

# Synopsis

International digest of children's palliative  
care research abstracts

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**Synopsis, International digest of children's palliative care research abstracts**  
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**Together for Short Lives is a UK wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.**

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## East Anglia's Children's Hospices (EACH) – New library and information service for children's hospices

For staff working in children's hospices it's not always easy to access the most up-to-date resources to support professional and evidence based practice. However, the good news is that a new online library service is now available to all children's hospices via the EACH library service.

The library has more than 3,000 resources, specialising in all aspects of caring for children and their families with life-limiting conditions. Library services and information can be provided over the telephone, by post or via email.

Services include:

- postal loans
- obtaining journal articles
- literature searching
- current awareness bulletin
- advice on accessing NHS electronic resources.

For more details about the long distance service visit [www.each.org.uk/library](http://www.each.org.uk/library)

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# Synopsis

## Abstracts – 01/02/2019 – 31/07/2019

**Synopsis Editor's Picks** We set out here 30 of the favourite articles from this edition of Synopsis as selected by our editorial team.

### From Toni

**Widger, K., et al. (2019). "Factor structure of the Quality of Children's Palliative Care Instrument (QCPCI) when complete by parents of children with cancer." BMC Palliat Care 18(1): 23.**

*I chose this article because I am especially interested in how children, young people and their families adapt to the long trajectory of the child's life limiting medical condition. Although there have been studies focusing on the end of life period for these children and families, little is written about the long term. I was especially interested to see this because the aim of the study was closely linked to the aims of my PhD and might provide a useful tool for clinical practice.*

**Ratislavova, K., et al. (2019). "Perinatal palliative care education: An integrative review." Nurse Educ Today 82: 58-66.**

*This review is very relevant to my role as Head of Practice Education & Quality at the children's hospice. It is interesting to see how improvements in knowledge and confidence can be measured to understand the impact of teaching in paediatric palliative care. The information from this review is useful to my own role and practice.*

**Hain, R. D. W. (2019). "Hospices and palliative care for children: converging stories." Br Med Bull 130(1): 81-88.**

*This article raises some timely questions for the sector of children's palliative care*

### From Nicky

**Spraker-Perlman, Tam, Bardsley et al: *The Impact of Pediatric Palliative Care Involvement in the Care of Critically Ill Patients without Complex Chronic Conditions*. Journal of Palliative Medicine 2019; 22(5):553-556. DOI: 10.1089/jpm.2018.0469**

Paediatric palliative care has a well-established role in supporting children with chronic complex conditions, but palliative care services are not usually involved with children who are normally well, even if admitted to hospital following serious acute-onset illness, accident, or a traumatic birth. This American paper explores deaths of children requiring ICU admission who were previously healthy, to determine the

impact of PPC involvement with this cohort. They performed a 4 year retrospective notes review for those who died in hospital >48 hours after admission to compare those who received input from PPC services with those who did not, looking for evidence and timing of multidisciplinary care conferences, documented end-of-life care planning, and DNR orders. Of this group of 167 children, most died in intensive care settings (89%) and few (20%) received PPC services. Those who did have input from PPC were more likely to have had multidisciplinary care conferences ( $P<.001$ ) and DNR orders in place ( $p<.004$ ) prior to death, and end-of-life planning occurred earlier (9.5 days vs 2 days,  $p<.001$ ) for those who received PPC consultation. The authors argue that PPC should be considered for ALL patients at high risk for death, to allow for timely care co-ordination and EOL planning.

As this was a notes review, there was no opportunity to explore the views of patients and bereaved families of PPC intervention. Given the limitations of prognostication, there must have been cases where PPC was involved and the children recovered – that perspective would also be interesting. The authors do not comment on the implications for workforce planning to meet this additional demand; neither do they report the views of intensivists. It would be fascinating to see qualitative feedback on this intervention.

The next two papers both relate to hospital-to-home transport for palliative care patients – an important but often overlooked component of providing a comprehensive range of choices to patients and families for end-of-life care. The challenges of home transport are explored in Raed's paper, and the added value of culturally-appropriate care is highlighted by Thorvilson. Both are well worth a read as full papers rather than just abstracts – the details of individual cases add valuable depth to discussion and development of this important aspect of service provision.

**Raed, Grossoehme, Brown, Friebert *Hospital to home transport at end of life: survey of clinician experience* Palliative Medicine 2019 1-6. DOI: 10.1177/0269216319870641**

This American paper explores the clinical and demographic diversity of patients receiving palliative transport and the perspectives of staff who provide this service, using a ten year retrospective chart review and staff survey. They found 23 patients who had received palliative transport from a tertiary paediatric hospital between 2004-13, of whom the 12 transported using critical care transport (aged 0.01-22 years) were included in this study. 75% died within 2 days of transport. Staff reported palliative transport as a positive experience, regarding it as an important job component, but 63% were dissatisfied or undecided about the plan should the patient die en-route. DNR documentation accompanied the patient in at least half the transfers, and medication en-route was uncommon. Six unanticipated events were described, five of these occurring on arrival home. Nearly all children required comfort medications at home. 48% of staff experienced some level of dissatisfaction with communication.

The authors suggest that transport home for end-of-life care is feasible but requires advanced discussion with all key stakeholders. They recommend detailed discussion of care plans amongst family, hospital, hospice, transport and pharmacy teams, including the en-route and arrival care plan, discontinuation of non-beneficial life-sustaining therapies and transition to EOL care, and above all the family goals and wishes. As transport is a relatively rare but clinically important event, they suggest collaboration between centres to share their accumulated experience, and to develop pre-transport protocols and patient-specific, high-fidelity simulations to minimise unanticipated events and support training for staff.

**Thorvilson, Manahan, Schiltz, Collura. *Homeward bound: A Case Series of Cross-Cultural care at End of Life, Enhanced by Pediatric Palliative Transport* journal of Palliative Medicine 2019; 22(4):464-467. DOI: 10.1089/jpm.2018.0301**

This paper describes a series of children with life-limiting conditions who were transferred from hospital to their home communities for end-of-life care, where particular cultural values were key for their families. Although the specific cultures (Amish, Hutterite, and Native American) are far from ubiquitous, the authors describe how the recognition of social and cultural values, customs and rituals informed end-of-life discussions between families and healthcare providers. The paper details the clinical and cultural aspects of three cases, and reflects on interdisciplinary care coordination, value-driven goals, and the opportunity to provide enhanced cross-cultural care. With modern culturally-diverse populations, this is an important issue for providers to address, and will support equitable access to end-of-life care in the location of a family's choosing.

### **From Sat**

The paper I would recommend is Friedrichsdorf 2019, From Tramadol to Methadone.

'An excellent paper written by a world expert in the field.'

### **From Susie**

**Harmoney, K., et al. (2019). "Differences in Advance Care Planning and Circumstances of Death for Pediatric Patients Who Do and Do Not Receive Palliative Care Consults: A Single-Center Retrospective Review of All Pediatric Deaths from 2012 to 2016." J Palliat Med 22(12): 1506-1514.**

An interesting study demonstrating the likely impact of paediatric palliative care involvement, particularly in relation to advance care planning. The research team undertook a retrospective review of case notes from a large tertiary care centre in the USA, relating to 558 children who had died. This found that patients with paediatric palliative care involvement were much more likely to have had advance care planning addressed before death, including documentation of goals of care and resuscitation status. They were also more likely to have hospice involvement at the time of death compared with those not having received palliative care involvement.

**Marcus, K. L., et al. (2019). "Impact of Specialized Pediatric Palliative Care: A Systematic Review." J Pain Symptom Manage.**

This review is important in interrogating the literature in relation to the impact of provision of specialised pediatric palliative care (SPPC) on patients, caregivers and systems. 24 studies were included in a qualitative synthesis of outcomes. Although the paucity and low certainty of the evidence precluded firm recommendations about SPPC practice, the review did find that receiving SPPC was associated with better child quality of life.

**Morell, E., et al. (2019). "Palliative care and paediatric cardiology: current evidence and future directions." Lancet Child Adolesc Health 3(7): 502-510.**

This is an important article, given that advanced heart disease remains a leading cause of paediatric mortality, as well as high morbidity, often involving multiple surgical interventions and long stays in intensive care. The article summarises relevant literature of the past decade and identifies gaps in parent and provider understanding of prognosis and communication. The authors propose indications for palliative care consultation, and summarise perceived barriers to it. Areas for additional research are identified, including paediatric cardiologist education, parental distress, socioeconomic disparities and patient-reported outcomes. The authors underline the need for interdisciplinary clinical and research efforts in order to improve integration of palliative care in the care of children with heart disease.

**Kase, S. M., et al. (2019). "A cross-sectional pilot study of compassion fatigue, burnout, and compassion satisfaction in pediatric palliative care providers in the United States." Palliat Support Care 17(3): 269-275.**

This is an important study as it investigated the both prevalence and likely determinants of compassion fatigue and burnout: these directly affect the wellbeing and professional performance of paediatric palliative care providers. The researchers distributed electronic surveys inquiring about compassion fatigue and compassion satisfaction, as well as professional and personal characteristics. They found that distress about a 'clinical situation', physical exhaustion and personal loss were significant determinants of compassion fatigue. Distress about 'coworkers', emotional depletion, social isolation and recent involvement in a challenging clinical situation were significant determinants of burnout. Predictors of lower Compassion Satisfaction scores included physical exhaustion, personal trauma, not discussing distressing issues and 'recent involvement in a clinical situation in which life prolonging activities were not introduced'.

These associations offer possible opportunities for intervention in the hope of reducing the prevalence of burnout and compassion fatigue.

**From Linda**

**Achieving beneficial outcomes for children with life threatening and life limiting conditions receiving palliative care and their families: a realist view**

**Mitchell S et al (2019) Palliative Medicine**

This paper will resonate with all those striving to better understand what influences good quality children's palliative care. This systematic realist review of the literature between 2015-2017 is a well-constructed theoretical explanation about the beneficial aspects of children's palliative care as described as important by children themselves and their families. Vital aspects were defined as feeling heard and respected and a sense of feeling that their emotional burden is shared.

This review explored four conceptual areas which, through realist analysis, were developed to propose how these beneficial outcomes are achieved through mechanisms which are often hidden. These include the fragility of the child's condition; living with chronic uncertainty; adapting to a situation which is outside cultural norms; needing to adapt family expectations through framing and re-framing hopes and expectations in order to develop expertise and coping strategies in managing their child's condition within their individual family context.

As the capacity to provide children's palliative care to the growing numbers of children who could benefit from it is diminishing, this paper provides a stimulus for policy makers; acute, community and voluntary sectors providers; and specialised and local commissioners to do something different. A focus on strategies which enable healthcare contexts to provide opportunities which can achieve child and family relevant outcomes in a more consistent and realistic way will be of interest to all working in the field.

### **Parents' experiences of requests for organ and tissue donation: the value of asking**

#### **Darlington A-S et al (2019) Archives of Diseases in Childhood**

Research with parents about organ and tissue donation (OTD) has previously focussed on the experiences of parents who have been approached for donation and thus considered eligible for donation by healthcare professionals. This retrospective qualitative study of health care professionals and parents (mostly bereaved) extends knowledge about this important topic through analysing end of life care experiences through health professional and parental lenses.

Factors which underpin decision making about OTD, recognising the complexity of the donation process and the impact on quality of end of life care were identified by both groups.

Analysis of parental experiences showed that many shared positive views about OTD even if they had not had any discussion with health professionals. For example, feeling proud about the possibility of helping others or for existential reasons. Those who were not asked about OTD revealed a number of assumptions about the physical well-being of their child or their organs, i.e. that their organs were not good enough or not usable. Some reported they would have welcomed a conversation if it

had been initiated. However, others described feeling that they may not have coped well if this issue been raised.

Raising discussion about OTD was reported to be difficult during health professional focus groups and there were concerns it could interfere with parental choices around decision making at end of life care, for example when preferred place of care is the home, or impact negatively upon the parent / health professional relationship. However, conversely, it was considered important to raise the topic with parents in order to give parents the opportunity and choice to reflect on the issue.

The law around organ donation for people over the age of 18 years in England is changing in Spring 2020 to an 'opt out' system. This means that all adults in England will be considered to have agreed to be an organ donor when they die unless they have recorded a decision not to donate or are in one of the [excluded groups](#).

<https://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/>

Whilst neonates and children are excluded groups this should not deter health professionals from raising this subject. This law change may, perhaps, make raising the issue with parents easier to do.

## ***Clinical and Ethical Decision Making***

**Ahmad, M. U., Farrell, R. M. and Weise, K. L. (2019). "Neonatal organ donation: Ethical insights and policy implications." J Neonatal Perinatal Med, 10.3233/npm-1850.**

In the realm of clinical ethics as well as in health policy and organizational ethics, the onus of our work as ethicists is to optimize the medical care and experience of the patient to better target ethical dilemmas that develop in the course of care delivery. The role of ethics is critical in all aspects of medicine, but particularly so in the difficult and often challenging cases that arise in the care of pregnant women and newborns. One exemplary situation is that when a pregnant woman and her partner consider neonatal organ donation after receiving news of a terminal diagnosis and expected death of the newborn. While a newer, less practiced form of organ donation, this approach is gaining greater visibility as an option for parents facing this terminal outcome. The aim of our paper is to highlight some of the key ethical issues associated with neonatal organ donation and identify clinical and logistical aspects of implementing such an approach to facilitate organ donation.

<https://www.ncbi.nlm.nih.gov/pubmed/31256079>

**Ayres, S., Gallacher, L., Stark, Z. and Brett, G. R. (2019). "Genetic counseling in pediatric acute care: Reflections on ultra-rapid genomic diagnoses in neonates." J Genet Couns 28(2): 273-282.**

As genomic sequencing has become available in pediatric clinical genetics settings, genetic counselors have been called upon to support individuals and families through the testing process. Technological and bioinformatic advancements, along with the availability of analytical expertise, have significantly reduced genomic sequencing turnaround times, enabling this powerful diagnostic tool to be used in neonatal intensive care units (NICUs) in place of or alongside traditional diagnostic strategies. It is important that pretest counseling for genomic sequencing prepares parents of critically unwell infants for the potential impacts of achieving a diagnosis, such as rare or ultra-rare diagnoses with limited disease-specific information, or the diagnosis of a life-limiting condition. Genetic counseling experiences and challenges arising in rapid genomic sequencing settings are yet to be discussed in the literature in detail. This paper uses illustrative cases as the basis to describe and discuss the emerging role of genetic counselors in NICU multidisciplinary care teams and the challenges and considerations which arise when facilitating ultra-rapid genomic diagnoses in acutely unwell neonates. Counseling issues discussed include providing pre- and posttest counseling in the medicalized NICU setting, facilitating informed decision-making at a time of acute distress for families, and special considerations around the possibility of ultra-rare diagnoses in neonates at the beginning of their diagnostic trajectory. As technology continues to drive practice, it is important genetic counselors remain abreast of these issues in order to appropriately support families through the genomic sequencing process and beyond.

<https://www.ncbi.nlm.nih.gov/pubmed/30663825>

**Blakeley, C., Smith, D. M., Johnstone, E. D. and Wittkowski, A. (2019). "Parental decision-making following a prenatal diagnosis that is lethal, life-limiting, or**

**has long term implications for the future child and family: a meta-synthesis of qualitative literature." BMC Med Ethics 20(1): 56.**

**BACKGROUND:** Information on the factors influencing parents' decision-making process following a lethal, life-limiting or severely debilitating prenatal diagnosis remains deficient. A comprehensive systematic review and meta-synthesis was conducted to explore the influencing factors for parents considering termination or continuation of pregnancy following identification of lethal, life-limiting or severely debilitating fetal abnormalities. **METHODS:** Electronic searches of 13 databases were conducted. These searches were supplemented by hand-searching Google Scholar and bibliographies and citation tracing. Thomas and Harden's (2008) thematic synthesis method was used to synthesise data from identified studies. **RESULTS:** Twenty-four papers were identified and reviewed, but two papers were removed following quality assessment. Three main themes were identified through systematic synthesis. Theme 1, entitled 'all life is precious', described parents' perception of the importance of the fetus' life, a fatalistic view of their situation alongside moral implications as well as the implications decisions would have on their own life, in consideration of previous life experiences. Theme 2 ('hope for a positive outcome') contained two sub-themes which considered the parent's own imagined future and the influence of other people's experiences. Finally, Theme 3 ('a life worth living') presented three sub-themes which may influence their parental decision-making: These described parental consideration of the quality of life for their unborn child, the possibility of waiting to try for another pregnancy, and their own responsibilities and commitments. **CONCLUSION:** The first review to fully explore parental decision-making process following lethal, life-limiting, or severely debilitating prenatal diagnosis provided novel findings and insight into which factors influenced parents' decision-making process. This comprehensive and systematic review provides greater understanding of the factors influential on decision-making, such as hope, morality and potential implications on their own and other's quality of life, will enable professionals to facilitate supported decision-making, including greater knowledge of the variables likely to influence parental choices.

<https://www.ncbi.nlm.nih.gov/pubmed/31395047>

**Diamond, D. M. (2019). "When a child dies of heatstroke after a parent or caretaker unknowingly leaves the child in a car: How does it happen and is it a crime?" Med Sci Law 59(2): 115-126.**

It is commonly reported that in the course of a drive, a parent or caretaker loses awareness of the presence of a child in the back seat of the car. Upon arriving at the destination, the driver exits the car and unknowingly leaves the child in the car. This incomprehensible lapse of memory exposes forgotten children to hazards, including death from heatstroke. More than 400 children in the past 20 years have suffered from heatstroke after being unknowingly forgotten in cars. How can loving and attentive parents, with no evidence of substance abuse or an organic brain disorder, have a catastrophic lapse of memory that places a child's welfare in jeopardy? This article addresses this question at multiple levels of analysis. First, it is concluded that the loss of awareness of a child in a car is a failure of a type of memory referred to as prospective memory (PM), that is, failure to remember to execute a plan in the future. Second, factors that increase the likelihood that PM will fail are identified. Third, research on the neurobiology of PM and PM-related memory failures are

reviewed, including a discussion of how competition between brain structures contributes to a failure of PM. Finally, the issue of whether a failure of PM that results in harm to a child qualifies as a criminal offence is discussed. Overall, this neuropsychological perspective on how catastrophic memory errors occur should be of value to the scientific community, the public and law-enforcement agencies.  
<https://www.ncbi.nlm.nih.gov/pubmed/30835167>

**Edwin, F. (2019). "Palliation of Functionally Single Ventricle Patients in Sub-Saharan Africa-Is It Justifiable?" World J Pediatr Congenit Heart Surg 10(2): 171-173.**

Resource constraints in many sub-Saharan African countries undermine efforts to provide the full spectrum of pediatric cardiology and cardiac surgery. Palliation of the child born with functionally single ventricle is the lowest priority for policymakers when viewed from the perspective of cost-effectiveness. This commentary focuses on the relative importance of different criteria that policymakers and the general public consider important in setting health-care priorities as it relates to palliation of the patient with functionally single ventricle in sub-Saharan Africa. It argues the position that cost-effectiveness analysis tends to exclude those with high cost-to-treat illness, and decisions made on that basis alone are not acceptable to the general population on whose behalf those decisions are made.

<https://www.ncbi.nlm.nih.gov/pubmed/30841827>

**Flaig, F., Lotz, J. D., Knochel, K., Borasio, G. D., Fuhrer, M. and Hein, K. (2019). "Perinatal Palliative Care: A qualitative study evaluating the perspectives of pregnancy counselors." Palliat Med 33(6): 704-711.**

**BACKGROUND:** A prenatal diagnosis of a life-limiting disease raises complex ethical, emotional, and medical issues. Studies suggest that 40%-85% of parents decide to continue the pregnancy if given the option of Perinatal Palliative Care. However, structured Perinatal Palliative Care programs are missing in many European countries. In Germany, parents have the right to free psychosocial support from pregnancy counseling services after the prenatal diagnosis of a life-limiting disease. **AIM:** We aimed to investigate whether German professional pregnancy counselors perceive the need for structured Perinatal Palliative Care and if so, how it should be conceived. **DESIGN:** This is a qualitative interview study with purposeful sampling. The interviews were analyzed with the coding method of Saldana. **SETTING/PARTICIPANTS:** A total of 10 professionals from three different pregnancy counseling services participated in the study. **RESULTS:** The main topics raised by the professionals were as follows: (1) counseling and parental support during the decision-making process; (2) fragmented or missing support infrastructure for parents; and (3) challenges, hesitations, and barriers, particularly from the different stakeholders, regarding a Perinatal Palliative Care framework. They highlighted the importance of the integration of Perinatal Palliative Care in existing structures, a multi-professional approach, continuous coordination of care and education for all healthcare providers involved. **CONCLUSION:** A structured Perinatal Palliative Care program is considered as necessary by the pregnancy counselors. Future research should focus on (1) needs reported by concerned parents; (2) attitude and role of all healthcare providers involved; (3) strategies to

include stakeholders in the development of Perinatal Palliative Care networks; and (4) outcome parameters for evaluation of Perinatal Palliative Care frameworks.  
<https://www.ncbi.nlm.nih.gov/pubmed/30843464>

**Gamble, J. L., Gamble, N. K. and Pruski, M. (2019). "To die, to sleep, perchance to dream? A response to DeMichelis, Shaul and Rapoport." J Med Ethics 45(12): 832-834.**

In developing their policy on paediatric medical assistance in dying (MAID), DeMichelis, Shaul and Rapoport decide to treat euthanasia and physician-assisted suicide as ethically and practically equivalent to other end-of-life interventions, particularly palliative sedation and withdrawal of care (WOC). We highlight several flaws in the authors' reasoning. Their argument depends on too cursory a dismissal of intention, which remains fundamental to medical ethics and law. Furthermore, they have not fairly presented the ethical analyses justifying other end-of-life decisions, analyses and decisions that were generally accepted long before MAID was legal or considered ethical. Forgetting or misunderstanding the analyses would naturally lead one to think MAID and other end-of-life decisions are morally equivalent. Yet as we recall these well-developed analyses, it becomes clear that approving of some forms of sedation and WOC does not commit one to MAID. Paediatric patients and their families can rationally and coherently reject MAID while choosing palliative care and WOC. Finally, the authors do not substantiate their claim that MAID is like palliative care in that it alleviates suffering. It is thus unreasonable to use this supposition as a warrant for their proposed policy.

