of pregnancy, such as Ireland. We conducted a retrospective chart review of all

neonatal deaths, between January 2010 and January 2013, within a single Irish maternity centre. The mode of dying was classified as one of (1) withholding life-sustaining treatment (LST), (2) withdrawal of LST in moribund infants, (3) withdrawal of LST for quality of life reasons or (4) death despite maximal intensive care treatment. There were a total of 64 deaths during the study period. Congenital abnormalities accounted for 47 % of deaths and prematurity for 41 % of deaths. Withholding LST was the most frequent mode of dying, occurring in 38 % of all deaths. A total of 12 % of neonatal deaths occurred despite maximal intensive care treatment. CONCLUSIONS: Congenital abnormalities were the most common cause of neonatal deaths. A high proportion followed LST being withheld, most likely a reflection of the low rates of medical termination in Ireland. Modes of dying in the neonatal period vary between maternity centres with culturally different backgrounds.

<http://www.ncbi.nlm.nih.gov/pubmed/24916041>

Galland, B. C. and Elder, D. E. (2014). "Sudden unexpected death in infancy: biological mechanisms." *Paediatr Respir Rev* 15(4): 287-292.

Sudden unexpected death in infancy (SUDI) covers both explained and unexplained deaths. Unexplained cases or SIDS are likely to have multiple neural mechanisms contributing to the final event. The evidence ranges from subtle physiological signs related to autonomic control, to findings at autopsy of altered neurotransmitter systems, including the serotonergic system, a network that has an extensive homeostatic role in cardio-respiratory and thermoregulatory control. Processes may be altered by the vulnerability of the infant due to age, poor motor ability, or a genetic predisposition. The fatal event may occur in response to an environmental stress. A single final physiological route to death seems unlikely. An understanding of the reasons for explained SUDI also reminds us that a thorough investigation is required after each death occurs.

<http://www.ncbi.nlm.nih.gov/pubmed/25301029>

Hakeem, G. F., Oddy, L., Holcroft, C. A. and Abenhaim, H. A. (2014). "Incidence and determinants of sudden infant death syndrome: a population-based study on 37 million births." *World J Pediatr*.

BACKGROUND: The objective of our study is to measure the incidence of sudden infant death syndrome (SIDS), estimate the birth to death interval, and identify associated maternal and infant risk factors. METHODS: We carried out a population-based cohort study on 37 418 280 births using data from the Centers for Disease Control and Prevention's "Linked Birth-Infant Death" and "Fetal Death" data files from 1995 to 2004. Descriptive statistics and cox-proportional hazard models were used to estimate the adjusted effect of maternal and newborn characteristics on the risk of SIDS. RESULTS: There were 24 101 cases of SIDS identified for an overall 10-year incidence of 6.4 cases per 10 000 births. Over the study period, the incidence decreased from 8.1 to 5.6 per 10 000 and appeared to be most common among infants aged 2-4 months. Risk factors included maternal age <20 years, black, non-Hispanic race, smoking, increasing parity, inadequate prenatal care, prematurity and growth restriction. CONCLUSIONS: While the incidence of SIDS in the US has declined, it currently remains the leading cause of post-neonatal mortality, highlighting an important public health priority. Educational campaigns should be targeted towards mothers at increased risk in order to

raise their awareness of modifiable risk factors for SIDS such as maternal smoking and inadequate prenatal care.

<http://www.ncbi.nlm.nih.gov/pubmed/25447630>

Hall, R. W. and Anand, K. J. (2014). "Pain management in newborns." Clin Perinatol 41(4): 895-924.

As a standard of care for preterm/term newborns effective pain management may improve their clinical and neurodevelopmental outcomes. Neonatal pain is assessed using context-specific, validated, and objective pain methods, despite the limitations of currently available tools. Therapeutic approaches reducing invasive procedures and using pharmacologic, behavioral, or environmental measures are used to manage neonatal pain. Nonpharmacologic approaches like kangaroo care, facilitated tucking, non-nutritive sucking, sucrose, and others can be used for procedural pain or adjunctive therapy. Local/topical anesthetics, opioids, NSAIDs/acetaminophen and other sedative/anesthetic agents can be incorporated into NICU protocols for managing moderate/severe pain or distress in all newborns.

<http://www.ncbi.nlm.nih.gov/pubmed/25459780>

Jacob, J., Kamitsuka, M., Clark, R. H., Kelleher, A. S. and Spitzer, A. R. (2015). "Etiologies of NICU deaths." Pediatrics 135(1): e59-65.

BACKGROUND AND OBJECTIVES: Infant mortality is an indicator of overall societal health, and a significant proportion of infant deaths occur in NICUs. The objectives were to identify causes of death and to define potentially preventable factors associated with death as areas for quality improvement efforts in the NICU. METHODS: In a prospectively defined study, the principal investigator in 46 level III NICUs agreed to review health care records of infants who died. For each infant, the principal investigator reviewed the medical record to identify the primary cause of death and to look for preventable factors associated with the infant's death. Infants born at ≥ 22 weeks estimated gestational age who were born alive were included. Stillborn infants were excluded. RESULTS: Data were collected on 641 infants who died. At lower gestational ages, mortality was most commonly due to extreme prematurity and the complications of premature birth (respiratory distress progressing to respiratory failure, intraventricular hemorrhage, necrotizing enterocolitis, and sepsis). With increasing gestational age, the etiology of mortality shifted to hypoxic-ischemic encephalopathy and genetic or structural anomalies. Reviewers of clinical care identified 197 (31%) infants with potentially modifiable factors that may have contributed to their deaths. CONCLUSIONS: The factors associated with death in infants admitted for intensive care are multifactorial and diverse, and they change with gestational age. In 31% of the deaths, potentially modifiable factors were identified, and these factors suggest important targets for reducing infant mortality.

<http://www.ncbi.nlm.nih.gov/pubmed/25489010>

Lacourpaille, L., Hug, F., Guevel, A., Pereon, Y., Magot, A., Hogrel, J. Y. and Nordez, A. (2015). "Non-invasive assessment of muscle stiffness in patients with Duchenne muscular dystrophy." Muscle Nerve 51(2): 284-286.

INTRODUCTION: Assessment of muscle mechanical properties may provide clinically valuable information for follow-up of patients with Duchenne muscular dystrophy (DMD) through the

course of their disease. In this study we aimed to assess the effect of DMD on stiffness of relaxed muscles using elastography (supersonic shear imaging). METHODS: Fourteen DMD patients and 13 control subjects were studied. Six muscles were measured at 2 muscle lengths (shortened and stretched): gastrocnemius medialis (GM); tibialis anterior (TA); vastus lateralis (VL); biceps brachii (BB); triceps brachii (TB); and abductor digiti minimi (ADM). RESULTS: Stiffness was significantly higher in DMD patients compared with controls for all the muscles (main effect for population, $P < 0.033$ in all cases), except for ADM. The effect size was small ($d = 0.33$ for ADM at both muscle lengths) to large ($d = 0.86$ for BB/stretched). CONCLUSIONS: Supersonic shear imaging is a sensitive non-invasive technique to assess the increase in muscle stiffness associated with DMD.

<http://www.ncbi.nlm.nih.gov/pubmed/25187068>

Lador, F., Sekarski, N. and Beghetti, M. (2015). "Treating pulmonary hypertension in pediatrics." *Expert Opin Pharmacother* 16(5): 711-726.

INTRODUCTION: Pulmonary hypertension is a hemodynamic condition occurring rarely in pediatrics. Nevertheless, it is associated with significant morbidity and mortality. When characterized by progressive pulmonary vascular structural changes, the disease is called pulmonary arterial hypertension (PAH). It results in increased pulmonary vascular resistance and eventual right ventricular failure. In the vast majority of cases, pediatric PAH is idiopathic or associated with congenital heart disease, and, contrary to adult PAH, is rarely associated with connective tissue, portal hypertension, HIV infection or thromboembolic disease. AREAS COVERED: This article reviews the current drug therapies available for the management of pediatric PAH. These treatments target the recognized pathophysiological pathways of PAH with endothelin-1 receptor antagonists, prostacyclin analogs and PDE type 5 inhibitors. New treatments and explored pathways are briefly discussed. EXPERT OPINION: Although there is still no cure for PAH, quality of life and survival have been improved significantly with specific drug therapies. Nevertheless, management of pediatric PAH remains challenging, and depends mainly on results from adult clinical trials and pediatric experts. Further research on PAH-specific treatments in the pediatric population and data from international registries are needed to identify optimal therapeutic strategies and treatment goals in the pediatric population.

<http://www.ncbi.nlm.nih.gov/pubmed/25665593>

Landier, W., Armenian, S. and Bhatia, S. (2015). "Late effects of childhood cancer and its treatment." *Pediatr Clin North Am* 62(1): 275-300.

Treatment for childhood cancer with chemotherapy, radiation and/or hematopoietic cell transplant can result in adverse sequelae that may not become evident for many years. A clear understanding of the association between therapeutic exposures and specific long-term complications, and an understanding of the magnitude of the burden of morbidity borne by childhood cancer survivors, has led to the development of guidelines to support lifelong risk-based follow up for this population. It is important to develop interventions to reduce the impact of treatment-related late effects on morbidity and mortality and to continue research regarding the etiopathogenesis of therapy-related cancers and other late effects.

<http://www.ncbi.nlm.nih.gov/pubmed/25435123>

Ling, J., O'Reilly, M., Balfe, J., Quinn, C. and Devins, M. (2015). "Children with life-limiting conditions: establishing accurate prevalence figures." *Ir Med J* 108(3): 93.
<http://www.ncbi.nlm.nih.gov/pubmed/25876306>

Maher, C., Crettenden, A., Evans, K., Thiessen, M., Toohey, M., Watson, A. and Dollman, J. (2015). "Fatigue is a major issue for children and adolescents with physical disabilities." *Dev Med Child Neurol*.

AIM: This study aimed to investigate fatigue, and its correlates, in children and adolescents with physical disabilities. METHOD: Sixty-five young people aged 8 to 17 years (35 males, 30 females; mean age 13y 2mo, SD 2y 8mo) with mild to moderate physical disabilities (Gillette Functional Assessment Questionnaire levels 7-10) were recruited. Self-reported fatigue was measured using the PedsQL Multidimensional Fatigue Scale. Physical activity was measured using 7-day hip-worn accelerometer. Associations between fatigue, physical activity, and socio-demographic characteristics were examined using analysis of covariance, with significance (alpha) set at 0.05. Results were compared with normative data from other paediatric populations. RESULTS: Among children with physical disabilities, fatigue was associated with being physically inactive (F-statistic=4.42, p=0.040), female (F=4.37, p=0.042), and of low socio-economic status (F=3.94, p=0.050). Fatigue was not associated with age, weight status, or functional impairment. Young people with physical disabilities experienced high levels of fatigue compared with other paediatric health populations, and comparable to the paediatric cancer population. INTERPRETATION: Fatigue is an important issue for young people with physical disabilities. Clinicians and researchers working with this group should be mindful that fatigue is likely to impact on an individual's ability to undertake new treatment regimens or interventions. Interventions aimed at reducing fatigue are warranted. Increasing physical activity might play a role in reducing fatigue.

<http://www.ncbi.nlm.nih.gov/pubmed/25808358>

Malek, N., Stewart, W. and Greene, J. (2015). "The progressive myoclonic epilepsies." *Pract Neurol* 15(3): 164-171.

Progressive myoclonic epilepsies are a group of disorders characterised by a relentlessly progressive disease course until death; treatment-resistant epilepsy is just a part of the phenotype. This umbrella term encompasses many diverse conditions, ranging from Lafora body disease to Gaucher's disease. These diseases as a group are important because of a generally poor response to antiepileptic medication, an overall poor prognosis and inheritance risks to siblings or offspring (where there is a proven genetic cause). A correct diagnosis also helps patients and their families to accept and understand the nature of their disease, even if incurable. Here, we discuss the phenotypes of these disorders and summarise the relevant specific investigations to identify the underlying cause.

<http://www.ncbi.nlm.nih.gov/pubmed/25720773>

Moseley, B. D. (2015). "Seizure-related autonomic changes in children." *J Clin Neurophysiol* 32(1): 5-9.

SUMMARY: Although sudden unexpected death in epilepsy is encountered less frequently in children versus adults, it is still an important direct epilepsy-related cause of death in this

population. Just as in adults, the pathophysiology of sudden unexpected death in epilepsy in children is believed to involve seizure-related autonomic dysfunction. Seizures that develop during the pediatric period can be marked by some of the most dramatic alterations in autonomic functions seen at any age. This article reviews such seizure-related autonomic changes, including ictal nausea/emesis, hypersalivation, hypoxemia, apnea, tachycardia, bradycardia, cardiac repolarization anomalies, reduced heart rate variability, and postictal generalized EEG suppression. Understanding age-related changes in the autonomic effects of seizures and how they relate to risk of sudden death may help us to one day better elucidate the pathophysiology of sudden unexpected death in epilepsy. Given the high rate of sudden unexpected death in epilepsy in certain pediatric populations (such as those with Dravet syndrome), this knowledge is desperately needed.

<http://www.ncbi.nlm.nih.gov/pubmed/25647767>

Neu, N., Duchon, J. and Zachariah, P. (2015). "TORCH infections." *Clin Perinatol* 42(1): 77-103, viii.

TORCH infections classically comprise toxoplasmosis, *Treponema pallidum*, rubella, cytomegalovirus, herpesvirus, hepatitis viruses, human immunodeficiency virus, and other infections, such as varicella, parvovirus B19, and enteroviruses. The epidemiology of these infections varies; in low-income and middle-income countries, TORCH infections are major contributors to prenatal, perinatal, and postnatal morbidity and mortality. Evidence of infection may be seen at birth, in infancy, or years later. For many of these pathogens, treatment or prevention strategies are available. Early recognition, including prenatal screening, is key. This article covers toxoplasmosis, parvovirus B19, syphilis, rubella, hepatitis B virus, hepatitis C virus, and human immunodeficiency virus.

<http://www.ncbi.nlm.nih.gov/pubmed/25677998>

Ning, M. S., Perkins, S. M., Dewees, T. and Shinohara, E. T. (2015). "Evidence of high mortality in long term survivors of childhood medulloblastoma." *J Neurooncol* 122(2): 321-327.

The diagnosis of pediatric medulloblastoma now carries a much improved overall survival; however as outcomes advance, late mortality, from causes such as disease recurrence and subsequent malignancies, are of increasing concern for these patients. Using the Surveillance, Epidemiology, and End Results database, the causes of late mortality in long term survivors of medulloblastoma were evaluated. Patients diagnosed with a medulloblastoma between the ages of 0-19 years who survived at least 5 years after diagnosis were included. Using U.S. population data, standardized mortality ratios (SMRs) were calculated. Cumulative incidence estimates and standardized incidence ratios (SIRs) of subsequent malignancies were calculated. A total of 455 patients were included in the analysis. All patients received radiation as part of therapy. Median age at diagnosis was 7 years, and mean follow-up was 16 years. By the time of last follow-up, 20.4 % of patients had died, representing an SMR of 24.0 (95 % CI 19.3-29.4). Overall survival at 30 years was 65.5 %. Primary recurrence accounted for 59 % of late deaths, while subsequent malignancy accounted for 11.8 %. SIR for subsequent malignancy in these patients was 10.4 (95 % CI 6.9-15.1). The most common

secondary tumor was another brain tumor (32 %), followed by thyroid cancer (21 %). These data demonstrate that late mortality remains a significant problem in these patients. The causes of death are largely attributable to disease recurrence and secondary malignancies. Efforts to improve risk stratification and tailor therapy will help in reducing late mortality in this population.

<http://www.ncbi.nlm.nih.gov/pubmed/25557108>

Oza, S., Lawn, J. E., Hogan, D. R., Mathers, C. and Cousens, S. N. (2015). "Neonatal cause-of-death estimates for the early and late neonatal periods for 194 countries: 2000-2013." *Bull World Health Organ* 93(1): 19-28.

OBJECTIVE: To estimate cause-of-death distributions in the early (0-6 days of age) and late (7-27 days of age) neonatal periods, for 194 countries between 2000 and 2013. METHODS: For 65 countries with high-quality vital registration, we used each country's observed early and late neonatal proportional cause distributions. For the remaining 129 countries, we used multinomial logistic models to estimate these distributions. For countries with low child mortality we used vital registration data as inputs and for countries with high child mortality we used neonatal cause-of-death distribution data from studies in similar settings. We applied cause-specific proportions to neonatal death estimates from the United Nations Inter-agency Group for Child Mortality Estimation, by country and year, to estimate cause-specific risks and numbers of deaths. FINDINGS: Over time, neonatal deaths decreased for most causes. Of the 2.8 million neonatal deaths in 2013, 0.99 million deaths (uncertainty range: 0.70-1.31) were estimated to be caused by preterm birth complications, 0.64 million (uncertainty range: 0.46-0.84) by intrapartum complications and 0.43 million (uncertainty range: 0.22-0.66) by sepsis and other severe infections. Preterm birth (40.8%) and intrapartum complications (27.0%) accounted for most early neonatal deaths while infections caused nearly half of late neonatal deaths. Preterm birth complications were the leading cause of death in all regions of the world. CONCLUSION: The neonatal cause-of-death distribution differs between the early and late periods and varies with neonatal mortality rate level. To reduce neonatal deaths, effective interventions to address these causes must be incorporated into policy decisions.

<http://www.ncbi.nlm.nih.gov/pubmed/25558104>

Patel, R. M., Kandefer, S., Walsh, M. C., Bell, E. F., Carlo, W. A., Lupton, A. R., Sanchez, P. J., Shankaran, S., Van Meurs, K. P., Ball, M. B., Hale, E. C., Newman, N. S., Das, A., Higgins, R. D. and Stoll, B. J. (2015). "Causes and timing of death in extremely premature infants from 2000 through 2011." *N Engl J Med* 372(4): 331-340.

BACKGROUND: Understanding the causes and timing of death in extremely premature infants may guide research efforts and inform the counseling of families. METHODS: We analyzed prospectively collected data on 6075 deaths among 22,248 live births, with gestational ages of 22 0/7 to 28 6/7 weeks, among infants born in study hospitals within the National Institute of Child Health and Human Development Neonatal Research Network. We compared overall and cause-specific in-hospital mortality across three periods from 2000 through 2011, with adjustment for baseline differences. RESULTS: The number of deaths per 1000 live births was 275 (95% confidence interval [CI], 264 to 285) from 2000 through 2003

and 285 (95% CI, 275 to 295) from 2004 through 2007; the number decreased to 258 (95% CI, 248 to 268) in the 2008-2011 period (P=0.003 for the comparison across three periods). There were fewer pulmonary-related deaths attributed to the respiratory distress syndrome and bronchopulmonary dysplasia in 2008-2011 than in 2000-2003 and 2004-2007 (68 [95% CI, 63 to 74] vs. 83 [95% CI, 77 to 90] and 84 [95% CI, 78 to 90] per 1000 live births, respectively; P=0.002). Similarly, in 2008-2011, as compared with 2000-2003, there were decreases in deaths attributed to immaturity (P=0.05) and deaths complicated by infection (P=0.04) or central nervous system injury (P<0.001); however, there were increases in deaths attributed to necrotizing enterocolitis (30 [95% CI, 27 to 34] vs. 23 [95% CI, 20 to 27], P=0.03). Overall, 40.4% of deaths occurred within 12 hours after birth, and 17.3% occurred after 28 days.

CONCLUSIONS: We found that from 2000 through 2011, overall mortality declined among extremely premature infants. Deaths related to pulmonary causes, immaturity, infection, and central nervous system injury decreased, while necrotizing enterocolitis-related deaths increased. (Funded by the National Institutes of Health.).

<http://www.ncbi.nlm.nih.gov/pubmed/25607427>

Piquer Gibert, M., Alsina, L., Giner Munoz, M. T., Cruz Martinez, O., Ruiz Echevarria, K., Dominguez, O., Plaza Martin, A. M., Arostegui, J. I., de Valles, G., Juan Otero, M. and Martin-Mateos, M. A. (2015). "Non-Hodgkin lymphoma in pediatric patients with common variable immunodeficiency." Eur J Pediatr.

Common variable immunodeficiency (CVID) is a heterogeneous primary immunodeficiency associated with an increased risk of malignancy in adulthood, with lymphoma as one of the major causes of death. The aim of this study is to describe those malignancies detected in our cohort of pediatric CVID patients. We reviewed the clinical and laboratory data and the treatments and their outcomes in all pediatric CVID patients from our institution that developed a neoplasia. Four malignancies were diagnosed in three out of 27 pediatric CVID patients. Three malignancies were non-Hodgkin lymphoma (NHL) of B cell origin (mean age at diagnosis: 8 years old), and the remaining was a low-grade astrocytoma. Among NHL, two were mucosa-associated lymphoid tissue (MALT) lymphomas and one was associated with Epstein-Barr virus infection. NHL developed before CVID diagnosis in two patients. CVID patients showed different clinical phenotypes and belonged to different groups according Euroclass and Pediatric classification criteria. Conclusions: Malignancies, especially lymphoma, may develop in pediatric CVID patients with no previous signs of lymphoid hyperplasia and even before CVID diagnosis. Consequently, strategies for cancer prevention and/or early diagnosis are required in pediatric CVID patients. What is Known: * Non-Hodgkin lymphomas are the most frequent neoplasm reported in pediatric CVID patients. * "Polyclonal lymphoproliferation" clinical phenotype is associated with increased risk of lymphoid malignancy and group smB-Tr hi of the Euroclass classification with an increased risk of lymphadenopathy. What is New: * We report a higher incidence of non-Hodgkin lymphomas compared to previous publications in pediatric patients, and our patients are younger than reported. * None of our patients belongs to "polyclonal lymphoproliferation" clinical phenotype, and a common B cell subphenotyping (smB+21 lo) was identified in two of the three patients.

<http://www.ncbi.nlm.nih.gov/pubmed/25749928>

Ravindranath, Y. (2015). "Evolution of modern treatment of childhood acute leukemia and cancer: adventures and battles in the 1970s and 1980s." Pediatr Clin North Am 62(1): 1-10.

This article summarizes the adventures and explorations in the 1970s and 1980s in the treatment of children with leukemia and cancer that paved the way for the current success in childhood cancers. Indeed, these were adventures and bold steps into uncharted waters. Because childhood leukemia the most common of the childhood cancers, success in childhood leukemia was pivotal in the push toward cure of all childhood cancers. The success in childhood leukemia illustrates how treatment programs were designed using clinical- and biology-based risk factors seen in the patients.

<http://www.ncbi.nlm.nih.gov/pubmed/25435108>

Rees, P., Panesar, S. S., Edwards, A. and Carson-Stevens, A. (2014). "Child mortality in the UK." Lancet 384(9958): 1923-1924.

<http://www.ncbi.nlm.nih.gov/pubmed/25435443>

Romitti, P. A., Zhu, Y., Puzhankara, S., James, K. A., Nabukera, S. K., Zamba, G. K., Ciafaloni, E., Cunniff, C., Druschel, C. M., Mathews, K. D., Matthews, D. J., Meaney, F. J., Andrews, J. G., Conway, K. M., Fox, D. J., Street, N., Adams, M. M. and Bolen, J. (2015). "Prevalence of Duchenne and Becker muscular dystrophies in the United States." Pediatrics 135(3): 513-521.

OBJECTIVE: To estimate prevalence of childhood-onset Duchenne and Becker muscular dystrophies (DBMD) in 6 sites in the United States by race/ethnicity and phenotype (Duchenne muscular dystrophy [DMD] or Becker muscular dystrophy [BMD]). METHODS: In 2002, the Centers for Disease Control and Prevention established the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet) to conduct longitudinal, population-based surveillance and research of DBMD in the United States. Six sites conducted active, multiple-source case finding and record abstraction to identify MD STARnet cases born January 1982 to December 2011. We used cross-sectional analyses to estimate prevalence of DBMD per 10 000 boys, ages 5 to 9 years, for 4 quinquennia (1991-1995, 1996-2000, 2001-2005, and 2006-2010) and prevalence per 10 000 male individuals, ages 5 to 24 years, in 2010. Prevalence was also estimated by race/ethnicity and phenotype. RESULTS: Overall, 649 cases resided in an MD STARnet site during ≥ 1 quinquennia. Prevalence estimates per 10 000 boys, ages 5 to 9 years, were 1.93, 2.05, 2.04, and 1.51, respectively, for 1991-1995, 1996-2000, 2001-2005, and 2006-2010. Prevalence tended to be higher for Hispanic individuals than non-Hispanic white or black individuals, and higher for DMD than BMD. In 2010, prevalence of DBMD was 1.38 per 10 000 male individuals, ages 5 to 24 years. CONCLUSIONS: We present population-based prevalence estimates for DBMD in 6 US sites. Prevalence differed by race/ethnicity, suggesting potential cultural and socioeconomic influences in the diagnosis of DBMD. Prevalence also was higher for DMD than BMD. Continued longitudinal surveillance will permit us to examine racial/ethnic and socioeconomic differences in treatment and outcomes for MD STARnet cases.

<http://www.ncbi.nlm.nih.gov/pubmed/25687144>

Scott-Jupp, R. (2015). "Child mortality in the developed world: the UK and the rest." *Arch Dis Child* 100(3): 211-212.
<http://www.ncbi.nlm.nih.gov/pubmed/25589562>

Seth, R. and Singh, A. (2015). "Leukemias in Children." *Indian J Pediatr*.

Childhood cancers are rare but an important cause of morbidity and mortality in children younger than 15y of age. Common childhood malignancies include leukemias (commonest, 30-40%), brain tumors (20%) and lymphoma (12%) followed by neuroblastoma, retinoblastoma and tumors arising from soft tissues, bones and gonads. Leukemias, the commonest childhood cancer, arise from clonal proliferation of abnormal hematopoietic cells leading to disruption of normal marrow function and marrow failure. The various clinical manifestations of leukemia result from unregulated proliferation of the malignant clone and bone marrow failure. There are two main subtypes, the commoner, acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML). A small proportion may have chronic myeloid leukemia (CML) and juvenile myelomonocytic leukemia (JMML). A systematic approach is necessary for diagnosis. Treatment should be initiated as early as possible to avoid complications. A timely referral to a cancer center must be done if facilities for diagnosis/treatment, management of complications and provision for supportive care are not available at the treating center.
<http://www.ncbi.nlm.nih.gov/pubmed/25680783>

Seydel, K. B., Kampondeni, S. D., Valim, C., Potchen, M. J., Milner, D. A., Muwalo, F. W., Birbeck, G. L., Bradley, W. G., Fox, L. L., Glover, S. J., Hammond, C. A., Heyderman, R. S., Chilingulo, C. A., Molyneux, M. E. and Taylor, T. E. (2015). "Brain swelling and death in children with cerebral malaria." *N Engl J Med* 372(12): 1126-1137.

BACKGROUND: Case fatality rates among African children with cerebral malaria remain in the range of 15 to 25%. The key pathogenetic processes and causes of death are unknown, but a combination of clinical observations and pathological findings suggests that increased brain volume leading to raised intracranial pressure may play a role. Magnetic resonance imaging (MRI) became available in Malawi in 2009, and we used it to investigate the role of brain swelling in the pathogenesis of fatal cerebral malaria in African children. METHODS: We enrolled children who met a stringent definition of cerebral malaria (one that included the presence of retinopathy), characterized them in detail clinically, and obtained MRI scans on admission and daily thereafter while coma persisted. RESULTS: Of 348 children admitted with cerebral malaria (as defined by the World Health Organization), 168 met the inclusion criteria, underwent all investigations, and were included in the analysis. A total of 25 children (15%) died, 21 of whom (84%) had evidence of severe brain swelling on MRI at admission. In contrast, evidence of severe brain swelling was seen on MRI in 39 of 143 survivors (27%). Serial MRI scans showed evidence of decreasing brain volume in the survivors who had had brain swelling initially. CONCLUSIONS: Increased brain volume was seen in children who died from cerebral malaria but was uncommon in those who did not die from the disease, a finding that suggests that raised intracranial pressure may contribute to a fatal outcome. The natural history indicates that increased intracranial pressure is transient in survivors. (Funded by the National Institutes of Health and Wellcome Trust U.K.).
<http://www.ncbi.nlm.nih.gov/pubmed/25785970>

Taylor-Robinson, D., Bradshaw, J., Barr, B. and Whitehead, M. (2014). "Child mortality in the UK." *Lancet* 384(9958): 1923.

<http://www.ncbi.nlm.nih.gov/pubmed/25435444>

Tian, N., Shaw, E. C., Zack, M., Kobau, R., Dykstra, H. and Covington, T. M. (2015). "Cause-specific mortality among children and young adults with epilepsy: Results from the U.S. National Child Death Review Case Reporting System." *Epilepsy Behav* 45: 31-34.

We investigated causes of death in children and young adults with epilepsy by using data from the U.S. National Child Death Review Case Reporting System (NCDR-CRS), a passive surveillance system composed of comprehensive information related to deaths reviewed by local child death review teams. Information on a total of 48,697 deaths in children and young adults 28 days to 24 years of age, including 551 deaths with epilepsy and 48,146 deaths without epilepsy, was collected from 2004 through 2012 in 32 states. In a proportionate mortality analysis by official manner of death, decedents with epilepsy had a significantly higher percentage of natural deaths but significantly lower percentages of deaths due to accidents, homicide, and undetermined causes compared with persons without epilepsy. With respect to underlying causes of death, decedents with epilepsy had significantly higher percentages of deaths due to drowning and most medical conditions including pneumonia and congenital anomalies but lower percentages of deaths due to asphyxia, weapon use, and unknown causes compared with decedents without epilepsy. The increased percentages of deaths due to pneumonia and drowning in children and young adults with epilepsy suggest preventive interventions including immunization and better instruction and monitoring before or during swimming. State-specific and national population-based mortality studies of children and young adults with epilepsy are recommended.

<http://www.ncbi.nlm.nih.gov/pubmed/25794682>

van Ruiten, H. J., Straub, V., Bushby, K. and Guglieri, M. (2014). "Improving recognition of Duchenne muscular dystrophy: a retrospective case note review." *Arch Dis Child* 99(12): 1074-1077.

BACKGROUND: Over the last 30 years, there has been little improvement in the age of diagnosis of Duchenne muscular dystrophy (DMD) (mean age of 4.5-4.11 years). **AIM:** To review the diagnostic process for DMD in boys without a family history in order to identify where delays occur and suggest areas for improvement. **DESIGN:** A retrospective case note review. **SETTING:** A tertiary centre for neuromuscular diseases in England. **PATIENTS:** All boys without family history diagnosed with DMD in the last 10 years (n=20). **OUTCOME MEASURES:** Mean age at four key steps in the diagnostic pathway of DMD. **RESULTS:** (1) Age at first reported symptoms of DMD was 32.5 (8-72) months (2.7 years). (2) First engagement of a healthcare professional was at 42.9 (10-90) months. (3) Creatine kinase (CK) levels were checked at 50.1 (14-91) months. (4) Diagnosis of DMD was confirmed at 51.7 (16-91) months (4.3 years). The total delay from parental concern to diagnosis was 19.2 (4-50) months (1.6 years). **CONCLUSIONS:** Our study shows an improvement in the age of diagnosis of DMD although there continues to be a delay in presentation to a health professional and a delay in obtaining a CK

test. To reduce these delays, we propose screening for DMD as part of the Child Health Surveillance Programme, in addition to lowering the threshold for CK testing in primary care by promoting a new DMD mnemonic MUSCLE. An earlier diagnosis of DMD will allow timely access to genetic counselling, standards of care and clinical trials.

<http://www.ncbi.nlm.nih.gov/pubmed/25187493>

Vetter, V. L., Covington, T. M., Dugan, N. P., Haley, D. M., Dykstra, H., Overpeck, M., Iyer, V. R. and Shults, J. (2015). "Cardiovascular deaths in children: General overview from the National Center for the Review and Prevention of Child Deaths." Am Heart J 169(3): 426-437 e423.

BACKGROUND: Cardiovascular conditions rank sixth in causes of death in 1- to 19-year-olds. Our study is the first analysis of the cardiovascular death data set from the National Center for the Review and Prevention of Child Deaths, which provides the only systematic collection of cardiovascular deaths in children. METHODS: We developed an analytical data set from the National Center for the Review and Prevention of Child Deaths database for cardiovascular deaths in children 0 to 21 years old, reviewing 1,098 cases from 2005 to 2009 in 16 states who agreed to participate. RESULTS: Cardiovascular cases were aged 4.8 +/- 6.6 years; 55.3%, < /=1 year; 24.6%, > /=10 years; male, 58%; white, 70.5%; black, 22.3%; Hispanic, 19.5%. Prior conditions were present in 48.5%: congenital heart disease, 23%; cardiomyopathies, 4.6%; arrhythmia, 1.7%; and congestive heart failure, 1.6%. Deaths occurred most frequently in urban settings, 49.2%; and in the hospital, 40.4%; home, 26.1%; or at school/work/sports, 4.8%. Emergency medical services were not evenly distributed with differences by age, race, ethnicity, and area. Autopsies (40.4%) occurred more often in those >10 years old (odds ratio [OR] 2.9), blacks (OR 1.6), or in those who died at school/work/sports (OR 3.9). The most common cardiovascular causes of death included congenital heart disease, 40.8%; arrhythmias, 27.1%; cardiomyopathy, 11.8%; myocarditis, 4.6%; congestive heart failure, 3.6%; and coronary artery anomalies, 2.2%. CONCLUSIONS: Our study identified differences in causes and frequencies of cardiovascular deaths by age, race, and ethnicity. Prevention of death may be impacted by knowledge of prior conditions, emergency plans, automated external defibrillator programs, bystander cardiopulmonary resuscitation education, and by a registry for all cardiovascular deaths in children.

<http://www.ncbi.nlm.nih.gov/pubmed/25728734>

Wolf, S. M. and McGoldrick, P. E. (2015). "Seizure patterns in childhood." Pediatr Ann 44(2): e24-29.

Seizures are alarming and can be life-threatening. It is essential that pediatric providers be able to identify those paroxysmal events most likely to be seizures and to know which require immediate evaluation. Severity can range from childhood syndromes that are controlled relatively easily and usually outgrown to epileptic encephalopathies that are associated with severe developmental delay and sometimes death. Familiarity with seizure semiology can guide early diagnosis and treatment. [Pediatr Ann. 2015;44(2):e24-e29].

<http://www.ncbi.nlm.nih.gov/pubmed/25658215>

Wright, J. C. and Barlow, A. D. (2015). "The current status of neonatal organ donation in the UK." Arch Dis Child Fetal Neonatal Ed 100(1): F6-7.

<http://www.ncbi.nlm.nih.gov/pubmed/25114185>

Yiu, E. M. and Kornberg, A. J. (2015). "Duchenne muscular dystrophy." J Paediatr Child Health.

Duchenne muscular dystrophy, an X-linked disorder, has an incidence of one in 5000 boys and presents in early childhood with proximal muscle weakness. Untreated boys become wheelchair bound by the age of 12 years and die of cardiorespiratory complications in their late teens to early 20s. The use of corticosteroids, non-invasive respiratory support, and active surveillance and management of associated complications have improved ambulation, function, quality of life and life expectancy. The clinical features, investigations and management of Duchenne muscular dystrophy are reviewed, as well as the latest in some of the novel therapies.

<http://www.ncbi.nlm.nih.gov/pubmed/25752877>

Outcomes and instruments

Adamson, P. C. (2015). "Improving the outcome for children with cancer: Development of targeted new agents." CA Cancer J Clin 65(3): 212-220.

The outcome for children with cancer has improved significantly over the past 60 years, with greater than 80% of patients today becoming 5-year survivors. Despite this progress, cancer remains the leading cause of death from disease in children in the United States, and significant short-term and long-term treatment toxicities continue to impact the majority of children with cancer. The development of targeted new agents offers the prospect of potentially more effective and less toxic treatment for children. More than a decade since imatinib mesylate was introduced into the treatment of children with Philadelphia chromosome-positive acute lymphoblastic leukemia, transforming its outcome, a range of targeted agents has undergone study in pediatric cancer patients. Early lessons learned from these studies include a better understanding of the adverse event profile of these drugs in children, the challenge of developing pediatric-specific formulations, and the continued reliance on successful development for adult cancer indications on pediatric drug development. The collaborative research infrastructure for children with cancer in the United States is well positioned to advance novel treatments into clinical investigations for a spectrum of rare and ultra-rare childhood cancers. A greater investment of resources in target discovery and validation can help drive much needed development of new, more effective treatments for children with cancer. *CA Cancer J Clin* 2015;65: 212-220. (c) 2015 American Cancer Society.

<http://www.ncbi.nlm.nih.gov/pubmed/25754421>

Aldenhoven, M., Wynn, R. F., Orchard, P. J., O'Meara, A., Veys, P., Fischer, A., Valayanopoulos, V., Neven, B., Rovelli, A., Prasad, V. K., Tolar, J., Allewelt, H., Jones, S. A., Parini, R., Renard, M., Bordon, V., Wulffraat, N. M., de Koning, T. J., Shapiro, E. G., Kurtzberg, J. and Boelens, J. J. (2015). "Long-term outcome of Hurler syndrome patients after hematopoietic cell transplantation: an international multi-center study." Blood.

Mucopolysaccharidosis type I - Hurler syndrome (MPS-IH) is a lysosomal storage disease characterized by multi-system morbidity and death in early childhood. Although hematopoietic-cell transplantation (HCT) has been performed in these patients for more than 30 years, large studies on the long-term outcome of MPS-IH patients after HCT are lacking. The goal of this international study was to identify predictors of the long-term outcome of MPS-IH patients after successful HCT. 217 MPS-IH patients successfully engrafted with a median follow-up age of 9.2 years were included in this retrospective analysis. Primary endpoints were neurodevelopmental outcomes and growth. Secondary endpoints included neurologic, orthopedic, cardiac, respiratory, ophthalmologic, audiologic, and endocrinologic outcomes. Considerable residual disease burden was observed in the majority of the transplanted MPS-IH patients, with high variability between patients. Preservation of cognitive function at HCT and a younger age at transplantation were major predictors for superior cognitive development post-transplant. A normal IDUA enzyme level obtained post-HCT was another highly

significant predictor for superior long-term outcome in most organ systems. The long-term prognosis of MPS-IH patients receiving HCT can be improved by reducing the age at HCT through earlier diagnosis as well as using exclusively non-carrier donors and achieving complete donor chimerism.

<http://www.ncbi.nlm.nih.gov/pubmed/25624320>

Allen, C. E., Kelly, K. M. and Bollard, C. M. (2015). "Pediatric lymphomas and histiocytic disorders of childhood." *Pediatr Clin North Am* 62(1): 139-165.

Although there have been dramatic improvements in the treatment of children with non-hodgkin lymphoma, hodgkin lymphoma and histiocytic disorders over the past 3 decades, many still relapse or are refractory to primary therapy. In addition, late effects such as 2nd malignancies, cardiomyopathy and infertility remain a major concern. Thus, this review focuses on the current state of the science and, in particular, novel treatment strategies that are aimed at improving outcomes for all pediatric patients with lymphoma and histiocytic disorders while reducing treatment related morbidity.

<http://www.ncbi.nlm.nih.gov/pubmed/25435117>

Alsoufi, B., Kanter, K., McCracken, C., Kogon, B., Vincent, R., Mahle, W. and Deshpande, S. (2015). "Outcomes and risk factors for heart transplantation in children with end-stage cardiomyopathy." *Eur J Cardiothorac Surg*.

OBJECTIVES: Heart transplantation (HT) is the treatment of choice in children with end-stage cardiomyopathy. Several clinical, morphological, demographic, donor and recipient transplant factors have been demonstrated to affect survival in those patients following listing for HT and following HT. We aim to report our single institution results of HT in children with cardiomyopathy, and explore variables affecting survival and the need for heart retransplantation (RHT). **METHODS:** Between 1988 and 2013, 125 children with cardiomyopathy underwent HT. Competing risks analysis modelled events after HT (RHT, death without RHT). Multivariable regression analysis examined risk factors affecting outcomes and parametric models were used to compare survival between diverse groups of patients. **RESULTS:** There were 62 males (50%). Cardiomyopathy types were dilated (n = 104, 83%), restrictive (n = 10, 8%), chemotherapy-induced (n = 7, 6%), and other (n = 4, 3%). Median age at listing was 6.9 years and median age at HT was 7.0 years with median waiting list duration of 29 days. Thirty-four patients were infants <1 year. At time of HT, 106 patients (85%) were at United Network for Organ Sharing status-1, 25 (20%) were ventilated and 17 (14%) had mechanical circulatory support. There was 1 operative death. Competing risks analysis showed that at 10 years following HT, 10% of patients have undergone RHT, 32% have died without RHT and 58% of patients were alive without RHT. On multivariable analysis, risk factors for death following HT were panel-reactive antibodies >10% {hazard ratio [HR]: 4.1 [95% confidence interval (CI): 1.7-9.9], P = 0.002}, age group >10 years [HR: 3.2 (95% CI: 1.4-8.1), P = 0.009] and pre-HT mechanical circulatory support [HR: 2.9 (95% CI: 1.1-7.7), P = 0.033]. Additionally, earlier era <2000 was a significant risk factor for early phase mortality [HR: 8.7 (95% CI: 1.8-42.5), P = 0.017] but not for constant or late phase mortality [HR: 0.8 (95% CI 0.3-1.8), P = 0.6]. Following RHT, 6/11 (55%) expired yielding overall parametric survival estimates of 92, 77 and 57% at 1, 5 and 15 years, respectively. **CONCLUSIONS:** Despite remarkable improvement in operative mortality and 1-year survival of children undergoing HT for cardiomyopathy in the cur-

rent era, that advantage is reduced at the later follow-up, especially in teenagers indicating ongoing compliance and chronic management challenges. In children requiring pre-HT mechanical support, mid-term attrition is higher despite low operative mortality.

<http://www.ncbi.nlm.nih.gov/pubmed/25724907>

Anagnostopoulos, P. V. (2014). "Palliative and corrective surgery in low-weight infants is associated with an increased mortality risk: how can we do better?" *J Thorac Cardiovasc Surg* 148(6): 2515-2516.

<http://www.ncbi.nlm.nih.gov/pubmed/25451500>

Annett, R. D., Hile, S., Bedrick, E., Kunin-Batson, A. S., Krull, K. R., Embry, L., MacLean, W. E., Jr. and Noll, R. B. (2015). "Neuropsychological functioning of children treated for acute lymphoblastic leukemia: impact of whole brain radiation therapy." *Psychoneurology* 24(2): 181-189.

OBJECTIVES: To provide one of the first prospective reports examining neuropsychological outcomes for children treated with 1800 cGy whole brain radiotherapy (WBRT) and prophylactic chemotherapy versus prophylactic chemotherapy alone for acute lymphoblastic leukemia (ALL). Acute and long-term neuropsychological toxicities associated with WBRT are compared. METHODS: This multisite study included 188 children, ages 4-21 years at enrollment, who were assessed with standardized neuropsychological tests at 9, 21, and 48 months after diagnosis with intermediate risk ALL. All participating children were receiving treatment on a parent study CCG105. RESULTS: Verbal intelligence (VIQ) scores for children receiving WBRT was significantly lower than VIQ for prophylactic chemotherapy at the 48-month time point ($p < 0.05$). A significant cross-level interaction between time since diagnosis and treatment condition was observed ($p < 0.05$). WBRT did not result in differences in PIQ; both groups of children demonstrated comparable increases in PIQ. Neuropsychological findings at 48 months after diagnosis indicated diminished performance in neuromotor, visual-motor coordination, and executive functioning for children receiving WBRT. Academic achievement was unaffected by WBRT at 4 years after diagnosis. CONCLUSIONS: The measurement of verbal and performance IQ as a primary endpoint in ALL clinical trials is critical to characterizing neuropsychological late effects. A trajectory of decline in neuropsychological functioning, specifically verbal IQ, was observed. Missing data within the trial occurred at random and did not impact results observed. The impact of WBRT becomes evident at 48 months after diagnosis, suggesting the need for long-term follow-up beyond the time frame typically used in Phase III trials. Copyright (c) 2014 John Wiley & Sons, Ltd.

<http://www.ncbi.nlm.nih.gov/pubmed/24890730>

Armenian, S. H., Hudson, M. M., Mulder, R. L., Chen, M. H., Constine, L. S., Dwyer, M., Nathan, P. C., Tissing, W. J., Shankar, S., Sieswerda, E., Skinner, R., Steinberger, J., van Dalen, E. C., van der Pal, H., Wallace, W. H., Levitt, G. and Kremer, L. C. (2015). "Recommendations for cardiomyopathy surveillance for survivors of childhood cancer: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group." *Lancet Oncol* 16(3): e123-136.

Survivors of childhood cancer treated with anthracycline chemotherapy or chest radiation are at an increased risk of developing congestive heart failure. In this population, congestive

heart failure is well recognised as a progressive disorder, with a variable period of asymptomatic cardiomyopathy that precedes signs and symptoms. As a result, several clinical practice guidelines have been developed independently to help with detection and treatment of asymptomatic cardiomyopathy. These guidelines differ with regards to definitions of at-risk populations, surveillance modality and frequency, and recommendations for interventions. Differences between these guidelines could hinder the effective implementation of these recommendations. We report on the results of an international collaboration to harmonise existing cardiomyopathy surveillance recommendations using an evidence-based approach that relied on standardised definitions for outcomes of interest and transparent presentation of the quality of the evidence. The resultant recommendations were graded according to the quality of the evidence and the potential benefit gained from early detection and intervention.

<http://www.ncbi.nlm.nih.gov/pubmed/25752563>

Barry, S. C., Walsh, C. A., Burke, A. L., McParland, P., McAuliffe, F. M. and Morrison, J. J. (2015). "Natural history of fetal trisomy 13 after prenatal diagnosis." *Am J Med Genet A* 167(1): 147-150.

There are currently limited data describing the natural history and outcome for fetal trisomy 13 diagnosed prenatally. The aim of this study was to evaluate the fetal and neonatal outcome for pregnancies with an established prenatal diagnosis of fetal trisomy 13, and a parental decision for continuation of the pregnancy. To this end, the obstetric and neonatal outcome data for such pregnancies, diagnosed at two referral Fetal Medicine Centers, were retrospectively obtained and examined. During the study period, there were 45 cases of trisomy 13 diagnosed at both units, of which 26 (56%) continued with the pregnancy to its natural outcome. There were 12 intrauterine deaths in the cohort resulting in a rate of 46.2% of intrauterine lethality. Conversely, the live birth rate was 53.8%. For infants born alive, neonatal death on day 1 of life occurred in 78.6% of cases. The overall early neonatal mortality rate was 93%. There was one infant death at 6 weeks of age and no survival noted beyond this period. These data provide reliable information for parental counseling pertaining to risk of intrauterine death when trisomy 13 is diagnosed prenatally. These data also indicate that the survival outcome is worse than that previously accepted from studies of postnatal follow up of live born infants with this diagnosis. (c) 2014 Wiley Periodicals, Inc.

<http://www.ncbi.nlm.nih.gov/pubmed/25339456>

Benadiba, J., Michel, G., Auquier, P., Chastagner, P., Kanold, J., Poiree, M., Plantaz, D., Padovani, L., Berbis, J., Barlogis, V., Contet, A., Chambost, H. and Sirvent, N. (2015). "Health status and quality of life of long-term survivors of childhood acute leukemia: the impact of central nervous system irradiation." *J Pediatr Hematol Oncol* 37(2): 109-116.

We evaluated the impact of central nervous system irradiation (CNSI) on long-term health status and quality of life (QoL) of childhood lymphoblastic leukemia survivors included in the French L.E.A. (Childhood and Adolescent Leukemia) multicentric cohort. QoL was self-reported in adults and assessed by parents in children and adolescents, using adapted questionnaires. From 2004 to 2009, 630 nongrafted patients were assessed after 11.8+/-6.3 years from diagnosis. Patients receiving CNSI (18.6%) or chemotherapy alone (81.4%) were com-

pared. The risk of having long-term physical effects was increased with CNSI (odds ratio=3.3; 95% confidence interval, 1.8-5.9), especially regarding growth failure, second tumor, cataract, and overweight. QoL did not differ significantly according to the treatment received, despite a tendency toward lower scores with CNSI in children and adolescents (summary score 63.6+/-13.3 vs. 71.7+/-12.4, P=0.14). Compared with French norms, adult survivors had an impaired QoL, especially in mental domains (mental composite score 45.2+/-9.8 vs. 47.9+/-2.1, P<0.001). In pediatric survivors, QoL was not impaired and even tended to be higher than population norms (summary score 71.7+/-12.4 vs. 70.0+/-4.2, P=0.054), mainly in social and relational domains. In conclusion, QoL seems to be impaired by the trauma of a life-threatening illness in childhood, as well as by the treatment received.

<http://www.ncbi.nlm.nih.gov/pubmed/24936742>

Bradford, N. K., Armfield, N. R., Young, J., Herbert, A., Mott, C. and Smith, A. C. (2014). "Principles of a paediatric palliative care consultation can be achieved with home telemedicine." *J Telemed Telecare* 20(7): 360-364.

We compared the records of paediatric palliative consultations undertaken face-to-face, with telemedicine consultations undertaken in patients' homes. A convenience sample of consecutive paediatric palliative care patients was identified from the hospital's palliative care database. A total of 100 consultations was reviewed (50 telemedicine consultations during home visits and 50 face-to-face consultations) according to 14 established principles and components of a paediatric palliative care consultation. In the telemedicine group there was a higher proportion of patients in a stable condition (58% vs 7%), and a lower proportion of patients in terminal phase (2% vs 17%). Discussion about pain and anorexia were significantly more common in the telemedicine group. Discussion about follow up was significantly more common in the telemedicine group (86% vs 56%), whilst resuscitation planning was more common in deteriorating patients receiving inpatient care. All other components and principles of a palliative care consultation were documented equally regardless of method of consultation. The findings confirm that palliative consultations via telemedicine are just as effective as face-to-face consultations in terms of the documented components of the consultation.

<http://www.ncbi.nlm.nih.gov/pubmed/25399995>

Bryant, R. A., Kenny, L., Joscelyne, A., Rawson, N., Maccallum, F., Cahill, C., Hopwood, S., Aderka, I. and Nickerson, A. (2014). "Treating prolonged grief disorder: a randomized clinical trial." *JAMA Psychiatry* 71(12): 1332-1339.

IMPORTANCE: Prolonged grief disorder (PGD) is a potentially disabling condition that affects approximately 10% of bereaved people. Grief-focused cognitive behavior therapy (CBT) has been shown to be effective in treating PGD. Although treatments for PGD have focused on exposure therapy, much debate remains about whether exposure therapy is optimal for PGD. **OBJECTIVE:** To determine the relative efficacies of CBT with exposure therapy (CBT/exposure) or CBT alone for PGD. **DESIGN, SETTING, AND PARTICIPANTS:** A randomized clinical trial of 80 patients with PGD attending the outpatient University of New South Wales Traumatic Stress Clinic from September 17, 2007, through June 7, 2010. **INTERVENTIONS:** All patients received 10 weekly 2-hour group therapy sessions that consisted of CBT techniques. Patients

also received 4 individual sessions, in which they were randomized to receive exposure therapy for memories of the death or supportive counseling. MAIN OUTCOMES AND MEASURES: Measures of PGD by clinical interview and self-reported measures of depression, cognitive appraisals, and functioning at the 6-month follow-up. RESULTS: Intention-to-treat analyses at follow-up indicated a significant quadratic timex-treatment condition interaction effect (B [SE], 0.49 [0.16]; $t_{120.16}=3.08$ [95% CI, 0.18-0.81]; $P=.003$), indicating that CBT/exposure led to greater PGD reductions than CBT alone. At follow-up, CBT/exposure led to greater reductions in depression (B [SE], 0.35 [0.12]; $t_{112.65}=2.83$ [95% CI, 0.11-0.60]; $P=.005$), negative appraisals (B [SE], 0.68 [0.25]; $t_{109.98}=2.66$ [95% CI, 0.17-1.18]; $P=.009$), and functional impairment (B [SE], 0.24 [0.08]; $t_{111.40}=3.01$ [95% CI, 0.08-0.40]; $P=.003$) than CBT alone. In terms of treatment completers, fewer patients in the CBT/exposure condition at follow-up (14.8%) met criteria for PGD than those in the CBT condition (37.9%) (odds ratio, 3.51; 95% CI, 0.96-12.89; $\chi^2=3.81$; $P=.04$). CONCLUSIONS AND RELEVANCE: Including exposure therapy that promotes emotional processing of memories of the death is an important component to achieve optimal reductions in PGD severity. Facilitating emotional responses to the death may promote greater changes in appraisals about the loss, which are associated with symptom reduction. Promotion of emotional processing techniques in therapies to treat patients with PGD is needed. TRIAL REGISTRATION: anzctr.org.au Identifier: ACTRN12609000229279.

<http://www.ncbi.nlm.nih.gov/pubmed/25338187>

Chaves, C., Vazquez, C. and Hervas, G. (2015). "Positive interventions in seriously-ill children: Effects on well-being after granting a wish." J Health Psychol.

We examined whether a positive intervention (i.e. granting a wish) could promote positive psychological and physical changes (e.g. reduced nausea and pain) in seriously-ill children. Children and their parent were randomly assigned to a wish group (completed measures 2-3 days before the wish and 3 weeks later) or to a waiting-list control group (with an equivalent time-lag and receiving the wish after the assessment). Wish intervention significantly increased levels of positive emotions, satisfaction with life, personal strengths, and reduced rates of nausea compared with the control group. Mothers in the wish group also perceived positive changes in children's benefit finding and quality of life.

<http://www.ncbi.nlm.nih.gov/pubmed/25637070>

Chintagumpala, M. and Gajjar, A. (2015). "Brain tumors." Pediatr Clin North Am 62(1): 167-178.

The past 2 decades have witnessed a revolution in the management of childhood brain tumors, with the establishment of multidisciplinary teams and national and international consortiums that led to significant improvements in the outcomes of children with brain tumors. Unprecedented cooperation within the pediatric neuro-oncology community and sophisticated rapidly evolving technology have led to advances that are likely to revolutionize treatment strategies and improve outcomes.

<http://www.ncbi.nlm.nih.gov/pubmed/25435118>

Chu, S. M., Hsu, J. F., Lee, C. W., Lien, R., Huang, H. R., Chiang, M. C., Fu, R. H. and Tsai, M. H. (2014). "Neurological complications after neonatal bacteremia: the clinical characteristics, risk factors, and outcomes." *PLoS One* 9(11): e105294.

BACKGROUND: Neonates with bacteremia are at risk of neurologic complications. Relevant information warrants further elucidation. STUDY DESIGN: This was a retrospective cohort study of neonates with bacteremia-related neurologic complications (BNCs) in a tertiary-level neonatal intensive care unit (NICU). A systemic chart review was performed conducted to identify clinical characteristics and outcomes. A cohort of related conditions was constructed as the control group. Logistic regression analysis was used to identify independent risk factors for BNC. RESULTS: Of 1037 bacteremia episodes, 36 (3.5%) had BNCs. Twenty-four cases of BNCs were related to meningitis, five were presumed meningitis, and seven occurred after septic shock. The most common causative pathogens were Group B streptococcus (41.7%) and *E. coli* (16.7%). The major BNCs consisted of seizures (28), hydrocephalus (20), encephalomalacia (11), cerebral infarction (7), subdural empyema (6), ventriculitis (8), and abscess (4). Eight (22.8%) neonates died and six (16.7%) were discharged in critical condition when the family withdrew life-sustaining treatment. Among the 22 survivors, eight had neurologic sequelae upon discharge. After multivariate logistic regression analysis, neonates with meningitis caused by Group B streptococcus (adjusted odds ratio [OR]: 8.90, 95% confidence interval [CI]: 2.20-36.08; $p = 0.002$) and combined meningitis and septic shock (OR, 5.94; 95% CI: 1.53-23.15; $p = 0.010$) were independently associated with BNCs. CONCLUSIONS: Neonates with bacteremia-related neurologic complications are associated with adverse outcomes or sequelae. Better strategies aimed at early detection and reducing the emergence of neurologic complications and aggressive treatment of Group B streptococcus sepsis are needed in neonates with meningitis and septic shock.

<http://www.ncbi.nlm.nih.gov/pubmed/25364821>

Clarke-Pounder, J. P., Boss, R. D., Roter, D. L., Hutton, N., Larson, S. and Donohue, P. K. (2015). "Communication intervention in the neonatal intensive care unit: can it backfire?" *J Palliat Med* 18(2): 157-161.

BACKGROUND: For parents of a critically ill infant, good communication may help alleviate stress and anxiety. To improve communication, physicians must be responsive to families' needs and values surrounding the care of their hospitalized infant. OBJECTIVE: We adapted a Decision-Making Tool for the Neonatal Intensive Care Unit (N-DMT) to encourage consideration of family concerns and preferences in daily care planning. DESIGN: This was a randomized controlled design. SETTING/SUBJECTS: Parents and providers of critically ill neonates were eligible. Parents were randomized to an intervention group (using the N-DMT) or standard of care. N-DMT information was shared through the electronic medical record and communicated directly to the primary provider. MEASUREMENTS: Daily rounds on all infants were audio recorded. Parents completed the State-Trait Anxiety Inventory at the first interview and 2 weeks later. Parents completed the Family Inventory of Needs-Pediatrics (FIN-PED) survey and an N-DMT-specific survey 2 weeks postenrollment. RESULTS: Complete data were obtained on 10 control and 9 intervention families. Groups did not differ on demographics or mean infant Score of Neonatal Acute Physiology (SNAP) scores (36 versus 37). FIN-PED scores were similar for both groups. The control group showed decreased anxiety over time. The content of rounds did not differ between groups. The intervention group re-

ported lower satisfaction with care, specifically in questions regarding communication. CONCLUSIONS: In this pilot study, we found that families in the intervention group were less satisfied with communication. Families who are primed to expect better communication, such as those participating in a communication intervention, may be less satisfied with standard care. <http://www.ncbi.nlm.nih.gov/pubmed/24983892>

Connolly, A. M., Malkus, E. C., Mendell, J. R., Flanigan, K. M., Miller, J. P., Schierbecker, J. R., Siener, C. A., Golumbek, P. T., Zaidman, C. M., McDonald, C. M., Johnson, L., Nicorici, A., Karachunski, P. I., Day, J. W., Kelecic, J. M., Lowes, L. P., Alfano, L. N., Darras, B. T., Kang, P. B., Quigley, J., Pasternak, A. E. and Florence, J. M. (2015). "Outcome reliability in non-ambulatory boys/men with Duchenne muscular dystrophy." *Muscle Nerve* 51(4): 522-532.

INTRODUCTION: Therapeutic trials in Duchenne muscular dystrophy (DMD) often exclude non-ambulatory individuals. Here we establish optimal and reliable assessments in a multi-center trial. METHODS: Non-ambulatory boys/men with DMD (N = 91; 16.7 +/- 4.5 years of age) were assessed by trained clinical evaluators. Feasibility (percentage completing task) and reliability [intraclass correlation coefficients (ICCs) between morning and afternoon tests] were measured. RESULTS: Forced vital capacity (FVC), assessed in all subjects, showed a mean of 47.8 +/- 22% predicted (ICC 0.98). Brooke Upper Extremity Functional Rating (Brooke) and Egen Klassifikation (EK) scales in 100% of subjects showed ICCs ranging from 0.93 to 0.99. Manual muscle testing, range of motion, 9-hole peg test, and Jebsen-Taylor Hand Function Test (JHFT) demonstrated varied feasibility (99% to 70%), with ICCs ranging from 0.99 to 0.64. We found beneficial effects of different forms of corticosteroids for the Brooke scale, percent predicted FVC, and hand and finger strength. CONCLUSIONS: Reliable assessment of non-ambulatory boys/men with DMD is possible. Clinical trials will have to consider corticosteroid use.

<http://www.ncbi.nlm.nih.gov/pubmed/25056178>

Daher, A., Versloot, J. and Costa, L. R. (2014). "The cross-cultural process of adapting observational tools for pediatric pain assessment: the case of the Dental Discomfort Questionnaire." *BMC Res Notes* 7: 897.