<https://www.ncbi.nlm.nih.gov/pubmed/31320406>

**Gostin, L. O. (2019). "Living, Aging, and Dying in Healthy and Just Societies: Life Lessons From my Father." Milbank Q 97(1): 24-30.**

<https://www.ncbi.nlm.nih.gov/pubmed/30656756>

**Landrum Peay, H., Fischer, R., Tzeng, J. P., Hesterlee, S. E., Morris, C., Strong Martin, A., Rensch, C., Smith, E., Ricotti, V., Beaverson, K., Wand, H. and Mansfield, C. (2019). "Gene therapy as a potential therapeutic option for Duchenne muscular dystrophy: A qualitative preference study of patients and parents." PLoS One 14(5): e0213649.**

**OBJECTIVES:** Duchenne muscular dystrophy (DMD) is a rare neuromuscular disorder that causes progressive weakness and early death. Gene therapy is an area of new therapeutic development. This qualitative study explored factors influencing parents' and adult patients' preferences about gene therapy. **METHODS:** We report qualitative data from 17 parents of children with DMD and 6 adult patients. Participants responded to a hypothetical gene therapy vignette with features including non-curative stabilizing benefits to muscle, cardiac and pulmonary function; a treatment-related risk of death; and one-time dosing with time-limited benefit of 8-10 years. We used NVivo 11 to code responses and conduct thematic analyses. **RESULTS:** All participants placed high value on benefits to skeletal muscle, cardiac, and pulmonary functioning, with the relative importance of cardiac and pulmonary function increasing with disease progression. More than half tolerated a hypothetical 1% risk of death when balanced against Duchenne progression and limited

treatment options. Risk tolerance increased at later stages. Participants perceived a 'right time' to initiate gene therapy. Most preferred to wait until a highly-valued function was about to be lost. CONCLUSION: Participants demonstrated a complex weighing of potential benefits against harms and the inevitable decline of untreated Duchenne. Disease progression increased risk tolerance as participants perceived fewer treatment options and placed greater value on maintaining remaining function. In the context of a one-time treatment like gene therapy, our finding that preferences about timing of initiation are influenced by disease state suggest the importance of assessing 'lifetime' preferences across the full spectrum of disease progression.  
<https://www.ncbi.nlm.nih.gov/pubmed/31042754>

**Lanzel, A. F. and Lavery, J. V. (2019). "Unintended Consequences of the Right to Try Act for Palliative Care in Pediatric Oncology." JAMA Oncol 5(5): 603-604.**  
<https://www.ncbi.nlm.nih.gov/pubmed/30844025>

**Macauley, R. C. (2019). "The Limits of "Life-Limiting"." J Pain Symptom Manage 57(6): 1176-1181.**

The field of hospice and palliative medicine has struggled to define the conditions that are appropriate for palliative care. "Life-threatening" appropriately encompasses lethal conditions and helpfully incorporates the concept of probability, which is a necessary variable in any risk calculation. Yet it leaves one important group of patients unaccounted for: those whose primary need for palliative care is not expected abbreviation of life but rather the quality of that life. In an attempt to include these patients, the term "life-limiting" has come to be used more frequently. Although attractive in its breadth-and at first glance appearing to be a less threatening way to introduce palliative care-the term is inherently flawed. It denotes a certain outcome, without any consideration of the likelihood of that outcome. Rather than "softening the blow" of introducing palliative care, the term seems to condemn a patient to the very outcome that palliative care is tasked to ameliorate, namely, the limitation of life. As such, it may provide a distorted view of what palliative care is, especially in pediatrics where the term is used with disproportionate frequency. The inherent misplaced certainty of "life-limiting" and the self-defeating message it sends to patients should be acknowledged.

<https://www.ncbi.nlm.nih.gov/pubmed/30904413>

**Mitchell, S., Spry, J. L., Hill, E., Coad, J., Dale, J. and Plunkett, A. (2019). "Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a qualitative interview study." BMJ Open 9(5): e028548.**

OBJECTIVES: To provide an in-depth insight into the experience and perceptions of bereaved parents who have experienced end of life care decision-making for children with life-limiting or life-threatening conditions in the paediatric intensive care unit (PICU). DESIGN: An in-depth qualitative interview study with a sample of parents of children with life-limiting or life-threatening conditions who had died in PICU within the previous 12 months. A thematic analysis was conducted on the interview transcripts. SETTING: A PICU in a large National Health Service (NHS)

tertiary children's hospital in the West Midlands, UK. PARTICIPANTS: 17 parents of 11 children who had died in the PICU. RESULTS: Five interconnected themes were identified related to end of life care decision-making:(1) parents have significant knowledge and experiences that influence the decision-making process.(2) Trusted relationships with healthcare professionals are key to supporting parents making end of life decisions.(3) Verbal and non-verbal communication with healthcare professionals impacts on the family experience.(4) Engaging with end of life care decision-making can be emotionally overwhelming, but becomes possible if parents reach a 'place of acceptance'.(5) Families perceive benefits to receiving end of life care for their child in a PICU. CONCLUSIONS AND IMPLICATIONS: The death of a child is an intensely emotional experience for all involved. This study adds to the limited evidence base related to parental experiences of end of life care decision-making and provides findings that have international relevance, particularly related to place of care and introduction of end of life care discussions. The expertise and previous experience of parents is highly relevant and should be acknowledged. End of life care decision-making is a complex and nuanced process; the information needs and preferences of each family are individual and need to be understood by the professionals involved in their care.

<https://www.ncbi.nlm.nih.gov/pubmed/31072863>

**Mooney-Doyle, K., Keim-Malpass, J. and Lindley, L. C. (2019). "The ethics of concurrent care for children: A social justice perspective." Nurs Ethics 26(5): 1518-1527.**

Recent estimates indicate that over 40,000 children die annually in the United States and a majority have life-limiting conditions. Children at end of life require extensive healthcare resources, including multiple hospital readmissions and emergency room visits. Yet, many children still suffer from symptoms at end of life-including fatigue, pain, dyspnea, and anxiety-with less than 10% of these children utilizing hospice care services. A critical barrier to pediatric hospice use was the original federal regulations associated with the hospice care that required a diagnosis of 6 months to live and the discontinuation of all curative treatments. The Concurrent Care Provision of the United States' Affordable Care Act eliminated the need to forgo curative therapies in order to enroll in hospice for children in Medicaid or Children's Health Insurance Program. Concurrent care for children can help mitigate the tension families experience in choosing between essential forms of care, as well as contribute to improved end-of-life outcomes for the child and possibly bereavement outcomes for the family. Understanding concurrent care for children from a social justice perspective has important advocacy and research implications for hospice and palliative care clinicians providing care for children and their families. We apply Powers and Faden's theory of social justice "as the moral foundation of public health and health policy" to the provision of concurrent care to children near end of life and families in the United States. The goals of applying this theory are to explore additional insights and perspectives into concurrent care policy may provide and to assess the usefulness of this theory when applied to end-of-life health policy. We argue that concurrent care policy is socially just since it has potential to promote well-being in vulnerable children and families and can limit the inequity children at end-of-life experience in access to high-quality hospice care.

<https://www.ncbi.nlm.nih.gov/pubmed/29656703>

**Moreton, K. L. (2019). "Reflecting on 'Hannah's Choice': Using the Ethics of Care to Justify Child Participation in End of Life Decision-Making." Med Law Rev, 10.1093/medlaw/fwz011.**

It has been ten years since the case of Hannah Jones-the 12-year-old girl who was permitted to refuse a potentially life-saving heart transplant. In the past decade, there has been some progress within law and policy in respect of children's participatory rights (UNCRC-Article 12), and a greater understanding of family-centred decision-making. However, the courts still largely maintain their traditional reluctance to find children Gillick competent to refuse medical treatment. In this article, I revisit Hannah's case through the narrative account provided by Hannah and her mother, to ascertain what lessons can be learnt. I use an Ethics of Care framework specially developed for children in mid-childhood, such as Hannah, to argue for more a creative and holistic approach to child decision-making in healthcare. I conclude that using traditional paradigms is untenable in the context of palliative care and at the end of life, and that the law should be able to accommodate greater, and even determinative, participation of children who are facing their own deaths.

<https://www.ncbi.nlm.nih.gov/pubmed/31257451>

**O'Connell, O., Meaney, S. and O'Donoghue, K. (2019). "Anencephaly; the maternal experience of continuing with the pregnancy. Incompatible with life but not with love." Midwifery 71: 12-18.**

**OBJECTIVE:** As advances in prenatal diagnosis increasingly enable detection of life-limiting conditions, end-of-life care may start before birth. Termination of these pregnancies may have been default management, but in the Republic of Ireland, where termination is not a legal option, skilled experience in caring for mothers who continue their pregnancies has developed. This study examines the lived experience of four such mothers. **METHOD:** A qualitative study was designed using interpretive phenomenological analysis, which examined the maternal experience of continuing pregnancy with a prenatal diagnosis of anencephaly. Four mothers participated in semi-structured interviews on their experience of pregnancy and delivery of a baby with anencephaly. **RESULTS:** A profoundly emotional journey represented an adaptive grieving process, which culminated in rich experiences of transformative growth for all the parents. The parents' relationship with their caregivers facilitated this process and the development of a meaningful parenting relationship with their babies. This positive finding coexists alongside a parallel experience of ongoing deep sense of loss and sadness. **CONCLUSION:** Perinatal palliative care for those with a prenatal lethal diagnosis is a positive life experience for some mothers. The role of relationship with healthcare professionals is vital to the process and consideration must be given to a comprehensive multi-disciplinary team approach.

<https://www.ncbi.nlm.nih.gov/pubmed/30640134>

**Pechmann, A., Langer, T. and Kirschner, J. (2019). "Decision-Making Regarding Ventilator Support in Children with SMA Type 1-A Cross-Sectional Survey among Physicians." Neuropediatrics 50(6): 359-366.**

Spinal muscular atrophy (SMA) is a neuromuscular disorder characterized by muscle atrophy and severe proximal muscle weakness. In the absence of curative treatment, it has been controversial whether critically ill infants with SMA type 1 should receive

ventilator support. The aim of this study was to investigate the process of decision-making regarding ventilator support in children with SMA type 1 from the perspectives of physicians. A web-based survey with 17 questions and 2 case vignettes was conducted in 671 physicians in Germany and Switzerland from 12/2016 to 03/2017. The survey focused on factors influencing the decision about ventilator support and the content in informed consent discussions. Additionally, physicians were asked about their general attitude towards mechanical ventilation in children with SMA type 1 and their hypothetical clinical management in emergency settings using case vignettes. Hundred and sixty-five physicians participated in the survey (50.3% child neurologists, 18.8% specialists for ventilator support, 6.1% pediatric palliative care physicians, and 6.1% with more than one of these specializations). Of all physicians, 44.2% confirmed to have experience with SMA type 1 patients using ventilator support. In summary, our results show that physicians' attitudes and experiences about mechanical ventilation in children with SMA type 1 vary considerably and are likely to influence the outcome in informed consent discussions and the hypothetical management in emergency settings.  
<https://www.ncbi.nlm.nih.gov/pubmed/31408889>

**Sasazuki, M., Sakai, Y., Kira, R., Toda, N., Ichimiya, Y., Akamine, S., Torio, M., Ishizaki, Y., Sanefuji, M., Narama, M., Itai, K., Hara, T., Takada, H., Kizawa, Y. and Ohga, S. (2019). "Decision-making dilemmas of paediatricians: a qualitative study in Japan." *BMJ Open* 9(8): e026579.**

**OBJECTIVE:** To delineate the critical decision-making processes that paediatricians apply when treating children with life-threatening conditions and the psychosocial experience of paediatricians involved in such care. **DESIGN:** We conducted semistructured, individual face-to-face interviews for each participant from 2014 to 2015. The content of each interview was subjected to a comprehensive qualitative analysis. The categories of dilemma were extracted from a second-round content analysis. **PARTICIPANTS:** Participants were board-certified paediatricians with sufficient experience in making decisions in relation to children with severe illnesses or disabilities. We repeated purposive sampling and analyses until we reached saturation of the category data. **RESULTS:** We performed interviews with 15 paediatricians. They each reported both unique and overlapping categories of dilemmas that they encountered when making critical decisions. The dilemmas included five types of causal elements: (1) paediatricians' convictions; (2) the quest for the best interests of patients; (3) the quest for medically appropriate plans; (4) confronting parents and families and (5) socioenvironmental issues. Dilemmas occurred and developed as conflicting interactions among these five elements. We further categorised these five elements into three principal domains: the decision-maker (decider); consensus making among families, colleagues and society (process) and the consequential output of the decision (consequence). **CONCLUSIONS:** This is the first qualitative study to demonstrate the framework of paediatricians' decision-making processes and the complex structures of dilemmas they face. Our data indicate the necessity of establishing and implementing an effective support system for paediatricians, such as structured professional education and arguments for creating social consensus that assist them to reach the best plan for the management of severely ill children.  
<https://www.ncbi.nlm.nih.gov/pubmed/31431444>

**Schneider, K., Metze, B., Buhner, C., Cuttini, M. and Garten, L. (2019). "End-of-Life Decisions 20 Years after EURONIC: Neonatologists' Self-Reported Practices, Attitudes, and Treatment Choices in Germany, Switzerland, and Austria." J Pediatr 207: 154-160.**

**OBJECTIVE:** To assess changes in attitudes of neonatologists regarding the care of extremely preterm infants and parental involvement over the last 20 years. **STUDY DESIGN:** Internet-based survey (2016) involving 170 tertiary neonatal intensive care units in Austria, Switzerland, and Germany using the European Project on Parents' Information and Ethical Decision Making in Neonatal Intensive Care Units questionnaire (German edition) with minor modifications to the original survey from 1996 to 1997. **RESULTS:** The 2016 survey included 104 respondents (52.5% response rate). In 2016, significantly more neonatologists reported having ever withheld intensive care treatment (99% vs 69%) and withdrawn mechanical ventilation (96% vs 61%) or life-saving drugs (99% vs 79%), compared with neonatologists surveyed in 1996-1997. Fewer considered limiting intensive care as a slippery slope possibly leading to abuse (18% vs 48%). In the situation of a deteriorating clinical condition despite all treatment, significantly more neonatologists would ask parental opinion about continuation of intensive care (49% vs 18%). In 2016, 21% of German neonatologists would resuscitate a hypothetical infant at the limits of viability, even against parental wishes. **CONCLUSIONS:** Withholding or withdrawing intensive care for extremely preterm infants at the limits of viability with parental involvement has become more acceptable than it was 20 years ago. However, resuscitating extremely preterm infants against parental wishes remains an option for up to one-fifth of the responding neonatologists in this survey.  
<https://www.ncbi.nlm.nih.gov/pubmed/30772016>

**Sieg, S. E., Bradshaw, W. T. and Blake, S. (2019). "The Best Interests of Infants and Families During Palliative Care at the End of Life: A Review of the Literature." Adv Neonatal Care 19(2): E9-e14.**

**BACKGROUND:** Palliative care is an integral element of care provision in neonatal intensive care units (NICUs). Healthcare providers working in NICUs are likely to provide palliative care at some point in their career. **PURPOSE:** This article examines what neonatal palliative care entails, how parents perceive healthcare providers' actions, what they potentially need at the end of their infant's life, and what bereavement interventions are most supportive for parents. **SEARCH STRATEGY:** We conducted a search of full-text articles published in English in PubMed and CINAHL using the following key words: "NICU bereavement care," "end-of-life care," "infant loss," and "palliative care." **FINDINGS:** Healthcare providers should consider alleviation of the infant's pain and suffering when discussing whether to provide or continue aggressive medical interventions. The timing of these discussions is important. Parents appear to be most comforted by compassionate, caring healthcare providers who show competence and knowledge in the provision of medical/nursing and palliative care. **IMPLICATIONS FOR PRACTICE:** Healthcare providers working in NICUs require specific training in bereavement/palliative care for infants. Families facing the death of their infant must receive support from qualified providers both during and after that death. Furthermore, the infant's quality of life must be considered when discussing withholding or withdrawing care. **IMPLICATIONS FOR RESEARCH:** There is a need for further research investigating

the specific types of training required by healthcare providers in NICU settings who are providing bereavement/palliative care to neonates, in order to best support the families' needs in these situations.

<https://www.ncbi.nlm.nih.gov/pubmed/30394915>

**Stanak, M. and Hawlik, K. (2019). "Decision-making at the limit of viability: the Austrian neonatal choice context." *BMC Pediatr* 19(1): 204.**

**BACKGROUND:** We aimed to explore the shared decision-making context at the limit of viability (weeks 22-25 of gestation) through analyzing neonatologist's communication strategies with parents and their possible impact on survival and neurodevelopmental impairment (NDI) outcomes. **METHODS:** A mixed methods approach was applied where a systematic literature search and in-depth semi-structured interviews with five heads of neonatology departments and one clinical ethicist from the Austrian context were integrated into a literature review. The aim was to identify decision practice models and the choice context specific to Austria. **RESULTS:** Professional biases, parental understanding, and the process of information giving were identified as aspects possibly influencing survival and NDI outcomes. Institutions create self-fulfilling prophecies by recommending intensive/palliative care based upon their institutional statistics, yet those vary considerably among high-income countries. Labelling an extremely preterm (EP) infant by the gestational week was shown to skew the estimates for survival while the process of information giving was shown to be subject to framing effect and other cognitive biases. **CONCLUSION:** Communication strategies of choice options to parents may have an impact on the way parents decide and hence also on the outcomes of EP infants.

<https://www.ncbi.nlm.nih.gov/pubmed/31221128>

**Waldrop, D. P., McGinley, J. M., Dailey, M. W. and Clemency, B. (2019). "Decision-Making in the Moments Before Death: Challenges in Prehospital Care." *Prehosp Emerg Care* 23(3): 356-363.**

**BACKGROUND:** The primary charge of Emergency Medical Services (EMS) is to save lives. However, EMS personnel are frequently called to scenes where prolonging life may not be the primary goal. When someone is nearing death, family members may feel compelled to call 9-1-1 because they are feeling uncertain about how to manage symptoms at the end of life. **OBJECTIVE:** We sought to explore prehospital providers' perspectives on how the awareness of dying and documentation of end-of-life wishes influence decision-making on emergency calls near the end of life. **METHODS:** The study design was exploratory, descriptive, and cross-sectional. Qualitative methods were chosen to explore participants' perspectives in their own words. In-depth in-person interviews were conducted with 43 EMS providers. Interviews were audio recorded and professionally transcribed. Interview transcripts were entered in Atlas.ti for data management and coding. The analysis was deductive and guided by a conceptual model of 4 contexts of end-of-life decision-making that is not setting-specific, but has been applied to prehospital care in this study. **RESULTS:** The findings illustrate the relationship between awareness of dying and documentation of wishes in EMS calls. The 4 decisional contexts are: (1) Awareness of Dying-Wishes Documented: Families were prepared but validation and/or support was needed in the moment; (2) Awareness of Dying-Wishes

Undocumented: EMS must initiate treatment, medical control guidance was needed; (3) Unaware of Dying-Wishes Documented: Shock, expectation that EMS can stop the dying; and (4) Unaware of Dying-Wishes Undocumented: Families were unprepared, uncertain, frantic. Each context is illustrated by representative quotes from participants. Discordance and conflict was found in each decisional context. CONCLUSIONS: This study illustrates that EMS providers are acutely aware of the impact of their decisions and actions on families at the end of life. How emergency calls near the end of life are handled influences how people die, whether their preferences are honored, and the appropriate use of ambulance transport and ED care. The findings highlight how the intersection of awareness of dying and documentation of wishes influence prehospital decision-making in end-of-life emergencies and demonstrate the key role EMS providers have in this critical period. <https://www.ncbi.nlm.nih.gov/pubmed/30183448>

**Wilkinson, D. J., Villanueva-Uy, M. E., Hayden, D. and McTavish, J. (2019). "Decision-making around resuscitation of extremely preterm infants in the Philippines: A consensus guideline." J Paediatr Child Health 55(9): 1023-1028.**

While the vast majority of preterm births globally occur in low- and middle-income countries, existing published guidelines relating to the decision-making and resuscitation of extremely preterm infants (EPIs) largely focus on high-income countries. In 2018-2019, a working group of the Philippine Society of Newborn Medicine aimed to develop the first national guideline relating to the care of EPIs. The working group reviewed data on the outcomes of EPIs in the Philippines, surveyed paediatricians and neonatologists in the Philippines about current practice and held a consensus workshop. This paper describes the guideline development process and presents a summary of the guidelines. The national guidelines endorse consistency in decision-making. Health professionals should take into consideration the views and wishes of the infant's parents and the availability of resources to treat the newborn infant. Active management would be appropriate to provide for potentially viable preterm infants at moderate to high risk of poor outcomes, where parents have expressed their wish for this management (and where there are resources available to provide this treatment). For such infants, where parents have expressed their wish to withhold active management, palliative management would also be appropriate to provide. The guideline endorses a grey zone for neonatal resuscitation from approximately 24 to 28 weeks' gestation in the Philippines, reflecting the context for resuscitation in low- and middle-income countries. Disparities in resource availability are themselves an ethical concern for neonatologists and should be a stimulus for advocacy and improvements in health-care delivery.