BACKGROUND: A rigorous cross-cultural adaptation process of an existing instrument could be the best option for measuring health in different cultures, instead of developing a new tool, and prior to psychometric and validation testing. The Dental Discomfort Questionnaire (DDQ), a validated instrument for assessing toothache in young children, has not been cross-culturally adapted so far. This study aimed to explore the detailed phases of the cross-cultural adaptation process of a pain assessment tool, presenting the example of the DDQ Brazilian-Portuguese adapted version. METHODS: The study design was based on the universalist approach, which consists of a sequential analysis to assess the relevant phases of a cross-cultural process before testing the measures of the instrument: conceptual, item, semantic, and operational equivalences. Systematic information was gathered from the literature, expert discussions, translations, and pre-testing through cognitive interviews with Brazilian population. RESULTS: Detailed description of the three major phases for a cross-cultural adaptation process was given. Notes of the changes done in the structure of the presented instrument (DDQ) were specifically pointed out at each phase. Conceptual and item

analyses showed that there are similarities in the DDQ construct between the original and Brazilian cultures that require minor modifications. Translations and back-translations allowed the development of the preliminary Brazilian-Portuguese version of the DDQ, which was tested and underwent other minor changes to improve its comprehensibility. CONCLUSIONS: Describing the phases was important to show how changes are made in a cross-cultural adaptation process of an instrument. This also could help researchers in adapting similar pediatric pain assessment tools to different cultures. A Brazilian-Portuguese version of the DDQ was presented.

<http://www.ncbi.nlm.nih.gov/pubmed/25494713>

Dion, M., Rowe, N., Shum, J., Weernink, C., Felbel, S., McAlister, V. C., Sener, A. and Luke, P. P. (2015). "Donation after cardiac death pediatric en bloc renal transplantation." *J Urol* 193(1): 281-285.

PURPOSE: Use of small pediatric kidneys obtained from extremely young donors after cardiac death has been limited. This potential organ source remains under used by transplant teams. MATERIALS AND METHODS: We reviewed all renal transplants at our institution from 2000 to 2013 to identify recipients of an en bloc pair of kidneys from deceased pediatric donors younger than 4 years. The outcomes of donation after cardiac death en bloc allografts were compared with neurological determination of death en bloc allografts. RESULTS: A total of 21 recipients of en bloc renal allografts were identified, of which 4 organ pairs were obtained through donation after cardiac death. Mean +/- SD donor age was 20.6 +/- 11.6 months and weight was 12.4 +/- 3.7 kg. Delayed allograft function occurred in 2 of 4 recipients of allografts obtained from donation after cardiac death en bloc and 3 of 17 recipients of allografts from neurological determination of death en bloc. One year after transplantation mean +/- SD glomerular filtration rates were similar, at 80.7 +/- 15.3 and 85.7 +/- 33.4 ml/minute/1.73 m² in the cardiac and neurological allograft groups, respectively (difference not significant). Surgical complications occurred in 3 patients, and no allograft was lost to thrombosis. CONCLUSIONS: We report successful transplantation of a small cohort of pediatric en bloc kidneys obtained through donation after cardiac death from donors younger than 4 years. Outcomes at 1 year are comparable to those in neurological determination of death en bloc allograft recipients.

<http://www.ncbi.nlm.nih.gov/pubmed/25066870>

Elea, M. C., N'Guyen, M., Valdeyron, M. L., Quessada, T., Goudable, J., Loras-Duclaux, I., Marotte, S., Heissat, S., Restier, L., Lachaux, A. and Peretti, N. (2015). "Dramatic increase of central venous catheter-related infections associated with a high turnover of the nursing team." *Clin Nutr*.

BACKGROUND & AIMS: This retrospective study evaluated the impact of new organization during the moving to a new university pediatric hospital on the incidence of central catheter-related blood stream infections (CRBSIs) among children on long-term parenteral nutrition. METHODS: The study ran from April 2007 to March 2014, starting a year prior to reorganisation of the department of pediatric Hepato-Gastroenterology and Nutrition associated to moving the children to a new hospital in April 2008, and continuing for 6 years following the move. During this time, data from all children hospitalized in this department who received parenteral nutrition (PN) for more than 15 days were analysed. RESULTS: During this 7-years

study, 183 children aged 4.6 +/- 0.5 years received prolonged PN. Intestinal diseases were the main aetiologies (89%), primarily short bowel syndrome (18.4%), Hirschsprung disease and CIPO (13.5%) and inflammatory bowel disease (13.8%). The mean durations of hospitalization and of PN during hospitalization were, respectively, 70 +/- 2.1 and 55.7 +/- 3.6 days. During the study period, 151 CRBSIs occurred in 77 children (42% of all patients), i.e. 14.8 septic episodes/1000 PN days and 12.0 septic episodes/1000 CVC days. No patient died of a central venous catheter-related infection. However, following the move from the older hospital to the newer one, the rate of CRBSIs significantly doubled, from 3.9/1000 to 8.8/1000 CVC days ($p = 0.02$). During the following 4 years, the incidence of CRBSIs tended to increase between the 2nd and the 5th year after the move: 11.3 ($p = \text{NS}$); 21.4 ($p = 0.01$); 17.3 ($p = \text{NS}$), 20.3/1000 ($p = \text{NS}$) CVC days. We also observed that after evaluations by the Department of Infection Control, nurse training and stabilization of the nursing team, the incidence decreased significantly from 20.3 to 11.1/1000 CVC days during the 6th year after the move ($p = 0.01$). CONCLUSION: Our results reveal the deleterious impact of the reorganization during the hospital moving on the CRBSI incidence rate, and the possible implication of inexperienced team of nurses.

<http://www.ncbi.nlm.nih.gov/pubmed/25886708>

Eltayeb, A. A., Monazea, E. M. and Elsayeh, K. I. (2015). "Cardiac Arrest in Children: Relation to Resuscitation and Outcome." *Indian J Pediatr.*

OBJECTIVE: To determine the outcome of cardiac arrest in pediatric intensive care unit in relation to event variables. METHODS: The study included children with cardiac arrest who required resuscitation in pediatric intensive care unit over 1 y period. Two outcome variables were measured. The first was success [return of spontaneous circulation (ROSC)] and the second was survival to discharge from pediatric intensive care unit. RESULTS: Out of 700 admissions, 172 (24.6 %) patients developed cardiac arrest that required resuscitation. Return of spontaneous circulation was achieved in 78 cases (45.3 %), 25 patients (14.5 %) survived to discharge and 94 patients (54.7 %) did not respond to resuscitations. Success and survival rates were significantly higher in cases resuscitated for ≤ 20 min than in cases resuscitated for > 20 min (100 % and 33.3 % vs. 32.4 % and 10.1 % respectively). Success and survival rates were better in patients undergoing mechanical ventilation than those not (48.1 % and 17.8 % vs. 37.2 % and 4.7 % respectively). Defibrillation was successful in 10 cases (25 %) and survival was in 1 case (0.5 %) and out of survivors, 80 % had good neurological outcome. CONCLUSIONS: The frequency of in-hospital cardiac arrest was 24.6 % where 45.3 % of them achieved successful resuscitation. The duration of cardiopulmonary resuscitation (< 20 min) and mechanical ventilation were an indicator for better success and survival rates.

<http://www.ncbi.nlm.nih.gov/pubmed/25604246>

Fauroux, B., Quijano-Roy, S., Desguerre, I. and Khirani, S. (2015). "The value of respiratory muscle testing in children with neuromuscular disease." *Chest* 147(2): 552-559.

Routine lung function and respiratory muscle testing are recommended in children with neuromuscular disease (NMD), but these tests are based on noninvasive volitional maneuvers, such as the measurement of lung volumes and maximal static pressures, that young children may not always be able to perform. The realization of simple natural maneuvers such as a sniff or a cough, and the measurement of esophageal and gastric pressures during sponta-

neous breathing can add valuable information about the strength and endurance of the respiratory muscles in young children. Monitoring respiratory muscles in children with NMD may improve understanding of the natural history of NMD and the evaluation of disease severity. It may assist and guide clinical management and it may help the identification and selection of optimal end points, as well as the most informative parameters and patients for clinical trials.

<http://www.ncbi.nlm.nih.gov/pubmed/25644908>

Fuchs, H., Schoss, J., Mendler, M. R., Lindner, W., Hopfner, R., Schulz, A., Hoenig, M., Steinbach, D., Debatin, K. M., Hummler, H. D. and Schmid, M. (2015). "The Cause of Acute Respiratory Failure Predicts the Outcome of Noninvasive Ventilation in Immunocompromised Children." Klin Padiatr.

Background: Noninvasive ventilation (NIV) may be superior to conventional therapy in immunocompromised children with respiratory failure. Methods: Mortality, success rate, prognostic factors and side effects of NIV for acute respiratory failure (ARF) were investigated retrospectively in 41 in children with primary immunodeficiency, after stem cell transplantation or chemotherapy for oncologic disease. Results: In 11/41 (27%) children invasive ventilation was avoided and patients were discharged from ICU. In children with NIV failure ICU-mortality was 19/30 (63%). 8/11 (72%) children with NIV success had recurrence of ARF after 27 days. Only 4/11 (36%) children with first episode NIV success and 8/30 (27%) with NIV failure survived to hospital discharge. Lower FiO₂, SpO₂/FiO₂ and blood culture positive bacterial sepsis were predictive for NIV success, while fungal sepsis or culture negative ARF were predictive for NIV failure. We observed catecholamine treatment in 14/41 (34%), pneumothorax in 2/41 (5%), mediastinal emphysema in 3/41 (7%), a life threatening nasopharyngeal hemorrhage and need for resuscitation during intubation in 5/41 (12%) NIV-episodes. Conclusions: The prognosis of ARF in immunocompromised children remains guarded independent of initial success or failure of NIV due to a high rate of recurrent ARF. Reversible causes like bacterial sepsis had a higher NIV response rate. Relevant side effects of NIV were observed.

<http://www.ncbi.nlm.nih.gov/pubmed/25650869>

Giordano, V., Deindl, P., Kuttner, S., Waldhor, T., Berger, A. and Olischar, M. (2014). "The Neonatal Pain, Agitation and Sedation Scale reliably detected oversedation but failed to differentiate between other sedation levels." Acta Paediatr 103(12): e515-521.

AIM: The aim of this study was to analyse the sedation subscale of the Neonatal Pain, Agitation and Sedation Scale (N-PASS), because the N-PASS has only been validated for the assessment of acute and prolonged pain. METHODS: The nurses' expert opinion regarding the level of sedation of the study patients was used as reference scale. Paired assessments of both the N-PASS sedation subscale and the nurses' expert opinion were performed in 50 sedated neonates from 23 to 44 weeks of postmenstrual age. RESULTS: A total set of 503 paired observations was included into analysis. The median N-PASS sedation subscale scores were significantly different for the three nurses' expert opinion categories, with minus eight for oversedation, minus two for adequate sedation and zero for undersedation ($p < 0.0001$). Interobserver agreement for the N-PASS sedation subscale was excellent - linearly weighted Cohen's Kappa was 0.93 - as was the internal consistency of 0.88, estimated by a Cronbach's

alpha. The internal consistency increased to 0.90 if the vital sign item of the subscale was deleted. CONCLUSION: The N-PASS sedation subscale reliably detected oversedation, but failed to differentiate between adequate and undersedation. We therefore recommend using additional methods to ensure adequate assessment of sedation in neonates.

<http://www.ncbi.nlm.nih.gov/pubmed/25110233>

Guan, L., Collet, J. P., Yuskiv, N., Skippen, P., Brant, R. and Kisson, N. (2014). "The effect of massage therapy on autonomic activity in critically ill children." Evid Based Complement Alternat Med 2014: 656750.

Objectives. Our main objective was to describe the effect of foot and hand (F&H) massage on the autonomic nervous system (ANS) activity in children hospitalized in a pediatric intensive care unit (PICU); the secondary objectives were to assess the relationship between ANS function and the clinical severity and to explore the effects of repeated massage sessions on the ANS. Methods. Design was a descriptive experimental study. Intervention was single or six session(s) of F&H massage. ANS function was assessed through the frequency-domain analysis of heart rate variability. Main metrics included high and low frequency power (HF and LF), HF + LF, and LF/HF ratio. Results. Eighteen children participated in the study. A strong Spearman's correlation ($\rho = -0.77$) was observed between HF + LF and clinical severity. During massage, the parasympathetic activity (measured by HF) increased significantly from baseline ($P = 0.04$) with a mean percentage increase of 75% (95% CI: 20% approximately 130%). LF increased by 56% (95% CI: 20% approximately 92%) ($P = 0.026$). Repeated sessions were associated with a persistent effect on HF and LF which peaked at the second session and remained stable thereafter. Conclusions. HF + LF is positively correlated with clinical severity. F&H massage can improve the ANS activity and the effect persists when repeated sessions are offered.

<http://www.ncbi.nlm.nih.gov/pubmed/25587344>

Hvidtjorn, D., Wu, C., Schendel, D., Thorlund Parner, E. and Brink Henriksen, T. (2015). "Mortality in mothers after perinatal loss: a population-based follow-up study." BJOG.

OBJECTIVE: To assess whether mothers who lost a child from stillbirth or in the first week of life have an increased overall mortality and cause-specific mortality. DESIGN: A population based follow-up study. SETTING: Data from Danish national registers. POPULATION: All mothers in Denmark were included in the cohort at time of their first delivery from 1 January 1980 to 31 December 2008 and followed until 31 December 2009 or death, whichever came first. METHODS: The association between perinatal loss and total and cause-specific mortality in mothers was estimated with hazard ratios (HR) and 95% confidence intervals (95% CI) calculated using Cox proportional hazards regression analyses. MAIN OUTCOME MEASURES: Overall mortality and cause-specific mortality. RESULTS: During the follow-up period, 838 331 mothers in the cohort gave birth to one or more children and 7690 mothers (0.92%) experienced a perinatal loss. During follow-up, 8883 mothers (1.06%) died. There was an increased overall mortality for mothers who experienced a perinatal loss adjusted for maternal age and educational level, hazard ratio (HR) 1.83 [95% confidence interval (CI) 1.55-2.17]. The strongest association was seen in mortality from cardiovascular diseases (CVD) with an HR of 2.29 (95% CI 1.48-3.52) adjusted for CVD at time of delivery. We found no association be-

tween a perinatal loss and mortality from traumatic causes. CONCLUSIONS: Mothers who experience a perinatal loss have an increased mortality, especially from CVD.

<http://www.ncbi.nlm.nih.gov/pubmed/25565567>

Kaufman, S. S. and Matsumoto, C. S. (2015). "Management of pediatric intestinal failure." Minerva Pediatr.

Intestinal Failure (IF) is defined as the state of the intestinal tract where the function is below the minimum required for the absorption of macronutrients, water, and electrolytes. The etiology may be a multitude of causes, but short bowel syndrome (SBS) remains the most common. The successful management and prognosis of SBS in infants and children depends a multitude of variables such as length, quality, location, and anatomy of the remaining intestine. Prognosis, likewise, depends on these factors, but also is dependent on the clinical management of these patients. Strategies for a successful outcome and the success of therapeutic interventions are dependent upon understanding each individual's remaining intestinal function. Medical intervention success is defined by a graduated advancement of enteral nutrition (EN) and a reduction of parenteral nutrition (PN). Complications of IF and PN include progressive liver disease, bacterial overgrowth, dysmotility, renal disease, catheter related bloodstream infections, and loss of venous access. Surgical interventions such as bowel lengthening procedures show promise in carefully selected patients. Intestinal transplantation is reserved for those infants and children suffering from life-threatening complications of PN.

<http://www.ncbi.nlm.nih.gov/pubmed/25752806>

Lafond, D. A., Kelly, K. P., Hinds, P. S., Sill, A. and Michael, M. (2015). "Establishing Feasibility of Early Palliative Care Consultation in Pediatric Hematopoietic Stem Cell Transplantation." J Pediatr Oncol Nurs.

Children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) encounter a number of distressing physical symptoms and existential distress but may not be afforded timely access to palliative care services to help ameliorate the distress. This feasibility study investigated the acceptability and outcomes of early palliative care consultation to promote comfort in this population. A longitudinal, descriptive cohort design examined both provider willingness to refer and willingness of families to receive palliative care interventions as well as satisfaction. Feasibility was demonstrated by 100% referral of eligible patients and 100% of patient and family recruitment (N = 12). Each family received 1 to 3 visits per week (ranging from 15 to 120 minutes) from the palliative care team. Interventions included supportive care counseling and integrative therapies. Families and providers reported high satisfaction with the nurse-led palliative care consultation. Outcomes included improvement or no significant change in comfort across the trajectory of HSCT, from the child and parental perspective. Early integration of palliative care in HSCT is feasible and acceptable to families and clinicians.

<http://www.ncbi.nlm.nih.gov/pubmed/25616372>

Marr, C., Leonard, H., Torode, I. and Downs, J. (2015). "Spinal fusion in girls with Rett syndrome: post-operative recovery and family experiences." Child Care Health Dev.

BACKGROUND: Rett syndrome is a severe neurodevelopmental disorder mainly affecting females and scoliosis is a common co-morbidity. Spinal fusion may be recommended if the scoliosis is progressive. This qualitative study investigated recovery of girls with Rett syndrome during the first 12 post-operative months and explored family perspectives and coping around the time of surgery. METHOD: Parents registered with the population-based Australian Rett Syndrome Database were recruited to this study if their daughter had a confirmed pathogenic MECP2 mutation and spinal fusion between 2006 and 2012. Twenty-five interviews were conducted to determine their daughter's recovery and parental stresses and coping. Themes in the interview data were identified with content analysis, and the regaining of gross motor skills over the first 12 post-operative months was described with time-to-event (survival) analysis. RESULTS: Pain and energy levels, appetite, mood and coinciding health issues influenced their daughter's post-operative recovery. The majority of girls recovered preoperative sitting (88%), standing (81%) and walking (80%) by 12 months. The decision to proceed with surgery was associated with feelings of fear, obligation, relief and guilt for families. Development of complications, poor support and feelings of isolation increased their emotional burden whereas adequate information and discharge preparation, confidence in self and staff, and balancing personal needs with their daughter's care relieved this burden. INTERPRETATION: Our study identified clinical practice issues in relation to families whose daughter with Rett syndrome undergoes spinal fusion, issues that are also relevant to other severe disabilities. Return of wellness and gross motor skills following spinal fusion in girls with Rett syndrome occurred within the first 12 post-operative months in most cases. Parents require information and practical support to alleviate their emotional burden.

<http://www.ncbi.nlm.nih.gov/pubmed/25752500>

McCrary, M. C., Lee, K. J., Scanlon, M. C. and Wakeham, M. K. (2015). "Predictors of need for mechanical ventilation at discharge after tracheostomy in the PICU." Pediatr Pulmonol.

BACKGROUND: The objective of this study was to determine factors predictive of need for mechanical ventilation (MV) upon discharge from the pediatric intensive care unit (PICU) among patients who receive a tracheostomy during their stay. METHODS: This was a retrospective cohort study using the Virtual PICU Systems (VPS) database. Patients <18 years old admitted between 2009-2011 who required MV for at least 3 days and received a tracheostomy during their PICU stay were included. RESULTS: A total of 680 pediatric patients from 74 PICUs were included, of whom 347 (51%) remained on MV at the time of PICU discharge. Neonates (30/38, 79%) and infants (129/203, 64%) required MV at PICU discharge after tracheostomy more often than adolescents (66/141, 47%) and children (122/298, 41%). Time on MV pre-tracheostomy was longer among those who required MV at discharge (median 18.3 vs. 13.8 days, $P < 0.0001$); however, number of failed extubations was similar (median 1 for both groups, $P = 0.97$). On mixed-effects multivariable regression analysis, the age categories of neonate (OR 2.9, 95%CI 1.1-7.6, $P = 0.03$), and infant (OR 1.7, 95%CI 1.1-2.8, $P = 0.03$), and ventilator days prior to tracheostomy (OR 1.01, 95%CI 1.0-1.02, $P = 0.01$) were significantly associated with increased odds of MV upon PICU discharge, while being a trauma admission was associated with decreased odds (OR 0.45, 95%CI 0.28-0.73, $P = 0.001$).

CONCLUSIONS: Younger patients and those with prolonged courses of MV prior to tracheostomy are more likely to continue to need MV upon PICU discharge. *Pediatr Pulmonol.* (c) 2015 Wiley Periodicals, Inc.

<http://www.ncbi.nlm.nih.gov/pubmed/25823590>

Morley, T. E., Cataudella, D., Fernandez, C. V., Sung, L., Johnston, D. L., Nesin, A. and Zelcer, S. (2014). "Development of the Pediatric Advanced Care Quality of Life Scale (PAC-QoL): evaluating comprehension of items and response options." *Pediatr Blood Cancer* 61(10): 1835-1839.

BACKGROUND: Validated tools that measure quality of life (QOL) for children with poor prognosis malignancies are not available. We are developing a novel instrument, The Pediatric Advanced Care-Quality of Life Scale (PAC-QoL), in order to address this gap. Instrument development requires a phase of item reduction and assessment of item comprehension in the target population. This manuscript provides a report on this phase in the development of the PAC-QoL. PROCEDURE: Children with poor prognosis cancer and/or their parents were invited to participate in cognitive probing interviews. Participants' understanding of each item was rated from 0 (did not understand) to 4 (completely understood). To evaluate the response scale, an overall percentage of respondents' ability to accurately distinguish between the four response options was calculated. RESULTS: Four age- and reporter-specific versions of the PAC-QoL were tested with 74 participants. Mean (+/-SD) comprehension scores across versions ranged from 3.40 +/- .030 (child self-report) to 3.69 +/- 0.23 (parent of toddler report). The number of items deleted or modified to improve understandability ranged from 46% of all items on the parent-of-child report to 56% for the child and adolescent self-reports. Respondent's abilities to accurately distinguish between response-scale options ranged from 84% (child-report) to 98% (parent-toddler report). CONCLUSIONS: We demonstrate a high degree item understandability and response-scale separation in the current version of the PAC-QoL. The scale is ready for psychometric evaluation in its target population.

<http://www.ncbi.nlm.nih.gov/pubmed/24947009>

Noel, M., Palermo, T. M., Essner, B., Zhou, C., Levy, R. L., Langer, S. L., Sherman, A. L. and Walker, L. S. (2015). "A developmental analysis of the factorial validity of the parent-report version of the Adult Responses to Children's Symptoms in children versus adolescents with chronic pain or pain-related chronic illness." *J Pain* 16(1): 31-41.

The widely used Adult Responses to Children's Symptoms measures parental responses to child symptom complaints among youth aged 7 to 18 years with recurrent/chronic pain. Given developmental differences between children and adolescents and the impact of developmental stage on parenting, the factorial validity of the parent-report version of the Adult Responses to Children's Symptoms with a pain-specific stem was examined separately in 743 parents of 281 children (7-11 years) and 462 adolescents (12-18 years) with chronic pain or pain-related chronic illness. Factor structures of the Adult Responses to Children's Symptoms beyond the original 3-factor model were also examined. Exploratory factor analysis with oblique rotation was conducted on a randomly chosen half of the sample of children and adolescents as well as the 2 groups combined to assess underlying factor structure. Confirmatory factor analysis was conducted on the other randomly chosen half of the sample to

cross-validate factor structure revealed by exploratory factor analyses and compare it to other model variants. Poor loading and high cross-loading items were removed. A 4-factor model (Protect, Minimize, Monitor, and Distract) for children and the combined (child and adolescent) sample and a 5-factor model (Protect, Minimize, Monitor, Distract, and Solicitousness) for adolescents was superior to the 3-factor model proposed in previous literature. Future research should examine the validity of derived subscales and developmental differences in their relationships with parent and child functioning. PERSPECTIVE: This article examined developmental differences in the structure of a widely used measure of caregiver responses to chronic pain or pain-related chronic illness in youth. Results suggest that revised structures that differ across developmental groups can be used with youth with a range of clinical pain-related conditions.

<http://www.ncbi.nlm.nih.gov/pubmed/25451623>

Rahn, D. A., 3rd, Mundt, A. J., Murphy, J. D., Schiff, D., Adams, J. and Murphy, K. T. (2014). "Clinical outcomes of palliative radiation therapy for children." Pract Radiat Oncol.

PURPOSE: In contrast to studies of adults, there are limited published data regarding palliative radiation therapy (RT) for children, and further study is greatly needed. METHODS AND MATERIALS: We performed a retrospective review of all pediatric patients referred to our radiation oncology department over a 5-year span from January 1, 2007, to December 31, 2011. RESULTS: Of 244 total pediatric patients referred, a subset of 45 (18.4%) were treated specifically with palliative intent for a total of 83 courses of RT. Follow-up data until study closure or death were available for 98% of patients. The median survival after initiation of palliative RT was 6.5 months. Overall, 23% of the children were alive at last follow-up visit, and 77% were deceased. The prescribed RT was completed in 93% of courses; 7% of courses were discontinued because of clinical deterioration due to systemic disease progression. The overall symptom response rate (partial or complete) was 72%. Overall response rate by symptom was 80% for bone pain, 55% for dyspnea or chest pain, 58% for neurologic symptoms, 50% for bleeding, and 100% for liver pain or ascites. Response rates by histology were 100% for leukemias, 91% for neuroblastoma, 76% for Ewing sarcoma, 64% for rhabdomyosarcoma, 54% for osteosarcoma, and 50% for primary central nervous system neoplasms. For responders, the median time from RT initiation to response was 1 week. For 7% of patients, a repeat course of RT for the same site and symptom was performed. No patients experienced RTOG (Radiation Therapy Oncology Group) grade 3 or greater acute or late toxicities. CONCLUSIONS: RT is a useful palliative tool for pediatric patients that merits continued use and further study.

<http://www.ncbi.nlm.nih.gov/pubmed/25413394>

Raitio, K., Kaunonen, M. and Aho, A. L. (2015). "Evaluating a bereavement follow-up intervention for grieving mothers after the death of a child." Scand J Caring Sci.

AIM: The aim of this study was to produce information about parental grief intervention and its impacts on maternal grief. BACKGROUND: The grief after death of a child is a lifelong process. Social support is often stated as the most important factor in coping after the death of a child. DESIGN: A single measure post-test control group design was used to evaluate whether there are differences in the grief reactions between the mothers in the intervention

program (n = 83) and the mothers in the control group (n = 53). METHOD: The data were collected by using a questionnaire which included background variables and Hogan Grief Reactions Checklist 6 months after the child's death. The data were analysed by statistical methods. RESULTS: There were no significant differences in the grief reactions between the intervention group and the control group. However, greater support from the healthcare professionals was associated with stronger personal growth. The mothers' age, self-perceived health status and the age of deceased child were associated with the grief reactions. This study emphasises the importance of social support to grieving mothers. CONCLUSION: Health care professionals are in an important role when considering support for grieving mothers; the given support may relieve the mothers' grief reactions.

<http://www.ncbi.nlm.nih.gov/pubmed/25623822>

Rajan, S., Wissenberg, M., Folke, F., Hansen, C. M., Lippert, F. K., Weeke, P., Karlsson, L., Sondergaard, K. B., Kragholm, K., Christensen, E. F., Nielsen, S. L., Kober, L., Gislason, G. H. and Torp-Pedersen, C. (2015). "Out-of-hospital cardiac arrests in children and adolescents: Incidences, outcomes, and household socioeconomic status." *Resuscitation* 88: 12-19.

BACKGROUND: There is insufficient knowledge of out-of-hospital cardiac arrest (OHCA) in the very young. OBJECTIVES: This nationwide study sought to examine age-stratified OHCA characteristics and the role of parental socioeconomic differences and its contribution to mortality in the young population. METHODS: All OHCA patients in Denmark, ≤ 21 years of age, were identified from 2001 to 2010. The population was divided into infants (< 1 year); pre-school children (1-5 years); school children (6-15 years); and high school adolescents/young adults (16-21 years). Multivariate logistic regression analyses were used to investigate associations between pre-hospital factors and study endpoints: return of spontaneous circulation and survival. RESULTS: A total of 459 individuals were included. Overall incidence of OHCA was 3.3 per 100,000 inhabitants per year. The incidence rates for infants, pre-school children, school children and high school adolescents were 11.5, 3.5, 1.3 and 5.3 per 100,000 inhabitants. Overall bystander CPR rate was 48.8%, and for age groups: 55.4%, 41.2%, 44.9% and 63.0%, respectively. Overall 30-day survival rate was 8.1%, and for age groups: 1.4%, 4.5%, 16.1% and 9.3%, respectively. High parental education was associated with improved survival after OHCA (OR 3.48, CI 1.27-9.41). Significant crude difference in survival (OR 3.18, CI 1.22-8.34) between high household incomes vs. low household incomes was found. CONCLUSION: OHCA incidences and survival rates varied significantly between age groups. High parental education was found to be associated with improved survival after OHCA.

<http://www.ncbi.nlm.nih.gov/pubmed/25500748>

Rosenbaum, J. L., Smith, J. R., Yan, Y., Abram, N. and Jeffe, D. B. (2014). "Impact of a Neonatal-Bereavement-Support DVD on Parental Grief: A Randomized Controlled Trial." *Death Stud*: 1-10.

This study tested the effect of a neonatal-bereavement-support DVD on parental grief after their baby's death in a Neonatal Intensive Care Unit compared with standard bereavement care (controls). Following a neonatal death, the authors measured grief change from a 3- to 12-month follow-up using a mixed-effects model. Intent-to-treat analysis was not significant,

but only 18 parents selectively watched the DVD. Thus, we subsequently compared DVD viewers with DVD nonviewers and controls. DVD viewers reported higher grief at 3-month interviews compared with DVD nonviewers and controls. Higher grief at 3 months was negatively correlated with social support and spiritual/religious beliefs. These findings have implications for neonatal-bereavement care.

<http://www.ncbi.nlm.nih.gov/pubmed/25530502>

Rosenberg, A. R., Starks, H. and Jones, B. (2014). "I know it when I see it." The complexities of measuring resilience among parents of children with cancer." Support Care Cancer 22(10): 2661-2668.

PURPOSE: Promoting parent resilience may provide an opportunity to improve family-level survivorship after pediatric cancer; however, measuring resilience is challenging. METHODS: The "Understanding Resilience in Parents of Children with Cancer" was a cross-sectional, mixed-methods study of bereaved and non-bereaved parents. Surveys included the Connor-Davidson Resilience scale, the Kessler-6 psychological distress scale, the Post-Traumatic Growth Inventory, and an open-ended question regarding the ongoing impact of cancer. We conducted content analyses of open-ended responses and categorized our impressions as "resilient," "not resilient," or "unable to determine." "Resilience" was determined based on evidence of psychological growth, lack of distress, and parent-reported meaning/purpose. We compared consensus impressions with instrument scores to examine alignment. Analyses were stratified by bereavement status. RESULTS: Eighty-four (88 %) non-bereaved and 21 (88 %) bereaved parents provided written responses. Among non-bereaved, 53 (63 %) were considered resilient and 15 (18 %) were not. Among bereaved, 11 (52 %) were deemed resilient and 5 (24 %) were not. All others suggested a mixed or incomplete picture. Rater-determined "resilient" parents tended to have higher personal resources and lower psychological distress ($p = <0.001-0.01$). Non-bereaved "resilient" parents also had higher post-traumatic growth ($p = 0.02$). Person-level analyses demonstrated that only 50-62 % of parents had all three instrument scores aligned with our impressions of resilience. CONCLUSIONS: Despite multiple theories, measuring resilience is challenging. Our clinical impressions of resilience were aligned in 100 % of cases; however, instruments measuring potential markers of resilience were aligned in approximately half. Promoting resilience therefore requires understanding of multiple factors, including person-level perspectives, individual resources, processes of adaptation, and emotional well-being.

<http://www.ncbi.nlm.nih.gov/pubmed/24756554>

Sabati, A. A., Szmuszkovicz, J. R., Herrington, C., Hermes, M., Mahmoud, H. A., Phei Wee, C., Starnes, V. A. and Menteeer, J. (2015). "Survival and quality of life for children with end-stage heart failure who are not candidates for cardiac transplant." J Heart Lung Transplant.

BACKGROUND: Some pediatric patients referred for heart transplant (HTx) are sub-optimal candidates. Their outcomes without HTx are presumed to be dismal, but have not been well described. Knowledge about their outcomes is critical when weighing the risks between a high-risk transplant and "terminal" palliation. METHODS: We retrospectively reviewed all HTx referrals from January 2005 to July 2013. We excluded those who were listed for HTx, or who were denied HTx due to being "too well," seeking only those who were in need of but not

suitable for HTx. End-points included mortality and length of survival. RESULTS: Of 212 referrals, 39 (19%) (age 0 to 19 years, median 3.5 years) were denied HTx for reasons other than being too well. Twenty-eight (72%) had palliated congenital heart disease. Overall mortality during the follow-up period was 38% (n = 15) with a median follow-up time of 195 days (8 to 2,832 days). Ten patients received subsequent cardiac surgery with 1 death (10%) and median follow-up of 2.6 years. Mortality risk was not influenced by age, weight, growth failure, congenital heart disease or single-ventricle physiology. Mechanical ventilation (hazard ratio 6.31, p = 0.001) and inotrope dependence (hazard ratio 4.79, p = 0.006) were associated with the highest risk of mortality. Quality of life was measured with the PedsQL cardiac module and completed by 11 of 16 eligible patients with an overall average score of 70.2 +/- 23.9. CONCLUSIONS: An advanced heart failure program can achieve satisfactory results for pediatric patients who are not suitable candidates for HTx. For some children, high-risk palliative surgery can result in better outcome than high-risk HTx. Mortality was related to the degree of heart failure at presentation rather than underlying heart disease.

<http://www.ncbi.nlm.nih.gov/pubmed/25765370>

Sanchez Fernandez, I., An, S. and Loddenkemper, T. (2015). "Pediatric refractory epilepsy: A decision analysis comparing medical versus surgical treatment." *Epilepsia* 56(2): 263-272.

OBJECTIVES: To quantify the life expectancy of surgically eligible children with refractory epilepsy comparing two treatment strategies: medical treatment only versus epilepsy surgery. METHODS: Decision analysis model populated with available parameters from the literature. One- and two-way sensitivity analyses and second-order Monte Carlo simulations evaluated the robustness of the results across wide variations of the input parameters. The time horizon was lifetime and the main outcome was life expectancy. RESULTS: Across the range of pediatric ages, epilepsy surgery yielded a higher life expectancy. For a cohort of 10-year-old children with refractory epilepsy, the gain in life expectancy with epilepsy surgery (compared to medical treatment only) was 5.9 years for temporal epilepsy and 5.6 years for extratemporal epilepsy. One- and two-way sensitivity analyses and second-order Monte Carlo simulations demonstrated the robustness of results across a wide variation of input parameters. There was no adjustment for quality of life, but we estimated the percentage of life expectancy spent in seizure freedom. For a cohort of 10-year-old patients with refractory epilepsy: (1) in temporal lobe epilepsy, epilepsy surgery yielded 48.9% of life expectancy years in seizure freedom while medical treatment yielded 14.3%; and (2) in extratemporal epilepsy, epilepsy surgery yielded 43.0% of life expectancy years in seizure freedom while medical treatment yielded 14.3%. SIGNIFICANCE: Epilepsy surgery yields a substantially higher life expectancy than continued medical treatment for surgically eligible children with refractory epilepsy. This conclusion remains robust across a wide range of parameter variations.

<http://www.ncbi.nlm.nih.gov/pubmed/25599894>

Sellers, D. E., Dawson, R., Cohen-Bearak, A., Solomond, M. Z. and Truog, R. D. (2015). "Measuring the quality of dying and death in the pediatric intensive care setting: the clinician PICU-QODD." *J Pain Symptom Manage* 49(1): 66-78.

CONTEXT: In the pediatric intensive care setting, an accurate measure of the dying and death experience holds promise for illuminating how critical care nurses, physicians, and allied psy-

chosocial staff can better manage end-of-life care for the benefit of children and their families, as well as the caregivers. OBJECTIVES: The aim was to assess the reliability and validity of a clinician measure of the quality of dying and death (Pediatric Intensive Care Unit-Quality of Dying and Death 20 [PICU-QODD-20]) in the pediatric intensive care setting. METHODS: In a retrospective cohort study, five types of clinicians (primary nurse, bedside nurse, attending physician, and the psychosocial clinician and critical care fellow most involved in the case) were asked to complete a survey for each of the 94 children who died over a 12 month period in the pediatric intensive care units of two children's hospitals in the northeast U.S. Analyses were conducted within type of clinician. RESULTS: In total, 300 surveys were completed by 159 clinicians. Standard item analyses and substantive review led to the selection of 20 items for inclusion in the PICU-QODD-20. Cronbach alpha for the PICU-QODD-20 ranged from 0.891 for bedside nurses to 0.959 for attending physicians. For each type of clinician, the PICU-QODD-20 was significantly correlated with the quality of end-of-life care and with meeting the family's needs. In addition, when patient/family or team barriers were encountered, the PICU-QODD-20 score tended to be significantly lower than for cases in which the barrier was not encountered. CONCLUSION: The PICU-QODD-20 shows promise as a valid and reliable measure of the quality of dying and death in pediatric intensive care. <http://www.ncbi.nlm.nih.gov/pubmed/24878067>

Siddaway, A. P., Wood, A. M., Schulz, J. and Trickey, D. (2015). "Evaluation of the CHUMS Child Bereavement Group: A Pilot Study Examining Statistical and Clinical Change." Death Stud 39(2): 99-110.

This article describes the largest evaluation of a UK child bereavement service to date. Change was assessed using conventional statistical tests as well as clinical significance methodology. Consistent with the fact that the intervention was offered on a universal, preventative basis, bereaved young people experienced a statistically significant, small to medium-sized decrease in symptoms over time. This change was equivalent across child age and gender. Type of bereavement had a slight impact on change when rated by parents. Potential clinical implications are highlighted, and various limitations are discussed that we hope to address using an experimental design in future research.

<http://www.ncbi.nlm.nih.gov/pubmed/25153045>

Solana, M. J., Lopez-Herce, J., Fernandez, S., Gonzalez, R., Urbano, J., Lopez, J. and Belion, J. M. (2015). "Assessment of pain in critically ill children. Is cutaneous conductance a reliable tool?" J Crit Care.

PURPOSE: The purpose of this study is to assess the usefulness and accuracy of skin conductance (SC) as a tool to evaluate the level of sedation and pain in pediatric critical patients during painful procedures and to compare it with hemodynamic variables, clinical scales, and bispectral index (BIS). MATERIALS AND METHODS: This is a prospective observational study in 61 critical children undergoing invasive procedures. Hemodynamic data (heart rate and arterial blood pressure), clinical scales punctuation (Ramsay, COMFORT, and numeric rating pain scales), BIS, and the number of fluctuations of SC per second were collected before, during, and at the end of the procedure. RESULTS: The mean age of the patients was 42.9 (range, 1 month to 16 years). Seventy-two point six percent were postcardiac surgery patients. Nonmuscle-relaxed patients showed a moderate increase in heart rate ($P = .02$), nu-

meric rating pain scales ($P = .03$), and Ramsay scale ($P = .002$). The number of fluctuations of SC per second increased significantly during the procedure (basal, 0.1; maneuver, 0.2; $P = .015$), but it never reached the level considered as pain or stress nor did it precede clinical scales or BIS. None of the variables studied showed a significant change during the procedure in muscle-relaxed patients. CONCLUSIONS: Skin conductance was not found to be more sensitive or faster than clinical scales for the assessment of pain or stress in critical children undergoing painful procedures. Skin conductance was not useful in muscle-relaxed children.

<http://www.ncbi.nlm.nih.gov/pubmed/25758636>

Wilcox, H. C., Mittendorfer-Rutz, E., Kjeldgard, L., Alexanderson, K. and Runeson, B. (2015). "Functional impairment due to bereavement after the death of adolescent or young adult offspring in a national population study of 1,051,515 parents." Soc Psychiatry Psychiatr Epidemiol.

PURPOSE: This study addresses the burden of grief after the death of an adolescent or young adult offspring. Parental bereavement following the death of an adolescent or young adult offspring is associated with considerable psychiatric and somatic impairment. Our aim is to fill a research gap by examining offspring death due to suicide, accidents, or natural causes in relation to risk of parental sickness absence with psychiatric or somatic disorders. METHODS: This whole population-based prospective study included mothers and fathers of all offspring aged 16-24 years in Sweden on December 31, 2004 ($n = 1,051,515$). This study had no loss to follow-up and exposure, confounders, and the outcome were recorded independently of each other. Cox survival analysis was used to model time to sickness absence exceeding 30 days, adjusting for parental demographic characteristics, previous parental sickness absence and disability pension, and inpatient and outpatient psychiatric and somatic healthcare prior to offspring death in 2001-2004. This large study population provided satisfactory statistical power for stratification by parents' sex and adolescent and young adults' cause of death. RESULTS: Mothers and fathers of offspring suicide and accident decedents both had over tenfold higher risk for psychiatric sickness absence exceeding 30 days as compared to parents of live offspring. Fathers of suicide decedents were at 40 % higher risk for somatic sickness absence. CONCLUSIONS: This is the largest study to date of parents who survived their offspring's death and the first study of work-related outcomes in bereaved parents. This study uses a broad metric of work-related functional impairment, sickness absence, for capturing the burden of sudden offspring death.

<http://www.ncbi.nlm.nih.gov/pubmed/25552253>

Pain and symptom assessment

Aukes, D. I., Roofthoof, D. W., Simons, S. H., Tibboe, D. and van Dijk, M. (2014). "Pain Management in Neonatal Intensive Care: Evaluation of the Compliance with Guidelines." Clin J Pain.

BACKGROUND: A pain management protocol was implemented in our Neonatal Intensive Care Unit in 2005, including individual pain assessments and pain treatment guidelines with a decision tree. OBJECTIVES: To prospectively evaluate the degree of compliance of medical and nursing staff with the pain protocol. METHODS: Prospectively recorded pain scores (COMFORTneo score) and all prescribed analgesics and sedatives for the calendar year 2011 were retrieved. The primary outcome is the degree of compliance to the protocol with respect to pain assessments and treatment; the secondary outcome consists of reasons for non-compliance. RESULTS: Of the 732 included patients, 660 (90%) received fewer than the stipulated 3 assessments per day. Eighty-six per cent of all assessments yielded a score between 9 and 14, suggesting a comfortable patient. In cases of high pain scores (≥ 14), reassessment within 60 minutes took place in 31% of cases and in 40% treatment was started or adjusted. In cases of low pain scores (≤ 8) during treatment, 13% of the 457 assessments were reassessed within 120 minutes and in 17% a dose reduction was performed. CONCLUSIONS: Although the majority of pain assessments suggested comfortable patients, there is room for improvement with respect to reassessments after adjustment of analgesic/sedative treatment. Some protocol violations such as oversedation in palliative patients are acceptable but should be well documented.

<http://www.ncbi.nlm.nih.gov/pubmed/25370139>

Beecham, E., Candy, B., Howard, R., McCulloch, R., Laddie, J., Rees, H., Vickerstaff, V., Bluebond-Langner, M. and Jones, L. (2015). "Pharmacological interventions for pain in children and adolescents with life-limiting conditions." Cochrane Database Syst Rev 3: CD010750.

BACKGROUND: Pain is one of the most common symptoms in children and young people (CYP) with life-limiting conditions (LLCs) which include a wide range of diagnoses including cancer. The current literature indicates that pain is not well managed, however the evidence base to guide clinicians is limited. There is a clear need for evidence from a systematic review to inform prescribing. OBJECTIVES: To evaluate the evidence on the effectiveness of different pharmacological interventions used for pain in CYP with LLCs. SEARCH METHODS: The following electronic databases were searched up to December 2014: CENTRAL (in the Cochrane Library), MEDLINE, EMBASE, PsycINFO and CINAHL. In addition, we searched conference proceedings and reference lists of included studies. For completeness, we also contacted experts in the field. No language restrictions were applied. SELECTION CRITERIA: Randomised controlled trials (RCTs), quasi-randomised studies and other studies that included a clearly defined comparator group were included. The studies investigated pharmacological treatments for pain associated with LLCs in CYP. The treatment included those specifically developed to treat pain and those that acted as an adjuvant, where the treatment was not primarily devel-

oped to treat pain but has pain relieving properties. The LLC was identified by its inclusion in the Richard Hain Directory of LLCs. DATA COLLECTION AND ANALYSIS: Citations were screened by five review authors. Data were extracted by one review author and checked by a second. Two review authors assessed the risk of bias of included studies. A sufficient number of studies using homogeneous outcomes was not identified so a meta-analysis was not possible. MAIN RESULTS: We identified 24,704 citations from our database search. Nine trials with 379 participants fulfilled our inclusion criteria. Participants had cerebral palsy (CP) in five of the studies and osteogenesis imperfecta (OI) in the other four. Participants across the trials ranged in age from 2 to 19 years. All studies, apart from one cross-over trial, were parallel designed RCTs. Three of the trials on CP evaluated intrathecal baclofen (ITB) and two botulinum toxin A (BoNT-A). All of the OI trials evaluated the use of bisphosphonates (two alendronate and one pamidronate). No trials were identified that evaluated a commonly used analgesic in this patient group. Pain was a secondary outcome in five of the eight identified studies. Overall the quality of the trials was mixed. Only one study involved over 100 participants. For the two ITB studies for pain in CP, in the same study population but assessed at different time points in their disease, both found an effect on pain favouring the intervention compared to the control group (standard care or placebo) (mean difference (MD) 4.20, 95% confidence interval (CI) 2.15 to 6.25; MD 26.60, 95% CI 2.61 to 50.59, respectively). In these studies most of the adverse events related to the procedure or device for administration rather than the drug, such as swelling at the pump site. In one trial there were also eight serious adverse effects; these included difficulty swallowing and an epileptic seizure. The trial did not state if these occurred in the intervention group. At follow-up in both BoNT-A trials there was no evidence of a difference in pain between the trial arms among CP participants. The adverse events in the BoNT-A trials mostly involved those who received the intervention drug and involved seizures. Gastrointestinal problems were the most frequent adverse event in those who received alendronate. The trial investigating pamidronate found no evidence of a difference in pain compared to the control group. No adverse events were reported in this trial. AUTHORS' CONCLUSIONS: Published, controlled evidence on the pharmacological interventions for pain in CYP with LLCs is limited. The evidence that is currently available evaluated pain largely as a secondary outcome and the drugs used were all adjuvants and not always commonly used in general paediatric palliative care for pain. Based on current data this systematic review is unable to determine the effects of pharmacological interventions for pain for CYP with LLCs. Future trials with larger populations should examine the effects of the drugs commonly used as analgesics; with the rising prevalence of many LLCs this becomes more necessary.

<http://www.ncbi.nlm.nih.gov/pubmed/25768935>

Bhalla, T., Shepherd, E. and Tobias, J. D. (2014). "Neonatal pain management." Saudi J Anaesth 8(Suppl 1): S89-97.

The past 2-3 decades have seen dramatic changes in the approach to pain management in the neonate. These practices started with refuting previously held misconceptions regarding nociception in preterm infants. Although neonates were initially thought to have limited response to painful stimuli, it was demonstrated that the developmental immaturity of the central nervous system makes the neonate more likely to feel pain. It was further demonstrated that untreated pain can have long-lasting physiologic and neurodevelopmental conse-

quences. These concerns have resulted in a significant emphasis on improving and optimizing the techniques of analgesia for neonates and infants. The following article will review techniques for pain assessment, prevention, and treatment in this population with a specific focus on acute pain related to medical and surgical conditions.

<http://www.ncbi.nlm.nih.gov/pubmed/25538531>

Brandow, A. M., Farley, R. A., Dasgupta, M., Hoffmann, R. G. and Panepinto, J. A. (2015). "The use of neuropathic pain drugs in children with sickle cell disease is associated with older age, female sex, and longer length of hospital stay." *J Pediatr Hematol Oncol* 37(1): 10-15.

Although neuropathic pain is increasingly recognized in sickle cell disease (SCD), it is unknown how neuropathic pain drugs are used in children with SCD. Thus, we investigated use of these drugs and hypothesized older age and female sex are associated with increased neuropathic drug use and the use of these drugs is associated with longer length of stay. We analyzed the Pediatric Health Information System (2004 to 2009) including all inpatient visits aged 0 to 18 years with any SCD-related (all genotypes) discharge diagnosis. To limit confounding we excluded psychiatric and seizure visits. Antiepileptics, tricyclic antidepressants, and selective serotonin reuptake inhibitors were drugs of interest. Generalized Estimating Equations determined the impact of age and sex on neuropathic drug use and the impact of neuropathic drug use on length of stay. We analyzed 53,557 visits; 2.9% received ≥ 1 neuropathic drugs. The odds of receiving a neuropathic drug increased significantly with age (reference group, 0 to 4 y: 5 to 10, odds ratio [OR], 5.7; 11 to 14: OR, 12.5; 15 to 18: OR, 22.8; all $P < 0.0001$) and female sex (OR, 1.5; $P = 0.001$). Neuropathic drug use was associated with longer length of stay (risk ratio, 8.3; $P < 0.0001$). Neuropathic drug use in children with SCD was associated with older age, female sex, and longer length of stay.

<http://www.ncbi.nlm.nih.gov/pubmed/25222053>

Brands, M. M., Gungor, D., van den Hout, J. M., Karstens, F. P., Oussoren, E., Plug, I., Boelens, J. J., van Hasselt, P. M., Hollak, C. E., Mulder, M. F., Gozalbo, E. R., Smeitink, J. A., Smit, G. P., Wijburg, F. A., Meutgeert, H. and van der Ploeg, A. T. (2015). "Pain: a prevalent feature in patients with mucopolysaccharidosis. Results of a cross-sectional national survey." *J Inherit Metab Dis* 38(2): 323-331.

BACKGROUND: While clinical observations suggest that many patients with mucopolysaccharidosis (MPS) experience chronic pain, few studies have assessed its extent and impact. We therefore investigated its prevalence in patients with all types of MPS in the Netherlands. We also examined the association between pain and health related quality of life (HRQoL) and other clinical variables. **METHODS:** We conducted a nationwide MPS survey that used questionnaires on MPS and disease-related symptoms (MPS-specific questionnaire), developmental level (Vineland Screener 0-6 years), quality of life (PedsQL and SF-36), and disability (Childhood Health Assessment Questionnaire). Depending on their age and developmental level, patients or their parents were asked to assess pain by keeping a pain diary for five consecutive days: either the Non-communicating Children's Pain Checklist - Revised (3-18 years intellectually disabled and children <8 years), the VAS-score (> 18 years), or the Faces Pain Scale - Revised (8-18 years). **RESULTS:** Eighty-nine MPS patients were invited, 55 of whom agreed to participate (response rate 62 %; median age 10.9 years, range 2.9-47.2 years). They

covered a wide spectrum in all age groups, ranging from no pain to severe pain. Forty per cent scored above the cut-off value for pain. Most reported pain sites were the back and hips. While the MPS III group experienced the highest frequency of pain (52.9 %), 50 % of patients with an intellectual disability seemed to experience pain, versus 30 % of patients with a normal intelligence. MPS patients scored much lower (i.e., more pain) than a random sample of the Dutch population on the bodily pain domain of the SF-36 scale and the PedsQI. CONCLUSION: With or without intellectual disabilities, many MPS patients experience pain. We recommend that standardized pain assessments are included in the regular follow-up program of patients with MPS.

<http://www.ncbi.nlm.nih.gov/pubmed/25048386>

Breau, L. M. (2014). "Parents of non-verbal children with learning disability (LD) most commonly recognise their child's pain through vocalisations, social behaviour and facial expressions." *Evid Based Nurs* 17(4): 111.

<http://www.ncbi.nlm.nih.gov/pubmed/24520133>

Chidambaran, V., Olbrecht, V., Hossain, M., Sadhasivam, S., Rose, J. and Meyer, M. J. (2014). "Risk predictors of opioid-induced critical respiratory events in children: naloxone use as a quality measure of opioid safety." *Pain Med* 15(12): 2139-2149.

BACKGROUND: Opioid-induced respiratory depression (OIRD) is a life-threatening complication of opioid therapy in children. Naloxone administration triggered by OIRD has been used to monitor safety of opioid therapy in adults. We used this trigger as a quality measure of opioid safety in hospitalized children to identify risk predictors of OIRD. METHODS: We retrospectively reviewed medical records of 38 patients identified from the hospital risk management database as requiring naloxone for critical respiratory events between January 2010 and June 2012 for demographics, comorbidities, surgery, naloxone event details, and outcomes. These data were compared with baseline prevalence in contemporary patients followed by pain service, who did not receive naloxone, to calculate unadjusted odds ratios. Thematic classification of preventable events was undertaken based on analysis of each event. RESULTS: The incidence of naloxone use among hospital inpatients, who received opioids at-least once, was 0.06% compared with 0.23% for patients on the pain service. A majority of naloxone events occurred in postoperative patients (n = 27/38, 71.1%) within the first 24 hours of surgery (n = 20/27, 75.1%) and in the critical care unit (50%). Patients undergoing airway surgeries had higher risk for OIRD (P = 0.01). Patient risk factors for naloxone use included age <1 year (P < 0.001), obstructive sleep apnea (P < 0.001), obesity (P = 0.019), being underweight (P < 0.0001), prematurity (P < 0.001), and developmental delay (P < 0.001). Majority of events (87%) were found to be preventable, which were classified into six main themes based on type of event. CONCLUSION: OIRD is an important, albeit mostly preventable, complication of opioid therapy in children. Naloxone use can be used as a measure to track opioid safety in children, identify contributing factors, and formulate preventive strategies to reduce the risk for OIRD.

<http://www.ncbi.nlm.nih.gov/pubmed/25319840>

Chin, R. F. (2014). "What are the best ways to deliver benzodiazepines in children/patients with prolonged convulsive seizures?" *Epileptic Disord* 16 Suppl 1: 50-58.

Aetiology is the main determinant of morbidity and mortality in convulsive status epilepticus (CSE) but longer seizure durations may also increase risk of worse outcome. Thirty minutes of seizure activity is usually the time period used in longstanding definitions of CSE but it is not acceptable to wait for 30 minutes before treatment. Whilst intravenous therapy is best, pre-hospital treatment by a non-intravenous route is most practical in treating children. Benzodiazepines are the main class of first-line emergency antiepileptic drugs. This review will examine the available data on benzodiazepines according to: stability in the conditions of the emergency room services, drug absorption via non-intravenous route, clinical efficacy and safety, and ease of delivery and social acceptability.

<http://www.ncbi.nlm.nih.gov/pubmed/25322913>

Cong, X., McGrath, J. M., Delaney, C., Chen, H., Liang, S., Vazquez, V., Keating, L., Chang, K. and Dejong, A. (2014). "Neonatal nurses' perceptions of pain management: survey of the United States and China." *Pain Manag Nurs* 15(4): 834-844.

Despite growing knowledge, neonatal pain remains unrecognized, undertreated, and generally challenging. A cross-sectional survey study was conducted to investigate neonatal nurses' perceptions, knowledge, and practice of infant pain in the United States and China, including 343 neonatal nurses (American nurses [n = 237]; Chinese nurses [n = 106]). Nurses' responses regarding neonatal pain reflected adequate knowledge in general pain concepts, but knowledge deficits related to several topics were found (e.g., preterm infants are more sensitive to pain and long-term consequences of pain). Most reported regular use of pain assessment tools, but fewer agreed that the tool used was appropriate and accurate. More American nurses (83%) than Chinese nurses (58%) felt confident in the use of pain medications, while more Chinese nurses (78%) than American nurses (61%) acknowledged the effectiveness of nonpharmacologic interventions. About half reported that pain in their units was well managed (American: 44.3%; Chinese: 55.7%), and less than half felt that pain guidelines/protocols were research-based (American: 42.6%; Chinese: 34.9%). Nurses' perceptions of well-managed pain in their units were significantly correlated with adequate education/training, use of accurate tools, and use of research-based protocols. Barriers to effective pain management included resistance to change, lack of knowledge, lack of time, fear of side effects of pain medication, and lack of trust in the tools. The survey reflects concerns that pain has not been well managed in many neonatal intensive care units in the United States and China. Further actions are needed to solve the issues of inadequate training, lack of clinically feasible pain tools, and absence of evidence-based guidelines/protocols.

<http://www.ncbi.nlm.nih.gov/pubmed/24508269>

Cousins, L. A., Cohen, L. L. and Venable, C. (2014). "Risk and Resilience in Pediatric Chronic Pain: Exploring the Protective Role of Optimism." *J Pediatr Psychol*.

OBJECTIVE: Fear of pain and pain catastrophizing are prominent risk factors for pediatric chronic pain-related maladjustment. Although resilience has largely been ignored in the pediatric pain literature, prior research suggests that optimism might benefit youth and can be learned. We applied an adult chronic pain risk-resilience model to examine the interplay of risk factors and optimism on functioning outcomes in youth with chronic pain. **METHOD:** Participants included 58 children and adolescents (8-17 years) attending a chronic pain clinic and their parents. Participants completed measures of fear of pain, pain catastrophizing, op-

timism, disability, and quality of life. RESULTS: Consistent with the literature, pain intensity, fear of pain, and catastrophizing predicted functioning. Optimism was a unique predictor of quality of life, and optimism contributed to better functioning by minimizing pain-related fear and catastrophizing. CONCLUSIONS: Optimism might be protective and offset the negative influence of fear of pain and catastrophizing on pain-related functioning.

<http://www.ncbi.nlm.nih.gov/pubmed/25355543>

Crabtree, V. M., Rach, A. M., Schellinger, K. B., Russell, K. M., Hammarback, T. and Mandrell, B. N. (2015). "Changes in sleep and fatigue in newly treated pediatric oncology patients." *Support Care Cancer* 23(2): 393-401.

BACKGROUND: Fatigue has been reported as one of the most distressing symptoms in oncology patients, yet few have investigated the longitudinal course of sleep and fatigue in newly diagnosed pediatric oncology patients. PROCEDURE: To longitudinally assess presence and changes of sleep complaints and fatigue, we administered questionnaires designed to measure sleep complaints, sleep habits, daytime sleepiness, and fatigue to parents of pediatric oncology patients ages 2-18 and to pediatric oncology patients, themselves, ages 8-18 within 30 days of diagnosis (n = 170) and again 8 weeks later (n = 153). RESULTS: Bedtimes, wake times, and sleep duration remained relatively stable across the first 8 weeks of treatment. Sleep duration and fatigue were not related for the entire sample, though children's self-reported sleep duration was positively correlated with fatigue only at the baseline time point. Parent reports of fatigue significantly decreased for leukemia patients but remained rather high for solid tumor and brain tumor patients. CONCLUSIONS: Because fatigue remained high for solid tumor and brain tumor patients across the initial 8 weeks of treatment, this may highlight the need for intervention in this patient population.

<http://www.ncbi.nlm.nih.gov/pubmed/25112560>

Dalic, L., Mullen, S. A., Roulet Perez, E. and Scheffer, I. (2015). "Lamotrigine can be beneficial in patients with Dravet syndrome." *Dev Med Child Neurol* 57(2): 200-202.

Dravet syndrome, a severe infantile epilepsy syndrome, is typically resistant to anti-epileptic drugs (AED). Lamotrigine (LTG), an AED that is effective for both focal and generalized seizures, has been reported to aggravate seizures in Dravet syndrome. Therefore, LTG is usually avoided in Dravet syndrome. We describe two adults and a child with Dravet syndrome in whom LTG resulted in decreased seizure duration and frequency. This benefit was highlighted in each patient when LTG was withdrawn after 6 to 15 years, and resulted in an increased frequency of convulsive seizures together with longer seizure duration. A 25-year-old male required hospital admission for frequent seizures for the first time in 7 years, 6 weeks after ceasing LTG. Reintroduction of LTG improved seizure control, suggesting that in some patients with Dravet syndrome, LTG may be beneficial.

<http://www.ncbi.nlm.nih.gov/pubmed/25243660>

Downing, J., Jassal, S. S., Mathews, L., Brits, H. and Friedrichsdorf, S. J. (2015). "Pediatric pain management in palliative care." *Pain Manag* 5(1): 23-35.

The management of pain in pediatric palliative care (PPC) is essential. Whilst the field of pain management has developed over the years, much of what is done in PPC is based on anecdotal

dotal evidence or adult studies. This review explores recent developments in pain management in PPC, in particular the WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. Key issues discussed include the definition, assessment, pharmacological and integrative management of pain, availability of medications, education and research. Whilst advances have been made, including publication of the guidelines, significant gaps exist in terms of the evidence base, education and access to essential medications and both interdisciplinary and international collaboration are required to meet these gaps.

<http://www.ncbi.nlm.nih.gov/pubmed/25537696>

Fisher, E., Law, E., Palermo, T. M. and Eccleston, C. (2015). "Psychological therapies (remotely delivered) for the management of chronic and recurrent pain in children and adolescents." *Cochrane Database Syst Rev* 3: CD011118.