<https://www.ncbi.nlm.nih.gov/pubmed/31343809>

**Winter, M. C., Friedman, D. N., McCabe, M. S. and Voigt, L. P. (2019). "Content review of pediatric ethics consultations at a cancer center." Pediatr Blood Cancer 66(5): e27617.**

BACKGROUND/OBJECTIVES: Ethical challenges in pediatric oncology arise at every stage of illness. However, there are sparse data on the content of and reason for ethics consultations in the field. We sought to evaluate the content and characteristics of ethics consultations in pediatric patients at a cancer center.

DESIGN/METHODS: We retrospectively identified ethics consultations performed for patients diagnosed with cancer at  $\leq 21$  years of age who were treated in the Department of Pediatrics from 2007 to 2017. Using an established coding schema, two independent reviewers analyzed the content of ethics consultation notes and identified core ethical issues and relevant contextual issues. Demographic, clinical, and consultation-specific data were also collected. RESULTS: Thirty-five consultations were performed for 32 unique patients. The most commonly identified ethical issues were obligation to provide nonbeneficial treatment (29%) and resuscitation preferences (26%). Communication conflicts were the most commonly identified contextual issue (40%). There were two themes that emerged repeatedly but were not a part of the original coding schema-four consultations (11%) that involved physicians questioning their obligation to provide potentially toxic treatment in the setting of poor patient/parent compliance, and two consultations (6%) related to complex risk-benefit analysis in the setting of an invasive procedure with uncertain benefit. CONCLUSIONS: Pediatric ethics consultations are infrequent at this specialty cancer hospital. Ethical issues focused on treatment and end-of-life care and included a diversity of communication conflicts.

<https://www.ncbi.nlm.nih.gov/pubmed/30666797>

## ***Educational, Professional and Research***

(2019). "Emotional Intelligence in Neonatal Intensive Care Unit Nurses: Decreasing Moral Distress in End-of-Life Care and Laying a Foundation for Improved Outcomes: An Integrative Review." J Hosp Palliat Nurs 21(4): E28. <https://www.ncbi.nlm.nih.gov/pubmed/31268970>

(2019). "[Criteria and practical guidance for determination of brain death in children]." Zhonghua Er Ke Za Zhi 57(5): 331-335. <https://www.ncbi.nlm.nih.gov/pubmed/31060123>

Aldiss, S., Fern, L. A., Phillips, R. S., Callaghan, A., Dyker, K., Gravestock, H., Groszmann, M., Hamrang, L., Hough, R., McGeachy, D., Morgan, S., Smith, S., Upadhyaya, S., Veitch, H., Veitch, L., Williamson, M., Whelan, J. S. and Gibson, F. (2019). "Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance." BMJ Open 9(8): e028119.

**OBJECTIVES:** To conduct a UK-wide survey of young people who have experienced cancer, carers and professionals, to identify and prioritise research questions to inform decisions of research funders and support the case for research with this unique cancer population. **DESIGN:** James Lind Alliance Priority Setting Partnership. **SETTING:** UK health service and community. **METHODS:** A steering group oversaw the initiative and partner organisations were recruited. Unanswered questions were collected in an online survey. Evidence searching verified uncertainties. An interim survey was used to rank questions prior to a final prioritisation workshop. **PARTICIPANTS:** Young people aged 13-24 years with a current or previous cancer diagnosis, their families, friends, partners and professionals who work with this population. **RESULTS:** Two hundred and ninety-two respondents submitted 855 potential questions. Following a refining process and removal of 'out of scope' questions, 208 unique questions remained. Systematic evidence checking identified seven answered questions and 16 were the subject of ongoing studies. The interim survey was completed by 174 participants. The top 30 questions were prioritised at a workshop attended by 25 young people, parents and multidisciplinary professionals. The top three priorities are: (1) What psychological support package improves psychological well-being, social functioning and mental health during and after treatment? (2) What interventions, including self-care, can reduce or reverse adverse short-term and long-term effects of cancer treatment? (3) What are the best strategies to improve access to clinical trials? The remaining questions reflect the complete cancer pathway: new therapies, life after cancer, support, education/employment, relapse and end-of-life care. **CONCLUSIONS:** We have identified shared research priorities for young people with cancer using a rigorous, person-centred approach involving stakeholders typically not involved in setting the research agenda. The breadth of priorities suggest future research should focus on holistic and psychosocial care delivery as well as traditional drug/biology research. <https://www.ncbi.nlm.nih.gov/pubmed/31383701>

**Aparicio, M., Centeno, C., Julia, G. and Arantzamendi, M. (2019). "Gratitude from patients and relatives in palliative care-characteristics and impact: a national survey." BMJ Support Palliat Care, 10.1136/bmjspcare-2019-001858.**

**OBJECTIVES:** To explore the expressions of gratitude (EoG) received from patients and relatives and their influence on palliative care professionals (PCPs). **METHODS:** A national online survey was sent to a representative of PCPs of each service listed in the national directory of palliative care (PC) services (n=272) (ie, hospital PC support team, hospice, paediatrics, etc). The questionnaire was pilot tested with experts. It comprised three sections: the overall perspective of receiving gratitude in the service, the personal experience of its influence and sociodemographic questions. A mailing schedule was designed to enhance the response rate. **RESULTS:** 186 representatives from all over Spain completed the questionnaire (68% response rate). 79% of service representatives reported that they almost always received EoG. These came mainly from families (93%). These EoG were very often put on display (84%) and shared with other health professionals (HPs) involved in care (45%). EoG evoked positive feelings in the team members. Based on their experience, respondents attributed different functions to these EoG: increased professional satisfaction (89%), a source of support in difficult times (89%), mood improvement, encouragement to continue and rewards for effort (88%). Services, where gratitude was more frequently received, were associated with PCPs who more frequently reported being proud of their work (p=0.039, Pearson's correlation test). **CONCLUSIONS:** Gratitude from patients and relatives was frequent and significant to those who work in PC. HPs considered that EoG offer multiple beneficial effects and also a protective role in their practice against distress and an increase in resilience skills.

<https://www.ncbi.nlm.nih.gov/pubmed/31471493>

**Benini, F., Cauzzo, C., Congedi, S., Da Dalt, L., Cogo, P., Biscaglia, L. and Giacomelli, L. (2019). "Training in pediatric palliative care in Italy: still much to do." Ann Ist Super Sanita 55(3): 240-245.**

**AIM:** This survey investigated the availability of training programs in pediatric palliative care (PPC) for Italian postgraduates specializing in pediatric medicine. **METHODS:** Two questionnaires were developed: (i) a questionnaire addressed to the Directors of Italian postgraduate pediatric medicine programs (n = 37); and (ii) a survey to the postgraduate students in pediatric medicine at the University Hospitals of Padua and Udine (n = 127). **RESULTS:** 14 directors participated (response rate: 37.8%). In 85.7% of cases (n = 12), lectures on PPC were offered, for a supposed maximum of 90 minutes/year. 116 students responded (response rate: 91%): they stated that, approximately 40 min/year of training on PPC was provided. In total, 37% of responders stated they attended a PPC Service during their training. The majority of responders (68.1%, n = 79) did not feel ready to care for a pediatric patient with life-limiting disease. **CONCLUSIONS:** Although PPC is well-recognized as part of a pediatrician's training, it receives poor attention.

<https://www.ncbi.nlm.nih.gov/pubmed/31553316>

**Berger, I., Thompson, K. and Joubert, L. (2019). "An Exploratory Study into the Experience of Health Care Professionals Caring for Adolescents and Young Adults with Incurable Cancer." J Adolesc Young Adult Oncol 8(4): 458-462.**

Adolescents and young adults 15 to 25 years of age with incurable cancer are a unique patient group. There is growing evidence of the emotionally taxing nature of this work, yet limited understanding of the health care professional experience across professional disciplines. This exploratory study, comprising in-depth semistructured interviews, undertaken at a major cancer center in Melbourne, Australia, describes the challenges facing health care professionals and the factors enabling them to deliver care with greater confidence. The findings provide a platform for further research with key recommendations to enhance the delivery of care to young people with a life-limiting cancer diagnosis.

<https://www.ncbi.nlm.nih.gov/pubmed/30920328>

**Brock, K. E., Tracewski, M., Allen, K. E., Klick, J., Petrillo, T. and Hebbar, K. B. (2019). "Simulation-Based Palliative Care Communication for Pediatric Critical Care Fellows." Am J Hosp Palliat Care 36(9): 820-830.**

**BACKGROUND:** Pediatric palliative care (PPC) education is lacking in pediatric critical care medicine (PCCM) fellowships, despite the desire of many program directors and fellows to expand difficult conversation training. Simulation-based training is an experiential method for practicing challenging communication skills such as breaking bad news, disclosing medical errors, navigating goals of care, and supporting medical decision-making. **METHODS:** We describe a simulation-based PPC communication series for PCCM fellows, including presimulation session, simulation session, debriefing, and evaluation methods. From 2011 to 2017, 28 PCCM fellows participated in a biannual half-day simulation session. Each session included 3 scenarios (allowing for participation in up to 18 scenarios over 3 years). Standardized patients portrayed the child's mother. PCCM and interprofessional PPC faculty cofacilitated, evaluated, and debriefed the fellows after each scenario. Fellows were evaluated in 4 communication categories (general skills, breaking bad news, goals of care, and resuscitation) using a 3-point scale. A retrospective descriptive analysis was conducted. **RESULTS:** One hundred sixteen evaluations were completed for 18 PCCM fellows. Median scores for general communication items, breaking bad news, and goals of care ranged from 2.0 to 3.0 (interquartile range [IQR]: 0-1) with scores for resuscitation lower at 1.0 (IQR: 1.5-2).

**DISCUSSION:** This experiential simulation-based PPC communication curriculum taught PCCM fellows valuable palliative communication techniques although revealed growth opportunities within more complex communication tasks. The preparation, methods, and lessons learned for an effective palliative simulation curriculum can be expanded upon by other pediatric training programs, and a more rigorous research program should be added to educational series.

<https://www.ncbi.nlm.nih.gov/pubmed/30974949>

**Chong, P. H., Walshe, C. and Hughes, S. (2019). "Perceptions of a Good Death in Children with Life-Shortening Conditions: An Integrative Review." J Palliat Med 22(6): 714-723.**

**Background:** For children with life-shortening illness, achieving a "good death" can be a tacit goal. There is little understanding of how different stakeholders perceive what a "good death" might be. **Objective:** To review empirical literature to construct an understanding of a "good death" for children with life-shortening conditions.

Design: An integrative review approach was followed. This involved searching across Embase, Web of Science, Medline, CINAHL, and PsycINFO (no date limits set), as well as identifying eligible studies tracking reference lists. Appraisal of shortlisted articles in full text was performed, followed by data extraction, synthesis, and interpretation. Results: Analysis of articles (n = 24) yielded a dynamic and layered narrative about a good death that revolved around three themes. (1) Level of needs: includes both practical support and aspirational goals such as "do everything." (2) The composite experience: whether positive or negative adds to produce a sense of suffering. (3) Control (preservation and letting go): moving from maintaining status quo to acceptance of the child's death, the experience of which also contributes to suffering. Framed using a health care system perspective, a concept map that interprets a good death in children with life-shortening conditions is represented. Conclusions: A single yet holistic understanding of a good death experienced in the "real world" is suggested. Pediatric health and social care providers, and even policy makers, can use this new understanding to conceive alternative approaches to enhance support to dying children and their families. <https://www.ncbi.nlm.nih.gov/pubmed/30540549>

**Cote, A. J., Payot, A. and Gaucher, N. (2019). "Paediatric palliative care in practice: Perspectives between acute and long-term healthcare teams." Acta Paediatr, 10.1111/apa.14969.**

AIM: To explore and compare acute and long-term care professionals' perspectives about paediatric palliative care. METHODS: Focus group interviews were conducted in 2016-2017 with professionals from acute (Emergency Department, Intensive Care Unit) and long-term care (Complex Care Service, Palliative Care) teams. RESULTS: Fifty-eight participants were enrolled. Palliative care definitions were similar throughout groups: to provide active care early in the illness, focusing on the child as a whole and supporting families. Each group perceived a different role in the patient's illness trajectory, reflecting their own culture of care. They demonstrated important differences in their approach to palliative care. Disagreements regarding when or how to discuss goals of care were expressed. Acute care professionals reported discomfort when having to introduce these discussions for the first time, while long-term care professionals perceived negative judgements about their patients' quality of life by acute care teams during health events. Personalised care, communication with families and continuity of care were thought to be key elements to improve care. CONCLUSION: Paediatric palliative care is well recognised throughout specialties, yet continuity of care is challenged by groups' roles and interventions in a patient's illness. A reflective and mutual clinical approach is needed to improve quality of care and professionals' satisfaction. <https://www.ncbi.nlm.nih.gov/pubmed/31444801>

**Davis, C. S., Snider, M. J., King, L., Shukraft, A., Sonda, J. D., Hicks, L. and Irvin, L. (2019). "A Time to Live and a Time to Die: Heterotopian Spatialities and Temporalities in a Pediatric Palliative Care Team." Health Commun 34(9): 931-941.**

The death of a child creates especially poignant feelings and extreme stress, distress, and devastation for family members and healthcare providers. In addition, serious or long-term illness forces a reconstruction of our experiences with time and

space. In this paper, we report on a long-term ethnographic study of a Pediatric Palliative Care Team (PPCT). Using the concepts of spatiality and temporality; Deleuze's concepts of smooth and striated spaces; Innis's concepts of space and time biases; Foucault's concept of heterotopian space-places with multiple layers of meaning; and a related concept of heterokairoi-moments in time with multiple possibilities-we consider how the PPCT constructs and reconstructs meaning in the midst of chaos, ethical dilemmas, and heartbreaking choices.

<https://www.ncbi.nlm.nih.gov/pubmed/29485293>

**De Clercq, E., Rost, M., Rakic, M., Ansari, M., Brazzola, P., Wangmo, T. and Elger, B. S. (2019). "The conceptual understanding of pediatric palliative care: a Swiss healthcare perspective." BMC Palliat Care 18(1): 55.**

**BACKGROUND:** Health care providers' perception of pediatric palliative care might negatively influence timely implementation. The aim of the study was to examine understanding of and attitudes towards pediatric palliative care from the perspective of health care providers working in pediatric oncology in Switzerland to promote the timely implementation of pediatric palliative care. **METHODS:** Five mixed focus groups were conducted with 29 health care providers (oncologists, nurses, psychologists, and social workers) at five Swiss pediatric oncology group centers. The focus group interviews were analyzed using thematic coding. **RESULTS:** Most participants associated pediatric palliative care with non-curative treatment. They regularly reported difficulties in addressing palliative care services to families due to the strong stigma surrounding this term. They also thought that the notion of palliative care is very much linked to a policy context, and difficult to reconcile with children's everyday life. To overcome these obstacles many participants used synonyms such as comfort or supportive care. A few providers insisted on the need of using palliative care and reported the importance of positive "word of mouth". **CONCLUSIONS:** The use of synonyms might be a pragmatic approach to overcome initial barriers to the implementation of palliative care in pediatrics. However, this tactic might ultimately prove to be ineffective as these terms might acquire the same negative connotations as palliative care. Positive word-of-mouth by satisfied families and healthcare providers might be a more sustainable way to advocate for pediatric palliative care than replacing it with a euphemistic term.

<https://www.ncbi.nlm.nih.gov/pubmed/31296209>

**Dimoula, M., Kotronoulas, G., Katsaragakis, S., Christou, M., Sgourou, S. and Patiraki, E. (2019). "Undergraduate nursing students' knowledge about palliative care and attitudes towards end-of-life care: A three-cohort, cross-sectional survey." Nurse Educ Today 74: 7-14.**

**BACKGROUND:** Ensuring adequate knowledge about palliative care and positive attitudes towards death and dying are crucial educational aspects when preparing undergraduate nursing students to respond effectively to the complexities of care for people affected by a progressive, life-limiting illness. In undergraduate nursing education in Greece, the level of students' attained knowledge and developed attitudes towards palliative and end-of-life care remain unknown. **PURPOSE:** To investigate undergraduate nursing students' knowledge about palliative care and attitudes towards death and end-of-life care, and explore demographic and academic factors as potential moderators of student knowledge and attitudes. **METHODS:** We

conducted a descriptive, cross-sectional, questionnaire-based survey. We recruited 2nd, 3rd and 4th year undergraduate nursing students from the country's two University Faculties. Participants completed a demographic form, the Palliative Care Quiz for Nursing (PCQN), and the Frommelt Attitudes Towards Care of the Dying (FATCOD) questionnaire. RESULTS: The final sample was 529 students (response rate=87.6%). Mean total PCQN scores revealed low levels of knowledge. Knowledge about pain/symptom management and psychosocial/spiritual care was insufficient. Mean total FATCOD scores indicated positive, liberal and supportive attitudes towards end-of-life care, with 60% of respondents keen to care for a dying person and their family. We noted less positive attitudes mainly in relation to student comfort with the care of a dying person and his/her imminent death. Academic parameters (year of study) and student demographic characteristics (older age) were the most significant moderators of both knowledge and attitudes. Greater knowledge about palliative care was a relatively weak, yet significant, predictor of more liberal attitudes towards care of the dying. CONCLUSION: Our findings suggest that structured courses in palliative care can be a core part of undergraduate nursing education. Specific attention could be given to such areas patient-health professional communication, misconceptions and biases towards death and dying, and comfort in caring for the dying in order to prepare student nurses to psychologically deal with the sensitive and challenging process of death and dying.

<https://www.ncbi.nlm.nih.gov/pubmed/30554033>

**Dopson, S. and Long-Sutehall, T. (2019). "Exploring nurses' knowledge, attitudes and feelings towards organ and tissue donation after circulatory death within the paediatric intensive care setting in the United Kingdom: A qualitative content analysis study." Intensive Crit Care Nurs 54: 71-78.**

OBJECTIVE: This study explored nurses' knowledge, attitudes and feelings towards donation after circulatory death identifying these domains as barriers and facilitators to nurses effectively undertaking their role in the donation after circulatory death donation process. DESIGN: A single-phase qualitative study design. SETTING: One paediatric cardiac intensive care unit in a tertiary paediatric hospital in England. METHODS: Data was collected from eight paediatric cardiac intensive care nurses using semi-structured face to face or telephone interviews facilitated by a clinical vignette. Qualitative content analysis was undertaken adopting both inductive and deductive lenses. KEY FINDINGS: Three categories were deductively generated within which eleven inductively generated themes were situated. Barriers included: knowledge deficits of both process and resources; assumptions about parental views and reluctance to facilitate sensitive discussions, facilitators included positive attitudes toward donation aligned with a strong professional ethos and family-centred values. CONCLUSIONS: The paper identifies barriers to the donation after circulatory death process including nurses feeling unprepared for their role, anxiety over family approach and communication methods and support. Highlighted is the need for specific educational interventions, appropriate resources and development of paediatric focussed policy to guide practice. Facilitators to donation include timely, sensitive and appropriate family discussions, trusting nurse-family relationships and improved public awareness.

<https://www.ncbi.nlm.nih.gov/pubmed/31350064>

**Fadadu, P. P., Liu, J. C., Schiltz, B. M., Xoay, T. D., Phuc, P. H., Kumbamu, A. and Ouellette, Y. (2019). "A Mixed-Methods Exploration of Pediatric Intensivists' Attitudes toward End-of-Life Care in Vietnam." J Palliat Med 22(8): 885-893.**

Background: Although the need for palliative care is gaining recognition in Southeast Asia, knowledge about how decisions are made for children near the end of life remains sparse. Objective: To explore pediatric intensivists' attitudes and practices surrounding end-of-life care in Vietnam. Methods: This is a mixed-methods study conducted at a tertiary pediatric and neonatal intensive care unit in Hanoi. Physicians and nurses completed a quantitative survey about their views on end-of-life care. A subset of these providers participated in semistructured interviews on related topics. Analysis of surveys and interviews were conducted. Results were triangulated. Results: Sixty-eight providers (33 physicians and 35 nurses) completed the quantitative survey, and 18 participated in interviews. Qualitative data revealed three overarching themes with numerous subthemes and supporting quotations. The first theme was factors influencing providers' decision-making process to escalate or withdraw treatment. Quantitative data showed that 40% of providers valued the family's ability to pay to continue life-sustaining treatment. Second, communication dynamics in decision making were highlighted; 72% of providers would be willing to override a family's wishes to withdraw life-sustaining treatment. Third, provider perceptions of death varied, with 68% regarding their patients' deaths as a personal failure. Conclusions: We elicited and documented how pediatric intensivists in Vietnam currently think about and provide end-of-life care. These findings indicate a need to strengthen palliative care training, increase family involvement in decision making, implement standardized and official do-not-resuscitate documentation, and expand pediatric hospice services at the individual, hospital, and national levels in Vietnam.