BACKGROUND: Chronic pain is common during childhood and adolescence and is associated with negative outcomes such as increased severity of pain, reduced function (e.g. missing school), and low mood (e.g. high levels of depression and anxiety). Psychological therapies, traditionally delivered face-to-face with a therapist, are efficacious at reducing pain intensity and disability. However, new and innovative technology is being used to deliver these psychological therapies remotely, meaning barriers to access to treatment such as distance and cost can be removed or reduced. Therapies delivered with technological devices, such as the Internet, computer-based programmes, smartphone applications, or via the telephone, can be used to deliver treatment to children and adolescents with chronic pain. **OBJECTIVES:** To determine the efficacy of psychological therapies delivered remotely compared to waiting-list, treatment-as-usual, or active control treatments, for the management of chronic pain in children and adolescents. **SEARCH METHODS:** We searched four databases (CENTRAL, MEDLINE, EMBASE, and PsycINFO) from inception to June 2014 for randomised controlled trials of remotely delivered psychological interventions for children and adolescents (0 to 18 years of age) with chronic pain. We searched for chronic pain conditions including, but not exclusive to, headache, recurrent abdominal pain, musculoskeletal pain, and neuropathic pain. We also searched online trial registries for potential trials. A citation and reference search for all included studies was conducted. **SELECTION CRITERIA:** All included studies were randomised controlled trials that investigated the efficacy of a psychological therapy delivered remotely via the Internet, smartphone device, computer-based programme, audio-tapes, or over the phone in comparison to an active, treatment-as-usual, or waiting-list control. We considered blended treatments, which used a combination of technology and face-to-face interaction. We excluded interventions solely delivered face-to-face between therapist and patient from this review. Children and adolescents (0 to 18 years of age) with a primary chronic pain condition were the target of the interventions. Each comparator arm, at each extraction point had to include 10 or more participants. **DATA COLLECTION AND ANALYSIS:** For the analyses, we combined all psychological therapies. We split pain conditions into headache and mixed (non-headache) pain and analysed them separately. Pain, disability, depression, anxiety, and adverse events were extracted as primary outcomes. We also extracted satisfaction with treatment as a secondary outcome. We considered outcomes at two time points: first immediately following the end of treatment (known as 'post-treatment'), and second, any follow-up time point post-treatment between 3 and 12 months (known as 'follow-up'). We assessed all included studies for risk of bias. **MAIN RESULTS:** Eight

studies (N = 371) that delivered treatment remotely were identified from our search; five studies investigated children with headache conditions, one study was with children with juvenile idiopathic arthritis, and two studies included mixed samples of children with headache and mixed (i.e. recurrent abdominal pain, musculoskeletal pain) chronic pain conditions. The average age of children receiving treatment was 12.57 years. For headache pain conditions, we found one beneficial effect of remotely delivered psychological therapy. Headache severity was reduced post-treatment (risk ratio (RR) = 2.65, 95% confidence interval (CI) 1.56 to 4.50, $z = 3.62$, $p < 0.01$, number needed to treat to benefit (NNTB) = 2.88). For mixed pain conditions, we found only one beneficial effect: psychological therapies reduced pain intensity post-treatment (standardised mean difference (SMD) = -0.61, 95% CI -0.96 to -0.25, $z = 3.38$, $p < 0.01$). No effects were found for reducing pain at follow-up in either analysis. For headache and mixed conditions, there were no beneficial effects of psychological therapies delivered remotely for disability post-treatment and a lack of data at follow-up meant no analyses could be run. Only one analysis could be conducted for depression outcomes. We found no beneficial effect of psychological therapies in reducing depression post-treatment for headache conditions. Only one study presented data in children with mixed pain conditions for depressive outcomes and no data were available for either condition at follow-up. Only one study presented anxiety data post-treatment and no studies reported follow-up data, therefore no analyses could be run. Further, there were no data available for adverse events, meaning that we are unsure whether psychological therapies are harmful to children who receive them. Satisfaction with treatment is described qualitatively. 'Risk of bias' assessments were low or unclear. We judged selection, detection, and reporting biases to be mostly low risk for included studies. However, judgements made on performance and attrition biases were mostly unclear. **AUTHORS' CONCLUSIONS:** Psychological therapies delivered remotely, primarily via the Internet, confer benefit in reducing the intensity or severity of pain after treatment across conditions. There is considerable uncertainty around these estimates of effect and only eight studies with 371 children contribute to the conclusions. Future studies are likely to change the conclusions reported here. All included trials used either behavioural or cognitive behavioural therapies for children with chronic pain, therefore we cannot generalise our findings to other therapies. However, satisfaction with these treatments was generally positive. Larger trials are needed to increase our confidence in all conclusions regarding the efficacy of remotely delivered psychological therapies. Implications for practice and research are discussed.

<http://www.ncbi.nlm.nih.gov/pubmed/25803793>

Forgeron, P. A. and Stinson, J. (2014). "Fundamentals of chronic pain in children and young people. Part 2." *Nurs Child Young People* 26(9): 31-36.

Chronic pain is common in childhood and can have severe physical and psychological consequences but, unlike acute pain, it is not always recognised by nurses and other health professionals. A holistic and multidisciplinary approach to treatment is required and nurses can play a significant role in helping children and families to cope with the negative effects of the condition. The first part of this article, published in October, looked at the prevalence, anatomy and physiology of pain, and factors associated with chronic pain and its consequences. In part 2, assessment strategies as well as pharmacological and psychological interventions, are discussed, along with self-help programmes and strategies that can be used to aid sleep and help the child at school manage their pain.

<http://www.ncbi.nlm.nih.gov/pubmed/25369105>

Fosdal, M. B. (2015). "Perception of pain among pediatric patients with sickle cell pain crisis." *J Pediatr Oncol Nurs* 32(1): 5-20.

Pain related to vasoocclusion is the most common reason for emergency department visits and hospital stays among pediatric patients with sickle cell disease. Using a prospective descriptive design, patients hospitalized with sickle cell pain were asked to complete the Adolescent Pediatric Pain Tool on each day of their hospital stay, providing data on the location, intensity, and quality of their pain. Data for 82 hospital stays were collected from 40 African American study participants. Mean age was 14.8 years, and mean length of stay (LOS) was 5.1 days. Mean LOS for 8 to 12 year olds (3.23 days; n = 22) was shorter than mean LOS for 13 to 19 year olds (5.85 days; n = 60). This LOS difference was significant (P = .004). Difference in LOS by gender was not significant. Higher initial number of body sites with pain was significantly associated with longer LOS (r = .39; P < .001). Higher initial pain intensity scores were significantly associated with longer LOS (r = .37; P = .001). Higher initial number of word descriptors was only weakly associated with longer LOS. Neither gender nor age differences were significant for Adolescent Pediatric Pain Tool data.

<http://www.ncbi.nlm.nih.gov/pubmed/25416521>

Hauer, J. M. and Solodiuk, J. C. (2015). "Gabapentin for management of recurrent pain in 22 nonverbal children with severe neurological impairment: a retrospective analysis." *J Palliat Med* 18(5): 453-456.

BACKGROUND: Children with severe impairment of the central nervous system (CNS) have a high incidence of distressing symptoms, with many experiencing frequent recurrent pain episodes. OBJECTIVE: The study objective was to describe presenting pain behaviors, daily dose, and response to gabapentin for the management of frequent recurrent pain in this population. METHODS: A retrospective analysis was performed with data from 22 children with severe impairment of the CNS residing at a long-term care facility, treated with gabapentin for recurrent pain behaviors. Response was considered significant if the frequency and severity of symptoms decreased by more than 50% as assessed by nursing staff. RESULTS: Pain behaviors commonly reported included facial grimacing, crying, or moaning. Intermittent increase in muscle tone was identified in 86% (n=19). Gastrointestinal (GI) symptoms occurred in 64% (n=14), including pain localized to the GI tract and vomiting. All were assessed for nociceptive pain sources, many with repeated testing. Most were on medications for spasticity (n=20, 91%) and gastroesophageal reflux disease (GERD) (n=22, 100%) prior to gabapentin use. Of the 22 treated with gabapentin, 21 (91%) had a significant decrease in symptoms. No serious adverse events occurred. The mean gabapentin dose for children five years of age or less (n=11) was 50 mg/kg/day (95% CI 45-56) compared to children older than 11 years (n=11) with a mean dose of 36 mg/kg/day (95% CI 34-38). CONCLUSIONS: Gabapentin appears to be an effective treatment for children with severe impairment of the CNS and recurrent pain behaviors, including intermittent changes in muscle tone. Dosing information can guide treatment trials and future prospective studies.

<http://www.ncbi.nlm.nih.gov/pubmed/25658145>

Hechler, T., Wager, J. and Zernikow, B. (2014). "Chronic pain treatment in children and adolescents: less is good, more is sometimes better." *BMC Pediatr* 14: 262.

BACKGROUND: In children with chronic pain, interdisciplinary outpatient and intensive inpatient treatment has been shown to improve pain intensity and disability. However, there are few systematic comparisons of outcomes of the two treatments. The present naturalistic study aimed to compare the clinical presentation and achieved changes at return in three outcome domains (pain intensity, disability, school absence) between a) outpatients vs. inpatients and b) patients who declined intensive inpatient treatment and completed outpatient treatment instead (decliners) vs. those who completed inpatient treatment (completers). **METHODS:** The study compared treatment outcomes between n = 992 outpatients vs. n = 320 inpatients (Analysis A) who were treated at a tertiary treatment centre and returned for a return visit within a one-year interval. In Analysis B, treatment outcomes were compared between n = 67 decliners vs. n = 309 completers of inpatient treatment. The three outcome domains were compared by calculating standardized change scores and clinically significant changes. **RESULTS:** In analysis A, outpatients and inpatients reported comparably low levels of pain intensity (NRS 0-10; mean = 4, SD = 2.7) and disability (Paediatric Pain Disability Index (PPDI: 12-60; mean = 24; SD = 10) at the return visit. Compared to outpatients, more inpatients achieved clinically significant changes in pain intensity (52% vs. 45%) and disability (46% vs. 31%). There were also significantly greater changes in disability in the inpatient group (change score outpatients = 1.0; change score inpatients = 1.4; $F(1,1138) = 12.6$, $p = .011$). School absence was substantially reduced, with approximately 80% in each group attending school regularly. Analysis B showed that even though inpatient decliners achieved improvements in the outcome domains, they reported greater disability at the return visit (PPDI mean decliners = 27, SD = 9.9; PPDI mean completers = 24, SD = 10) because they had achieved fewer changes in disability (change score decliners = 0.9; change score completers = 1.4; $F(1,334) = 5.7$, $p = .017$). In addition, less decliners than completers achieved clinically significant changes in disability (25% vs. 47%). **CONCLUSIONS:** Inpatient and outpatient treatments are able to elicit substantial changes in pain intensity, disability and school absence. The results highlight the necessity of intensive inpatient pain treatment for highly affected children, as children who declined inpatient treatment and were treated as outpatients did less well.

<http://www.ncbi.nlm.nih.gov/pubmed/25308551>

Korzeniewska-Eksterowicz, A., Przyslo, L., Fendler, W., Stolarska, M. and Mlynarski, W. (2014). "Palliative sedation at home for terminally ill children with cancer." *J Pain Symptom Manage* 48(5): 968-974.

CONTEXT: The presence of symptoms that are difficult to control always requires adjustment of treatment, and palliative sedation (PS) should be considered. **OBJECTIVES:** We analyzed our experience in conducting PS at home for terminally ill children with cancer during a seven-year period. **METHODS:** We performed a retrospective analysis of medical records of children with cancer treated at home between the years 2005 and 2011. **RESULTS:** We analyzed the data of 42 cancer patients (18% of all patients); in 21 cases, PS was initiated (solid tumors n = 11, brain tumors [5], bone tumors [4], leukemia [1]). Sedation was introduced because of pain (n = 13), dyspnea (9), anxiety (5), or two of those symptoms (6). The main drug

used for sedation was midazolam; all patients received morphine. There were no significant differences in the dose of morphine or midazolam depending on the patient's sex; age was correlated with an increase of midazolam dose ($R = 0.68$; $P = 0.005$). Duration of sedation ($R = 0.61$; $P = 0.003$) and its later initiation ($R = 0.43$; $P = 0.05$) were correlated with an increase of the morphine dose. All patients received adjuvant treatment; in patients who required a morphine dose increase, metoclopramide was used more often ($P = 0.0002$). Patients did not experience any adverse reactions. Later introduction of sedation was associated with a marginally higher number of intervention visits and a significantly higher number of planned visits ($R = 0.53$; $P = 0.013$). **CONCLUSION:** Sedation may be safely used at home. It requires close monitoring and full cooperation between the family and hospice team. Because of the limited data on home PS in pediatric populations, further studies are needed.

<http://www.ncbi.nlm.nih.gov/pubmed/24751437>

Lima, M., Silva, K., Amaral, I., Magalhaes, A. and de Sousa, L. (2014). "Can you help when it hurts? Dogs as potential pain relief stimuli for children with profound intellectual and multiple disabilities." *Pain Med* 15(11): 1983-1986.

<http://www.ncbi.nlm.nih.gov/pubmed/25234702>

Lundeberg, S. (2015). "Pain in children--are we accomplishing the optimal pain treatment?" *Paediatr Anaesth* 25(1): 83-92.

Morphine, paracetamol and local anesthetics have for a long time been the foremost used analgesics in the pediatric patient by tradition but not always enough effective and associated with side effects. The purpose with this article is to propose alternative approaches in pain management, not always supported up by substantial scientific work but from a combination of science and clinical experience in the field. The scientific literature has been reviewed in parts regarding different aspects of pain assessment and analgesics used for treatment of diverse pain conditions with focus on procedural and acute pain. Clinical experience has been added to form the suggested improvements in accomplishing an improved pain management in pediatric patients. The aim with pain management in children should be a tailored analgesic medication with an individual acceptable pain level and optimal degree of mobilization with as little side effects as possible. Simple techniques of pain control are as effective as and complex techniques in pediatrics but the technique used is not of the highest importance in achieving a good pain management. Increased interest and improved education of the doctors prescribing analgesics is important in accomplishing a better pain management. The optimal treatment with analgesics is depending on the analysis of pain origin and analgesics used should be adjusted thereafter. A multimodal treatment regime is advocated for optimal analgesic effect.

<http://www.ncbi.nlm.nih.gov/pubmed/25279762>

Mathew, E., Kim, E. and Goldschneider, K. R. (2014). "Pharmacological treatment of chronic non-cancer pain in pediatric patients." *Paediatr Drugs* 16(6): 457-471.

Chronic pain in children and young adults occurs frequently and contributes to early disability as well as personal and familial distress. A biopsychosocial approach to evaluation and treatment is recommended. Within this approach, there is a role for pharmacologic intervention. A variety of medications are used for chronic pain conditions in pediatric patients. Medication classes include anticonvulsants, muscle relaxants, antidepressants, opioids, local

anesthetics, and anti-inflammatory drugs. Data is sparse, and most medications are used without condition-specific approval by national regulatory agencies such as the Food and Drug Administration in the US and the European Medicines Agency. In the absence of evidence on which to base practice, optimal drug therapy decisions rest on understanding proposed mechanisms of pain conditions, extrapolation from adult data-when such exists, and empirical and experiential knowledge. Drug delivery systems have evolved, and practitioners have to decide amongst not only medication classes, but also routes of delivery. Opioids are not recommended for use by non-pain specialists for the treatment of pediatric chronic pain, and even then the issues are more complex than can be addressed here. This article reviews the major medications used for pediatric chronic pain conditions.

<http://www.ncbi.nlm.nih.gov/pubmed/25304005>

Mherekumombe, M. F. and Collins, J. J. (2014). "Patient-Controlled Analgesia for Children at Home." *J Pain Symptom Manage.*

CONTEXT: Pain is a common and significant symptom experienced by children with advanced malignant disease. There is limited research on pain management of these children at home. OBJECTIVES: To describe and review the indications for using patient-controlled analgesia (PCA) in the form of a Computerized Ambulatory Drug Delivery device (CADD(R)) in the home setting. METHODS: A retrospective chart review was conducted in children discharged home with opioid infusions using a CADD. Charts from January 2008 to February 2012 were surveyed. RESULTS: Thirty-seven CADDs were dispensed during the study period, and of these, 33 were prescribed for patients with cancer-related pain. A third of the CADDs were commenced at home and almost all PCA CADDs were used for end-of-life care. Hydromorphone was the most commonly prescribed opioid. Patients remained at home and pain control was achieved by either increasing the opioid dose or switching the opioid and using adjuvant therapy. Sixteen patients were readmitted to hospital from home and three admissions were related to pain. The median duration on a PCA CADD at home was 33.7 days (range, 1-150 days), and the mean morphine equivalent dose was 2.13 mg/kg/day. CONCLUSION: PCA with a CADD can be used to manage pain in the home setting. Dose adjustments and opioid switches were performed with no adverse incidents.

<http://www.ncbi.nlm.nih.gov/pubmed/25546288>

Nolt, D., Lindemulder, S., Meyrowitz, J., Chang, B. H., Malempati, S., Thomas, G. and Stork, L. (2015). "Preventive antibiotics in pediatric patients with acute myeloid leukemia (AML)." *Pediatr Blood Cancer* 62(7): 1149-1154.

BACKGROUND: Treatment of acute myeloid leukemia (AML) comes with a significant risk of life-threatening infection during periods of prolonged severe neutropenia. We studied the impact of preventive intravenous (IV) antibiotic administration at onset of absolute neutropenia on the incidence and outcome of life-threatening infections during treatment of childhood AML. PROCEDURES: This is a retrospective study on pediatric patients (aged 0-18 years) consecutively diagnosed with de novo AML and treated at a single institution from April 2005 through February 2013. Patients were treated on the Children's Oncology Group (COG) AAML0531 protocol or with a modified United Kingdom Medical Research Council (UK MRC) AML 10 regimen. Pertinent data were extracted from hard copy or electronic chart review. RESULTS: A total of 76 chemotherapy phases were analyzed from 29 patients. In each

phase reported, preventive antibiotics were initiated when the daily absolute neutrophil count was <500 cells/mcl, before onset of fever. Seven episodes of bacteremia were documented with predominantly coagulase-negative staphylococci and viridans group streptococci. One infection-related death occurred, attributed to progressive respiratory failure occurring months after documented candidal pneumonia. CONCLUSIONS: Initiation of preventive antibiotics at the onset of absolute neutropenia was associated with no mortality from bacteremia. This preventive approach appears feasible and safe. *Pediatr Blood Cancer* 2015;62:1149-1154. (c) 2015 Wiley Periodicals, Inc.

<http://www.ncbi.nlm.nih.gov/pubmed/25728418>

Panoff, J., Simoneaux, R. V., Shah, N., Scott, M., Buchsbaum, J. C., Johnstone, P. A. and McMullen, K. P. (2015). "Radiation therapy at end of life in children." *J Palliat Med* 18(2): 167-169.

OBJECTIVE: Few data exist on evaluating utilization patterns of radiotherapy (RT) at the end of life (EOL) in children. Metastatic disease in pediatric patients is not pathognomonic for palliative treatment intent; further complicating the issue are complexities surrounding the very select population of children receiving proton therapy (PrT). We compared data for RT and PrT in terms of death rate within 30 days. METHODS: We performed chart reviews for patients receiving radiation therapy at age ≤ 21 years treated at Indiana University Health Proton Therapy Center (IUHPTC) between June 2008 and June 2013 and University of Miami Radiation Oncology Department (UM) between June 2000 and June 2013. Included were patients not completing prescribed courses of RT, and those dying within 30 days of therapy. Comparison was made of differences between practice data for PrT and conventional RT. RESULTS: At IUHPTC, 2 children of 272 did not complete their courses and died within 30 days (0.7%). At UM, data are available for 425 children; 9 did not complete their courses and 7 died within 30 days (1.6%). Neither the number of patients who did not complete treatment nor the 30-day death rates ($P=.21$) for PrT and RT were significantly different. CONCLUSIONS: Delivery of RT for children at EOL is complex. Frequency of RT at EOL in children occurs in is <2% of cases, and is not significantly less frequent in the proton milieu. This appears to be about an order of magnitude less than in adults.

<http://www.ncbi.nlm.nih.gov/pubmed/25216446>

Quinn, B. L., Sheldon, L. K. and Cooley, M. E. (2014). "Pediatric pain assessment by drawn faces scales: a review." *Pain Manag Nurs* 15(4): 909-918.

Pediatric pain assessment is a significant issue yet the topic is understudied. Unique challenges, namely reporting biases, are present when assessing pain in children. The aim of this review of the literature is to increase awareness of biases when assessing pain in children, suggest changes in practice, and state priorities for future research. Five computerized databases were searched to identify original research pertaining to the use of drawn faces scales for pediatric pain assessment. Twelve studies met inclusion criteria. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines provided a framework for this review. Relevant articles were identified and data were extracted from the studies. Content analyses were then used to synthesize the findings. The age of a child being assessed contributed to biases in pain assessment. Drawn faces scales may provide inaccurate pain assessment results if a child has difficulty separating the feelings of pain and mood. Smiling

faces on pain assessment scales may lead to overestimation of pain intensity. Nurses should consider biases when selecting and implementing a drawn faces pain assessment tool and when planning pain management interventions. An increase in the use of technology in pediatric pain assessment practices may provide opportunities to implement individualized pain assessment in practice. Further research is needed to determine the most reliable methods for pediatric pain assessment including the use of technology. Evidence would assist nurses in determining the best tool to assess each child based on cognitive abilities and developmental level.

<http://www.ncbi.nlm.nih.gov/pubmed/24973799>

Rasmussen, V. F., Lundberg, V., Jespersen, T. W. and Hasle, H. (2015). "Extreme doses of intravenous methadone for severe pain in two children with cancer." Pediatr Blood Cancer.

We describe the effect and side effects in two children with cancer treated with intravenous methadone in extreme doses (>10 mg/kg/day) due to vincristine-induced neuropathy where surgical procedures provoked severe neuropathic pain. The maximum daily dose was 33 and 25 mg/kg/day. Methadone remained effective at adjusted doses. Few side effects were reported. No significant changes in paraclinical data were observed. Prolonged QTc-interval occurred only during concomitant treatment with fluconazole. In conclusion, methadone should be seen as a part of the armamentarium against cancer-related pain. Methadone can be used in extreme doses with appropriate monitoring by clinicians experienced in its use. *Pediatr Blood Cancer* (c) 2015 Wiley Periodicals, Inc.

<http://www.ncbi.nlm.nih.gov/pubmed/25641929>

Rosen, G., Harris, A. K., Liu, M., Dreyfus, J., Krueger, J. and Messinger, Y. H. (2015). "The effects of dexamethasone on sleep in young children with acute lymphoblastic leukemia." Sleep Med 16(4): 503-509.

PURPOSE: Corticosteroids, which are a mainstay in the treatment of acute lymphoblastic leukemia (ALL), have a well-documented adverse effect on sleep. We sought to characterize the effects of dexamethasone on sleep over an entire 28-day treatment cycle using actigraphy, an objective measure of sleep. **METHODS:** The sleep of 25 children aged 2-9 years (mean 4.5 years) with ALL treated with dexamethasone were evaluated during maintenance chemotherapy using a within-subject experimental design, actigraphy, and standardized questionnaires to assess sleep, sleep problems, and fatigue. **RESULTS:** During the five days of dexamethasone treatment, sleep time increased during the night (535 vs. 498 min; $p = 0.004$) and daytime napping increased the following day (14 vs. 0 min; $p = 0.002$), and the number of wake episodes during the night was lower (14 vs. 20; $p = </= 0.001$). However, when assessed individually, sleep-onset time, efficiency, and wake after sleep onset during the night were unchanged during dexamethasone treatment; when the cumulative effect of all of these factors was assessed, there was a statistically and clinically significant increase in nighttime sleep duration during dexamethasone treatment. **CONCLUSIONS:** During the five days of treatment with dexamethasone, an increase in nighttime sleep as well as daytime napping was observed in young children with ALL. The increases in sleep duration return to baseline one day after the discontinuation of dexamethasone.

<http://www.ncbi.nlm.nih.gov/pubmed/25799940>

Schuurmans, J., Benders, M., Lemmers, P. and van Bel, F. (2015). "Neonatal morphine in extremely and very preterm neonates: its effect on the developing brain - a review." J Matern Fetal Neonatal Med 28(2): 222-228.

OBJECTIVE: Preterm infants requiring intensive care experience a large number of stressful and painful procedures. Management of stress and pain is therefore an important issue. This review provides an overview of the research on the use of morphine and its neurodevelopmental effects on this vulnerable group of neonates. METHODS: A structural literature search of both experimental and clinical data has been done using an electronic database (PubMed), but also relevant reference lists and related articles were used. RESULTS: A total of 39 sources were considered relevant for this review to elucidate the effects of morphine on the developing brain. The results showed that both animal experimental and clinical data displayed conflicting results on the effects of neonatal morphine on neurodevelopmental outcome. However, in contrast to specific short-term neurological outcomes long-term neurodevelopmental outcome does not seem to be adversely affected by morphine. CONCLUSION: After a careful review of the literature, no definite conclusions concerning the effects of neonatal morphine on the long-term neurodevelopmental outcome in extremely premature neonates can be drawn. More prospectively designed trials should be conducted using reliable and validated pain assessment scores to evaluate effects of morphine on long-term neurodevelopmental outcome to demonstrate a beneficial or adverse effect of morphine in preterm infants.

<http://www.ncbi.nlm.nih.gov/pubmed/24670240>

Segal, L. S., Odgers, R., Carpentieri, D. and Shrader, M. W. (2015). "Back pain in Duchenne muscular dystrophy: steroids are not always the culprit." J Pediatr Orthop B.

We report on a child with Duchenne muscular dystrophy on prolonged corticosteroid treatment who presented with back pain and was subsequently found to have a monostotic fibrous dysplasia lesion of the spine. It is the intent of this case report to emphasize the need to maintain a high index of suspicion for other potential causes of back pain in Duchenne muscular dystrophy besides vertebral compression fractures.

<http://www.ncbi.nlm.nih.gov/pubmed/25714938>

Suresh, S., Long, J., Birmingham, P. K. and De Oliveira, G. S., Jr. (2015). "Are caudal blocks for pain control safe in children? an analysis of 18,650 caudal blocks from the Pediatric Regional Anesthesia Network (PRAN) database." Anesth Analg 120(1): 151-156.

BACKGROUND: The caudal block is the most commonly performed regional anesthesia technique in pediatric patients undergoing surgical procedures, but safety concerns raised by previous reports remain to be addressed. Our main objective in current investigation was to estimate the overall and specific incidence of complications associated with the performance of caudal block in children. METHODS: This was an observational study using the Pediatric Regional Anesthesia Network database. A complication after a caudal block was defined by the presence of at least 1 of the following: block failure, vascular puncture, intravascular test dose, dural puncture, seizure, cardiac arrest, sacral pain, or neurologic symptoms. In addition,

if a complication was also coded, the presence of temporary or permanent sequelae was evaluated. Additional exploratory analyses were performed to identify patterns of local anesthetic dosage. RESULTS: Eighteen thousand six hundred-fifty children who received a caudal block were included in the study. The overall estimated incidence (95% confidence interval [CI]) of complications after caudal blocks was 1.9% (1.7%-2.1%). Patients who developed complications were younger, median (interquartile range) of 11 (5-24) months, compared to those who did not develop any complications, 14 (7-29) months, P = 0.001. The most common complications were block failure, blood aspiration, and intravascular injection. No cases of temporary or permanent sequelae were identified leading to an estimated incidence (95% CI) of 0.005% (- % to 0.03%). Four thousand four hundred-six of 17,867 (24.6%; 95% CI, 24%-25.2%) subjects received doses (>2 mg of bupivacaine equivalents/kg) that could be potentially unsafe. CONCLUSIONS: Safety concerns should not be a barrier to the use of caudal blocks in children assuming an appropriate selection of local anesthetic dosage.

<http://www.ncbi.nlm.nih.gov/pubmed/25393589>

Twycross, A., Voepel-Lewis, T., Vincent, C., Franck, L. S. and von Baeyer, C. L. (2014). "A Debate on the Proposition that Self-Report is the Gold Standard in Assessment of Pediatric Pain Intensity." *Clin J Pain*.

OBJECTIVES AND METHODS:: Self-report is often represented as "the gold standard" in assessment of pain intensity in children. We evaluate arguments for and against this claim and consider its implications for pain management. RESULTS:: Those in the support of the proposition argue that, when children are able to self-report, treatment decisions should be made based on these scores in line with current evidence-based recommendations. Pain is a subjective phenomenon and can be assessed only via self-report. Treating self-report scores as the gold standard is the only valid way for health care professionals to decide on appropriate treatment. Those against the proposition contend that reliance on self-reported pain scores for analgesic treatment decisions is inappropriate since they over-simplify the pain experience, yield only marginal information on which to base treatment decisions, and potentially place children at significant risk for adverse events. Self-reports of pain intensity sometimes contradict well-founded estimates based on other evidence. Wide variation between children in the meaning of pain scores precludes easy interpretation. DISCUSSION:: We conclude that self-report, when available, can be considered a primary source of evidence about pain intensity. However, it cannot be treated as an unquestioned gold standard. Instead, hierarchical or bundled approaches should be used, taking into account self-report as well as the many individual and contextual factors that influence pain including clinical history, patient preferences, and response to previous treatments. Alternate models are presented to guide further practice and research.

<http://www.ncbi.nlm.nih.gov/pubmed/25370143>

Providing services for children and families

(2014). "Care plan for families who experience infant death in Northern Ireland."

Community Pract 87(12): 7.

<http://www.ncbi.nlm.nih.gov/pubmed/25626283>

Agarwal, A., Willis, D., Tang, X., Bauer, M., Berlinski, A., Com, G., Ward, W. L. and Carroll, J. L. (2015). "Transition of respiratory technology dependent patients from pediatric to adult pulmonology care." Pediatr Pulmonol.

OBJECTIVE: Recent advances in medicine have allowed children with chronic life-threatening disorders to survive longer than ever before with the use of complex medical device technology (e.g., mechanical ventilation, dialysis, etc.). The care of children with chronic pulmonary disorders and respiratory-technology dependence is often complex, involving a high level of ongoing interaction between caregivers and the health care team. Unmanaged, non-standardized transition of respiratory technology dependent (RTD) patients to adult care potentially increases the risk of adverse outcomes. Pediatric Pulmonary programs at US children's hospitals were surveyed to ascertain whether a standardized process is utilized for transitioning RTD patients from pediatric to adult subspecialty pulmonology care. METHOD- OLOGY: Pediatric pulmonology programs with Accreditation Council for Graduate Medical Education certification were invited to participate in an electronic survey inquiring about practices and processes used to transition RTD patients from pediatric to adult pulmonology. RESULTS: The majority of respondents, 78.1% (25/32), reported that they do not utilize a standard protocol for transition while 41.4% (12/29) have no process in place. No program surveyed uses a designated transition leader. Referral to an adult pulmonologist within the same health system occurs more frequently than referral to private practice. Forty-three percent are not satisfied with involvement from the adult pulmonology care team. Coordination of care with other specialty services such as adult otolaryngology is provided by 31% of respondents. Of respondents, 13.8% assessed "readiness to transition" to adult pulmonary for RTD patients. Pediatric pulmonary providers are not satisfied with their current practices or involvement from the adult team, and only 24% track the transition process until the first visit with the adult pulmonologist. CONCLUSION: The survey results highlight a lack of standardized transition programs at US children's hospitals for the transfer of RTD patients from a pediatric to an adult care setting. Improvement in the standardized management of transitions of complex RTD patients from pediatric to adult care may decrease the risk for adverse health outcomes and the stresses associated with changing the health care setting. *Pediatr Pulmonol*. (c) 2015 Wiley Periodicals, Inc.