<https://www.ncbi.nlm.nih.gov/pubmed/30724688>

**Fernando, G. and Prathapan, S. (2019). "What do young doctors know of palliative care; how do they expect the concept to work? : A 'palliative care' knowledge and opinion survey among young doctors." BMC Res Notes 12(1): 419.**

OBJECTIVES: Discipline of palliative care is still evolving in developed parts of the world while it remains at an infantile stage in Sri Lanka which has not been formally assessed as of today. We aimed at evaluating the level of palliative care knowledge and opinions among young medical graduates. A descriptive cross-sectional study was carried out among pre-residency medical graduates of Sri Lanka through a social media based online survey. The pre-tested questionnaire assessed the level of knowledge on general principles, service organization, clinical management and ethical considerations while it also evaluated their opinions. RESULTS: Response rate was 35.8% (n = 351). The average score among the respondents was 37.25% [standard deviation (SD) = 11.975]. Specific knowledge on "general principles" was adequate (score  $\geq$  50%) with an average of 62.61%, SD = 24.5 while "ethics" was observed to be the area with the poorest knowledge (average score = 19.55%, SD = 22). Average scores for "service organization" and "managerial aspects" were 34.54%, SD = 17.6 and 32.26%, SD = 22.3, respectively. The majority (> 90%) believed that de-novo establishment of hospice, hospital and community-based

palliative services would sustainably improve holistic patient care. Measures must be taken to optimize basic palliative care knowledge among the undergraduates in view of achieving Universal Health Coverage in the long term.

<https://www.ncbi.nlm.nih.gov/pubmed/31311576>

**Feudtner, C., Rosenberg, A. R., Boss, R. D., Wiener, L., Lyon, M. E., Hinds, P. S., Bluebond-Langner, M. and Wolfe, J. (2019). "Challenges and Priorities for Pediatric Palliative Care Research in the U.S. and Similar Practice Settings: Report From a Pediatric Palliative Care Research Network Workshop." J Pain Symptom Manage 58(5): 909-917.e903.**

CONTEXT: To dramatically advance the evidence base for pediatric palliative care (PPC) interventions, practices, and programs in the U.S. and similar practice settings, the field needs to better understand the challenges and opportunities for rigorous scholarship. OBJECTIVES: The Pediatric Palliative Care Research Network conducted a workshop to clarify challenges and identify key priorities. METHODS: The workshop focused on PPC research topics and methods, including outcomes measurement, qualitative inquiry, analyses of big data, prospective collection of research data, case series and cohort studies, and intervention trials, with synthesizing summary and follow-up discussions. All attendees reviewed and approved the final report. RESULTS: Five common challenges were identified: patient diversity and small population size; interdependencies and dynamic interactions between child, family members, and disease processes over time; outcomes and measurement; workforce and infrastructure limitations; and presumed burden of PPC research on participants. Seven priorities emerged: bolster training and development of PPC investigators; develop core resources; advance symptom measurement (and measurements of other exposures and outcomes); improve symptom management and quality of life interventions; improve communication, elicitation of goals of care, and decision making; understand family impact and facilitate or improve family adaptation and coping; and analyze and improve systems of care, policy, and education. CONCLUSION: These challenges and priorities identify key research areas that can guide individual investigators and research funders to advance the field.

<https://www.ncbi.nlm.nih.gov/pubmed/31445136>

**Flannery, R. B., Jr. and Lomke, E. (2019). "SUDEP and Grief: Overview and Current Issues." Psychiatr Q 90(1): 129-136.**

The medical community and the general public are aware of sudden deaths in apparently healthy infants (SIDS) and in cases of cardiac arrest (SCD). However, there is a third, less-well known, form of sudden death that occurs in persons with epilepsy (SUDEP). This paper provides a detailed overview what is known about SUDEP, including the current important, unresolved issues being considered in the field (research, education, informed consent). This paper also includes an overview of the grieving process common to all three conditions. Again, the current issues being considered in the field of grieving are presented (major depression, posttraumatic stress disorder). It is written for physicians, including psychiatrists, and for the health community beyond neurologists and serves as a provider resource for persons with epilepsy, their families, and for the general public. This information

about SUDEP and grief becomes also additionally important as national health care moves toward an interdisciplinary primary care model of service delivery.

<https://www.ncbi.nlm.nih.gov/pubmed/30338420>

**Fleishman, R. (2019). "Deaths in the Neonatal ICU: A vignette." J Palliat Care 34(3): 208-209.**

A narrative account of several deaths in the neonatal intensive care unit,,detailing the author's journey in leading others through this process.

<https://www.ncbi.nlm.nih.gov/pubmed/30845876>

**Fujita, A. and Hamada, Y. (2019). "Bereavement care in Japanese pediatrics: Pediatrician awareness in practice." Pediatr Int 61(7): 658-663.**

**BACKGROUND:** A child's death affects not only family members but also the health-care professionals involved in patient care. The education system for bereavement care in Japan, however, is not set up in a systematic way, and the care provided is based on the individual experience of the health-care professional. The aim of this study was to investigate pediatrician awareness of and actual circumstances involved in bereavement care in Japan. **METHODS:** A qualitative descriptive study was conducted at four facilities in Japan. Data collected using semi-structured interviews of 11 pediatricians were assessed using inductive qualitative analysis. **RESULTS:** Pediatrician recognition of the elements of bereavement care was categorized as follows: (i) developing relationships with families before a child's death is important in bereavement care; (ii) after the child dies, family involvement is left to the doctor's discretion; (iii) coping with a child's death myself through past experience is essential; (iv) doctors involved in a child's death also experience mental burden; and (v) a system for the family's bereavement care must be established. Two categories were established according to actual circumstances involved in bereavement care: (i) attention must be given to the emotions of the families who lost a child; and (ii) doctor involvement with bereaved families depends on doctor awareness and expertise. **CONCLUSION:** Japanese pediatricians provided bereavement care to families who lost their children in a non-systematic manner. This necessitates improvement of the self-care of health-care professionals with regard to grief by improving bereavement care-related education. Additionally, health-care professionals must be trained, and a national-level provision system must be established to provide high-quality bereavement care to families who lose a child.

<https://www.ncbi.nlm.nih.gov/pubmed/31102485>

**Gofton, T. E., Wong, N., Hirsch, L. J. and Hocker, S. E. (2019). "Communication Challenges: A Spotlight on New-Onset Refractory Status Epilepticus." Mayo Clin Proc 94(5): 857-863.**

New-onset refractory status epilepticus (NORSE) is a rare, potentially devastating condition that occurs abruptly in previously healthy patients of any age but most commonly in children and young adults. It has an unpredictable clinical course requiring immediate, often prolonged, critical care support with multiple specialists involved and frequently results in severe life-altering sequelae or death.

Communication in NORSE is challenging because its etiology in a given patient is

initially unknown (and often remains so), the clinical course and outcome are unpredictable, and many health care team members are involved in the care of a patient. We address the communication challenges seen in NORSE through proactive communication on 3 levels: (1) in the shared decision-making process with the family, (2) within an individual hospital, and (3) across institutions. Intentional organizational change and enhanced information dissemination may help break down barriers to effective communication. Key initiatives for enhancing information dissemination in NORSE are (1) the identification of a most responsible physician to integrate information from subspecialties, to communicate frequently and candidly with the family, and to provide continuity of care over a prolonged period of time and (2) the early involvement of palliative care services alongside ongoing therapies with curative intent to support families and the medical team in decision making and communication.

<https://www.ncbi.nlm.nih.gov/pubmed/30935709>

**Gough, N., Ross, J. R., Riley, J., Judson, I. and Koffman, J. (2019). "When something is this rare ... how do you know bad really is bad...?'-views on prognostic discussions from patients with advanced soft tissue sarcoma." BMJ Support Palliat Care 9(1): 100-107.**

**OBJECTIVES:** Prognostic disclosure among patients with cancer permits open informed discussion about treatment preferences and encourages advance care planning. In rare cancers such as soft tissue sarcoma, discussions regarding prognostication are challenging. Little is known about the consequences of this for patients or their preferences for such information. This qualitative study explores patient-centered accounts of the value and timing of prognostic discussions. **METHODS:** 24 semistructured interviews were conducted with soft tissue sarcoma patients attending one London cancer centre: 66% female, median age 53 (range 19-82). The study was cross-sectional and participants were at different stages of the advanced disease trajectory. Interviews were digitally recorded, transcribed verbatim and analysed thematically using the framework approach. **RESULTS:** All participants understood the incurable nature of advanced sarcoma. However, prognostic discussions were rare, always patient initiated and did not include known survival data, despite direct participant enquiry. Most participants did not wish to discuss prognosis at initial diagnosis but wished to be offered the opportunity to discuss this at intervals of disease progression, despite reservations it may not be helpful. Participants expected discussions to be clinician initiated. Three themes emerged to explain this position and included (1) Rarity causing prognostic uncertainty referring to patient belief that prognostication in rare cancers was less likely to be accurate than for common tumours; (2) Avoiding the negatives referring to a wish not to hear unfavourable information and (3) Physical symptoms a better prognostic indicator than 'physician guess'. **CONCLUSIONS:** Although 17/24 participants preferred not to discuss prognosis at initial diagnosis, they wished to have the opportunity to revisit prognostic discussions at intervals of disease progression. This may facilitate better advance care planning and end of life care.

<https://www.ncbi.nlm.nih.gov/pubmed/26715566>

**Guillaume, A. W. D., Miller, A. C. and Nguyen, M. C. (2019). "Enterocolitis in a Child With Hirschsprung Disease." Pediatr Emerg Care 35(7): e131-e132.**

Hirschsprung disease is a congenital abnormality that can be surgically corrected. However, Hirschsprung-associated enterocolitis can be a life-threatening sequela. Very little has been published in the emergency medicine literature about the risk of enterocolitis and shock in patients with a history of Hirschsprung disease. We describe the case of a 6-month-old male infant with a history of multiple surgeries for Hirschsprung disease who presented to the emergency department with a seemingly benign viral gastrointestinal illness. His stable condition led him to be discharged. However, 4 days later, he returned to the emergency department with severe diarrhea and was subsequently admitted to the pediatric intensive care unit for the management of enterocolitis and shock. With this case report, we aim to raise emergency physicians' awareness of the serious and possibly fatal complications of Hirschsprung disease. We argue that this single element of a patient's medical history can alter the management of seemingly simple viral gastrointestinal illnesses; rather than be discharged, such a patient requires surgical consultation and possibly admission for close monitoring and treatment.

<https://www.ncbi.nlm.nih.gov/pubmed/28328696>

**Hassankhani, H., Rahmani, A., Taleghani, F., Sanaat, Z. and Dehghannezhad, J. (2019). "Palliative Care Models for Cancer Patients: Learning for Planning in Nursing (Review)." J Cancer Educ, 10.1007/s13187-019-01532-3.**

Cancer is the second cause of mortality in the world. Increased incidence of cancer and its growing trend have drawn attention to care for these patients. Palliative care is a solution for improving the quality of cancer care. However, only 14% of cancer patients in the world are receiving palliative care and most nurses lack the adequate knowledge and education to implement different palliative care models for cancer patients. This review of the literature intended to identify the palliative care models used by nurses for cancer patients as well as the similarities and differences between these models. Databases such as PubMed, ProQuest, google scholar, and CINAHL were searched, and experimental studies that presented palliative care models for cancer patients that nurses were involved were selected. From a total of articles selected by searching the databases, 16 experimental articles were selected. These articles presented 12 palliative care models that involved nurses and participants were cancer patients. The palliative care models presented in the experimental articles were based on hospice, hospital, home care, ambulatory, community, pediatric, spirituality, early, family, telehealth, dignity, and integrated. It was found out that several palliative care nursing models for cancer patients can be employed by nurses as they are the key agents in the provision of palliative care. The collaborative nature of the models, their positive consequences for patients being common components of models, and the implementation of the models considering the disease trajectory were among their distinctions.

<https://www.ncbi.nlm.nih.gov/pubmed/31020622>

**Hill, D. L., Walter, J. K., Szymczak, J. E., DiDomenico, C., Parikh, S. and Feudtner, C. (2019). "Seven Types of Uncertainty When Clinicians Care for Pediatric Patients With Advanced Cancer." J Pain Symptom Manage, 10.1016/j.jpainsymman.2019.08.010.**

CONTEXT: Clinicians deciding whether to refer a patient or family to specialty palliative care report facing high levels of uncertainty. Most research on medical

uncertainty has focused on prognostic uncertainty. As part of a pediatric palliative referral intervention for oncology teams we explored how uncertainty might influence palliative care referrals. OBJECTIVES: To describe distinct meanings of the term "uncertainty" that emerged during the qualitative evaluation of the development and implementation of an intervention to help oncologists overcome barriers to palliative care referrals. METHODS: We conducted a phenomenological qualitative analysis of "uncertainty" as experienced and described by interdisciplinary pediatric oncology team members in discussions, group activities and semistructured interviews regarding the introduction of palliative care. RESULTS: We found that clinicians caring for patients with advanced cancer confront seven broad categories of uncertainty: prognostic, informational, individual, communication, relational, collegial, and inter-institutional. Each of these kinds of uncertainty can contribute to delays in referring patients to palliative care. CONCLUSION: Various types of uncertainty arise in the care of pediatric patients with advanced cancer. To manage these forms of uncertainty, providers need to develop strategies and techniques to handle professionally challenging situations, communicate bad news, manage difficult interactions with families and colleagues, and collaborate with other organizations. <https://www.ncbi.nlm.nih.gov/pubmed/31020622>

**Hopper, A. and Crane, S. (2019). "Evaluation of the burdens and benefits of participation in research by parents of children with life-limiting illnesses." *Nurse Res* 27(3): 8-13.**

BACKGROUND: Research is needed to improve care and diminish suffering for children with life-limiting illnesses and their parents. However, there are doubts about whether it is possible to conduct paediatric end of life research safely and ethically, as it may unduly burden or inadvertently harm participants. AIM: To compare and evaluate responses from participants to the assessments of burdens and benefits that were conducted at two timepoints during a phenomenological study that investigated parents' experiences of having a child with life-limiting cancer participate in a Phase I clinical trial. DISCUSSION: Parents reported that participating in the study was beneficial and resulted in minimal burden or distress. The assessment of benefits and burdens at the first timepoint appeared sufficient to understand participants' experiences. CONCLUSION: This study adds to the evidence that research may be safely and effectively conducted with parents of children who are deceased or have life-limiting illnesses. Further research is needed to evaluate the most effective timing of assessments of the burdens and benefits of their participation in research. IMPLICATIONS FOR PRACTICE: It is important when conducting research with people with life-limiting illnesses or their family members to assess the burdens and benefits of their participation, to understand their experiences and assist in its conduct. <https://www.ncbi.nlm.nih.gov/pubmed/31468872>

**Jankovic, M., De Zen, L., Pellegatta, F., Lazzarin, P., Bertolotti, M., Manfredini, L., Aprea, A., Memo, L., Del Vecchio, A., Agostiniani, R. and Benini, F. (2019). "A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy." *Ital J Pediatr* 45(1): 89.**

BACKGROUND: The definition of the eligibility criteria of newborn, infant, child, or adolescent patients for palliative care (PC) is complicated by the fact that these

patients generally present with very specific case histories that make it inadvisable to directly adopt existing PC protocols devised for adult patients. Thus, the goal of this paper is to define a standard set of criteria for establishing pediatric palliative care (PPC) eligibility. **METHODS:** The method adopted was that of the consensus conference. According to the guidelines issued by the Higher Institute of Health, the Board of the Italian Society for Palliative Care (i.e. steering committee) appointed a multidisciplinary group of eight health care professionals (i.e. doctors, nurses and psychologists) who worked from May 2014 to February 2016 to reach a consensus over PPC eligibility. This panel of relevant experts redacted a report summarizing all available scientific information concerning PPC, which was then submitted to the attention of a multidisciplinary jury composed of specialists and non-specialists of the field. The document thus produced was subsequently reviewed by an extended team of experts. **RESULTS:** The consensus conference drafted a final document determining the guidelines for PPC eligibility of newborns, infants, children, and adolescents suffering from either oncological or non-oncological diseases. **CONCLUSIONS:** This report provides health care providers with practical guidelines on how to define the eligibility of pediatric patients for PPC. Given the current situation in Italy, these guidelines will be instrumental in assisting the implementation of adequate generalist and specialist PPC services as well as in helping policymakers draft and implement national legislation pertaining to PPC. <https://www.ncbi.nlm.nih.gov/pubmed/31331362>

**Janvier, A., Farlow, B., Barrington, K. J., Bourque, C. J., Brazg, T. and Wilfond, B. (2019). "Building trust and improving communication with parents of children with Trisomy 13 and 18: A mixed-methods study." Palliat Med, 10.1177/0269216319860662: 269216319860662.**

**BACKGROUND:** Trisomy 13 and trisomy 18 are common life-limiting conditions associated with major disabilities. Many parents have described conflictual relationships with clinicians, but positive and adverse experiences of families with healthcare providers have not been well described. **AIM:** (1) To investigate parental experiences with clinicians and (2) to provide practical recommendations and behaviors clinicians could emulate to avoid conflict. **DESIGN:** Participants were asked to describe their best and worse experiences, as well as supportive clinicians they met. The results were analyzed using mixed methods. **SETTING/PARTICIPANTS:** Parents of children with trisomy 13 and 18 who were part of online social support networks. A total of 503 invitations were sent, and 332 parents completed the questionnaire about 272 children. **RESULTS:** The majority of parents (72%) had met a supportive clinician. When describing clinicians who changed their lives, the overarching theme, present in 88% of answers, was trust. Parents trusted clinicians when they felt he or she cared and valued their child, their family, and made them feel like good parents (69%), had appropriate knowledge (66%), and supported them and gave them realistic hope (42%). Many (42%) parents did not want to make-or be part of-life-and-death decisions. Parents gave specific examples of supportive behaviors that can be adopted by clinicians. Parents also described adverse experiences, generally leading to conflicts and lack of trust. **CONCLUSION:** Realistic and compassionate support of parents living with children with trisomy 13 and 18 is possible. Adversarial interactions that lead to distrust and conflicts can be avoided. Many supportive behaviors that inspire trust can be emulated.

<https://www.ncbi.nlm.nih.gov/pubmed/31280664>

**Jiang, Q., Lu, Y., Ying, Y. and Zhao, H. (2019). "Attitudes and knowledge of undergraduate nursing students about palliative care: An analysis of influencing factors." Nurse Educ Today 80: 15-21.**

**BACKGROUND:** With the growing aging population, continual increase of the number of the old, and increase of cancer survival rate, palliative care is being considered a global public health issue. As a core force for the sustainable development of the nursing field, undergraduate nursing students' knowledge about and attitudes toward palliative care will directly affect the quality of care for dying patients in the future. **OBJECTIVE:** To investigate undergraduate nursing students' knowledge about and attitudes toward palliative care and analyze their influencing factors. **METHODS:** This descriptive and cross-sectional survey was conducted in 2016. A total of 1200 Chinese undergraduate nursing students were randomly selected as the survey subjects using stratified sampling method. The revised palliative care quiz for nursing (PCQN) and a self-designed questionnaire were used to measure students' knowledge and attitudes. **RESULTS:** The mean score of the revised PCQN was 16.10+/-5.04. Only a few respondents (19.8%) expressed desire to work in palliative care in the future. The findings show that knowledge and school, grade, gender, birthplace, and religious beliefs have statistically significant impacts ( $P<0.01$ ). In addition, logistic regression analysis showed that talking about death and caring for dying family members can have a significant influence on students' attitudes ( $P<0.05$ ). **CONCLUSION:** At present, Chinese undergraduate nursing students' knowledge about palliative care is minimal with the majority holding negative attitudes. Thus, the development of an effective end-of-life care program for nursing students is critical.

<https://www.ncbi.nlm.nih.gov/pubmed/31203031>

**Jones, T. A., Olds, T. S., Currow, D. C. and Williams, M. T. (2019). "Use of time in people with a life-limiting illness: A longitudinal cohort feasibility pilot study." Palliat Med, 10.1177/0269216319867214: 269216319867214.**

**BACKGROUND:** To date, time-use studies in palliative care have been limited to exploration of time commitments of caregivers. Understanding time-use in people with a life-limiting illness might provide insight into disease progression, symptom management and quality of life. **AIM:** To determine the feasibility of a repeated-measures, time-use study in people with a life-limiting illness, and their primary caregivers, and to explore associations between time-use and perceived quality of life. **DESIGN:** An observational repeated-measures feasibility pilot study. A priori criteria were established for study uptake (70%), retention (80%) and study value/burden (7 Numerical Rating Scale 0-10). Burden and value of the study, use of time (Multimedia Activity Recall for Children and Adults with adjunctive accelerometry) and quality of life data (EuroQol-5 Dimension-5-Level Health Questionnaire and Australia-modified Karnofsky Performance Status scale) were assessed at time-points across five consecutive months. **SETTING/PARTICIPANTS:** People living with a life-limiting illness and caregivers recruited from Southern Adelaide Palliative Services outpatient clinics. **RESULTS:** A total of 10 participants (2 caregivers and 8 people with a life-limiting illness) enrolled in the study. All but one of the criteria thresholds was met: 66% of participants who consented to be screened

were enrolled in the study, 80% of enrolled participants (n = 8) completed all assessments (two participants died during the study) and mean Numerical Rating Scale scores for acceptable burden and value of the study exceeded the criteria thresholds at every time-point. CONCLUSION: A repeated-measures time-use study design is feasible and was not unduly burdensome for caregivers and people living with a life-limiting illness.