<http://www.ncbi.nlm.nih.gov/pubmed/25652000>

Amin, R., Sayal, A., Syed, F., Daniels, C., Hoffman, A., Moraes, T. J. and Cox, P. (2015). "How long does it take to initiate a child on long-term invasive ventilation? Results from a Canadian pediatric home ventilation program." Can Respir J 22(2): 103-108.

OBJECTIVE: To assess the length of stay required to initiate long-term invasive ventilation at the authors' institution, which would inform future interventional strategies to streamline the

in-hospital stay for these families. METHODS: A retrospective chart review of children initiated on invasive long-term ventilation via tracheostomy at the authors' acute care centre between January 2005 and December 2013 was performed. RESULTS: Thirty-five children were initiated on long-term invasive ventilation via tracheostomy at the acute care hospital; 19 (54%) were male. The median age at time of admission was 0.52 years (interquartile range [IQR] 0.06 to 9.58 years) . Musculoskeletal disease (n=11 [31%]) was the most common reason for tracheostomy insertion. Two children died during the hospital admission. Fifteen children were discharged home directly from the acute care hospital and 18 were moved to the rehabilitation hospital. Six are current inpatients of the rehabilitation centre and were never discharged home. Combining the length of stay at the acute care and rehabilitation hospitals for the entire cohort, the median length of stay was 162.0 days (IQR 98.0 to 275.0 days) and 97.0 days (IQR 69.0 to 210.0 days), respectively, from the time of tracheostomy insertion. CONCLUSIONS: The median length of stay from the initiation of invasive long-term ventilation to discharge home from the rehabilitation hospital was somewhat long compared with other ventilation programs worldwide. Additionally, approximately 20% of the cohort never transitioned home. There is a timely need to benchmark across the country and internationally, to identify and implement strategies for cohesive, coordinated care for these children to decrease overall length of stay.

<http://www.ncbi.nlm.nih.gov/pubmed/25848720>

Baird, J., Davies, B., Hinds, P. S., Baggott, C. and Rehm, R. S. (2015). "What impact do hospital and unit-based rules have upon patient and family-centered care in the pediatric intensive care unit?" *J Pediatr Nurs* 30(1): 133-142.

Patient and family-centered care (PFCC) is the foundation for pediatric healthcare. The existence of hospital rules can, however, impact the extent to which PFCC is delivered. This qualitative, grounded theory study identified the existence of explicit and implicit rules in a pediatric intensive care unit, all of which negatively affected the family's ability to receive care that was attentive to their needs. The rules also placed the registered nurse in the challenging position of serving as rule enforcer and facilitator of PFCC. Further work is needed to explore how to adapt the hospital environment to better meet families' needs.

<http://www.ncbi.nlm.nih.gov/pubmed/25450441>

Bergstraesser, E., Zimmermann, K., Eskola, K., Luck, P., Ramelet, A. S. and Cignacco, E. (2015). "Paediatric end-of-life care needs in Switzerland: current practices, and perspectives from parents and professionals. A study protocol." *J Adv Nurs*.

AIM: To present a protocol for a multi-phase study about the current practice of end-of-life care in paediatric settings in Switzerland. BACKGROUND: In Switzerland, paediatric palliative care is usually provided by teams, who may not necessarily have specific training. There is a lack of systematic data about specific aspects of care at the end of a child's life, such as symptom management, involvement of parents in decision-making and family-centred care and experiences and needs of parents, and perspectives of healthcare professionals. DESIGN: This retrospective nationwide multicentre study, Paediatric End-of-Life Care Needs in Switzerland (PELICAN), combines quantitative and qualitative methods of enquiry. METHODS: The PELICAN study consists of three observational parts, PELICAN I describes practices of end-of-life care (defined as the last 4 weeks of life) in the hospital and home care setting of

children (0-18 years) who died in the years 2011-2012 due to a cardiac, neurological or oncological disease, or who died in the neonatal period. PELICAN II assesses the experiences and needs of parents during the end-of-life phase of their child. PELICAN III focuses on healthcare professionals and explores their perspectives concerning the provision of end-of-life care. CONCLUSION: This first study across Switzerland will provide comprehensive insight into the current end-of-life care in children with distinct diagnoses and the perspectives of affected parents and health professionals. The results may facilitate the development and implementation of programmes for end-of-life care in children across Switzerland, building on real experiences and needs. Trial registration: ClinicalTrials.gov Identifier: NCT01983852. <http://www.ncbi.nlm.nih.gov/pubmed/25740472>

Bogetz, J. F., Schroeder, A. R., Bergman, D. A., Cohen, H. J. and Sourkes, B. (2014). "Palliative care is critical to the changing face of child mortality and morbidity in the United States." *Clin Pediatr (Phila)* 53(11): 1030-1031. <http://www.ncbi.nlm.nih.gov/pubmed/24817074>

Brown, S. (2014). "Blended food for enteral feeding via a gastrostomy." *Nurs Child Young People* 26(9): 16-20.

A blended diet for enteral nutrition is defined as home-made everyday food blended to a smooth 'single cream' consistency. At present, blended food is not recommended as a first choice. However, the wishes of parents who prefer to use blended food for their child need to be respected, and hospice policy for Children's Hospice South West is to replicate home conditions as far as possible. Therefore guidelines have been created for use of a blended diet. However, benefits in physical and emotional health need to be balanced against risks of tube blockage, contamination and digestive upsets. <http://www.ncbi.nlm.nih.gov/pubmed/25369102>

Cardenas-Turanzas, M., Tovalin-Ahumada, H., Romo, C. G. and Okhuysen-Cawley, R. (2015). "Assessing need for palliative care services for children in Mexico." *J Palliat Med* 18(2): 162-166.

BACKGROUND: Pediatric palliative care increasingly became integrated into health care institutions worldwide over the last decade. However, in Mexico and other developing countries with large populations of children, little is known regarding the need for palliative care services. We aimed to assess the need for palliative and end-of-life care for children dying in public hospitals affiliated with Secretaria de Salud in Mexico. MEASUREMENT: We conducted a retrospective review of deaths of children (1-17 years old) occurring during 2011 and determined deaths associated with underlying complex chronic conditions by reviewing the four causes of death listed in the death certificate. We collected sociodemographic and clinical data and utilized univariate and multivariate analyses to determine factors associated with complex chronic conditions. RESULTS: A total of 2715 pediatric deaths were studied. We found 41% were associated with a complex chronic condition. The most frequent types of conditions were malignancies (47%), neuromuscular (18%), cardiovascular (12%), and renal (10%). Children with renal and malignant conditions died at an older age than children with other types of complex chronic conditions. Multivariate analysis indicated the independent predictors of death with complex chronic condition were no indigenous ethnicity, lack of

admission to the intensive care unit during the final hospital stay, and having affiliation with an institution for health care. CONCLUSIONS: A large proportion of pediatric deaths are associated with complex chronic conditions indicating the provision of adequate funding for professional education and palliative care initiatives for children in Mexico, should be a topic of the national health care agenda.

<http://www.ncbi.nlm.nih.gov/pubmed/25353338>

Caruso Brown, A. E., Howard, S. C., Baker, J. N., Ribeiro, R. C. and Lam, C. G. (2014). "Reported availability and gaps of pediatric palliative care in low- and middle-income countries: a systematic review of published data." *J Palliat Med* 17(12): 1369-1383.

BACKGROUND: The majority of young people in need of palliative care live in low- and middle-income countries, where curative treatment is less available. OBJECTIVE: We systematically reviewed published data describing palliative care services available to young people with life-limiting conditions in low- and middle-income countries and assessed core elements with respect to availability, gaps, and under-reported aspects. METHODS: PubMed, CINAHL, EMBASE (1980-2013), and secondary bibliographies were searched for publications that included patients younger than 25 years with life-limiting conditions and described palliative care programs in low- and middle-income countries. A data extraction checklist considered 15 items across seven domains: access, education/capacity building, health system support, pain management, symptom management, end-of-life care, and bereavement. Data were aggregated by program and country. RESULTS: Of 1572 records, 238 met criteria for full-text review; 34 qualified for inclusion, representing 30 programs in 21 countries. The median checklist score was 7 (range, 1-14) of 10 reported (range, 3-14). The most pervasive gaps were in national health system support (unavailable in 7 of 17 countries with programs reporting), specialized education (unavailable in 7 of 19 countries with programs reporting), and comprehensive opioid access (unavailable in 14 of 21 countries with programs reporting). Underreported elements included specified practices for pain management and end-of-life support. CONCLUSION: Comprehensive pediatric palliative care provision is possible even in markedly impoverished settings. Improved national health system support, specialized training and opioid access are key targets for research and advocacy. Application of a checklist methodology can promote awareness of gaps to guide program evaluation, reporting, and strengthening.

<http://www.ncbi.nlm.nih.gov/pubmed/25225748>

Casavant, D. W., McManus, M. L., Parsons, S. K., Zurakowski, D. and Graham, R. J. (2014). "Trial of telemedicine for patients on home ventilator support: feasibility, confidence in clinical management and use in medical decision-making." *J Telemed Telecare* 20(8): 441-449.

We investigated whether telemedicine (videoconferencing) was feasible in patients with special care needs on home ventilation, whether it affected the confidence of families about the clinical management of their child, and whether it supported clinical decision-making. Videoconferencing software was provided free for 14 families who had a computer and webcam. Families completed questionnaires about clinical management before the addition of telemedicine and 2-3 months after they had used telemedicine. They also completed a questionnaire about their experience with videoconferencing. There were 27 telemedicine en-

counters during the 9-month study. Families reported higher confidence in clinical care with telemedicine compared to telephone. They also reported that the videoconferencing was high-quality, easy to use, and did not increase their telecommunication costs. The telemedicine encounters supported clinical decision-making, especially in patients with active clinical problems or when the patient was acutely ill. The telemedicine encounters prevented the need for 23 clinic visits, three emergency room visits, and probably one hospital admission. Although the study was small, videoconferencing appears useful in the management of medically fragile patients on home ventilator support, producing high levels of family confidence in clinical management and value to clinicians in their decision-making.

<http://www.ncbi.nlm.nih.gov/pubmed/25316042>

Cawkwell, P. B., Gardner, S. L. and Weitzman, M. (2015). "Persistent racial and ethnic differences in location of death for children with cancer." *Pediatr Blood Cancer*.

BACKGROUND: Approximately one in 285 children will be diagnosed with cancer before reaching their 20th birthday. While both oncologists and parents report a preference that these children die at home rather than in a hospital, there are limited data exploring this issue in depth. PROCEDURE: We performed a retrospective analysis of national-level data from 1999 to 2011 from the National Center for Health Statistics "Underlying Cause of Death" database. Characteristics investigated included sex, race, age, ethnicity, cancer type, geographic location, and population density where the child lived. RESULTS: Of the 2,130 children with a death attributable to neoplasm in 2011, 37.6% (95% CI, 35.5-39.6%) died at home compared to 36.9% (95% CI, 35.0-38.8%) in 1999. In 2011, there were statistically significant racial differences between white, black, and Hispanic children across nearly every age group, with white children consistently most likely to die at home. Children of non-Hispanic origin were significantly more likely to die at home than Hispanic children (40.3% vs. 29.3%, $P < 0.001$). Children with CNS tumors are more likely to die at home than children with neoplasms as a whole, while children with leukemia are less likely. Statistically significant differences by race and ethnicity persist regardless of cancer type. CONCLUSIONS: There has been no significant change in the rate of children with cancer who die at home over the past decade. Racial and ethnic differences have persisted in end of life care for children with cancer with white non-Hispanic children being most likely to die at home. *Pediatr Blood Cancer* (c) 2015 Wiley Periodicals, Inc.

<http://www.ncbi.nlm.nih.gov/pubmed/25787675>

Clark, B. A., Siden, H. and Straatman, L. (2014). "An integrative approach to music therapy in pediatric palliative care." *J Palliat Care* 30(3): 179-187.

<http://www.ncbi.nlm.nih.gov/pubmed/25265742>

Coller, R. J., Nelson, B. B., Sklansky, D. J., Saenz, A. A., Klitzner, T. S., Lerner, C. F. and Chung, P. J. (2014). "Preventing hospitalizations in children with medical complexity: a systematic review." *Pediatrics* 134(6): e1628-1647.

BACKGROUND AND OBJECTIVES: Children with medical complexity (CMC) account for disproportionately high hospital use, and it is unknown if hospitalizations may be prevented. Our objective was to summarize evidence from (1) studies characterizing potentially preventable hospitalizations in CMC and (2) interventions aiming to reduce such hospitalizations.

METHODS: Our data sources include Medline, Cochrane Central Register of Controlled Trials, Web of Science, and Cumulative Index to Nursing and Allied Health Literature databases from their originations, and hand search of article bibliographies. Observational studies (n = 13) characterized potentially preventable hospitalizations, and experimental studies (n = 4) evaluated the efficacy of interventions to reduce them. Data were extracted on patient and family characteristics, medical complexity and preventable hospitalization indicators, hospitalization rates, costs, and days. Results of interventions were summarized by their effect on changes in hospital use. **RESULTS:** Preventable hospitalizations were measured in 3 ways: ambulatory care sensitive conditions, readmissions, or investigator-defined criteria. Postsurgical patients, those with neurologic disorders, and those with medical devices had higher preventable hospitalization rates, as did those with public insurance and nonwhite race/ethnicity. Passive smoke exposure, nonadherence to medications, and lack of follow-up after discharge were additional risks. Hospitalizations for ambulatory care sensitive conditions were less common in more complex patients. Patients receiving home visits, care coordination, chronic care-management, and continuity across settings had fewer preventable hospitalizations. **CONCLUSIONS:** There were a limited number of published studies. Measures for CMC and preventable hospitalizations were heterogeneous. Risk of bias was moderate due primarily to limited controlled experimental designs. Reductions in hospital use among CMC might be possible. Strategies should target primary drivers of preventable hospitalizations.

<http://www.ncbi.nlm.nih.gov/pubmed/25384492>

Donovan, L. A., Wakefield, C. E., Russell, V. and Cohn, R. J. (2015). "Hospital-based bereavement services following the death of a child: a mixed study review." Palliat Med 29(3): 193-210.

BACKGROUND: There has been a breadth of research on the grief experience of parents following the death of a child. However, the role and impact of hospital-based bereaved services remain unclear. **AIM:** To identify services offered to bereaved families in perinatal, neonatal, and pediatric hospital settings and summarize the psychosocial impact of these services and published recommendations for best practice hospital-based bereavement care. **DESIGN:** Systematic review of qualitative, quantitative, and mixed method studies guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist and methodological quality appraised in accordance with the Mixed Method Appraisal Tool. **DATA SOURCES:** MEDLINE, EMBASE, Cumulative Index to Nursing and Allied Health, and PsychINFO were searched to find studies describing hospital-based bereavement services/interventions for parents, siblings, and grandparents. **RESULTS:** In all, 14 qualitative, 6 quantitative, and 10 mixed method studies were identified. Nine descriptive articles were also included. Qualitatively, family members described feeling cared for and supported by staff, a reduction in sense of isolation, and improved coping and personal growth. Quantitatively, bereavement services have most effect for parents experiencing more complex mourning. It is recommended that bereavement services be theoretically driven and evidence based, offer continuity of care prior to and following the death of a child, and provide a range of interventions for the "whole family" and flexibility in service delivery. **CONCLUSIONS:** There is a role for transitional hospital-based services/interventions for families in the lead up to and following the death of a child. Further mixed method research is required to

inform best practice bereavement care guidelines in the perinatal, neonatal, and pediatric hospital settings.

<http://www.ncbi.nlm.nih.gov/pubmed/25395578>

Endo, K., Yonemoto, N. and Yamada, M. (2015). "Interventions for bereaved parents following a child's death: A systematic review." *Palliat Med*.

BACKGROUND: A child's death is one of the most stressful events that parents and siblings may experience. Interventions for bereaved families following a child's death have been examined over the last several decades. However, there is little high-quality evidence to support any rationale for determining optimal interventions for bereaved parents and siblings. AIM: This study objectives were to evaluate the efficacy of interventions for bereaved parents and siblings following a child's death, to collect empirical evidence of the quality of these intervention studies, and to identify methodological challenges. DESIGN: A systematic review of data from randomized controlled trials of interventions for parents or siblings bereaved after a child loss. DATA SOURCES: We searched MEDLINE (from 1949), PsycINFO (from 1806), and CINAHL (from 1806) databases for key terms and checked the reference lists of potentially relevant articles. RESULTS: We identified nine articles describing eight eligible trials from which we extracted data. The four types of intervention included support groups, counseling, psychotherapy, and crisis intervention. Most intervention trials showed some effect on participants in at least one outcome measure. However, we identified many severe methodological issues and outcome sets in these trials. CONCLUSION: Very little evidence of sufficient quality is available to confirm the effects of intervention measures on bereaved parents and siblings following a child's death. Well-designed randomized controlled trials are needed to improve our understanding of the efficacy and implementation of interventions targeting bereaved parents and siblings.

<http://www.ncbi.nlm.nih.gov/pubmed/25805741>

Friedrichsdorf, S. J., Postier, A., Dreyfus, J., Osenga, K., Sencer, S. and Wolfe, J. (2015). "Improved quality of life at end of life related to home-based palliative care in children with cancer." *J Palliat Med* 18(2): 143-150.

BACKGROUND: Nearly 2000 children die due to a malignancy in the United States annually. Emerging data suggest that home is the desired location of care for children with cancer at end of life. However, one obstacle to enrollment in a pediatric palliative care (PPC) home care program may be fear that distressing symptoms at end of life cannot be adequately managed outside the hospital. OBJECTIVE: To compare the symptom distress and quality-of-life experience for children who received concurrent end-of-life care from a PPC home care program (PPC/Oncology) with that of those who died without exposure to the PPC program (Oncology). METHODS: We conducted a retrospective survey study of a cohort of bereaved parents of children who died of cancer between 2002 and 2008 at a U.S. tertiary pediatric institution. RESULTS: Sixty bereaved parents were surveyed (50% PPC/Oncology). Prevalence of constipation and high distress from fatigue were more common in the PPC/Oncology group; other distressing symptoms were similar between groups, showing room for improvement. Children who received PPC/Oncology were significantly more likely to have fun (70% versus 45%), to experience events that added meaning to life (89% versus 63%), and to die at home (93% versus 20%). CONCLUSIONS: This is the first North American study to as-

sess outcomes among children with cancer who received concurrent oncology and palliative home care compared with those who received oncology care alone. Symptom distress experiences were similar in groups. However, children enrolled in a PPC home care program appear to have improved quality of life and are more likely to die at home.

<http://www.ncbi.nlm.nih.gov/pubmed/25401507>

Gaab, E. and Steinhorn, D. M. (2014). "Families' Views of Pediatric Palliative Aquatics: A Qualitative Study." Pain Manag Nurs.

Although pediatric palliative care policies and services have been developed, research in this area continues to lag. An integrated model of palliative care has been suggested by the American Academy of Pediatrics and includes complementary and alternative services aimed at improving the well-being of children and their families. The first-known pediatric palliative aquatics program (PPAP) in California uses several techniques to decrease pain and promote well-being through relaxation and interaction between patients, specialists, and family members. This study investigates the perceptions of family members of their children's experiences with a PPAP. Researchers from an outside institution conducted focus groups and interviews. Themes were extracted from the focus group transcripts using Braun and Clarke's method of inductive thematic analysis. Data were collected at the host site, local libraries, and participant homes. Participants were primary caregivers and siblings (n = 23) of children in a PPAP, an independent children's respite, transitional, and end-of-life care facility in California. The research described and drew implications from the diverse perceptions that family members expressed about the benefits of having a child in the PPAP, including sensory, physical, and social experiences. Although the PPAP aims to promote well-being through relaxation, several other benefits were expressed by family members of children going through the program, including pain relief.

<http://www.ncbi.nlm.nih.gov/pubmed/25547919>

Han, Y. J., Park, J. D., Lee, B., Choi, Y. H., Suh, D. I., Lim, B. C. and Chae, J. H. (2015). "Home mechanical ventilation in childhood-onset hereditary neuromuscular diseases: 13 years' experience at a single center in Korea." PLoS One 10(3): e0122346.

INTRODUCTION: Children with hereditary neuromuscular diseases (NMDs) are at a high risk of morbidity and mortality related to respiratory failure. The use of home mechanical ventilation (HMV) has saved the lives of many children with NMD but, due to a lack of studies, dependable guidelines are not available. We drew upon our experience to compare the various underlying NMDs and to evaluate HMV with regard to respiratory morbidity, the proper indications and timing for its use, and to develop a policy to improve the quality of home noninvasive ventilation (NIV). METHODS: We retrospectively analyzed the medical records of 57 children with childhood-onset hereditary NMDs in whom HMV was initiated between January 2000 and May 2013 at Seoul National University Children's Hospital. The degree of respiratory morbidity was estimated by the frequency and duration of hospitalizations caused by respiratory distress. RESULTS: The most common NMD was spinal muscular atrophy (SMA, n = 33). Emergent mechanical ventilation was initiated in 44% of the patients before the confirmed diagnosis, and the indicators of pre-HMV respiratory morbidity (e.g., extubation trials, hypoxia, hospitalizations, and intensive care unit stay) were greater in these patients than in others. The proportion of post-HMV hospitalizations (range, 0.00-0.52; median, 0.01) was

lower than that of pre-HMV hospitalizations (0.02-1.00; 0.99) ($P < 0.001$). Eight patients were able to maintain home NIV. The main causes of NIV failure were air leakage and a large amount of airway secretions. CONCLUSIONS: The application of HMV helped reduce respiratory morbidity in children with childhood-onset hereditary NMD. Patients with SMA type I can benefit from an early diagnosis and the timely application of HMV. The choice between invasive and noninvasive HMV should be based on the patient's age and NIV trial tolerance. Systematic follow-up guidelines provided by a multidisciplinary team are needed.

<http://www.ncbi.nlm.nih.gov/pubmed/25822836>

Holmstrom, R. (2015). "Enabling children with complex health needs to stay with their families in the community." *Nurs Child Young People* 27(1): 8-9.

'I HEARD someone ask a mum I work with recently what we do and she told them "they're my cheerleaders". When families say things like that, you realise it is worth getting up in the morning and coming to work,' says Aileen Crichton.

<http://www.ncbi.nlm.nih.gov/pubmed/25671739>

Horridge, K., Tennant, P. W., Balu, R. and Rankin, J. (2015). "Variation in health care for children and young people with cerebral palsies: a retrospective multicentre audit study." *Dev Med Child Neurol*.

AIM: To explore the provision and variations in care for children and young people with cerebral palsies (CP) registered with the population-based North of England Collaborative Cerebral Palsy Survey (NECCPS). METHOD: This is a retrospective multicentre record audit of 389 children with CP (220 males, 148 females, 21 no data; median age at time of audit 12y 3mo), born between 1995 and 2002. Data were collected on cranial magnetic resonance imaging (MRI), hip and spine surveillance and management, and pain presence and management. Variations over time and between the districts in the north of England (Northumberland, North and West Cumbria, North and South Tyneside, Newcastle-upon-Tyne, Gateshead, Sunderland, Durham, Darlington, Bishop Auckland, Hartlepool, Stockton-on-Tees, Middlesbrough, Redcar, and Cleveland), and by socio-economic status (SES) (estimated from the Index of Multiple Deprivation [IMD] 2004) were estimated by generalized estimating equations. RESULTS: There was significant variation between districts in access to MRI ($p < 0.001$), orthopaedic surgeons ($p = 0.005$), recording state of spine ($p < 0.001$), and discussions about pain ($p < 0.001$). Fifty-seven per cent (95% CI 52-62) had evidence of a reported MRI brain scan, the proportion of which increased over time ($p < 0.001$). Sixty-seven per cent (95% CI 62-71) had a discussion about pain recorded. Of those in pain, 87% (95% CI 80-93) had a pain management plan. The proportion with documented discussion about pain increased with increasing SES ($p = 0.04$). INTERPRETATION: The provision of care for children with CP in the north of England varies between districts. Internationally agreed, evidence-based standards are urgently needed to ensure more equitable health care and improved outcomes for all.

<http://www.ncbi.nlm.nih.gov/pubmed/25808699>

Jamorabo, D. S., Belani, C. P. and Martin, E. W. (2015). "Complex Chronic Conditions in Rhode Island's Pediatric Populace: Implications for Palliative and Hospice Services, 2000-2012." *J Palliat Med* 18(4): 350-357.

BACKGROUND: Pediatric patients with complex chronic conditions (CCC) can benefit from pediatric palliative and hospice care (PP/HC) services. PP/HC can be delivered in a variety of health care settings and for a multitude of conditions, but data on hospitalization patterns and on secondary illnesses in pediatric CCC patients remains scant. **OBJECTIVE:** The study objective was to describe mortality trends for Rhode Island resident children aged 0-17 years, along with the demographics, subtypes, sites of death, and comorbidities of those with CCC. **METHODS:** This was a retrospective cohort study using demographic, hospitalization, and clinical data from all Rhode Island Department of Health death certificates from 2000 to 2012. **RESULTS:** Among the 1422 Rhode Island children aged 0-17 years old who died from 2000 to 2012, CCCs accounted for 27% (279/1049) of medically related deaths and 62% (145/233) of such deaths after infancy. CCC deaths were more likely at home (OR 5.202, 95% CI 2.984-9.203, $p < 0.001$) and to have had a secondary cause of death documented (OR 3.032, 95% CI 2.259-4.067, $p < 0.001$) than were other medically related deaths. Infants with CCCs were more likely to die in an inpatient setting (OR 5.141, 95% CI 2.718-10.026, $p < 0.001$), whereas 1-17 year-olds with CCCs were more likely to die at home (OR 5.346, 95% CI 2.200-14.811, $p < 0.001$) or in an emergency department (OR 3.281, 95% CI 1.363-8.721, $p < 0.040$). **CONCLUSIONS:** CCCs constitute a significant proportion of medically related pediatric deaths in Rhode Island and are associated with both secondary comorbidities and death at home. Specialized, multidisciplinary services are warranted and PP/HC is crucial for patient and family support.

<http://www.ncbi.nlm.nih.gov/pubmed/25522161>

Ladas, E. J., Lin, M., Antillion, F., Rivas, S., Chantada, G., Cacciavillano, W., Ortiz, R., Stein, K., Castillo, L., Rocha, V., Fu, L., Rodriguez, H. and Kelly, K. M. (2014). "Improving our understanding of the use of traditional complementary/alternative medicine in children with cancer." Cancer.

BACKGROUND: Children with cancer in high-income and low-income countries often use traditional complementary/alternative medicine (TCAM). With efforts by the World Health Organization and international twinning programs improving access to conventional care for patients with childhood cancer, understanding the global use of TCAM is important because reliance on TCAM may affect time to presentation, adherence, and abandonment of care. In the current study, the authors describe the process and validation of an international survey documenting the use of TCAM among children with cancer. **METHODS:** The survey was designed to collect information on TCAM use and associated factors through both open-ended and close-ended questions. During the period between June 2012 and December 2013, the survey was administered to 300 children and adolescents (or their parents) who were undergoing treatment for cancer at a collaborating institution located in Mexico, Uruguay, and Nicaragua. **RESULTS:** For the majority of constructs, the survey demonstrated strong test-retest reliability as evidenced by an intraclass correlation of at least ≥ 0.79 in each of the participating countries. The survey demonstrated good internal consistency and reliability across countries (alpha range from .77 to .85 for the belief scale; and an alpha range from .60 to .86 for the cause scale) and convergent validity between TCAM beliefs and behavior constructs (adjusted correlation range, 0.35-0.60). **CONCLUSIONS:** The results of the current study demonstrate the successful development of a cross-cultural survey that produced results that were reliable and valid. These findings will aid investigators in providing guidelines

concerning TCAM, support the development of education and research priorities, and identify variables associated with TCAM that are region-specific. Cancer 2014. (c) 2014 American Cancer Society.

<http://www.ncbi.nlm.nih.gov/pubmed/25557324>

Miller, E. G., Frizzola, M. A., Levy, C. and Greenspan, J. S. (2015). "Recent experience establishing a new pediatric palliative care team." *J Pediatr* 166(1): 4-5.

<http://www.ncbi.nlm.nih.gov/pubmed/25527850>

Nakawesi, J., Kasirye, I., Kavuma, D., Muziru, B., Businge, A., Naluwoza, J., Kabunga, G., Karamagi, Y., Akankwasa, E., Odiit, M. and Mukasa, B. (2014). "Palliative care needs of HIV exposed and infected children admitted to the inpatient paediatric unit in Uganda." *Ecancermedalscience* 8: 489.

Paediatric palliative care is an emerging subspecialty that focuses on achieving the best possible quality of life for children with life-limiting conditions and also for their families. It is a response to the suffering and unique needs of such children. Globally there is limited documented data available on the palliative care needs of children with HIV. A retrospective review of data of all the HIV exposed and positive children who were admitted to the ward from January to December 2012 was done to document their palliative care needs. A total of 243 children were admitted to the ward during the stated period. Of these, 139 (57.2%) were female and 104 (42.8%) were male. Among them 131 (54%) were aged five years and below whereas 112 (46%) were above five years. Some of the identified palliative care needs documented included physical needs: pneumonia 46 (19%), severe acute malnutrition 38 (16%), mild and moderate acute malnutrition 23 (9.6%), and respiratory tract infections 22 (9.3%). Social needs: poor social support 21 (41%), financial instability 16 (31%), and child neglect 4 (8%). Psychological needs: antiretroviral treatment (ART) counselling 127 (36%), HIV counselling and testing for the child and family 63 (18%), adherence support 53 (15%), and others 11 (3%). Spiritual needs: discontinuing ART because of belief in spiritual healing 18 (81%), loss of hope because of severe ill health 1 (5%), and others 3 (14%). These results emphasise the need for palliative care in children with HIV even in the era of ART. The needs identified are in keeping with studies done elsewhere and are similar to the palliative care needs of children with other life-limiting illnesses such as cancer. CONCLUSION: HIV positive and exposed children plus their families have vast palliative care needs and a holistic approach is the key in their management.

<http://www.ncbi.nlm.nih.gov/pubmed/25624870>

Pestana Knight, E. M., Schiltz, N. K., Bakaki, P. M., Koroukian, S. M., Lhatoo, S. D. and Kaiboriboon, K. (2015). "Increasing utilization of pediatric epilepsy surgery in the United States between 1997 and 2009." *Epilepsia* 56(3): 375-381.

OBJECTIVE: To examine national trends of pediatric epilepsy surgery usage in the United States between 1997 and 2009. METHODS: We performed a serial cross-sectional study of pediatric epilepsy surgery using triennial data from the Kids' Inpatient Database from 1997 to 2009. The rates of epilepsy surgery for lobectomies, partial lobectomies, and hemispherectomies in each study year were calculated based on the number of prevalent epilepsy cases in the corresponding year. The age-race-sex adjusted rates of surgeries were also esti-

mated. Mann-Kendall trend test was used to test for changes in the rates of surgeries over time. Multivariable regression analysis was also performed to estimate the effect of time, age, race, and sex on the annual incidence of epilepsy surgery. RESULTS: The rates of pediatric epilepsy surgery increased significantly from 0.85 epilepsy surgeries per 1,000 children with epilepsy in 1997 to 1.44 epilepsy surgeries per 1,000 children with epilepsy in 2009. An increment in the rates of epilepsy surgeries was noted across all age groups, in boys and girls, all races, and all payer types. The rate of increase was lowest in blacks and in children with public insurance. The overall number of surgical cases for each study year was lower than 35% of children who were expected to have surgery, based on the estimates from the Connecticut Study of Epilepsy. SIGNIFICANCE: In contrast to adults, pediatric epilepsy surgery numbers have increased significantly in the past decade. However, epilepsy surgery remains an underutilized treatment for children with epilepsy. In addition, black children and those with public insurance continue to face disparities in the receipt of epilepsy surgery. <http://www.ncbi.nlm.nih.gov/pubmed/25630252>

Pettersen, R., Omerov, P., Steineck, G., Dyregrov, A., Titelman, D., Dyregrov, K. and Nyberg, U. (2014). "Suicide-Bereaved Siblings' Perception of Health Services." Death Stud: 1-9.

The authors investigated suicide-bereaved siblings' reported reasons for seeking or not seeking professional support, their reported satisfaction when receiving it, and their recommendations to health services when meeting suicide-bereaved siblings. Using qualitative content analysis of 18 interviews with suicide-bereaved siblings, the authors found that the perception of health services as being helpful was influenced by both the participants' and by the deceased siblings' experiences with health services. They conclude that the bereaved sibling's and the deceased sibling's unmet needs may generate negative attitudes toward health services, which reduces the likelihood of seeking professional help as well as medication acceptance in some cases.

<http://www.ncbi.nlm.nih.gov/pubmed/25517404>

Prior, M., McManus, M., White, P. and Davidson, L. (2014). "Measuring the "triple aim" in transition care: a systematic review." Pediatrics 134(6): e1648-1661.

BACKGROUND AND OBJECTIVES: Without adequate support, adolescents transitioning from the pediatric to the adult health care system are at increased risk for poor health outcomes. Numerous interventions attempt to improve this transition, yet few comprehensively evaluate efficacy. To advance evaluation methods and ultimately the quality of transition services, it is necessary to understand the current state of health care transition measurement. This study examines and categorizes transition measures by using the "Triple Aim" framework of experience of care, population health, and cost of care. METHODS: Ovid Medline and the Cumulative Index to Nursing and Allied Health Literature were searched for articles published between 1995 and 2013. Two reviewers independently screened studies and included those that evaluated the impact of a health care transition intervention. Measures were subsequently classified according to population health, experience of care, and costs of care. RESULTS: Of the 2282 studies initially identified, 33 met inclusion criteria. Population health measures were used in 27 studies, with disease-specific measures collected most frequently. Fifteen studies measured cost, most often service utilization. Eight studies measured experi-

ence of care, with satisfaction assessed most commonly. Only 3 studies examined all 3 domains of the "Triple Aim." Transition interventions described in the gray literature were not reviewed. CONCLUSIONS: Transition programs are inconsistently evaluated in terms of their impact on population health, patient experience, and cost. To demonstrate improvement in the transition from pediatric to adult health care, a more robust and consistent set of measures is needed.

<http://www.ncbi.nlm.nih.gov/pubmed/25422015>

Ramji, S., Saugstad, O. D. and Jain, A. (2015). "Current concepts of oxygen therapy in neonates." *Indian J Pediatr* 82(1): 46-52.

Use of high oxygen concentrations in treating neonatal illness has been challenged in the past few decades. In the face of evidence suggesting adverse outcomes (both clinical and biochemical) with use of high oxygen concentrations, the current guidelines appear to favour use of the lowest possible concentrations of oxygen for the shortest time to treat ill neonates. Current delivery room guidelines recommend using room air when initiating positive pressure ventilation during resuscitation. Targeting appropriate oxygen saturation when delivering supplemental oxygen, both in the delivery room and neonatal intensive care unit (NICU), are now the new emerging standards in neonatal care. Investments in good quality pulse oximeters and oxygen blenders in neonatal care units is now seen as critical to improve newborn survival.

<http://www.ncbi.nlm.nih.gov/pubmed/25326155>

Reid, T., O'Riordan, D. L., Mazzini, A., Bruno, K. A. and Pantilat, S. Z. (2014). "Pediatric palliative care consultation services in California hospitals." *J Palliat Med* 17(12): 1306-1310.

BACKGROUND: The American Academy of Pediatrics recommends that palliative care be available to seriously ill hospitalized children, yet little is known about how these services are structured. OBJECTIVE: The study's aim is to report the prevalence of pediatric palliative care services (PCS) and compare the structure of pediatric PCS to adult PCS within California hospitals. METHODS: We surveyed 377 hospitals to assess the prevalence, structure, and characteristics of pediatric and adult PCS. Hospitals were categorized as children's hospitals with a pediatric-only PCS, mixed hospitals with pediatric and adult PCS, and hospitals with adult-only PCS. RESULTS: All 8 children's hospitals in the state reported having a pediatric PCS, and 36 pediatric PCSs were in mixed hospitals. Mixed hospitals saw fewer ($p=0.0001$) children per year (mean=5.6, standard deviation [SD]=3.6) than pediatric-only PCSs (mean=168, SD=73). Pediatric-only PCSs treated more patients for noncancer-related illness (82.5%) than pediatric PCSs in mixed hospitals (34.5%, $p=0.03$) or adult-only PCSs (52.4%, $p=0.001$). All PCSs were universally available (100%) during weekday business hours and half were available during weekend business hours. Pediatric-only PCSs had a mean total full-time equivalent (FTE) of 1.9, which was not significantly different ($p=0.3$) from the total FTE for pediatric PCSs in mixed hospitals (mean=1.1, SD=1.4) or for adult-only PCSs (mean=2.7, SD=2.0). However, in mixed hospitals the adult PCS had a significantly higher ($p=0.005$) total FTE (mean=2.4, SD=1.3) than the pediatric PCS (mean=1.1, SD=1.4). CONCLUSION: All children's hospital and a few mixed hospitals offer pediatric PCS. Better understanding of the palliative care

needs of seriously ill children in mixed hospitals and assessment of the quality of care provided will help ensure that children seen in these hospitals receive necessary care.

<http://www.ncbi.nlm.nih.gov/pubmed/25299845>

Rodger, S., Woods, K. L., Bladen, C. L., Stringer, A., Vry, J., Gramsch, K., Kirschner, J., Thompson, R., Bushby, K. and Lochmuller, H. (2015). "Adult care for Duchenne muscular dystrophy in the UK." *J Neurol* 262(3): 629-641.

Survival in Duchenne muscular dystrophy (DMD) has increased in recent years due to iterative improvements in care. We describe the results of the CARE-NMD survey of care practices for adults with DMD in the UK in light of international consensus care guidelines. We also compare the UK experience of adult care with the care available to pediatric patients and adults in other European countries (Germany, Denmark, Bulgaria, Czech Republic, Hungary, and Poland). UK adults experience less comprehensive care compared to children in their access to specialized clinics, frequency of cardiac and respiratory assessments, and access to professional physiotherapy. Access to the latter is especially poor when compared to other European adult cohorts. Although the total number of nights in hospital (planned and unplanned admissions) is lower among UK adults than elsewhere in Western Europe, social inclusion lags behind other Western European countries. We observe that attendance at specialized clinic is associated with more frequent cardiac and respiratory assessments among adults, in line with international best practice. Attendance at such clinics in the UK, though comparable to other countries, is still far from universal. With an increasing adult population living with DMD, and cardiac and respiratory failure the leading causes of death in this population, we suggest the need for an urgent improvement in adult access to specialized clinics and to consistent, comprehensive best practice care.

<http://www.ncbi.nlm.nih.gov/pubmed/25536903>

Silbermann, M., Fink, R. M., Min, S. J., Mancuso, M. P., Brant, J., Hajjar, R., Al-Alfi, N., Baider, L., Turker, I., ElShamy, K., Ghayeb, I., Al-Jadiry, M., Khader, K., Kav, S., Charalambous, H., Uslu, R., Kebudi, R., Barsela, G., Kuruku, N., Mutafoglu, K., Ozalp-Senel, G., Oberman, A., Kislev, L., Khleif, M., Keoppi, N., Nestoros, S., Abdalla, R. F., Rassouli, M., Morag, A., Sabar, R., Nimri, O., Al-Qadire, M., Al-Khalaileh, M., Tayyem, M., Doumit, M., Punjwani, R., Rasheed, O., Fallatah, F., Can, G., Ahmed, J. and Strode, D. (2015). "Evaluating palliative care needs in Middle Eastern countries." *J Palliat Med* 18(1): 18-25.

BACKGROUND: Cancer incidence in Middle Eastern countries, most categorized as low- and middle-income, is predicted to double in the next 10 years, greater than in any other part of the world. While progress has been made in cancer diagnosis/treatment, much remains to be done to improve palliative care for the majority of patients with cancer who present with advanced disease. OBJECTIVE: To determine knowledge, beliefs, barriers, and resources regarding palliative care services in Middle Eastern countries and use findings to inform future educational and training activities. DESIGN: Descriptive survey. SETTING/SUBJECTS: Fifteen Middle Eastern countries; convenience sample of 776 nurses (44.3%), physicians (38.3%) and psychosocial, academic, and other health care professionals (17.4%) employed in varied settings. MEASUREMENTS: Palliative care needs assessment. RESULTS: Improved pain management services are key facilitators. Top barriers include lack of designated palliative care

beds/services, community awareness, staff training, access to hospice services, and personnel/time. The nonexistence of functioning home-based and hospice services leaves families/providers unable to honor patient wishes. Respondents were least satisfied with discussions around advance directives and wish to learn more about palliative care focusing on communication techniques. Populations requiring special consideration comprise: patients with ethnic diversity, language barriers, and low literacy; pediatric and young adults; and the elderly. CONCLUSIONS: The majority of Middle Eastern patients with cancer are treated in outlying regions; the community is pivotal and must be incorporated into future plans for developing palliative care services. Promoting palliative care education and certification for physicians and nurses is crucial; home-based and hospice services must be sustained.

<http://www.ncbi.nlm.nih.gov/pubmed/25302525>

Williams-Reade, J., Lamson, A. L., Knight, S. M., White, M. B., Ballard, S. M. and Desai, P. P. (2015). "Paediatric palliative care: a review of needs, obstacles and the future." *J Nurs Manag* 23(1): 4-14.

AIM: This literature review offers a response to the current paediatric palliative care literature that will punctuate the need for a framework (i.e. the three world view) that can serve as an evaluative lens for nurse managers who are in the planning or evaluative stages of paediatric palliative care programmes. BACKGROUND: The complexities in providing paediatric palliative care extend beyond clinical practices to operational policies and financial barriers that exist in the continuum of services for patients. EVALUATION: This article offers a review of the literature and a framework in order to view best clinical practices, operational/policy standards and financial feasibility when considering the development and sustainability of paediatric palliative care programmes. KEY ASPECTS: Fifty-four articles were selected as representative of the current state of the literature as it pertains to the three world view (i.e. clinical, operational and financial factors) involved in providing paediatric palliative care. CONCLUSION: In developing efficient paediatric palliative care services, clinical, operational and financial resources and barriers need to be identified and addressed. IMPLICATIONS FOR NURSING MANAGEMENT: Nursing management plays a crucial role in addressing the clinical, operational and financial needs and concerns that are grounded in paediatric palliative care literature.

<http://www.ncbi.nlm.nih.gov/pubmed/24168724>

Psychosocial and family issues

Akard, T. F. and Gilmer, M. J. (2014). "Invisible communities of dying children and their loved ones." Palliat Support Care: 1-3.

<http://www.ncbi.nlm.nih.gov/pubmed/25341671>

Bann, C. M., Abresch, R. T., Biesecker, B., Conway, K. C., Heatwole, C., Peay, H., Scal, P., Strober, J., Uzark, K., Wolff, J., Margolis, M., Blackwell, A., Street, N., Montesanti, A. and Bolen, J. (2015). "Measuring quality of life in muscular dystrophy." Neurology 84(10): 1034-1042.

OBJECTIVES: The objectives of this study were to develop a conceptual model of quality of life (QOL) in muscular dystrophies (MDs) and review existing QOL measures for use in the MD population. **METHODS:** Our model for QOL among individuals with MD was developed based on a modified Delphi process, literature review, and input from patients and patient advocacy organizations. Scales that have been used to measure QOL among patients with MD were identified through a literature review and evaluated using the COSMIN (Consensus-Based Standards for the Selection of Health Measurement Instruments) checklist. **RESULTS:** The Comprehensive Model of QOL in MD (CMQM) captures 3 broad domains of QOL (physical, psychological, and social), includes factors influencing self-reported QOL (disease-related factors, support/resources, and expectations/aspirations), and places these concepts within the context of the life course. The literature review identified 15 QOL scales (9 adult and 6 pediatric) that have been applied to patients with MD. Very few studies reported reliability data, and none included data on responsiveness of the measures to change in disease progression, a necessary psychometric property for measures included in treatment and intervention studies. No scales captured all QOL domains identified in the CMQM model. **CONCLUSIONS:** Additional scale development research is needed to enhance assessment of QOL for individuals with MD. Item banking and computerized adaptive assessment would be particularly beneficial by allowing the scale to be tailored to each individual, thereby minimizing respondent burden.

<http://www.ncbi.nlm.nih.gov/pubmed/25663223>

Bates, A. T. and Kearney, J. A. (2015). "Understanding death with limited experience in life: dying children's and adolescents' understanding of their own terminal illness and death." Curr Opin Support Palliat Care 9(1): 40-45.

PURPOSE OF REVIEW: An up-to-date summary of the literature on children's and adolescents' understanding of their own terminal illness and death. **RECENT FINDINGS:** Clinicians still find it difficult to speak with pediatric patients about death even though guidelines for facilitating communication on the topic exist. As a result, pediatric patients are less likely to develop a clear understanding of their illness and there is a disconnect between clinicians and parents about prognosis, even when clinicians have concluded there is no longer possibility for cure. Insufficient communication and poor understanding may increase the risk of patients feeling isolated, mistrustful and anxious, and deprive them of a role model who can communicate about painful issues or share difficult feelings. Despite these complexities,

young people often show remarkable resiliency in the face of death and want to get the most out of the remaining time they have. SUMMARY: In addition to these most recent findings, this review examines the challenges in researching this topic, obstacles to patients receiving information about prognosis, and how physical symptoms affect patients' ability to develop an understanding. It also reviews sources of insight into pediatric patients' understanding including the development of concepts of death, fears about their own death, legal interpretations of what patients understand, and how terminally ill young people continue to treasure life. It concludes by addressing ways clinicians can use the knowledge we have to communicate well with dying children and adolescents and their families.

<http://www.ncbi.nlm.nih.gov/pubmed/25581454>

Bergstraesser, E., Inglin, S., Hornung, R. and Landolt, M. A. (2015). "Dyadic coping of parents after the death of a child." *Death Stud* 39(3): 128-138.

This article explores the grief process of parents following the death of a child due to a life-limiting illness, putting particular focus on dyadic coping. Participants included 46 married parents (23 couples). A mixed-methods design was used with in-depth interviews and standardized questionnaires. All parents were interviewed separately. Aspects of common dyadic coping (e.g., sharing emotions or maintaining bonds to the child) helped them work through their grief as a couple but also individually. The authors conclude that dyadic coping plays an important role in grief work and adjustment to bereavement.

<http://www.ncbi.nlm.nih.gov/pubmed/25204680>

Brooten, D., Youngblut, J. M., Hannan, J., Caicedo, C., Roche, R. and Malkawi, F. (2015). "Infant and child deaths: Parent concerns about subsequent pregnancies." *J Am Assoc Nurse Pract*.

PURPOSE: Examine parents' concerns about subsequent pregnancies after experiencing an infant or child death (newborn to 18 years). DATA SOURCES: Thirty-nine semistructured parent (white, black, Hispanic) interviews 7 and 13 months post infant/child death conducted in English and/or Spanish, audio-recorded, transcribed, and content analyzed. Mothers' mean age was 31.8 years, fathers' was 39 years; 11 parents were white, 16 black, and 12 Hispanic. CONCLUSIONS: Themes common at 7 and 13 months: wanting more children; fear, anxiety, scared; praying to God/God's will; thinking about/keeping the infant's/child's memory and at 7 months importance of becoming pregnant for family members; and at 13 months happy about a new baby. Parents who lost a child in neonatal intensive care unit (NICU) commented more than those who lost a child in pediatric intensive care unit (PICU). Black and Hispanic parents commented more on praying to God and subsequent pregnancies being God's will than white parents. IMPLICATIONS FOR PRACTICE: Loss of an infant/child is a significant stressor on parents with documented negative physical and mental health outcomes. Assessing parents' subsequent pregnancy plans, recognizing the legitimacy of their fears about another pregnancy, discussing a plan should they encounter problems, and carefully monitoring the health of all parents who lost an infant/child is an essential practitioner role.

<http://www.ncbi.nlm.nih.gov/pubmed/25761229>

Butler, A., Hall, H., Willetts, G. and Copnell, B. (2015). "Parents' experiences of healthcare provider actions when their child dies: An integrative review of the literature." *J Spec Pediatr Nurs* 20(1): 5-20.

PURPOSE: To review, critique and synthesise current research studies that examine parental perceptions of healthcare provider actions during and after the death of a child. CONCLUSIONS: Five main themes were synthesised from the literature: staff attitudes and affect; follow-up care and ongoing contact; communication; attending to the parents; and continuity of care. PRACTICE IMPLICATIONS: This review helps to identify important aspects of paediatric end-of-life care as recognised by parents, with the intention of placing the family at the centre of any future end-of-life care education or policy/protocol development.

<http://www.ncbi.nlm.nih.gov/pubmed/25443391>

Campbell-Jackson, L., Bezance, J. and Horsch, A. (2014). "'A renewed sense of purpose': Mothers' and fathers' experience of having a child following a recent stillbirth." *BMC Pregnancy Childbirth* 14(1): 423.

Background: Most research has focused on mothers' inverted question mark experiences of perinatal loss itself or on the subsequent pregnancy, whereas little attention has been paid to both parents' inverted question mark experiences of having a child following late perinatal loss and the experience of parenting this child. The current study therefore explored mothers' inverted question mark and fathers' experiences of becoming a parent to a child born after a recent stillbirth, covering the period of the second pregnancy and up to two years after the birth of the next baby. Method: In depth interviews were conducted with 7 couples (14 participants). Couples were eligible if they previously had a stillbirth (after 24 weeks of gestation) and subsequently had another child (their first live baby) who was now under the age of 2 years. Couples who had more than one child after experiencing a stillbirth and those who were not fluent in English were excluded. Qualitative analysis of the interview data was conducted using Interpretive Phenomenological Analysis. Results: Five superordinate themes emerged from the data: Living with uncertainty; Coping with uncertainty; Relationship with the next child; The continuing grief process; Identity as a parent. Overall, fathers' experiences were similar to those of mothers', including high levels of anxiety and guilt during the subsequent pregnancy and after the child was born. Coping strategies to address these were identified. Differences between mothers and fathers regarding the grief process during the subsequent pregnancy and after their second child was born were identified. Despite difficulties with bonding during pregnancy and at the time when the baby was born, parents' perceptions of their relationship with their subsequent child were positive. Conclusions: Findings highlight the importance of tailoring support systems not only according to mothers' but also to fathers' needs. Parents' inverted question mark, and particularly fathers', reported lack of opportunities for grieving as well as the high level of anxiety of both parents about their baby's wellbeing during pregnancy and after birth implies a need for structured support. Difficulties experienced in bonding with the subsequent child during pregnancy and once the child is born need to be normalised.

<http://www.ncbi.nlm.nih.gov/pubmed/25522655>

Christiansen, D. M., Olf, M. and Elklit, A. (2014). "Parents bereaved by infant death: sex differences and moderation in PTSD, attachment, coping and social support." Gen Hosp Psychiatry 36(6): 655-661.

OBJECTIVE: Parents bereaved by infant death experience a wide range of symptomatology, including posttraumatic stress disorder (PTSD) that may persist for years after the loss. Little research has been conducted on PTSD in fathers who have lost an infant. Mothers report most symptoms to a greater extent than fathers, but not much is known about other sex differences following infant death. METHOD: The present cross-sectional study examined sex differences in PTSD and sex differences in the relationship between PTSD severity and related variables. Subjects were 361 mothers and 273 fathers who had lost an infant either late in pregnancy, during birth or in the first year of life. Participants filled out questionnaires between 1.2 months and 18 years after the loss (M = 3.4 years). RESULTS: Mothers reported significantly more PTSD symptoms, attachment anxiety, emotion-focused coping and feeling let down, but significantly lower levels of attachment avoidance than fathers. Attachment anxiety, attachment avoidance and emotion-focused coping were significantly more strongly associated with PTSD severity in mothers than fathers, but only when examined alone. When all variables and time since the loss were examined together, there were no longer any significant moderation effects of sex. CONCLUSIONS: Persistent posttraumatic symptomatology exists in both mothers and fathers long after the loss. There are several sex differences in severity and correlates of PTSD, and a few moderation effects were identified for attachment and emotion-focused coping. Overall, more similarities than differences were found between mothers and fathers in the associations between PTSD and covariates.

<http://www.ncbi.nlm.nih.gov/pubmed/25218784>

Cipolletta, S., Marchesin, V. and Benini, F. (2015). "Family Functioning as a Constituent Aspect of a Child's Chronic Illness." J Pediatr Nurs.

This study explored how family functioning may contribute to trace a child's illness trajectory. We conducted semi-structured interviews with 33 parents of children in care at a hospice in northern Italy. We also examined the medical records of the children, and interviewed the physician who cared for them. Data analysis was based on the grounded theory approach. Different illness progressions corresponded to the different ways with which families experienced the illness: possibility, focus on illness, denial, and anger. Clinical interventions should involve the whole family and take into account their role in the construction of illness trajectories.

<http://www.ncbi.nlm.nih.gov/pubmed/25682020>

Coad, J., Kaur, J., Ashley, N., Owens, C., Hunt, A., Chambers, L. and Brown, E. (2015). "Exploring the perceived met and unmet need of life-limited children, young people and families." J Pediatr Nurs 30(1): 45-53.

This article presents an original study commissioned by the UK charity, Together for Short Lives which explored children and young people up to 25 years of age with life-threatening/limiting conditions and their families. Using Appreciative Inquiry and framework analysis, qualitative work sought to explore perceived met and unmet needs of services and care. Fifty-one families were interviewed from one UK area, 18 of which were children/young

people up to 25 years old. Findings indicated that children and their families felt medical/nursing needs were well met but provision was needed for broader financial, social and emotional support alongside more responsive specialist therapies.

<http://www.ncbi.nlm.nih.gov/pubmed/25301028>

Cohen, O. and Katz, M. (2015). "Grief and growth of bereaved siblings as related to attachment style and flexibility." *Death Stud* 39(3): 158-164.

This study examined the relationship between attachment style, coping flexibility, military/non-military cause of death, levels of grief reactions and posttraumatic growth (PTG), in 150 bereaved adult siblings in Israel. Insecurely attached participants, 72% of the sample, reported more grief and less PTG than did securely attached ones. Highly avoidant individuals exhibited the least amount of PTG. Securely attached siblings were more flexible and flexibly coping participants reported less grief and higher PTG. Cause of death was not related to grief and PTG. Discussion of these findings yields conditions enabling PTG after a sibling loss.

<http://www.ncbi.nlm.nih.gov/pubmed/25719968>

Compas, B. E., Bemis, H., Gerhardt, C. A., Dunn, M. J., Rodriguez, E. M., Desjardins, L., Preacher, K. J., Manring, S. and Vannatta, K. (2015). "Mothers and Fathers Coping With Their Children's Cancer: Individual and Interpersonal Processes." *Health Psychol.*

Objective: To examine individual and interpersonal processes of coping and emotional distress in a sample of mothers and fathers of children with recently diagnosed cancer. Method: A sample of 317 mothers and 166 fathers of 334 children were recruited near the time of the child's cancer diagnosis or relapse (M = 1.4 months, SD = 1.2). Mothers and fathers completed standardized measures of coping and depressive symptoms. Results: Analyses of individual coping responses revealed that, for both mothers and fathers, primary control coping (e.g., problem solving, emotional modulation) and secondary control coping (e.g., acceptance, cognitive reappraisal) were associated with lower depressive symptoms. Interpersonal analyses of coping and distress indicated that mothers' and fathers' coping as well as depressive symptoms were significantly correlated. Actor-partner interdependence model analyses indicated that mothers' coping was associated with fathers' depressive symptoms. Significant interactions also suggested that mothers' secondary control coping may have a compensatory effect against fathers' use of disengagement coping, both for themselves and their husbands. Conclusion: Mothers' and fathers' adaptation to a child's cancer diagnosis and treatment are characterized by both individual and interpersonal processes, with secondary control coping playing a central role in both of these processes. Implications for interventions to enhance effective coping for parents of children with cancer are highlighted.

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<http://www.ncbi.nlm.nih.gov/pubmed/25622077>

Eskola, K., Bergstraesser, E., Zimmermann, K. and Cignacco, E. (2015). "Paediatric end-of-life care in the home care setting (PELICAN HOME)--a mixed methods study protocol." *J Adv Nurs* 71(1): 204-213.

AIMS: (a) To explore parental experiences and needs during their child's end-of-life care at home; (b) to explore patient's characteristics and current provision of paediatric end-of-life

care in the home care setting in Switzerland; and (c) to determine influencing system factors impacting end-of-life care at home. **BACKGROUND:** Parental experiences/needs and paediatric end-of-life care services in the home care setting are influenced by national healthcare policy, determinants of the family and the individual patient. In Switzerland, there is a lack of information about the provision of paediatric end-of-life care at home and related parent's experiences/needs. **DESIGN:** Sub-study of the nationwide multicenter study 'Paediatric End-of-Life CARE Needs in Switzerland' using a concurrent qualitative embedded mixed methods design. **METHODS:** Data will be collected from January-May 2014 through community care organizations and children's hospitals. The study includes approximately 40-50 families whose child (0-18 years) died in the years 2011-2012 due to a cardiological, neurological or oncological condition and spent at least 21 days at home during the last 4 weeks of life. Qualitative data will be collected through semi-structured interviews with parents and analysed by 'thematic analysis'. Quantitative data about patient's characteristics will be obtained from patient's medical charts and parental experiences/needs through the parental questionnaire. Appropriate descriptive and inference statistical methods will be used for data analysis. **DISCUSSION:** This study will provide comprehensive basic information about parental needs and patient characteristics for the provision of paediatric end-of-life care and may promote the development of family-centred paediatric end-of-life care services at home. **STUDY REGISTRATION:** The PELICAN-study is registered in the database of Clinical Trial gov. Study ID-number: NCT 01983852.

<http://www.ncbi.nlm.nih.gov/pubmed/24909918>

Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J., Miller, V. A., Morrison, W. E., Munson, D., Kang, T. I. and Hinds, P. S. (2015). "Good-parent beliefs of parents of seriously ill children." *JAMA Pediatr* 169(1): 39-47.

IMPORTANCE: Parents' beliefs about what they need to do to be a good parent when their children are seriously ill influence their medical decisions, and better understanding of these beliefs may improve decision support. **OBJECTIVE:** To assess parents' perceptions regarding the relative importance of 12 good-parent attributes. **DESIGN, SETTING, AND PARTICIPANTS:** A cross-sectional, discrete-choice experiment was conducted at a children's hospital. Participants included 200 parents of children with serious illness. **MAIN OUTCOMES AND MEASURES:** Ratings of 12 good-parent attributes, with subsequent use of latent class analysis to identify groups of parents with similar ratings of attributes, and ascertainment of whether membership in a particular group was associated with demographic or clinical characteristics. **RESULTS:** The highest-ranked good-parent attribute was making sure that my child feels loved, followed by focusing on my child's health, making informed medical care decisions, and advocating for my child with medical staff. We identified 4 groups of parents with similar patterns of good-parent-attribute ratings, which we labeled as: child feels loved (n=68), child's health (n=56), advocacy and informed (n=55), and spiritual well-being (n=21). Compared with the other groups, the child's health group reported more financial difficulties, was less educated, and had a higher proportion of children with new complex, chronic conditions. **CONCLUSIONS AND RELEVANCE:** Parents endorse a broad range of beliefs that represent what they perceive they should do to be a good parent for their seriously ill child. Common patterns of how parents prioritize these attributes exist, suggesting future research to better understand the origins and development of good-parent beliefs among these parents. More important, engaging parents individually regarding what they perceive to be the

core duties they must fulfill to be a good parent may enable more customized and effective decision support.

<http://www.ncbi.nlm.nih.gov/pubmed/25419676>

Forster, E. M. and Windsor, C. (2014). "Speaking to the deceased child: Australian health professional perspectives in paediatric end-of-life care." *Int J Palliat Nurs* 20(10): 502-508.