<https://www.ncbi.nlm.nih.gov/pubmed/31368843>

**Kase, S. M., Waldman, E. D. and Weintraub, A. S. (2019). "A cross-sectional pilot study of compassion fatigue, burnout, and compassion satisfaction in pediatric palliative care providers in the United States." Palliat Support Care 17(3): 269-275.**

OBJECTIVE: Compassion fatigue (CF) is secondary traumatic distress experienced by providers from contact with patients' suffering. Burnout (BO) is job-related distress resulting from uncontrollable workplace factors that manifest in career dissatisfaction. Compassion satisfaction (CS) is emotional fulfillment derived from caring for others. The literature on BO in healthcare providers is extensive, whereas CF and CS have not been comprehensively studied. Because of ongoing exposure to patient and family distress, pediatric palliative care (PPC) providers may be at particular risk for CF. We conducted a cross-sectional pilot study of CF, BO, and CS among PPC providers across the United States. METHOD: The Compassion Fatigue and Satisfaction Self-Test for Helpers and a questionnaire of professional and personal characteristics were distributed electronically and anonymously to PPC physicians and nurses. Logistic and linear regression models for CF, BO, and CS as a function of potential risk factors were constructed. RESULTS: The survey response rate was 39%, primarily consisting of female, Caucasian providers. The prevalence of CF, BO, and CS was 18%, 12%, and 25%, respectively. Distress about a "clinical situation," physical exhaustion, and personal loss were identified as significant determinants of CF. Distress about "coworkers," emotional depletion, social isolation, and "recent involvement in a clinical situation in which life-prolonging activities were not introduced" were significant determinants of BO. Physical exhaustion, personal history of trauma, "recent involvement in a clinical situation in which life-prolonging activities were not introduced," and not discussing distressing issues were significant predictors of lower CS scores. Significance of results CF and BO directly influence the well-being and professional performance of PPC providers. To provide effective compassionate care to patients, PPC providers must be attentive to predictors of these phenomena. Further work is needed to explore additional causes of CF, BO, and CS in PPC providers as well as potential interventions.

<https://www.ncbi.nlm.nih.gov/pubmed/29397055>

**Kaufman, B. D., Hollander, S. A., Zhang, Y., Chen, S., Bernstein, D., Rosenthal, D. N., Almond, C. S., Murray, J. M., Burgart, A. M., Cohen, H. J., Kirkpatrick, J. N. and Blume, E. D. (2019). "Compassionate deactivation of ventricular assist devices in children: A survey of pediatric ventricular assist device clinicians' perspectives and practices." Pediatr Transplant 23(3): e13359.**

OBJECTIVES: This study's objective was to investigate compassionate ventricular assist device deactivation (VADdeact) in children from the perspective of the pediatric heart failure provider. BACKGROUND: Pediatric VAD use is a standard

therapy for advanced heart failure. Serious adverse events may affect relative benefit of continued support, leading to consideration of VADdeact. Perspectives and practices regarding VADdeact have been studied in adults but not in children. METHODS: A web-based anonymous survey of clinicians for pediatric VAD patients (<18 years) was sent to list-serves for the ISHLT Pediatric Council, the International Consortium of Circulatory Assist Clinicians Pediatric Taskforce, and the Pediatric Cardiac Intensivist Society. RESULTS: A total of 106 respondents met inclusion criteria of caring for pediatric VAD patients. Annual VAD volume per clinician ranged from <4 (33%) to >9 (20%). Seventy percent of respondents had performed VADdeact of a child. Response varied to VADdeact requests by parent or patient and was influenced by professional degree and region of practice. Except for the scenario of intractable suffering, no consensus on VADdeact appropriateness was reported. Age of child thought capable of making informed requests for VADdeact varied by subspecialty. The majority of respondents (62%) do not feel fully informed of relevant legal issues; 84% reported that professional society supported guidelines for VADdeact in children had utility. CONCLUSION: There is limited consensus regarding indications for VADdeact in children reported by pediatric VAD provider survey respondents. Knowledge gaps related to legal issues are evident; therefore, professional guidelines and educational resources related to pediatric VADdeact are needed.

<https://www.ncbi.nlm.nih.gov/pubmed/30734422>

**Kaulfus, M. E., Gardiner, H., Hashmi, S. S., Mendez-Figueroa, H., Miller, V. J., Stevens, B. and Carter, R. (2019). "Attitudes of clinicians toward cardiac surgery and trisomy 18." J Genet Couns 28(3): 654-663.**

Trisomy 18 is an autosomal trisomy condition characterized by minor to major birth defects, severe disabilities, and high rates of pre- and postnatal mortality. Interventions for these infants have traditionally been withheld with focus instead on palliative support. The issues and attitudes surrounding corrective surgery of congenital heart defects, which is a birth defect that occurs in approximately 90% of infants with trisomy 18, is of our study's interest as recent literature has indicated that cardiac surgery is being performed and may lead to improved survival compared to palliative care. Thus, our study aimed to describe clinician attitudes toward cardiac surgery and trisomy 18. We surveyed 378 clinicians from multiple specialties, including genetic counselors, involved in the pre- and postnatal care of infants with trisomy 18. Descriptive statistics were performed to describe all clinicians' responses, and a secondary analysis with stratifications by clinician type was also performed. Forty-eight percent (n = 378) of clinicians felt it was appropriate to discuss the option of cardiac surgery. Ethical concerns and insufficient outcome data were the most agreed upon reasons for not offering cardiac surgery. Trisomy 18 not being uniformly lethal and expressed parental wishes were the most agreed upon justifications for offering surgery. Clinicians felt the discussion of the option of cardiac surgery is appropriate, however are hesitant due to ethical concerns and insufficient outcome data. Results from this study aim to promote discussion and collaboration among clinicians to improve consistency in patient care.

<https://www.ncbi.nlm.nih.gov/pubmed/30688390>

**Kaye, E. C., Applegarth, J., Gattas, M., Kiefer, A., Reynolds, J., Zalud, K. and Baker, J. N. (2019). "Hospice nurses request paediatric-specific educational**

**resources and training programs to improve care for children and families in the community: Qualitative data analysis from a population-level survey." *Palliat Med*, 10.1177/0269216319866576: 269216319866576.**

**BACKGROUND:** Children with serious illness who receive hospice care often interface with nurses who lack training, experience and comfort in the provision of paediatric palliative and hospice care. Hospice nurse preferences for paediatric-specific training are not well known. **AIM:** To describe the types of paediatric-specific training received and educational content preferred by hospice nurses. **DESIGN:** Population-level dissemination of a cross-sectional survey with qualitative analysis of open-ended survey items. **SETTING/PARTICIPANTS:** Nurses from 71 community-based hospice organizations across 3 states completed the survey. **RESULTS:** An open-ended response was provided by 278/551 (50.5%) survey respondents. A total of 55 respondents provided 58 descriptions of prior paediatric-specific training, including a formal 2-day course (n = 36; 65.5%), on-the-job education (n = 13, 23.6%), online training (n = 5, 9.1%), nursing school (n = 2, 3.6%) and paediatric advanced life support courses (n = 2, 3.6%). A total of 67 respondents described 74 hospice-led educational efforts, largely comprised of a 2-day course (n = 39; 54.2%) or provision of written materials (n = 11; 15.3%). A total of 189 respondents described 258 preferences for paediatric-specific training, with nearly half (n = 93; 49.2%) requesting 'any' or 'all' types of education and the remainder requesting education around medication use (n = 48; 25.4%), symptom assessment/management (n = 32; 16.9%), pain assessment/management (n = 28; 14.8), communication (n = 29; 15.3%) and psychosocial assessment/management (n = 28; 14.8). **CONCLUSIONS:** Hospice nurses self-report inadequate exposure to educational resources and programs, in conjunction with a strong desire for increased paediatric-specific training. Identification of targetable gaps should inform the development of educational resources, policies and other supportive interventions to improve delivery of care to children and families in the community. <https://www.ncbi.nlm.nih.gov/pubmed/31347446>

**Kukora, S., Keefer, P., Pituch, K. and Firn, J. (2019). "Thematic Analysis of Interprofessional Provider Perceptions of Pediatric Death." *J Pediatr Nurs* 47: 92-99.**

**PURPOSE:** Though provider and patient perceptions of death are characterized in the adult population literature, there is limited information related to providers' perceptions in pediatric and neonatal patients. The purpose of this study was to better understand how interprofessional care team members perceive and experience neonatal and pediatric end-of-life situations. **DESIGN AND METHODS:** This survey questionnaire was administered to interprofessional providers following their participation in an institutional workshop, as part of an ongoing institutional effort to improve end-of-life experiences for patients/family and providers. Interprofessional care providers completed an electronic survey consisting of closed-ended and one open-ended question to elicit their perceptions of their participation in end of life care for a recent neonatal/pediatric patient in the period before the child's death. **RESULTS:** The qualitative analysis of 306 free-text responses commenting on the deaths of 138 patients, contained within 880 completed mixed-method surveys, is described. Thematic analysis of the free text discovered three primary themes from the data: favorable aspects of the death experience, unfavorable

aspects of the experience, and combined favorable and unfavorable aspects. Four subthemes contributed to the themes; namely, language, parental presence, trust/rapport in provider relationships and inclusion in decision-making, communication, and culture. CONCLUSIONS: Multiple factors contribute to how interprofessional care providers perceive end-of-life care experiences for neonatal/pediatric patients. The same death may be perceived differently by different providers. PRACTICE IMPLICATIONS: Understanding favorable and unfavorable aspects of providing end-of-life care will support strategies to provide resources, education and support to facilitate coping and resiliency in care providers.

<https://www.ncbi.nlm.nih.gov/pubmed/31082685>

**Lord, B. (2019). "Parent Perspective and Response to Challenges and Priorities for Pediatric Palliative Care Research." J Pain Symptom Manage 58(5): e9-e10.**

**Mahoney, D. P., Brook, I., Fossa, M. and Kang, T. (2019). "Attempting to Define Clinical Productivity Metrics among Pediatric Palliative Care Services at Academic Children's Hospitals." J Palliat Med, 10.1089/jpm.2019.0164.**

Introduction: Pediatric palliative care (PPC) programs have grown in size and number at academic children's hospitals in the United States for the past 20 years. Little is known about the relationships between program workforce staffing, billing and coding practices, clinical service requirements for billing providers, and sustainability of program models for billing providers. Methods: The authors contacted a convenience sample of 10 PPC program leaders at academic children's hospitals in the United States. Program leaders were asked to provide information about billing provider full-time equivalent (FTE) staffing, billing and coding practices, and productivity metrics for a three-month period, from January 1 to March 31, 2017. Results: Ten programs participated in the convenience sample survey, and seven provided information about billing and coding practices. For the seven programs that provided evaluation and management data, calculated estimate of mean work Relative Value Unit (wRVU) production per 1.0 FTE per year was 1626. Calculated estimate of consultations per 1.0 FTE per month was 15. Calculated estimate of total clinical encounters per 1.0 FTE per month was 70. Conclusions: The relationships between PPC billing provider productivity and clinical workload are complex and vary widely among a convenience sample of academic PPC programs. Given the high burnout rates in the field, efforts should be made to more clearly define these relationships to promote sustainability of both billing and nonbilling PPC providers.

<https://www.ncbi.nlm.nih.gov/pubmed/31419543>

**Naufel, L. Z., Sarno, M. and Alves, M. A. J. (2019). "PHYSICIANS' KNOWLEDGE ABOUT PATIENTS' RELIGIOUS BELIEFS IN PEDIATRIC CARE." Rev Paul Pediatr 37(4): 479-485.**

OBJECTIVE: To describe the knowledge of pediatricians and pediatric residents about the meaning of death according to the most prevalent religions in Brazil. METHODS: A cross-sectional survey was conducted among pediatricians and pediatric residents at a tertiary-level children's hospital in the city of Sao Paulo, SP, Brazil, questioning about their knowledge and experience related to spiritual care and the most common religious beliefs among pediatric palliative care patients in Brazil. RESULTS: 116 physicians answered the questionnaire, 98 (84.5%)

considered themselves religious, defined as followers of any spiritual creed around the world, and 18 (15.5%) non-religious. Of the total, 97 (83.6%) considered themselves capable of dealing with the spiritual care of Catholic patients, 49 (42.2%) of Protestant patients and 92 (79.3%) of patients that follow Spiritism in the process of death. Religious doctors used less chaplaincy services than non-religious doctors (relative risk - RR 2.54;  $p=0.0432$ ; confidence interval of 95% - 95%CI 1.21-5.34). Among the physicians, 111 (96%) believe that spirituality is beneficial in accepting the death process, responses were associated with the religiosity of the physicians (RR 1.18;  $p=0.0261$ ; 95%CI 0.95-1.45). Also, 106 (91.4%) are unaware of the religion of their patients and the same number of participants consider pediatricians, in general, unprepared to deal with the spiritual aspect of death. These data are not associated with the participants' religiosity. **CONCLUSIONS:** Although most pediatricians and residents consider themselves able to deal with the most prevalent religions in Brazil and affirm that spirituality is beneficial during the death process, little importance is given to the spiritual identity of their patients, which could limit an appropriate approach to their death process.

<https://www.ncbi.nlm.nih.gov/pubmed/31241691>

**Navya, M. K., Pramod, G. V., Sujatha, G. P. and Ashok, L. (2019). "Congenital insensitivity to pain in a 1-year-old boy." J Indian Soc Pedod Prev Dent 37(3): 308-310.**

Congenital insensitivity to pain (CIP) is a rare autosomal recessive genetic condition which causes reduced pain sensation, thermal sensation, and habit of self-mutilation. It is a life-threatening condition where due to reduced pain sensation, patient might not understand the severity of the injury which can eventually lead to death. Such people live a compromised life and can also affect them psychologically. Here, we are reporting a case of an infant with clinical features suggestive of CIP with a mutation in exon 5 of PRDM12 gene. The child has minimal response to pain along with self-mutilation and mental retardation.

<https://www.ncbi.nlm.nih.gov/pubmed/31584034>

**Needle, J. S., Peden-McAlpine, C. and Liaschenko, J. (2019). "Physicians' Perspectives on Adolescent and Young Adult Advance Care Planning The Fallacy of Informed Decision Making." J Clin Ethics 30(2): 131-142.**

Advance care planning (ACP) is a process that seeks to elicit patients' goals, values, and preferences for future medical care. While most commonly employed in adult patients, pediatric ACP is becoming a standard of practice for adolescent and young adult patients with potentially life-limiting illnesses. The majority of research has focused on patients and their families; little attention has been paid to the perspectives of healthcare providers (HCPs) regarding their perspectives on the process and its potential benefits and limitations. Focus groups were conducted with 15 physicians as part of a larger study of adolescent and young adult ACP in hematopoietic stem cell transplant (HSCT) patients. This study identified two categories important to the utility of ACP in pediatric HSCT patients; (1) the temporal context of ACP and decision making and (2) the limitations of pediatric ACP, with subcategories identified as (a) embodied and witnessed knowing, (b) the impact of clinical cascades-when the treatment of one organ system creates complications in another system that needs to be treated-and a creation of a "new normal" following

complications of illness and its treatment in the pediatric intensive care unit (PICU), (c) the balancing of adolescents' autonomy with their capacity to make informed medical decisions, and (d) the epistemological frames that differ between HCP and patients and their families. These findings support ACP in adolescent and young adult HSCT patients, with a number of implications for practice as this process becomes more common.

<https://www.ncbi.nlm.nih.gov/pubmed/31188790>

**Neilson, S. J. and Reeves, A. (2019). "The use of a theatre workshop in developing effective communication in paediatric end of life care." Nurse Educ Pract 36: 7-12.**

Being able to communicate effectively is an essential skill for all nurses. Communication in paediatric end of life care can be challenging for both the student and lecturer as it is a rare experience and challenging to teach. Innovative approaches to teaching communication skills such as role play, simulation and drama have been used; however there is a dearth of literature examining the use of drama in this specialist context. The aim of this study was to explore the effectiveness of a novel workshop in teaching transferable knowledge and skills in palliative, end of life and bereavement care communication to a convenience sample of first year pre-registration nursing students undertaking clinical skills training at a UK university. Qualitative and quantitative data were obtained from pre and post intervention questionnaires exploring student's perception of communication skills. Qualitative data were analysed thematically and quantitative data presented as standard descriptive statistics. The novel communication workshop facilitated students' exploration of how good and poor communication looks and feels and introduced aids to inform communication in clinical practice. Exposure to different learning approaches provided opportunities to both gain confidence in engaging in new learning activities and develop knowledge and skills through purposeful engagement.

<https://www.ncbi.nlm.nih.gov/pubmed/30831483>

**Niinomi, K., Soejima, M., Hiraga, K., Kodama, S., Okazaki, S. and Nakao, S. (2019). "Effectiveness of a Volunteer Training Program on the Learning Support of Children in Hospice Palliative Care." Am J Hosp Palliat Care, 10.1177/1049909119860249: 1049909119860249.**

**BACKGROUND:** Volunteers are expected to play a key role in children's hospice. However, there is a lack of information about how to cultivate effective volunteer training programs. **OBJECTIVE:** To verify the effect of a training program on volunteers' confidence in providing learning support and sharing experiences with children with life-threatening conditions and their families in a children's hospice. **METHODS:** In this pre-post study, participants were 48 undergraduate and graduate students from 3 universities in Japan. They received 5 lectures on children's hospice learning support. They evaluated the training program by rating their self-confidence in meeting each of the 15 program goals on a questionnaire. **RESULTS:** An exploratory factor analysis of the questionnaire yielded 12 goals in 4 factors: understanding of one's own and others' mental state, accommodating the learning needs of children with life-threatening conditions, understanding and accommodating the physical state of children with life-threatening conditions, and understanding the

significance of children's hospice. A paired t test revealed that participants' self-confidence had increased significantly in 3 of these 4 factors after the program. However, the score for accommodating the learning needs of children with life-threatening conditions decreased but not significantly. **CONCLUSION:** Although it needs some improvements, the program was effective for improving volunteers' self-confidence in and understanding of learning support and sharing experiences with children with life-threatening conditions.

<https://www.ncbi.nlm.nih.gov/pubmed/31272189>

**O'Sullivan, D., Stone, G., Mahomed, H., O'Reilly, P., Stewart, P., Noonan, H. and Murphy, A. M. (2019). "Bereavement Counselling for Healthcare Workers in the Aftermath of Child Death." *Ir Med J* 112(5): 931.**

<https://www.ncbi.nlm.nih.gov/pubmed/31411013>

**Piette, V. E., Cohen, J., Deliens, L., Pauwels, N., van der Werff Ten Bosch, J. and Beernaert, K. (2019). "Influence of health interventions on quality of life in seriously ill children at the end of life: a systematic review protocol." *Syst Rev* 8(1): 165.**

**BACKGROUND:** Seriously ill children suffer from numerous symptoms at the end of their lives, including pain, anxiety, and restricted communication. There are currently no comprehensive overviews of which health interventions have proven benefits and which have proven detrimental effects on the quality of life of children in an end-of-life context. In order to identify potential quality indicators to eventually improve care, a systematic review of available evidence is needed. The aim of the current systematic review will be to make an overview of the influence of health interventions on associated outcomes related to quality of life at the end of life in seriously ill children. **METHODS:** A systematic search will be conducted in MEDLINE, Embase, CENTRAL, CINAHL, and Web of Science. We will include quantitative empirical designs looking into the influence of a health intervention on (proxies of) quality of life at the end of life in seriously ill children. Three independent authors will review titles and abstracts and screen full texts against eligibility criteria. One reviewer will carry out full data extraction and quality assessment, and a 20% random sample will be extracted and assessed by two independent reviewers. We will use the QualSyst Tool for assessment of the quality of the included studies (QualSyst Tool) for quality assessment; overall strength of the body of evidence will be assessed using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) approach. An overview table of health interventions will be discussed through narrative synthesis. Should sufficient homogeneous publications arise, we will perform meta-analyses with a random-effects model. Our protocol adheres to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) checklist for study protocols. **DISCUSSION:** As part of a larger project, we will use the results of this review to identify a first set of quality indicators for the care for children at the end of life. Reviewing the current span of evidence and identifying research gaps will uncover future research priorities into the care for children at the end of life. **SYSTEMATIC REVIEW REGISTRATION:** PROSPERO CRD42018105109.

<https://www.ncbi.nlm.nih.gov/pubmed/31296266>

**Price, J. E., Mendizabal-Espinosa, R. M., Podsiadly, E., Marshall-Lucette, S. and Marshall, J. E. (2019). "Perinatal/neonatal palliative care: Effecting improved knowledge and multi-professional practice of midwifery and children's nursing students through an inter-professional education initiative." Nurse Educ Pract 40: 102611.**

This paper presents a study that examines the potential value of a new and innovative inter-professional education (IPE) experience for final year midwifery and children's nursing students focused on improving awareness of end-of-life care for infants in conjunction with the support of their families. The study uses an action research approach to examine midwifery and children's nursing student experiences of an IPE initiative in developing knowledge regarding perinatal/neonatal palliative care. The setting is a Higher Education Institute in the South of England that included final year midwifery students (n=39) and children's nursing students (n=34) taking part in the study. Qualitative and quantitative data indicated that the IPE intervention had proven worth in developing knowledge and confidence in the students as both student groupings felt they lacked knowledge and confidence about perinatal/neonatal palliative care before attending the study day. Students felt that learning with, from and about the other profession represented was important in generating their knowledge. Educators should explore innovative ways to enable the further development of the fledgling speciality of perinatal/neonatal palliative care through education on an interprofessional platform.

<https://www.ncbi.nlm.nih.gov/pubmed/31706207>

**Ratislavova, K., Buzgova, R. and Vejvodova, J. (2019). "Perinatal palliative care education: An integrative review." Nurse Educ Today 82: 58-66.**

**OBJECTIVES:** The aim of this review was to analyze the effectiveness of teaching healthcare professionals in perinatal palliative care, methods of evaluating the teaching, and the teaching strategies used. **DESIGN:** An integrative review. **METHODS:** A systematic search was conducted for English language peer reviewed publications of any research design via SCOPUS, Medline/PubMed, EBSCOhost, Science Direct, ERIC, Web of Science, Wiley, Nursing Ovid, and ProQuest databases. Fourteen research papers published between 2002 and 2017 that met the selection criteria were included in the review. **FINDINGS:** All 14 studies considered perinatal bereavement education to be effective. Eight studies reported statistical improvements in knowledge, security/comfort in providing end-of-life care, or increased perceptions of the emotional care needs of bereaved families, after attending an educational program. Questionnaires or interviews were used to evaluate the educational programs. Innovative teaching strategies, in particular, were evaluated positively (e.g., simulation, discussion, and arts-based methods). **CONCLUSION:** Perinatal palliative care education is essential in pregradual education for midwives and neonatal nurses. Other research is vital for finding out the effectiveness of this education for pregraduate nursing students. Perinatal palliative care education programs need to be available in postgraduate education for professionals who encounter perinatal death and bereaved families in hospital and community care.

<https://www.ncbi.nlm.nih.gov/pubmed/31442632>

**Rosenberg, A. R., Bona, K., Coker, T., Feudtner, C., Houston, K., Ibrahim, A., Macauley, R., Wolfe, J. and Hays, R. (2019). "Pediatric Palliative Care in the Multicultural Context: Findings From a Workshop Conference." J Pain Symptom Manage 57(4): 846-855.e842.**

CONTEXT: In our increasingly multicultural society, providing sensitive and respectful pediatric palliative care is vital. OBJECTIVES: We held a one-day workshop conference with stakeholders and pediatric clinicians to identify suggestions for navigating conflict when cultural differences are present and for informing standard care delivery. METHODS: Participants explored cases in one of four workshops focused on differences based on race/ethnicity, economic disparity, religion/spirituality, or family values. Each workshop was facilitated by two authors; separate transcriptionists recorded workshop discussions in real time. We used content analyses to qualitatively evaluate the texts and generate recommendations. RESULTS: Participants included 142 individuals representing over six unique disciplines, 25 of the U.S., and three nations. Although the conference focused on pediatric palliative care, findings were broadly generalizable to most medical settings. Participants identified key reasons cultural differences may create tension and then provided frameworks for communication, training, and clinical care. Specifically, recommendations included phrases to navigate emotional conflict, broken trust, unfamiliar family values, and conflict. Suggested approaches to training and clinical care included the development of core competencies in communication, history taking, needs assessment, and emotional intelligence. Important opportunities for scholarship included qualitative studies exploring diverse patient and family experiences, quantitative studies examining health disparities, and randomized clinical trials testing interventions designed to improve community partnerships, communication, or child health outcomes. CONCLUSION: Taken together, findings provide a foundation for collaboration between patients, families, and clinicians of all cultures.

<https://www.ncbi.nlm.nih.gov/pubmed/30685496>

**Sarpal, A. and Gofton, T. E. (2019). "Addressing the competency of breaking bad news: What are Canadian general paediatric residency programs currently doing." Paediatr Child Health 24(3): 173-178.**

OBJECTIVE: To describe how breaking bad news (BBN) is currently taught in Canadian general paediatric residency programs and the confidence level of fourth year paediatric residents (Ped-PGY4) in BBN and managing end-of-life-care (EOLC). Methods: A prospective, cross-sectional survey of General Paediatric Residency Program Directors (PDs) and Ped-PGY4s was conducted. Results: When learning to BBN, residents state faculty observation (22/23) and interactive workshops (14/23) are the most helpful, while PDs state interactive workshops (9/16) and deliberate practice (5/16) are ideal. Residents identified a knowledge gap and discomfort with providing anticipatory guidance, and symptom management, including prescribing opioids. Conclusions: In the era of competency-based medical education, there is an opportunity to create a standardized national curriculum addressing universal competencies related to BBN and EOLC.

<https://www.ncbi.nlm.nih.gov/pubmed/31110458>

**Sawin, K. J., Montgomery, K. E., Dupree, C. Y., Haase, J. E., Phillips, C. R. and Hendricks-Ferguson, V. L. (2019). "Oncology Nurse Managers' Perceptions of Palliative Care and End-of-Life Communication." J Pediatr Oncol Nurs 36(3): 178-190.**

The purpose of this study was to describe pediatric oncology nurse managers' (NMs) perspectives of palliative care/end-of-life (PC/EOL) communication. The study, guided by group-as-a-whole theory and empirical phenomenology, was part of a larger, multisite study aimed at understanding pediatric oncology nurses' experiences of PC/EOL communication. Nurses were assigned to focus groups based on length or type of experience (i.e., nurses with <1, 2-5, or >5 years' work experience and NMs). Eleven NMs from three Midwestern pediatric hospitals with large oncology programs participated in one focus group. The participants' mean years of experience was 15.8 in nursing and 12 in pediatric oncology; 90% had a BSN or higher degree; all had supervisory responsibilities. The authors identified 2,912 meaning statements, which were then analyzed using Colaizzi's method. Findings include NMs' overall experience of "Fostering a Caring Climate," which includes three core themes: (1) Imprint of Initial Grief Experiences and Emotions; (2) Constant Vigilance: Assessing and Optimizing Family-Centered Care; and (3) Promoting a Competent, Thoughtful, and Caring Workforce. Findings indicate that pediatric oncology NMs draw on their own PC/EOL experiences and their nursing management knowledge to address the PC/EOL care learning needs of nursing staff and patient/family needs. NMs need additional resources to support nursing staff's PC/EOL communication training, including specific training in undergraduate and graduate nursing programs and national and hospital-based training programs. <https://www.ncbi.nlm.nih.gov/pubmed/25556105>

**Schefft, M., Schroeder, A. R., Liu, D., Nicklas, D., Moher, J. M. and Quinonez, R. (2019). "Right Care for Children: Top Five Do's and Don'ts." Am Fam Physician 99(6): 376-382.**

Underuse and overuse of medical interventions, failure to use interventions known to be effective, and provision of tests or interventions in which benefits do not exceed harms are types of low-value care. The Lown Institute's Right Care Alliance Children's Health Council identified five "do" recommendations that highlight underuse and five "don't" recommendations that highlight overuse in children's health care. The five "do" recommendations include: do provide access to long-acting reversible contraception for adolescents, do use nonpharmacologic interventions first for treatment of attention-deficit/hyperactivity disorder, do discuss quality of life for children with complex medical conditions using a shared decision-making model and access resources such as palliative care subspecialists, do promote childhood literacy development by providing free, age-appropriate books in clinical settings, and do screen for socioeconomic status of the patient and family and provide access to community health and wellness resources. The five "don't" recommendations include: don't routinely prescribe antibiotics in children two to 12 years of age with a middle ear infection, don't perform computed tomography of the head for children with minor head trauma, don't use albuterol in children with bronchiolitis, don't routinely screen for hyperlipidemia in children and adolescents, and don't routinely perform preparticipation sports evaluations. These 10 examples

of underuse and overuse were identified with the intent of improving health care value and promoting "Right Care."

<https://www.ncbi.nlm.nih.gov/pubmed/30874414>

**Shanks, S. D. (2019). "Sharing Bad News." Arch Dis Child Educ Pract Ed, 10.1136/archdischild-2019-317847.**

<https://www.ncbi.nlm.nih.gov/pubmed/31401550>

**Smith, L. E., Maybach, A. M., Feldman, A., Darling, A., Akard, T. F. and Gilmer, M. J. (2019). "Parent and Child Preferences and Styles of Communication About Cancer Diagnoses and Treatment." J Pediatr Oncol Nurs 36(6): 390-401.**

Communication challenges frequently occur among families and health care providers of children with life-threatening conditions. These obstacles compound concerns related to children's diagnoses and treatment, the family's quality of life, and delivery of care. Developmentally appropriate and validated methods of addressing the communication preferences of families with chronically ill children are limited. This study used six focus groups to determine child and parent preferences and styles of communication centering on new diagnoses and changes in prognosis. Hypothetical situations were used to minimize feelings of self-consciousness among school-aged and adolescent participants. Qualitative analyses (interrater reliability 75%) of child and parent responses revealed 3 categories and 11 subcategories or themes. The category of Characteristics of Communication Exchange included (1) how to tell, (2) who should tell, (3) when to tell, (4) who should be included, and (5) what to tell. The Knowledge and Understanding category included themes of (1) side effects of treatment, (2) what children understand, and (3) questions when being diagnosed. The category of Feelings and Emotions included themes of (1) feelings about changes in prognosis, (2) children's feelings on being informed, and (3) coping and emotional regulation. Results reveal a need for developmentally appropriate, evidence-based education to inform parents on how, what, and when to communicate information concerning their child's disease, as well as instructions around facilitating those discussions. Moreover, a need for professional education and training programs for providers is demonstrated by some parental dissatisfaction with bedside manner and disclosure of information. The data collected from this study lay a foundation for future research in communication as a principal factor in quality of life for pediatric patients and their families.

<https://www.ncbi.nlm.nih.gov/pubmed/31342873>

**Sole-Ribalta, A., Rodriguez-Fanjul, X., Carretero-Bellon, J. M., Pascual-Sala, C., Martorell-Sampol, L., Bobillo-Perez, S. and Morillo-Palomo, A. M. (2019). "Neonatal Marfan Syndrome: A Rare, Severe, and Life-Threatening Genetic Disease." J Pediatr 211: 221-221.e222.**

<https://www.ncbi.nlm.nih.gov/pubmed/31053350>

**Sousa, A., Silva, L. F. D. and Paiva, E. D. (2019). "Nursing interventions in palliative care in Pediatric Oncology: an integrative review." Rev Bras Enferm 72(2): 531-540.**

**OBJECTIVE:** to identify, in scientific productions, nursing interventions in palliative care in children and adolescents with cancer. **METHOD:** integrative review of the literature through the databases: CINAHL, MEDLINE, IBECs, LILACS and SCIELO, carried out in October and November 2017. **RESULTS:** we analyzed 18 articles that met the inclusion criteria. The results showed that, among the articles selected, Brazil is the country with the largest number of publications and that interventions such as music therapy, massage, ludic application, early consultation of palliative care, social interventions and physical exercises aimed at the resolution of a specific symptom obtained better results when compared to interventions that aimed at the comprehensiveness of palliative care. **FINAL CONSIDERATION:** we conclude that greater emphasis should be given to palliative care in academic and professional training and that further studies in search of the best evidence should be conducted to support nursing Evidence-Based Practices.

<https://www.ncbi.nlm.nih.gov/pubmed/31017219>

**Stein, A., Dalton, L., Rapa, E., Bluebond-Langner, M., Hanington, L., Stein, K. F., Ziebland, S., Rochat, T., Harrop, E., Kelly, B. and Bland, R. (2019). "Communication with children and adolescents about the diagnosis of their own life-threatening condition." Lancet 393(10176): 1150-1163.**

When a child is diagnosed with a life-threatening condition, one of the most challenging tasks facing health-care professionals is how to communicate this to the child, and to their parents or caregivers. Evidence-based guidelines are urgently needed for all health-care settings, from tertiary referral centres in high-income countries to resource limited environments in low-income and middle-income countries, where rates of child mortality are high. We place this Review in the context of children's developing understanding of illness and death. We review the effect of communication on children's emotional, behavioural, and social functioning, as well as treatment adherence, disease progression, and wider family relationships. We consider the factors that influence the process of communication and the preferences of children, families, and health-care professionals about how to convey the diagnosis. Critically, the barriers and challenges to effective communication are explored. Finally, we outline principles for communicating with children, parents, and caregivers, generated from a workshop of international experts.

<https://www.ncbi.nlm.nih.gov/pubmed/30894271>

**Streuli, J. C., Widger, K., Medeiros, C., Zuniga-Villanueva, G. and Trenholm, M. (2019). "Impact of specialized pediatric palliative care programs on communication and decision-making." Patient Educ Couns 102(8): 1404-1412.**

**OBJECTIVE:** To summarize and analyze the impact of specialized pediatric palliative care (SPPC) programs on communication and decision-making for children with life-threatening conditions. **METHODS:** Our search strategy covered MEDLINE, PsycINFO, Cochrane Central Register of Controlled Trials, Web of Science, CINAHL, Scopus, and Embase through September 2018. **RESULTS:** We reviewed 13 studies analyzing the impact of SPPC programs on communication and decision-making using a wide range of outcome indicators. Study quality was poor in 58% of included papers. SPPC programs improved communication and decision-making between families and healthcare professionals (HCPs), within and between families, and among HCPs. **CONCLUSION:** SPPC programs generally support and improve

communication and decision-making for children with life-threatening conditions, their families and associated HCPs. Families referred to an SPPC program had more discussions with HCPs on a broad variety of topics. However, data on communication with children, siblings, and other family members was scarce and of poor quality. PRACTICE IMPLICATIONS: More research on SPPC program efficacy is needed from the perspective of the ill child, as well as about barriers to end-of-life discussions and the specific aspects of SPPC programs responsible for improving outcomes.

<https://www.ncbi.nlm.nih.gov/pubmed/30772117>

**Tager, J., Battles, H., Bedoya, S. Z., Gerhardt, C. A., Young-Saleme, T. and Wiener, L. (2019). "Participation in Online Research Examining End-of-Life Experiences: Is It Beneficial, Burdensome, or Both for Parents Bereaved by Childhood Cancer?" J Pediatr Oncol Nurs 36(3): 170-177.**

It is important for the health care community to understand the impact of a child's death on parent functioning. Yet involving bereaved parents in research that enquires about such a stressful time in their life can potentially bring harm to them. The current study examines the perceived benefit and burden of parents participating in a survey exploring their perceptions of their child's end-of-life (EoL) and bereavement experiences. Parents whose child died from cancer or complications of cancer treatment were invited to complete a survey developed by pediatric psychosocial oncology professionals with input from bereaved parent advocates through a closed social media (Facebook) group. One hundred seventy-eight parents of children aged 0 to 37 years at death (median age 12 years) participated. More than three quarters of parents reported at least "a little benefit" and half reported at least "a little burden" associated with participation. Less burden was perceived by younger and female parents, parents of younger children, those who had felt prepared to meet their children's emotional needs at EoL, and those not using bereavement services at the time of the survey. With the increasing use of social media as a source for bereaved parents to receive and provide emotional support, it is important for clinicians and researchers to understand the perceived benefits and risks of participating in research about EoL experiences via online recruitment. Our findings suggest that the benefit and burden of online research participation may vary for bereaved parents, but further research is necessary to replicate the findings and explore ways to optimize the use of this approach.

<https://www.ncbi.nlm.nih.gov/pubmed/30977432>

**Ten Koppel, M., Onwuteaka-Philipsen, B. D., van der Steen, J. T., Kylanen, M., Van den Block, L., Smets, T., Deliens, L., Gambassi, G., Collingridge Moore, D., Szczerbinska, K. and Pasman, H. R. W. (2019). "Care staff's self-efficacy regarding end-of-life communication in the long-term care setting: Results of the PACE cross-sectional study in six European countries." Int J Nurs Stud 92: 135-143.**

BACKGROUND: An important part of palliative care is discussing preferences at end of life, however such conversations may not often occur. Care staff with greater self-efficacy towards end-of-life communication are probably more likely to have such discussions, however, there is a lack of research on self-efficacy towards end-of-life discussions among long-term care staff in Europe and related factors. OBJECTIVES:

Firstly, to describe and compare the self-efficacy level of long-term care staff regarding end-of-life communication across six countries; secondly, to analyse characteristics of staff and facilities which are associated to self-efficacy towards end-of-life communication. DESIGN: Cross-sectional survey. SETTINGS: Long-term care facilities in Belgium, England, Finland, Italy, the Netherlands and Poland (n = 290). PARTICIPANTS: Nurses and care assistants (n = 1680) completed a self-efficacy scale and were included in the analyses. METHODS: Care staff rated their self-efficacy (confidence in their own ability) on a scale of 0 (cannot do at all) to 7 (certain can do) of the 8-item communication subscale of the Self-efficacy in End-of-Life Care survey. Staff characteristics included age, gender, professional role, education level, training in palliative care and years working in direct care. Facility characteristics included facility type and availability of palliative care guidelines, palliative care team and palliative care advice. Analyses were conducted using Generalized Estimating Equations, to account for clustering of data at facility level. RESULTS: The proportion of staff with a mean self-efficacy score >5 was highest in the Netherlands (76.4%), ranged between 55.9% and 60.0% in Belgium, Poland, England and Finland and was lowest in Italy (29.6%). Higher levels of self-efficacy (>5) were associated with: staff over 50 years of age (OR 1.86 95% CI[1.30-2.65]); nurses (compared to care assistants) (1.75 [1.20-2.54]); completion of higher secondary or tertiary education (respectively 2.22 [1.53-3.21] and 3.11 [2.05-4.71]); formal palliative care training (1.71 [1.32-2.21]); working in direct care for over 10 years (1.53 [1.14-2.05]); working in a facility with care provided by onsite nurses and care assistants and offsite physicians (1.86 [1.30-2.65]); and working in a facility where guidelines for palliative care were available (1.39 [1.03-1.88]). CONCLUSION: Self-efficacy towards end-of-life communication was most often low in Italy and most often high in the Netherlands. In all countries, low self-efficacy was found relatively often for discussion of prognosis. Palliative care education and guidelines for palliative care could improve the self-efficacy of care staff.

<https://www.ncbi.nlm.nih.gov/pubmed/30822706>

**Trowbridge, A., Bamat, T., Griffis, H., McConathey, E., Feudtner, C. and Walter, J. K. (2019). "Pediatric Resident Experience Caring for Children at the End of Life in a Children's Hospital." *Acad Pediatr*, 10.1016/j.acap.2019.07.008.**

OBJECTIVE: Pediatric residents are expected to be competent in end-of-life (EOL) care. We aimed to quantify pediatric resident exposure to patient deaths, and the context of these exposures. METHODS: Retrospective chart review of all deceased patients at one children's hospital over 3 years collected patient demographics, time, and location of death. Mode of death was determined after chart review. Each death was cross-referenced with pediatric resident call schedules to determine residents involved within 48 hours of death. Descriptive statistics are presented. RESULTS: Of 579 patients who died during the study period, 46% had resident involvement. Most deaths occurred in the NICU (30% of all deaths); however, resident exposure to EOL care most commonly occurred in the PICU (52% of resident exposures) and were after withdrawals of life-sustaining therapy (41%), followed by nonescalation (31%) and failed resuscitation (15%). During their postgraduate year (PGY)-1, <1% of residents encountered a patient death. During PGY-2 and PGY-3, 96% and 78%, respectively, of residents encountered at least 1 death. During PGY-2, residents encountered a mean of 3.5 patient deaths (range 0-12); during PGY-3, residents encountered a mean of 1.4 deaths (range 0-5). Residents observed for their full 3-

year residency encountered a mean of 5.6 deaths (range 2-10). CONCLUSIONS: Pediatric residents have limited but variable exposure to EOL care, with most exposures in the ICU after withdrawal of life-sustaining technology. Educators should consider how to optimize EOL education with limited clinical exposure, and design resident support and education with these variable exposures in mind.

<https://www.ncbi.nlm.nih.gov/pubmed/31376579>

**Udo, C., Kreicbergs, U., Axelsson, B., Bjork, O. and Lovgren, M. (2019). "Physicians working in oncology identified challenges and factors that facilitated communication with families when children could not be cured." *Acta Paediatr* 108(12): 2285-2291.**

AIM: We explored physicians' experiences of communicating with families when their child had cancer and a cure was no longer an option, by focusing on barriers and facilitating factors. METHODS: Physicians from the six cancer centres in Sweden took part in focus group discussions between December 2017 and May 2018, and the data were analysed using qualitative content analysis. Focus groups enabled us to gather individual and shared perspectives. RESULTS: The 35 physicians (20 male) had a mean age of 47 (range 31-74) and a mean of 11 years' experience in oncology, ranging from under one year to 43 years. They reported communication challenges when a cure was not possible, namely: emotional and mental drain, lack of mutual understanding and uncertainty about communication skills. They also reported facilitating factors: flexibility in complex conversations, the child's position in the conversations, continuity and trusting relationships, support from colleagues and having discussed the potentially life-threatening nature of cancer from the very start of treatment. CONCLUSION: Training to overcome communication issues could support the early integration of palliative care.

<https://www.ncbi.nlm.nih.gov/pubmed/31206784>

**Wada, R. K., Wong, L., Flohr, A., Kurahara, D., Arndt, R., Deutsch, M. J., Ing, D., Richardson, K., Munro, A., Kaneshige, L., Mullis, M., Hatae, M. and Albright, C. L. (2019). "Engaging a Community Chaplaincy Resource for Interprofessional Health Care Provider Training in Facilitating Family Decision Making for Children at End-of-Life." *Hawaii J Med Public Health* 78(6 Suppl 1): 37-40.**

Coordinating the care of terminally ill children is difficult for both parents and the health care team. An underutilized resource is spiritual care, such as that provided by Pacific Health Ministry, a community-based nonprofit established to develop hospital ministry training programs in Hawai'i and provide chaplaincy services to local facilities. This paper describes a training exercise, called the Pediatric Interprofessional Program (PIPP), which is modeled after an adult program, the Hawai'i Interprofessional Training for End of Life Communication in the intensive care unit (HITEC-ICU). Both programs were developed to introduce teams of learners consisting of Pacific Health Ministry spiritual care residents, internal medicine or pediatric residents, undergraduate students in nursing, and graduate students in social work to techniques in delivering serious, life-altering information, and the dynamics of working as an interprofessional team through use of progressively unfolding clinical simulations. PIPP facilitators included chaplaincy instructors at Pacific Health Ministry, university faculty, and community practitioners in pediatrics, nursing, and social work. The simulations were conducted at the

Translational Health Science Simulation Center (THSSC) of the University of Hawai'i at Manoa (UHM) School of Nursing and Dental Hygiene (SONDH), with simulated patients from the HealthCAST (Collaborative Acting Simulation Training) program, a collaborative agreement between SONDH and the UHM Department of Theatre and Dance. The training is ongoing, but has thus far demonstrated that interprofessional education programs are feasible across community, academic, and clinical lines, and benefit from the engagement of community resources.