Supporting a dying child and family surrounding the child's death is one of the most significant and challenging roles undertaken by health professionals in paediatric end-of-life care. An Australian study of parent and health-professional constructions of meanings around post-mortem care and communication revealed the practice of health professionals speaking to a child after death. This practice conveyed respect for the personhood of the deceased child, recognised the presence of the deceased child, and assisted in involving parents in their child's post-mortem care. Such findings illuminate an area of end-of-life-care practice that is not often addressed. Talking to a deceased child appeared to be a socially symbolic practice that may promote a continued bond between parent and child.

<http://www.ncbi.nlm.nih.gov/pubmed/25350216>

Furco, P., McCrackin, F. and Peaks, R. (2015). "Leukemia in children: getting back to school, part 2." *NASN Sch Nurse* 30(2): 119-123.

<http://www.ncbi.nlm.nih.gov/pubmed/25816443>

Graziano, S., Rossi, A., Spano, B., Petrocchi, M., Biondi, G. and Ammaniti, M. (2015). "Comparison of psychological functioning in children and their mothers living through a life-threatening and nonlife-threatening chronic disease: A pilot study." *J Child Health Care*.

Childhood chronic illness is a potential source of distress and can be a traumatic experience both for the child and for the family. Several studies highlighted the importance of integrating psychosocial care and standard medical practice in the child's care. The current pilot study is the first investigation that compared distress in children and their mothers living through a life-threatening illness (cancer) and a nonlife-threatening (juvenile rheumatoid arthritis) chronic disease. Findings show that there are differences in the psychological functioning in children with respect to age. Moreover, the presence of posttraumatic stress symptoms in mothers of children with cancer seems to be a possible key to understanding the psychological response in this specific population.

<http://www.ncbi.nlm.nih.gov/pubmed/25561695>

Greeff, A. P., Vansteenwegen, A. and Geldhof, A. (2014). "Resilience in families with a child with cancer." *Pediatr Hematol Oncol* 31(7): 670-679.

The aim of this study was to identify and explore resilience factors associated with family adaption after a child had been diagnosed with cancer. Using a cross-sectional survey research design, parents (n = 26), and children (n = 25) from the same families independently completed six self-report questionnaires, as well as responded to an open-ended question about those qualities that helped their family through the period following the diagnosis.

The most significant results came from the children's data. According to these results, connectedness within the family, the experience of control over life events, family routines, positive, and supportive communication, redefinition of crisis situations, and lastly, a passive appraisal of crisis situations, were positively linked to better family adaptation. The identified factors should be strengthened and developed in families finding themselves in a similar situation.

<http://www.ncbi.nlm.nih.gov/pubmed/24851714>

Havermans, T., Tack, J., Vertommen, A., Proesmans, M. and de Boeck, K. (2015). "Breaking bad news, the diagnosis of cystic fibrosis in childhood." *J Cyst Fibros.*

BACKGROUND: The day parents are told their child has cystic fibrosis (CF) is imprinted in their memory. Parents often show strong emotions (e.g. shock, anxiety); they need to cope with bad news and restructure their lives taking into account CF. AIMS: The aims of this study are (1) to explore how parents recall circumstances of the CF diagnosis and the information they received and (2) to investigate their current coping styles. METHODS: Parents (n=38) of 20 children (diagnosed during the past 5years) were interviewed using a semi-structured interview. Coping was assessed using the Utrecht Coping List. The association between coping and time since diagnosis/severity of illness was investigated. RESULTS: Fifteen parents first heard the term 'CF' from their local pediatrician or GP. All were informed in detail by the CF specialist. All parents recalled specifics about the information, the attitude of the doctor, their thoughts and emotions. Most parents were satisfied with the content and manner in which they had received information. Nineteen appreciated the doctor showing some emotions during the talks. One couple criticized the doctor for not showing emotions. Parents reported higher use (than normative scores) of the active coping style 'social support seeking' and the accommodative coping styles 'palliative reaction pattern' and 'comforting cognitions'. Perception of severity of illness was associated with higher scores on palliative coping. CONCLUSIONS: This study shows the importance of physicians and CF teams to tailor the way of providing bad news to parents' needs and preferences. It is important to help and encourage parents to use active or accommodative coping strategies. The diagnosis is the starting point of a long-term relationship. 'Doing things well from the start' helps families to learn to live with CF and treatment.

<http://www.ncbi.nlm.nih.gov/pubmed/25563520>

Holston, J. T. (2015). "Supporting families in neonatal loss: relationship and faith key to comfort." *J Christ Nurs* 32(1): 18-25.

Around 20,000 neonatal deaths occur each year, many from congenital heart defects such as hypoplastic left heart syndrome. Nurses are on the frontline of caring for families experiencing neonatal loss. Careful spiritual and cultural assessment, attention to beliefs, focusing on relationship, and helping families create legacy can assist with grieving and making meaning out of loss.

<http://www.ncbi.nlm.nih.gov/pubmed/25585464>

Hutti, M. H., Armstrong, D. S., Myers, J. A. and Hall, L. A. (2015). "Grief intensity, psychological well-being, and the intimate partner relationship in the subsequent pregnancy after a perinatal loss." *J Obstet Gynecol Neonatal Nurs* 44(1): 42-50.

OBJECTIVE: To examine the construct validity of the Perinatal Grief Intensity Scale (PGIS) and the associations of grief intensity with psychological well-being and the quality of intimate partner relationships of women in the subsequent pregnancy after perinatal loss. The consequences of intense grief due to perinatal loss may include significant couple relationship issues, depression, anxiety, and post-traumatic stress that may extend into the subsequent healthy pregnancy. DESIGN AND SETTING: A correlational, descriptive research design was used to collect survey data in this cross-sectional, web-based study. PARTICIPANTS: Participants were 227 currently pregnant women who experienced perinatal loss in their immediate past pregnancies. METHODS: Instruments included the Pregnancy Outcome Questionnaire (pregnancy-specific anxiety), Impact of Event Scale (post-traumatic stress), Center for Epidemiologic Studies-Depression Scale (depression symptoms), the Autonomy and Relatedness Inventory (quality of the intimate partner relationship), and the Perinatal Grief Intensity Scale (perinatal grief intensity). RESULTS: As hypothesized, greater grief intensity was associated with higher pregnancy-specific anxiety, depression symptoms, and post-traumatic stress as well as poorer quality of the intimate partner relationship. CONCLUSIONS: Support for the construct validity of the PGIS was demonstrated by its significant associations in the expected directions with pregnancy-specific anxiety, depression symptoms, post-traumatic stress, and the quality of the intimate partner relationship. The scale may be useful to health care providers in identifying mothers in need of follow-up for intense grief and other clinically relevant symptoms after perinatal loss.

<http://www.ncbi.nlm.nih.gov/pubmed/25782190>

Ito, Y., Okuyama, T., Ito, Y., Kamei, M., Nakaguchi, T., Sugano, K., Kubota, Y., Sakamoto, N., Saitoh, S. and Akechi, T. (2015). "Good death for children with cancer: a qualitative study." *Jpn J Clin Oncol*.

OBJECTIVE: This study aims to explore the characteristics of a good death for children with cancer. METHODS: A total of 10 pediatric cancer survivors, 10 bereaved family members and 20 medical professionals participated in in-depth interviews. Qualitative content analysis was performed on the transcribed data obtained from semi-structured interviews. RESULTS: Thirteen characteristics including unique and specific for children of a good death were identified: (i) sufficient opportunities to play freely, (ii) peer supporters, (iii) continued access to the patient's usual activities and relationships, (iv) assurance of privacy, (v) respect for the patient's decisions and preferences, (vi) a sense that others acknowledge and respect the patient's childhood, (vii) comfort care to minimize distressing symptoms, (viii) hope, (ix) not aware of the patient's own impending death, (x) constant dignity, (xi) strong family relationships, (xii) no sense of being a burden to family members and (xiii) good relationships with medical staffs. CONCLUSIONS: This study identifies important characteristics of a good death for children with cancer. These findings may help medical staffs provide optimal care for children with cancer and their families, enabling them to achieve a good death.

<http://www.ncbi.nlm.nih.gov/pubmed/25628351>

Jacobs, S., Perez, J., Cheng, Y. I., Sill, A., Wang, J. and Lyon, M. E. (2015). "Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer." Pediatr Blood Cancer 62(4): 710-714.

BACKGROUND: Little is known about how well family members accurately represent adolescents when making EOL decisions on their behalf. This study reports on surveys given to adolescents with cancer and their parents as part of a larger study facilitating advanced care discussions, as well as the results of a survey for health care providers. PROCEDURE: Trained facilitators administered surveys orally to adolescents and families in the intervention arm of the FAmily CEntered Advance Care Planning (ACP) for Teens with Cancer (FACE-TC) study. In addition, a post-hoc survey was sent to oncology providers. RESULTS: Seventeen adolescent/family dyads completed this survey. Seventy five percent of adolescents believed it was appropriate to discuss EOL decisions early and only 12% were not comfortable discussing death. Most preferred to be at home if dying. There were substantial areas of congruence between adolescents and their surrogates, but lower agreement on the importance of dying a natural death, dying at home and "wanting to know if I were dying." Among providers, 83% felt their patients' participation in the study was helpful to the patients and 78% felt it was helpful to them as providers. CONCLUSIONS: Adolescents with cancer were comfortable discussing EOL, and the majority preferred to talk about EOL issues before they are facing EOL. There were substantive areas of agreement between adolescents and their surrogates, but important facets of adolescents' EOL wishes were not known by their families, reinforcing the importance of eliciting individual preferences and engaging dyads so parents can understand their children's wishes. *Pediatr Blood Cancer* 2015;62:710-714. (c) 2014 Wiley Periodicals, Inc.

<http://www.ncbi.nlm.nih.gov/pubmed/25545105>

Jalmsell, L., Kontio, T., Stein, M., Henter, J. I. and Kreicbergs, U. (2015). "On the Child's Own Initiative: Parents Communicate with Their Dying Child About Death." Death Stud 39(2): 111-117.

Open and honest communication has been identified as an important factor in providing good palliative care. However, there is no easy solution to if, when, and how parents and a dying child should communicate about death. This article reports how bereaved parents communicated about death with their child, dying from a malignancy. Communication was often initiated by the child and included communication through narratives such as fairy tales and movies and talking more directly about death itself. Parents also reported that their child prepared for death by giving instructions about his or her grave or funeral and giving away toys.

<http://www.ncbi.nlm.nih.gov/pubmed/25153166>

Jonas-Simpson, C., Steele, R., Granek, L., Davies, B. and O'Leary, J. (2014). "Always With Me: Understanding Experiences of Bereaved Children Whose Baby Sibling Died." Death Stud: 1-10.

An arts-based qualitative method was used to explore the experiences of children's bereavement after a baby sibling's death, in the context of their family and school life. Data were collected during in-depth interviews with 9 bereaved children and 5 parents from 4 Ca-

nadian families and analyzed. A central process, evolving sibling relationship over the years, and a pattern of vulnerability/resilience, ran through all four themes, which reflected ideas of connection, impact of parental grief, disenfranchisement and growth. Findings indicated that home and school are critical to children in creating safe spaces for expressing the evolving nature of infant sibling bereavement.

<http://www.ncbi.nlm.nih.gov/pubmed/25551421>

Kapoor, S., Bhayana, S., Singh, A. and Kishore, J. (2014). "Co-morbidities leading to mortality or hospitalization in children with Down syndrome and its effect on the quality of life of their parents." *Indian J Pediatr* 81(12): 1302-1306.

OBJECTIVE: To study factors leading to mortality or hospitalization in children with Down syndrome and its effect on the quality of life of their parents. METHODS: The study was retrospective questionnaire based study conducted over 2 mo period at a genetic outpatient setting of a teaching medical college hospital. Seventy children with suggestive phenotype and confirmed Trisomy 21 on karyotyping were included. An essential criterion was a reasonable understanding of the language to construct history. The primary outcome variable evaluated was the co-morbidity in these children which led to either hospitalization or mortality. Pretested and validated questionnaire was given to parents/primary caregiver and data was constructed with help of previous hospital records or from verbal autopsy in patients who had lost all papers. RESULTS: The mean age of Down syndrome (DS) patients in study group was 5.09 +/- 2.5 y. All cases were diagnosed postnatally at a mean age of 5 y. The major reasons for hospitalization were congenital heart disease (cyanotic/acyanotic), multiple episodes of pneumonia and wheeze associated with lower respiratory infection. Cardiovascular failure was the major reason for mortality. Majority of parents in the study (57.5 %) agreed that there were changes requiring adaptation after the birth of a DS baby while 22.5 % reported this effort to cost them heavily and 3 % quoted that this had changed the life drastically. CONCLUSIONS: Cardiorespiratory system is major cause of morbidity/mortality in cases with DS. Majority of parents accepted the challenge of rearing a DS child but with adaptation.

<http://www.ncbi.nlm.nih.gov/pubmed/24820231>

McCann, D., Bull, R. and Winzenberg, T. (2015). "Sleep deprivation in parents caring for children with complex needs at home: a mixed methods systematic review." *J Fam Nurs* 21(1): 86-118.

A significant number of children with a range of complex conditions and health care needs are being cared for by parents in the home environment. This mixed methods systematic review aimed to determine the amount of sleep obtained by these parents and the extent to which the child-related overnight health or care needs affected parental sleep experience and daily functioning. Summary statistics were not able to be determined due to the heterogeneity of included studies, but the common themes that emerged are that parents of children with complex needs experience sleep deprivation that can be both relentless and draining and affects the parents themselves and their relationships. The degree of sleep deprivation varies by diagnosis, but a key contributing factor is the need for parents to be vigilant at night. Of particular importance to health care professionals is the inadequate overnight support provided to parents of children with complex needs, potentially placing these parents at

risk of poorer health outcomes associated with sleep deprivation and disturbance. This needs to be addressed to enable parents to remain well and continue to provide the care that their child and family require.

<http://www.ncbi.nlm.nih.gov/pubmed/25527511>

McNeil, S. B. (2015). "Spirituality in Adolescents and Young Adults With Cancer: A Review of Literature." *J Pediatr Oncol Nurs*.

PURPOSE: Spirituality and religion have been found to have a positive impact on adults with cancer, but these concepts have not been well examined in adolescents and young adults (AYA) with cancer. AYA often question and struggle with their religious and spiritual beliefs, so it is not clear if spirituality and religion have the same positive impact on this age group. The purpose of this review of literature was to examine the research that has been conducted in spirituality in AYA with cancer. **METHODS:** The review covered the years from 1980 to present. The terms cancer, adolescents, and young adults as well as the phrases spirit* and relig* were used to capture the different variations of words. Nine articles were found that explored spirituality and religiosity in AYA with cancer. **RESULTS:** This review highlighted the need for clarifying the terms used in describing the concept. This lack of continuity in terms makes it difficult to compare the studies. The methods used to measure spirituality are varied. **IMPLICATIONS FOR PRACTICE:** Pediatric oncology nurses need to be sensitive to the spiritual needs of their patients. This can be accomplished by keeping an open line of communication and ensuring uninterrupted time to pray or read scriptures. Because of the variety of ways to express spirituality, the important first step is to ask what spirituality means to them.

<http://www.ncbi.nlm.nih.gov/pubmed/25637188>

Melin-Johansson, C., Axelsson, I., Jonsson Grundberg, M. and Hallqvist, F. (2014). "When a child dies: parents' experiences of palliative care-an integrative literature review." *J Pediatr Nurs* 29(6): 660-669.

The aim of this integrative review was to increase knowledge about parents' experiences of palliative care when their child is dying or has died due to illness using Whitemore and Knaf (2005) analysis process. Computerized databases were used to search the literature. Nine papers met the inclusion criteria. The analysis resulted in five categories: genuine communication, sincere relationships, respect as an expert, and alleviation of suffering and need of support, including 15 subcategories. Health professionals need education to provide high-quality pediatric palliative care. They especially need training concerning existential issues, and further studies need to be performed.

<http://www.ncbi.nlm.nih.gov/pubmed/25038375>

Rosenberg, A. R., Postier, A., Osenga, K., Kreicbergs, U., Neville, B., Dussel, V. and Wolfe, J. (2015). "Long-term psychosocial outcomes among bereaved siblings of children with cancer." *J Pain Symptom Manage* 49(1): 55-65.

CONTEXT: The death of a child from cancer affects the entire family. Little is known about the long-term psychosocial outcomes of bereaved siblings. **OBJECTIVES:** To describe 1) the prevalence of risky health behaviors, psychological distress, and social support among be-

reaved siblings and 2) potentially modifiable factors associated with poor outcomes. METHODS: Bereaved siblings were eligible for this dual-center, cross-sectional, survey-based study if they were 16 years or older and their parents had enrolled in one of three prior studies about caring for children with cancer at the end of life. Linear regression models identified associations between personal perspectives before, during, and after the family's cancer experience and outcomes (health behaviors, psychological distress, and social support). RESULTS: Fifty-eight siblings completed surveys (62% response rate). They were approximately 12 years bereaved, with a mean age of 26 years at the time of the survey (SD 7.8). Anxiety, depression, and illicit substance use increased during the year after their brother/sister's death but then returned to baseline. Siblings who reported dissatisfaction with communication, poor preparation for death, missed opportunities to say goodbye, and/or a perceived negative impact of the cancer experience on relationships tended to have higher distress and lower social support scores ($P < 0.001-0.031$). Almost all siblings reported that their loss still affected them; half stated that the experience impacted current educational and career goals. CONCLUSION: How siblings experience the death of a child with cancer may impact their long-term psychosocial well-being. Sibling-directed communication and concurrent supportive care during the cancer experience and the year after the sibling death may mitigate poor long-term outcomes.

<http://www.ncbi.nlm.nih.gov/pubmed/24880001>

Santos, S., Crespo, C., Canavarro, M. C. and Kazak, A. E. (2015). "Family Rituals and Quality of Life in Children With Cancer and Their Parents: The Role of Family Cohesion and Hope." *J Pediatr Psychol*.

OBJECTIVE: Family rituals are associated with adaptive functioning in pediatric illness, including quality of life (QoL). This article explores the role of family cohesion and hope as mediators of this association in children with cancer and their parents. METHODS: Portuguese children with cancer ($N = 389$), on- and off-treatment, and one of their parents completed self-report measures. Structural equation modeling was used to examine direct and indirect links between family rituals and QoL. RESULTS: When children and parents reported higher levels of family rituals, they also reported more family cohesion and hope, which were linked to better QoL. At the dyadic level, children's QoL was related to parents' family rituals through the child's family cohesion. This model was valid across child's age-group, treatment status, and socioeconomic status. CONCLUSIONS: Family rituals are important in promoting QoL in pediatric cancer via family cohesion and hope individually and via family cohesion in terms of parent-child interactions.

<http://www.ncbi.nlm.nih.gov/pubmed/25775914>

van der Geest, I. M., van den Heuvel-Eibrink, M. M., Falkenburg, N., Michiels, E. M., van Vliet, L., Pieters, R. and Darlington, A. S. (2015). "Parents' Faith and Hope during the Pediatric Palliative Phase and the Association with Long-Term Parental Adjustment." *J Palliat Med* 18(5): 402-407.

BACKGROUND: The loss of a child is associated with an increased risk for developing psychological problems. However, studies investigating the impact of parents' faith and hope for a cure during the palliative phase on long-term parental psychological functioning are lim-

ited. OBJECTIVE: The study's objective was to explore the role of faith and hope as a source of coping and indicator of long-term parental adjustment. METHODS: Eighty-nine parents of 57 children who died of cancer completed questionnaires retrospectively, exploring faith, hope, and sources of coping, and measuring parents' current level of grief and depression. RESULTS: For 19 parents (21%) faith was very important during the palliative phase. The majority of parents remained hopeful for a meaningful time with their child (n=68, 76%); a pain-free death (n=58, 65%); and a cure (n=30, 34%). Their child (n=70, 79%) was parents' main source of coping. Twelve parents (14%) suffered from traumatic grief, and 22 parents (25%) showed symptoms of depression. Parents' faith was not associated with less long-term traumatic grief (OR=0.86, p=0.51) or symptoms of depression (OR=0.95, p=0.74), and parents' hope for a cure was not related to more long-term traumatic grief (OR=1.07, p=0.71) or symptoms of depression (OR=1.12, p=0.47). CONCLUSIONS: Faith was important for a minority of parents and was not associated with less long-term traumatic grief or symptoms of depression. The majority of parents remained hopeful. Hope for a cure was not associated with more long-term traumatic grief or symptoms of depression.

<http://www.ncbi.nlm.nih.gov/pubmed/25679453>

Vetsch, J., Rueegg, C. S., Gianinazzi, M. E., Bergstrasser, E., von der Weid, N. X. and Michel, G. (2015). "Information needs in parents of long-term childhood cancer survivors." *Pediatr Blood Cancer* 62(5): 859-866.

BACKGROUND: Parents' knowledge about cancer, treatment, potential late effects and necessary follow-up is important to reassure themselves and motivate their child to participate in regular follow-up. We aimed to describe (i) parents' perception of information received during and after treatment; (ii) parents' current needs for information today, and to investigate; and (iii) associations between information needs and socio-demographic and clinical characteristics. METHODS: As part of the Swiss Childhood Cancer Survivor Study, a follow-up questionnaire was sent to parents of survivors, diagnosed < 16 years and after 1990, and aged 11-17 years at study. We assessed parents' perception of information received and information needs, concerns about consequences of the cancer and socio-demographic information. Information on clinical data was available from the Swiss Childhood Cancer Registry. RESULTS: Of 309 eligible parents, 189 responded (67%; mean time since diagnosis: 11.3 years, SD = 2.5). Parents perceived to have received verbal information (on illness: verbal 91%, written 40%; treatment: verbal 88%, written 46%; follow-up: verbal 85% written 27%; late effects: verbal 75%, written 19%). Many parents reported current information needs, especially on late effects (71%). The preferred source was written general (28%) or verbal information (25%), less favored was online information (12%). Information needs were associated with migration background (P = 0.039), greater concerns about consequences of cancer (P = 0.024) and no information received (P = 0.035). CONCLUSION: Parents reported that they received mainly verbal information. However, they still needed further information especially about possible late effects. Individual long-term follow-up plans, including a treatment summary, should be provided to each survivor, preferably in written format.

<http://www.ncbi.nlm.nih.gov/pubmed/25663499>

West, C. H., Bell, J. M., Woodgate, R. L. and Moules, N. J. (2015). "Waiting to return to normal: an exploration of family systems intervention in childhood cancer." *J Fam Nurs* 21(2): 261-294.

The illness suffering of families in childhood cancer is characterized in part by a loss of family normalcy. Hermeneutic phenomenology and family process research methods were used to analyze videotaped family intervention sessions and post-intervention family/clinician interviews. Within this article, some of the findings from the larger doctoral study that focused on the illness suffering of family members and relational, family systems intervention based on the Illness Beliefs Model are described. Although the larger study included findings of family interventions that addressed several aspects of the illness suffering experienced, this article details specific findings related to the theme of the loss of family normalcy and a longing to return home. Family systems intervention practices which facilitated a lessening of illness suffering included the following: offering new interpretations of suffering within a reflecting team, articulating family strength, sensitively acknowledging the illness suffering, and eliciting the experiences of family members in a shared therapeutic conversation.

<http://www.ncbi.nlm.nih.gov/pubmed/25794512>

Wright, J., Elwell, L., McDonagh, J. E., Kelly, D. A. and Wray, J. (2015). "It's hard but you've just gotta get on with it' - The experiences of growing-up with a liver transplant." *Psychol Health*: 1-17.

The successful evolution of paediatric liver transplantation means that increasing numbers of young people survive into adulthood. Non-adherence to medication regimens leading to liver dysfunction, graft loss and patient death are prevalent in this vulnerable group. Insight into young people's experiences of living with a liver transplant (LTx) is vital to improve outcomes and guide future work in this area. Through semi-structured interviews, this study explored the experiences of living with a LTx for 13 young people transplanted as children and adolescents. Interviews were analysed using interpretative phenomenological analysis, revealing that young people felt different from their peers as a result of their LTx. Young people's perceptions of their scar, experiences of illness symptoms and taking medications acted as triggers of differences. This led to an ongoing struggle to be normal when faced with typical activities for young people and to attempts to take back control. Findings support the implementation of routine psychosocial screening to identify additional support needs and the development of a peer mentoring programme to allow young people to gain social support, thus reducing feelings of being different. It is hoped that such initiatives will have positive consequences for quality of life, self-management and adherence to medications.

<http://www.ncbi.nlm.nih.gov/pubmed/25727924>

Yoshida, S., Amano, K., Ohta, H., Kusuki, S., Morita, T., Ogata, A. and Hirai, K. (2014). "A comprehensive study of the distressing experiences and support needs of parents of children with intractable cancer." *Jpn J Clin Oncol* 44(12): 1181-1188.

OBJECTIVE: The primary endpoints of this study were: (1) to explore the distressing experiences of parents of patients with intractable pediatric cancer in Japan from disclosure of poor prognosis to the present and (2) to explore support they regarded as necessary.

METHODS: A multi-center questionnaire survey was conducted that included 135 bereaved

parents of patients with pediatric cancer in Japan. RESULTS: The top five distressing experiences shared by over half of the bereaved parents were: 'Realize that the child's disease was getting worse' (96.7%), 'Witness the child's suffering' (96.7%), 'Make many decisions on the basis that the child will die in the not-so-distant future' (83.6%), 'Feel anxious and nervous about the child's acute deterioration' (82.0%) and 'Realize that there was nothing that I could do for the child' (78.7%). The top five support regarded as necessary were: 'Visit the room and speak to the sick child every day' (90.2%), 'Provide up-to-date information' (80.3%), 'Sufficiently explain the disadvantages of each treatment option' (80.3%), 'Show a never-give-up attitude until the end' (78.7%) and 'Make arrangements to allow the sick child to spend time with his/her siblings' (73.8%). CONCLUSIONS: This study identified the common distressing experiences of parents and the support regarded as necessary by them. To provide efficient support with limited manpower in pediatric setting, healthcare professionals should recognize these tasks as high priorities when engage parents of intractable pediatric cancer patients.

<http://www.ncbi.nlm.nih.gov/pubmed/25249378>

Youngblut, J. M., Brooten, D., Blais, K., Kilgore, C. and Yoo, C. (2015). "Health and Functioning in Grandparents After a Young Grandchild's Death." J Community Health.

This cross-sectional study examined the physical and mental health, grief and role functioning of 136 grandparents in the first year after death of their young grandchild (newborn through 6 years). Grandparents were 36-77 years old; 73 % female; 24 % Hispanic, 38 % Black/African American, and 38 % White. Mean age of the 115 deceased grandchildren was 12.8 months (SD = 20.71) with 37 % <1 month old; 65 % were male, 77 % died in the hospital. Grandparents were recruited through state death records and interviewed by telephone. Grandparents experienced: clinical depression (31 %), PTSD (35 %); illnesses (28 %), hospitalizations, new chronic health conditions (mental disorders, hypertension, angina, cancer), and medication changes. Grandparents who provided care for the deceased grandchild had more intense symptoms of grief, depression and PTSD and more trouble focusing at their jobs. Severity of depressive and/or PTSD symptoms were more likely to be at clinically important levels for grandparents who had provided childcare for the deceased grandchild than for non-caregiving grandparents. Black grandparents had more severe symptoms of PTSD and thought more about their deceased grandchild on the job than White grandparents. The interaction effect of race/ethnicity and provision of child care was significant for PTSD and Blame and Anger. Hispanic grandparents who provided some child care for their deceased grandchild had less severe PTSD symptoms than caregiving Black and White grandparents. Caregiving Hispanic grandparents also experienced less Blame and Anger than White caregiving grandparents.

<http://www.ncbi.nlm.nih.gov/pubmed/25820932>

Zaider, T. I., Salley, C. G., Terry, R. and Davidovits, M. (2015). "Parenting challenges in the setting of terminal illness: a family-focused perspective." Curr Opin Support Palliat Care 9(1): 52-57.

PURPOSE OF REVIEW: In the advanced stages of illness, families with dependent children experience disruption across all dimensions of family life. The need for family support during palliative care is well recognized, yet little is understood about how parents and their chil-

dren navigate these difficult circumstances. This review summarizes the current body of research on parenting challenges in advanced cancer. RECENT FINDINGS: To date, the study of parental cancer has focused predominantly on the early stages of disease and its impact on children and adolescents. Less is known about how families with minor children prepare for parental loss. Evidence suggests that having dependent children influences parents' treatment decisions at the end of life, and that a central concern for children and parents is optimizing time spent together. Parents may feel an urgency to engage in accelerated parenting, and maintaining normalcy remains a consistent theme for the ill and healthy parent alike. There is a growing evidence base affirming the importance of responsive communication prior to death. SUMMARY: Advancing knowledge about the parenting experience at the end of life is critical for ensuring effective support to the entire family, as it accommodates and prepares for the loss of a vital member.

<http://www.ncbi.nlm.nih.gov/pubmed/25588207>

Zetumer, S., Young, I., Shear, M. K., Skritskaya, N., Lebowitz, B., Simon, N., Reynolds, C., Mauro, C. and Zisook, S. (2015). "The impact of losing a child on the clinical presentation of complicated grief." *J Affect Disord* 170: 15-21.

BACKGROUND: It is unclear whether bereaved parents with Complicated Grief (CG) struggle with their grief differently than others with CG. This study addressed this question by comparing CG severity, CG-related symptoms, thoughts and behaviors, and comorbid psychiatric diagnoses of bereaved parents with CG to the diagnoses and symptoms of others with CG. METHODS: Baseline data from 345 participants enrolled in the Healing Emotions After Loss (HEAL) study, a multi-site CG treatment study, were used to compare parents with CG (n=75) to others with CG (n=275). Data from the parent group was then used to compare parents with CG who had lost a younger child (n=24) to parents with CG who had lost an older child (n=34). Demographic and loss-related data were also gathered and used to control for confounders between groups. RESULTS: Parents with CG demonstrated slightly higher levels of CG (p=0.025), caregiver self-blame (p=0.007), and suicidality (p=0.025) than non-parents with CG. Parents who had lost younger children were more likely to have had a wish to be dead since the loss than parents who had lost older children (p=0.041). LIMITATIONS: All data were gathered from a treatment research study, limiting the generalizability of these results. No corrections were made for multiple comparisons. The comparison of parents who lost younger children to parents who lost older children was limited by a small sample size. CONCLUSIONS: Even in the context of CG, the relationship to the deceased may have a bearing on the degree and severity of grief symptoms and associated features. Bereaved parents with CG reported more intense CG, self-blame, and suicidality than other bereaved groups with CG, though this finding requires confirmation. The heightened levels of suicidal ideation experienced by parents with CG, especially after losing a younger child, suggest the value of routinely screening for suicidal thoughts and behaviors in this group.

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