<https://www.ncbi.nlm.nih.gov/pubmed/31285967>

**Weaver, M. S., Anderson, B., Cole, A. and Lyon, M. E. (2019). "Documentation of Advance Directives and Code Status in Electronic Medical Records to Honor Goals of Care." J Palliat Care, 10.1177/0825859719860129: 825859719860129.**

Advance care planning is a process that supports conversations about the values that matter most to patients and their family members. The documentation of advance directives and code status in a patient's electronic health record (EHR) is a critical step to ensure treatment preferences are honored in the medical care received. The current approach to advanced care planning documentation in electronic medical records often remains disparate within and across EHR systems. Without a standardized format for documentation or centralized location for documentation, advance directives and even code status content are often difficult to access within electronic medical records. This case report launched our palliative care team into partnership with the Information Technology team for implementation of a centralized, standardized, longitudinal, functional documentation of advance care planning and code status in the electronic medical record system.

<https://www.ncbi.nlm.nih.gov/pubmed/31280659>

**Weaver, M. S., Mooney-Doyle, K., Kelly, K. P., Montgomery, K., Newman, A. R., Fortney, C. A., Bell, C. J., Spruit, J. L., Kurtz Uveges, M., Wiener, L., Schmidt, C. M., Madrigal, V. N. and Hinds, P. S. (2019). "The Benefits and Burdens of Pediatric Palliative Care and End-of-Life Research: A Systematic Review." J Palliat Med 22(8): 915-926.**

**Objective:** The aim of this study is to report the benefits and burdens of palliative research participation on children, siblings, parents, clinicians, and researchers. **Background:** Pediatric palliative care requires research to mature the science and improve interventions. A tension exists between the desire to enhance palliative and end-of-life care for children and their families and the need to protect these potentially vulnerable populations from untoward burdens. **Methods:** Systematic review followed PRISMA guidelines with prepared protocol registered as PROSPERO #CRD42018087304. MEDLINE, CINAHL, PsycINFO, EMBASE, Scopus, and The Cochrane Library were searched (2000-2017). English-language studies depicting the benefits or burdens of palliative care or end-of-life research participation on either pediatric patients and/or their family members, clinicians, or study teams were eligible for inclusion. Study quality was appraised using the Mixed Methods Appraisal Tool (MMAT). **Results:** Twenty-four studies met final inclusion criteria. The benefit or burden of palliative care research participation was reported for the child in 6 papers; siblings in 2; parents in 19; clinicians in 3; and researchers in 5 papers. Benefits were more heavily emphasized by patients and family members, whereas burdens were more prominently emphasized by researchers and

clinicians. No paper utilized a validated benefit/burden scale. Discussion: The lack of published exploration into the benefits and burdens of those asked to take part in pediatric palliative care research and those conducting the research is striking. There is a need for implementation of a validated benefit/burden instrument or interview measure as part of pediatric palliative and end-of-life research design and reporting. <https://www.ncbi.nlm.nih.gov/pubmed/30835596>

**Weaver, M. S., Powell, A., Bace, S. and Wratchford, D. (2019). "Centering Care: The Role of Labyrinths for Fostering Reflection in Pediatric Palliative and Critical Care Settings." J Pain Symptom Manage 58(1): 167-170.** <https://www.ncbi.nlm.nih.gov/pubmed/30267846>

**Zuniga-Villanueva, G., Ramirez-GarciaLuna, J. L. and Weingarten, K. (2019). "Factors Associated With Knowledge and Comfort Providing Palliative Care: A Survey of Pediatricians in Mexico." J Palliat Care 34(2): 132-138.**

BACKGROUND:: Lack of education and training in palliative care has been described to be one of the most important barriers to pediatric palliative care implementation. OBJECTIVE:: To examine what factors determine the degree of knowledge and level of comfort Mexican pediatricians have providing pediatric palliative care. METHODS:: A questionnaire that assessed palliative care concepts was developed and applied online to Mexican pediatricians, both generalists and specialists. RESULTS:: A total of 242 pediatricians responded. The majority had not received palliative care education (92.6%) and felt uncomfortable discussing palliative needs with patients and families (92.1%). The mean score of the questionnaire was 6.8 (+/-1.4) of 10 correct answers. Knowledge in palliative care was associated with exposure to oncologic patients ( P = .01) and previous palliative care education ( P = .02) but inversely related to the pediatrician's age ( P = .01). Comfort addressing patient's palliative care needs was associated with knowledge in palliative care ( P < .01), exposure to oncologic patients ( P = .03), and previous education in palliative care ( P = .02). CONCLUSIONS:: Although Mexican pediatricians have basic knowledge of palliative care concepts, they do not feel comfortable addressing palliative care needs, suggesting that the main barrier for implementing palliative care is not the lack of knowledge but rather feeling uncomfortable when addressing these issues with patients and families. Educational programs should incorporate strategies that could help physicians develop comfort in approaching palliative care patients.

<https://www.ncbi.nlm.nih.gov/pubmed/30714468>

## ***Epidemiology and Pathology***

**(2019). "The global burden of childhood and adolescent cancer in 2017: an analysis of the Global Burden of Disease Study 2017." Lancet Oncol 20(9): 1211-1225.**

**BACKGROUND:** Accurate childhood cancer burden data are crucial for resource planning and health policy prioritisation. Model-based estimates are necessary because cancer surveillance data are scarce or non-existent in many countries. Although global incidence and mortality estimates are available, there are no previous analyses of the global burden of childhood cancer represented in disability-adjusted life-years (DALYs). **METHODS:** Using the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) 2017 methodology, childhood (ages 0-19 years) cancer mortality was estimated by use of vital registration system data, verbal autopsy data, and population-based cancer registry incidence data, which were transformed to mortality estimates through modelled mortality-to-incidence ratios (MIRs). Childhood cancer incidence was estimated using the mortality estimates and corresponding MIRs. Prevalence estimates were calculated by using MIR to model survival and multiplied by disability weights to obtain years lived with disability (YLDs). Years of life lost (YLLs) were calculated by multiplying age-specific cancer deaths by the difference between the age of death and a reference life expectancy. DALYs were calculated as the sum of YLLs and YLDs. Final point estimates are reported with 95% uncertainty intervals. **FINDINGS:** Globally, in 2017, there were 11.5 million (95% uncertainty interval 10.6-12.3) DALYs due to childhood cancer, 97.3% (97.3-97.3) of which were attributable to YLLs and 2.7% (2.7-2.7) of which were attributable to YLDs. Childhood cancer was the sixth leading cause of total cancer burden globally and the ninth leading cause of childhood disease burden globally. 82.2% (82.1-82.2) of global childhood cancer DALYs occurred in low, low-middle, or middle Socio-demographic Index locations, whereas 50.3% (50.3-50.3) of adult cancer DALYs occurred in these same locations. Cancers that are uncategorised in the current GBD framework comprised 26.5% (26.5-26.5) of global childhood cancer DALYs. **INTERPRETATION:** The GBD 2017 results call attention to the substantial burden of childhood cancer globally, which disproportionately affects populations in resource-limited settings. The use of DALY-based estimates is crucial in demonstrating that childhood cancer burden represents an important global cancer and child health concern. **FUNDING:** Bill & Melinda Gates Foundation, American Lebanese Syrian Associated Charities (ALSAC), and St. Baldrick's Foundation.

<https://www.ncbi.nlm.nih.gov/pubmed/31371206>

**Acacio, S., Mandomando, I., Nhampossa, T., Quinto, L., Vubil, D., Sacoor, C., Kotloff, K., Farag, T., Nasrin, D., Macete, E., Levine, M. M., Alonso, P. and Bassat, Q. (2019). "Risk factors for death among children 0-59 months of age with moderate-to-severe diarrhea in Manhica district, southern Mozambique." BMC Infect Dis 19(1): 322.**

**BACKGROUND:** Despite major improvements in child survival rates, the number of deaths due to diarrhea remains unacceptably high. We aimed to describe diarrhea-associated mortality and evaluate risk factors for death among Mozambican children with moderate-to-severe diarrhea (MSD). **METHODS:** Between December 2007 and

November 2012, children under-five with MSD were enrolled in Manhica district, as part of the Global Enteric Multicenter study (GEMS). Clinical, epidemiological, and socio-demographic characteristics were collected. Anthropometric measurements were performed and stool samples collected upon recruitment. A follow-up visit ~ 60 days post-enrolment was conducted and verbal autopsies performed in all death cases. RESULTS: Of the 916 MSD-cases analyzed; 90% (821/916) completed 60 days follow-up and 69 patients died. The case fatality rate at follow-up was 8% (69/821), and the mortality rate 10.2 (95%CI: 7.75-13.59) deaths per 1000 persons-week at risk. Nearly half of the deaths 48% (33/69) among study participants clustered within 2 weeks of the onset of diarrhea. Typical enteropathogenic Escherichia coli (typical EPEC) and Cryptosporidium were the two pathogens associated to an increased risk of death in the univariate analysis with (HR = 4.16, p = 0.0461) and (H = 2.84, p = 0.0001) respectively. Conversely, Rotavirus infection was associated to a decreased risk of death (HR = 0.52, p = 0.0198). According to the multivariate analysis, risk factors for death included co-morbidities such as malnutrition (HR = 4.13, p < 0.0001), pneumonia/lower respiratory infection (HR = 3.51, p < 0.0001) or invasive bacterial disease (IBD) (HR = 6.80, p = 0.0009), presenting on arrival with lethargy or overt unconsciousness (HR = 1.73, p = 0.0302) or wrinkled skin (HR = 1.71, p = 0.0393), and cryptosporidium infection (HR = 2.14, p = 0.0038). When restricting the analysis to those with available HIV results (n = 191, 22% of the total study sample), HIV was shown to be a significant risk factor for death (HR = 5.05, p = 0.0009). Verbal autopsies were conducted in 100% of study deaths, and highlighted diarrhea as the main underlying cause of death 39%, (27/69); followed by HIV/AIDS related deaths 29.0% (20/69) and sepsis 11.6% (8/69). CONCLUSION: Preventive strategies targeting Cryptosporidium, malnutrition and early identification and treatment of associated co-morbidities could contribute to the prevention of the majority of diarrhea associated deaths in Mozambican children. <https://www.ncbi.nlm.nih.gov/pubmed/30987589>

**Bandara, N. A., Jhauj, R. and Mehrnoush, V. (2019). "The Major Causes of Death in Children." *N Engl J Med* 380(14): 1384-1385.** <https://www.ncbi.nlm.nih.gov/pubmed/30943360>

**Bollinger, M. E., Butz, A., Tsoukleris, M., Lewis-Land, C., Mudd, S. and Morphew, T. (2019). "Characteristics of inner-city children with life-threatening asthma." *Ann Allergy Asthma Immunol* 122(4): 381-386.**

BACKGROUND: Intensive care unit (ICU) admission is a risk factor for fatal asthma. Little is known about risk factors for pediatric ICU admissions for asthma. OBJECTIVE: To examine characteristics of underserved minority children with prior ICU admissions for asthma. METHODS: Baseline survey data, salivary cotinine levels, and allergen specific IgE serologic test results were obtained from children with uncontrolled asthma enrolled in a randomized clinical trial of a behavioral education environmental control intervention. Characteristics of children with and without prior ICU admission were compared using chi(2) and t tests. Logistic regression assessed significance of higher odds of prior ICU admission comparing factor-level categories. RESULTS: Patients included 222 primarily African American (93.7%), male (56%), Medicaid-insured (92.8%) children with a mean (SD) age of 6.4 (2.7) years with uncontrolled asthma. Most (57.9%) had detectable cotinine

levels, 82.6% were sensitized to more than 1 environmental allergen, and 27.9% had prior ICU admissions. Prior ICU patients were more likely to be very poor (<\$10,000 per year) and sensitized to more than 1 allergen tested (most importantly mouse) ( $P < .05$ ). Allergen sensitization in the groups did not differ for cockroach, cat, dog, Alternaria, Aspergillus, dust mite, grass, or tree. Although more ICU patients received combination controller therapy, they also overused albuterol. Only 27.4% of ICU patients received specialty care in the previous 2 years, which was not significantly different from non-ICU patients. CONCLUSION: Children with high mortality risk, including history of ICU admission, were twice as likely to live in extreme poverty, have atopy (particularly mouse allergen), use combination controller therapy, and overuse albuterol. TRIAL REGISTRATION: ClinicalTrials.gov Identifier: NCT01981564.

<https://www.ncbi.nlm.nih.gov/pubmed/30742915>

**Boss, R. D. (2019). "Social Disparities and Death Among Children With Complex Chronic Conditions." *Pediatrics* 143(5).**

<https://www.ncbi.nlm.nih.gov/pubmed/30971432>

**Boyer, K. (2019). "When Epilepsy Grows Up." *Epilepsy Curr* 19(2): 99-100.**

Neurocognition in Childhood Epilepsy: Impact on Mortality and Complete Seizure Remission 50 Years Later Sillanpaa M, Saarinen MM, Karrasch M, Schmidt D, Hermann BP. *Epilepsia*. 2019;60(1):131-138. doi:10.1111/epi.14606. Epub 2018 Nov 22. OBJECTIVE: To study associations of the severity of impairment in childhood neurocognition (NC) with long-term mortality and complete seizure remission. METHODS: A population-based cohort of 245 subjects with childhood-onset epilepsy was followed up for 50 years (median = 45, range = 2-50). Childhood NC before age 18 years was assessed as a combination of formal intelligence quotient scores and functional criteria (school achievement, working history, and psychoneurological development). Impaired NC was categorized with respect to definitions of intellectual functioning in International Classification of Diseases, Tenth Revision (R41.83, F70-F73). The outcome variables, defined as all-cause mortality and 10-year terminal remission with the 5 past years off medication (10YTR), were analyzed with Cox regression models. RESULTS: Of the 245 subjects, 119 (49%) had normal childhood NC, whereas 126 (51%) had various degrees of neurocognitive impairment. During the 50-year observation period, 71 (29%) of the subjects died, 13% of those with normal and 44% of those with impaired NC. The hazard of death increased gradually in line with more impaired cognition, reaching significance in moderate, severe, and profound impairment versus normal NC (hazard ratio [Bonferroni corrected 95% confidence interval] = 3.3 [1.2-9.2], 4.2 [1.2-14.2], and 5.5 [2.4-12.3], respectively). The chance for 10YTR was highest among subjects with normal NC (61%), whereas none of those with profound impairment reached 10YTR. In the intermediate categories, the chance was, however, not directly related to the increasing severity of impairment. SIGNIFICANCE: The severity of neurocognitive impairment during childhood shows a parallel increase in the risk of death. In comparison with normal NC, subjects with lower childhood NC are less likely to enter seizure remission. However, normal NC does not guarantee complete remission or prevent premature death in some individuals with childhood-onset epilepsy.

<https://www.ncbi.nlm.nih.gov/pubmed/30955422>

**Clark, J., Barnes, A., Campbell, M. and Gardiner, C. (2019). "A Life or "Good Death" Situation? A Worldwide Ecological Study of the National Contexts of Countries That Have and Have Not Implemented Palliative Care." J Pain Symptom Manage 57(4): 793-801.e711.**

CONTEXT: Palliative care advocates argue that service implementation is feasible in all settings. Yet, services have developed patchily in low- and middle-income settings. Beyond Human Development Index indicators, there has been limited engagement with the broader development challenges facing nations tasked with implementing palliative care. OBJECTIVE: The objective of this study was to describe how indicators of national development relate to levels of palliative care services in 207 countries around the world. METHODS: We conducted an ecological study to identify relationships between potential predictor variables and the level of national palliative care development. A total of 28 predictor variables from the following six domains were selected using hypothesized relationships with levels of palliative care development: disease demographics, socioeconomics, health systems, politics, demographics, and economics. The outcome variable was level of national palliative care development on a six-point scale. Spearman's correlation was used to measure the strength of the association. RESULTS: Twenty-six of 28 variables were statistically significantly associated with levels of palliative care development in 207 countries. Palliative care is more developed in countries with high-percentage of deaths from noncommunicable disease, population proportion aged 65+ years, gross national income, and tourism. Development is lower in countries with high levels of political corruption, infant mortality, deaths by infectious diseases, and weak democracy. Prevalence of undernourishment and levels of private health expenditure were not significantly associated with palliative care development. CONCLUSION: Palliative care development is highly consistent with broader national development indicators. It is less in countries where sudden deaths are more likely and benefits from palliative care provision are likely to be very limited. In such countries, resources may be prioritized toward life-prolonging therapies and key aspects of palliative care need only be implemented before fully integrated palliative services. Findings suggest that there may be a "tipping point" in societies, where the relative need for life-prolonging therapies becomes less than the need for integrated palliative care services.

<https://www.ncbi.nlm.nih.gov/pubmed/30594568>

**Duque, J. A. P., Ferreira, C. F., Zachia, S. A., Sanseverino, M. T. V., Gus, R. and Magalhaes, J. A. A. (2019). "The natural history of pregnancies with prenatal diagnosis of Trisomy 18 or Trisomy 13: Retrospective cases of a 23-year experience in a Brazilian public hospital." Genet Mol Biol 42(1 suppl 1): 286-296.**

Trisomy 18 (T18) and trisomy 13 (T13) are polymalformative syndromes associated with a high rate of spontaneous abortions, intrauterine death, and short postnatal life. This study describes the overall outcome in a country where the therapeutic interruption of pregnancy is not available. The medical records of women with prenatal diagnosis of full trisomy of T13 or T18 between October 1994 and October 2017 were analyzed in order to describe their natural outcomes. Thirteen cases of T13 and 29 cases of T18 were included. The miscarriage rate was 9% for T18 and no cases for T13. Intrauterine fetal death occurred in 46% and 52% of cases for T13

and T18, respectively. The rate of live births for T13 was 54%, and the median survival was one day (95% CI -33.55 - 90.40) and 71% died in the first 24 hours of life. The rate of live births for T18 was 37% and the median survival was two days (95% CI -1.89 - 13.17); 90% of the affected babies died within first week of life. For the affected babies reaching the first year of life and for those who lived longer, multiple invasive and expensive procedures were required, without success in prolonging life beyond 180 days. This large series provides information for professionals and women regarding the natural histories of T13 and T18. Results of this study are consistent with those referenced in the literature, emphasizing the need of structured protocols and guidelines aiming early T13 and T18 diagnosis, prenatal care, gestation/parents follow-up, and counselling processes. For those couples with earlier diagnosis, a better follow-up and counselling during the prenatal care lead to the option for a support or palliative management of the newborn. Finally, when the counselling process is appropriate, it becomes easier to take decisions respecting the parent's autonomy and to look for better outcomes for both, the mother and the fetus.

<https://www.ncbi.nlm.nih.gov/pubmed/31170277>

**Elmstedt, S., Mogensen, H., Hallmans, D. E., Tavelin, B., Lundstrom, S. and Lindskog, M. (2019). "Cancer patients hospitalised in the last week of life risk insufficient care quality - a population-based study from the Swedish Register of Palliative Care." *Acta Oncol* 58(4): 432-438.**

**BACKGROUND:** One-quarter of all cancer deaths in Sweden occur in hospitals. If the place of death affects the quality of end-of-life (EOL) is largely unknown. **METHODS:** This population-based, retrospective study included all adults cancer deaths reported to the Swedish Register of Palliative Care in 2011-2013 (N = 41,729). Hospital deaths were compared to deaths occurring in general or specialised palliative care, or in nursing homes with respect to care quality indicators in the last week of life. Odds ratios (OR) with 95% confidence intervals (CI) were calculated with specialised palliative home care as reference. **RESULTS:** Preferred place of death was unknown for 63% of hospitalised patients and consistent with the actual place of death in 25% compared to 97% in palliative home care. Hospitalised patients were less likely to be informed when death was imminent (OR: 0.3; CI: 0.28-0.33) as were their families (OR: 0.51; CI: 0.46-0.57). Validated screening tools were less often used in hospitals for assessment of pain (OR: 0.32; CI: 0.30-0.34) or other symptoms (OR: 0.31; CI: 0.28-0.34) despite similar levels of EOL symptoms. Prescriptions of as needed drugs against anxiety (OR: 0.27; CI: 0.24-0.30), nausea (OR: 0.19; CI: 0.17-0.21), or pulmonary secretions (OR: 0.29; CI: 0.26-0.32) were less prevalent in hospitals. Bereavement support was offered after 57% of hospital deaths compared to 87-97% in palliative care units and 72% in nursing homes. **CONCLUSIONS:** Dying in hospital was associated with inferior end-of-life care quality among cancer patients in Sweden.

<https://www.ncbi.nlm.nih.gov/pubmed/30633611>

**French, C. E., Delon, I., Dolling, H., Sanchis-Juan, A., Shamardina, O., Megy, K., Abbs, S., Austin, T., Bowdin, S., Branco, R. G., Firth, H., Rowitch, D. H. and Raymond, F. L. (2019). "Whole genome sequencing reveals that genetic conditions are frequent in intensively ill children." *Intensive Care Med* 45(5): 627-636.**

**PURPOSE:** With growing evidence that rare single gene disorders present in the neonatal period, there is a need for rapid, systematic, and comprehensive genomic diagnoses in ICUs to assist acute and long-term clinical decisions. This study aimed to identify genetic conditions in neonatal (NICU) and paediatric (PICU) intensive care populations. **METHODS:** We performed trio whole genome sequence (WGS) analysis on a prospective cohort of families recruited in NICU and PICU at a single site in the UK. We developed a research pipeline in collaboration with the National Health Service to deliver validated pertinent pathogenic findings within 2-3 weeks of recruitment. **RESULTS:** A total of 195 families had whole genome analysis performed (567 samples) and 21% received a molecular diagnosis for the underlying genetic condition in the child. The phenotypic description of the child was a poor predictor of the gene identified in 90% of cases, arguing for gene agnostic testing in NICU/PICU. The diagnosis affected clinical management in more than 65% of cases (83% in neonates) including modification of treatments and care pathways and/or informing palliative care decisions. A 2-3 week turnaround was sufficient to impact most clinical decision-making. **CONCLUSIONS:** The use of WGS in intensively ill children is acceptable and trio analysis facilitates diagnoses. A gene agnostic approach was effective in identifying an underlying genetic condition, with phenotypes and symptomatology being primarily used for data interpretation rather than gene selection. WGS analysis has the potential to be a first-line diagnostic tool for a subset of intensively ill children.

<https://www.ncbi.nlm.nih.gov/pubmed/30847515>

**Gilbar, P. J., McPherson, I., Aisthorpe, G. G. and Kondalsamy-Chennakes, S. (2019). "Systemic anticancer therapy in the last 30 days of life: Retrospective audit from an Australian Regional Cancer Centre." J Oncol Pharm Pract 25(3): 599-606.**

**BACKGROUND:** Cessation of chemotherapy at an appropriate time is an important component of good quality palliative care. Published studies looking at administration of chemotherapy at the end of life vary widely. **OBJECTIVE:** To retrospectively determine the rate of death occurring within 14 and 30 days of chemotherapy and use this to benchmark against other cancer centres as a quality of care measure. **METHOD:** All adult patients who received systemic anticancer therapy for solid tumours and haematological malignancies at an Australian Regional Cancer Centre between 2011 and 2015 were included. **RESULTS:** Over a five-year period, 1215 patients received systemic anticancer therapy. Of these, 23 (1.89%) died within 14 days following systemic anticancer therapy and 68 (5.60%) within 30 days. All patients who died had been treated with palliative intent. Mean time to death was 17.7 days. The majority were female (61.8%) and the mean age was 62.3 years. The most common cause of death was disease progression (80.9%). Nearly half died at the Regional Cancer Centre, including 30.9% who lived in rural or remote localities. **CONCLUSION:** The rate of death observed in this study is at the lower end of the range seen in published studies for both the last 14 and 30 days post-systemic anticancer therapy. It is important to routinely collect data to enable benchmarking against other institutions, determine factors potentially associated with higher risks of mortality at the end of life and improve clinical decision making.

<https://www.ncbi.nlm.nih.gov/pubmed/29298626>

**Guner, Y. S., Delaplain, P. T., Zhang, L., Di Nardo, M., Brogan, T. V., Chen, Y., Cleary, J. P., Yu, P. T., Harting, M. T., Ford, H. R. and Nguyen, D. V. (2019). "Trends in Mortality and Risk Characteristics of Congenital Diaphragmatic Hernia Treated With Extracorporeal Membrane Oxygenation." Asaio j 65(5): 509-515.**

Although the mortality of infants with congenital diaphragmatic hernia (CDH) has been improving since the late 1990s, this observation has not been paralleled among the CDH cohort receiving extracorporeal membrane oxygenation (ECMO). We sought to elucidate why the mortality rate in the CDH-ECMO population has remained at approximately 50% despite consistent progress in the field by examining the baseline risk profile/characteristics of neonates with CDH before ECMO (pre-ECMO). Neonates with a diagnosis of CDH were identified in the Extracorporeal Life Support Organization (ELSO) Registry from 1992 to 2015. Individual pre-ECMO risk score (RS) for mortality was categorized to pre-ECMO risk-stratified cohorts. Temporal trends based on individual-level mortality by risk cohorts were assessed by logistic regression. We identified 6,696 neonates with CDH. The mortality rates during this time period were approximately 50%. The average baseline pre-ECMO RS increased during this period: mean increase of 0.35 (95% confidence interval [CI]: 0.324-0.380). In the low-risk cohort, the likelihood of mortality increased over time: each 5 year change was associated with a 7.3% increased likelihood of mortality (odds ratio [OR]: 1.0726; 95% CI: 1.0060-1.1437). For the moderate-risk cohort, the likelihood of mortality decreased by 7.05% (OR: 0.9295; 95% CI: 0.8822-0.9793). There was no change in the odds of mortality for the high-risk cohort (OR: 0.9650; 95% CI: 0.8915-1.0446). Although the overall mortality rate remained approximately constant over time, the individual likelihood of death has declined over time in the moderate-risk cohort, increased in the low-risk cohort, and remained unchanged in the high-risk cohort.

<https://www.ncbi.nlm.nih.gov/pubmed/29863628>

**Ishihara, T. and Tanaka, H. (2019). "Causes of death in critically ill paediatric patients in Japan: a retrospective multicentre cohort study." BMJ Paediatr Open 3(1): e000499.**

**Objectives:** The primary objective is to clarify the clinical profiles of paediatric patients who died in intensive care units (ICUs) or paediatric intensive care units (PICUs), and the secondary objective is to ascertain the demographic differences between patients who died with and without chronic conditions. **Methods:** In this retrospective multicentre cohort study, we collected data on paediatric death from the Japanese Registry of Pediatric Acute Care (JaRPAC) database. We included patients who were  $\leq 16$  years of age and had died in either a PICU or an ICU of a participating hospital between April 2014 and March 2017. The causes of death were compared between patients with and without chronic conditions. **Results:** Twenty-three hospitals participated, and 6199 paediatric patients who were registered in the JaRPAC database were included. During the study period, 126 (2.1%) patients died (children without chronic illness,  $n=33$ ; children with chronic illness,  $n=93$ ). Twenty-five paediatric patients died due to an extrinsic disease, and there was a significant difference in extrinsic diseases between the two groups (children without chronic illness, 15 (45%); children with chronic illness, 10 (11%);  $p<0.01$ ). Cardiovascular disease was the most common chronic condition (27/83, 29%). Eighty-three patients

(85%) in the chronic group died due to an intrinsic disease, primarily congenital heart disease (14/93, 15%), followed by sepsis (13/93, 14%). Conclusions: The majority of deaths were in children with a chronic condition. The major causes of death in children without a chronic illness were due to intrinsic factors such as cardiovascular and neuromuscular diseases, and the proportion of deaths due to extrinsic causes was higher in children without chronic illness.

<https://www.ncbi.nlm.nih.gov/pubmed/31531406>

**Kim, H. J., Kang, T. U., Park, K. Y., Kim, J., Ahn, H. S. and Yim, S. Y. (2019). "Which growth parameters can affect mortality in cerebral palsy?" PLoS One 14(6): e0218320.**

**BACKGROUND:** The objective of this study was to identify growth parameters that can affect mortality of cerebral palsy (CP). **METHOD:** This was a birth cohort study based on the National Health Screening Program for Infants and Children database along with the National Health Insurance Service, which were linked using a personal identifier number. The birth cohort consisted of 2 191 956 subjects, representing 93.5% of live births from 2007-2011, with maximal 10-year follow-up (range, 5-10 years) until October 2016. Subjects with CP were identified. Growth parameters in terms of birth weight, underweight (weight-for-age below the 3rd percentile), rate of body weight gain were collected, along with all-cause mortality after the age of 1 year. **RESULT:** Prevalence of CP was 2.0 per 1000 live births (95% CI, 1.94-2.06). All-cause mortality after the age of 1 year was 0.09 deaths/1000 person-years (95% CI, 0.08-0.09) in the general population (GP) and 2.85 deaths/1000 person-years (95% CI, 2.32-3.50) in subjects with CP during the follow-up. Therefore, the incidence rate ratio for all-cause mortality was 32.15 (95% CI, 25.72-39.76) in subjects with CP compared to GP. Presence of underweight was significantly associated with higher mortality in both subjects with CP and GP, where the adjusted hazard ratio of death was 2.60 (95% CI, 1.93-3.50) at the age of 18-24 months, 3.12 at 30-36 months, 4.37 at 42-48 months, 5.12 at 54-60 months, and 4.17 at 66-71 months. Birth weight did not affect mortality in both subjects with CP and GP after the age of 1 year ( $p > 0.05$ ). **CONCLUSION:** While subjects with CP shows higher mortality, underweight is an important growth parameter that affects all-cause mortality of both subjects with CP and GP. This study urges increased awareness that subjects with CP who are underweight require special care.

<https://www.ncbi.nlm.nih.gov/pubmed/31199836>

**Mark, M. S. J., Yang, G., Ding, L., Norris, R. E. and Thienprayoon, R. (2019). "Location of Death and End-of-Life Characteristics of Young Adults with Cancer Treated at a Pediatric Hospital." J Adolesc Young Adult Oncol 8(4): 417-422.**

**Background:** Location of death (LOD) is an important aspect of end-of-life (EOL) care. Adolescents and young adults (YAs) with pediatric malignancies are increasingly treated in pediatric institutions. YAs, generally defined as 18-39 years old, deserve specific attention because adults have unique developmental and social considerations compared with younger patients. **Objective:** The goal of this retrospective cohort study was to understand the effect of treatment by a pediatric oncology program on EOL experiences for YAs. Specifically, we examined LOD, hospice, and palliative care (PC) involvement in a cohort of YAs who died of cancer

in a large, quaternary care pediatric hospital. Methods: This was a retrospective cohort study of patients  $\geq 18$  years of age, who died of cancer between January 1, 2010, and December 31, 2017. Standardized data were abstracted from the institutional cancer registry and the electronic medical record. Results: YAs in this cohort more commonly died in the hospital (54.9%). Lack of hospice involvement and the presence of a documented do-not-resuscitate (DNR) order were significantly associated with inpatient death. The majority of patients had long-standing PC involvement (95.8%, median 318 days), a DNR order (78.9%), and had enrolled in hospice care (60.6%) before death. Conclusions: These results suggest that a significant proportion of YAs with cancer remain inpatient for EOL care. Pediatric oncologists and PC teams may benefit from additional training in the unique psychosocial needs of YAs to optimize EOL care for these older patients.

<https://www.ncbi.nlm.nih.gov/pubmed/31013460>

**Myland, M., Buysse, B., Tsong, W., Power, G. S., Nordli, D. and Chin, R. F. M. (2019). "Seizure frequency, healthcare resource utilisation and mortality in childhood epilepsy: a retrospective cohort study using the THIN database." *Arch Dis Child* 104(11): 1070-1076.**

**OBJECTIVE:** To understand the association of seizure frequency with healthcare resource utilisation (HCRU) and mortality in UK children with epilepsy (CWE). **DESIGN:** Retrospective cohort study. **SETTING:** Routinely collected data in primary care from The Health Improvement Network UK database. **PATIENTS:** CWE  $\geq 1$  and  $< 18$  years of age with a record of seizure frequency were included in mortality analyses from 2005 to 2015 and HCRU analyses from 2010 to 2015. **MAIN OUTCOME MEASURES:** Frequency of HCRU contacts during the year following latest seizure frequency and mortality (descriptive and Cox proportional hazards regression) from first record of seizure frequency. **RESULTS:** Higher seizure frequency was related to increased HCRU utilisation and mortality. In negative binomial regression, each category increase in seizure frequency related to 11% more visits to general practitioners, 35% more inpatient admissions, 15% more outpatient visits and increased direct HCRU costs (24%). 11 patients died during 12 490 patient-years follow-up. The unadjusted HR of mortality per higher category of seizure frequency was 2.56 (95% CI: 1.52 to 4.31). Adjustment for age and number of prescribed anti-epileptic drugs at index attenuated this estimate to 2.11 (95% CI: 1.24 to 3.60). **CONCLUSION:** Higher seizure frequency is associated with greater HCRU and mortality in CWE in the UK. Improvement in seizure control may potentially lead to better patient outcomes and reduced healthcare use.

<https://www.ncbi.nlm.nih.gov/pubmed/31272968>

**Orsini, A., Valetto, A., Bertini, V., Esposito, M., Carli, N., Minassian, B. A., Bonuccelli, A., Peroni, D., Michelucci, R. and Striano, P. (2019). "The best evidence for progressive myoclonic epilepsy: A pathway to precision therapy." *Seizure* 71: 247-257.**

Progressive Myoclonus Epilepsies (PMEs) are a group of uncommon clinically and genetically heterogeneous disorders characterised by myoclonus, generalized epilepsy, and neurological deterioration, including dementia and ataxia. PMEs may have infancy, childhood, juvenile or adult onset, but usually present in late childhood or adolescence, at variance from epileptic encephalopathies, which start with

polymorphic seizures in early infancy. Neurophysiologic recordings are suited to describe faithfully the time course of the shock-like muscle contractions which characterize myoclonus. A combination of positive and negative myoclonus is typical of PME. The gene defects for most PMEs (Unverricht-Lundborg disease, Lafora disease, several forms of neuronal ceroid lipofuscinoses, myoclonus epilepsy with ragged-red fibers [MERRF], and type 1 and 2 sialidoses) have been identified. PMEs are uncommon disorders, difficult to diagnose in the absence of extensive experience. Thus, aetiology is undetermined in many patients, despite the advance in molecular medicine. Treatment of PMEs remains essentially symptomatic of seizures and myoclonus, together with palliative, supportive, and rehabilitative measures. The response to therapy may initially be relatively favourable, afterwards however, seizures may become more frequent, and progressive neurologic decline occurs. The prognosis of a PME depends on the specific disease. The history of PMEs revealed that the international collaboration and sharing experience is the right way to proceed. This emerging picture and biological insights will allow us to find ways to provide the patients with meaningful treatment.

<https://www.ncbi.nlm.nih.gov/pubmed/31476531>

**Quinlan, C. S., Capra, M. and Dempsey, M. (2019). "Paediatric malignant melanoma in Ireland: A population study and review of the literature." J Plast Reconstr Aesthet Surg 72(8): 1388-1395.**

INTRODUCTION: Malignant melanoma is increasing in frequency worldwide; however, this disease is rare in children. As large-scale studies on paediatric melanoma are lacking, management is currently often based upon the understanding of the disease process in adults. The aim of this study was to characterise cases of paediatric melanoma diagnosed in the Republic of Ireland over a 21-year period. METHODS: This was a retrospective, multicentre study using national data provided by the National Cancer Registry of Ireland and individual practitioners. RESULTS: Twenty-four cases of melanoma treated in 11 different centres were included in the study. The median patient age at diagnosis was 15 years. The majority of cases arose on the limbs. The median Breslow thickness in patients of the pre-pubertal age group was 8.25mm, while in children more than 13 years, it was 1.65mm. Eight patients had disease recurrence and five patients died. CONCLUSION: The diagnosis of melanoma remains rare in children. This study contributes to our current understanding of malignant melanoma in paediatric patients; however, further investigation of the disease characteristics in this group is necessary to achieve optimal management of these cases and therefore improve outcomes.

<https://www.ncbi.nlm.nih.gov/pubmed/31101426>

**Ryvlin, P., Rheims, S. and Lhatoo, S. D. (2019). "Risks and predictive biomarkers of sudden unexpected death in epilepsy patient." Curr Opin Neurol 32(2): 205-212.**

PURPOSE OF REVIEW: The current review updates our knowledge regarding sudden unexpected death in epilepsy patient (SUDEP) risks, risk factors, and investigations of putative biomarkers based on suspected mechanisms of SUDEP. RECENT FINDINGS: The overall incidence of SUDEP in adults with epilepsy is 1.2/1000 patient-years, with surprisingly comparable figures in children in recently published population-based studies. This risk was found to decrease over time in

several cohorts at a rate of -7% per year, for unknown reasons. Well established risk factors include frequency of generalized tonic-clonic seizures, while adding antiepileptic treatment, nocturnal supervision and use of nocturnal listening device appear to be protective. In contrast, recent data failed to demonstrate the predictive value of heart rate variability, periictal cardiorespiratory dysfunction, and postictal generalized electroencephalography suppression. Preliminary findings suggest that brainstem and thalamic atrophy may be associated with a higher risk of SUDEP. Novel experimental and human data support the primary role of generalized tonic-clonic seizure-triggered respiratory dysfunction and the likely contribution of altered brainstem serotonergic neurotransmission, in SUDEP pathophysiology. SUMMARY: Although significant progress has been made during the past year in the understanding of SUDEP mechanisms and investigation of numerous potential biomarkers, we are still missing reliable predictors of SUDEP beyond the well established clinical risk factors.

<https://www.ncbi.nlm.nih.gov/pubmed/30694923>

**Seid, S. S., Ibro, S. A., Ahmed, A. A., Olani Akuma, A., Reta, E. Y., Haso, T. K. and Fata, G. A. (2019). "Causes and factors associated with neonatal mortality in Neonatal Intensive Care Unit (NICU) of Jimma University Medical Center, Jimma, South West Ethiopia." Pediatric Health Med Ther 10: 39-48.**

Background: The neonatal period is the most susceptible phase of life. In Ethiopia changes in neonatal mortality are not as significant as changes in post-neonatal and child mortality. The aim of this study was to assess the causes and factors associated with neonatal mortality at Jimma Medical Center. Materials and methods: A cross-sectional study was conducted for 11 days from February 12, 2018 at the Neonatal ICU of Jimma Medical Center. Data were extracted from the medical records of neonates admitted during a three year period from September 07, 2014 to August 31, 2017, using pretested checklists. Bivariate and multivariate logistic regressions were used to determine factors associated with neonatal mortality and P-values <0.05 were considered statistically significant. Results: Of 3,276 neonates admitted during the study period, 412 (13.3%) died, equating to a rate of 30 deaths per 1,000 institutional live births. The majority (249, 60.4%) of deceased neonates had low birth weight, while 230 (55.8%) were premature and 169(41%) had Respiratory Distress Syndrome (RDS). Residency being outside Jimma city (AOR 1.89, 95% CI: 1.43, 2.51) and the length of stay <7Days (AOR 3.93, 95% CI: 2.82, 5.50), low birth weight (AOR 1.54, 95% CI: 1.06, 2.25), prematurity (AOR 2.2, 95% CI: 1.41, 3.42), RDS (AOR 4.15, 95% CI: 2.9, 5.66), perinatal asphyxia (AOR 4.95, 95% CI: 3.6, 7.34), and congenital malformations (AOR 4, 95% CI: 2.55, 2.68) were significantly associated with neonatal mortality. Conclusions: A significant proportion of neonates attending the neonatal ICU died. Parental residency, the length of stay, low birth weight, prematurity, RDS, perinatal asphyxia, and congenital malformations were factors associated with neonatal mortality, which could be avoidable. Therefore, preventive measures such as enhancing the utilization of antenatal care services and, early identification and referral of high risk pregnancy and neonates could reduce the neonatal deaths.

<https://www.ncbi.nlm.nih.gov/pubmed/31191085>

**Song, J., Mailick, M. R., Greenberg, J. S. and Floyd, F. J. (2019). "Mortality in parents after the death of a child." Soc Sci Med 239: 112522.**

**OBJECTIVE:** The death of a child is a traumatic stressor that takes a toll on the health of parents. This study examined long-term impacts of the death of a child on the risk of early mortality in bereaved parents. In a follow-up analysis, a twin subsample was analyzed to examine potential genetic confounding. **METHOD:** We analyzed data from the Midlife in the United States (MIDUS) study. The primary sample consists of two groups of MIDUS 2 participants (2004-06); (1) parents who experienced the death of a child prior to MIDUS 2 (n=451) and (2) comparison parents who had not experienced death of any children (n=1804) (mean age=63). We also analyzed 52 twin pairs in which one twin experienced the death of a child and 271 twin pairs in which both twins had all living children. Mortality status of parents was assessed in 2017. **RESULTS:** Parents who had experienced the death of a child had a 32% higher likelihood of early mortality (defined as dying earlier than life expectancy) than their peers who did not have any deceased children, and they were more likely to die of heart disease. Analyses of the twin subsample revealed significantly lower concordance for early mortality among the pairs with a bereaved twin than among control twins, consistent with non-genetic effects. **CONCLUSIONS:** The findings suggest that the death of a child has lasting impacts on the risk of early mortality in bereaved parents. This study provides the first U.S. estimate of bereavement effects on mortality extending through the parents' full life course, with significant public health implications. In addition, analysis of concordance of early death rates in the twin subsample suggests the impact on mortality of parental bereavement, net of genetic factors.

<https://www.ncbi.nlm.nih.gov/pubmed/31487567>

**Svane, J., Lynge, T. H., Pedersen-Bjergaard, U., Jespersen, T., Gislason, G. H., Risgaard, B., Winkel, B. G. and Tfelt-Hansen, J. (2019). "Cause-specific mortality in children and young adults with diabetes mellitus: A Danish nationwide cohort study." *Eur J Prev Cardiol*, 10.1177/2047487319836550: 2047487319836550.**

**AIMS:** Persons with diabetes mellitus have increased all-cause mortality compared with the general population. Nationwide studies on causes of death and mortality among young persons with diabetes mellitus are sparse. The aim of this study was to examine all-cause and cause-specific mortality in children and young adults with and without diabetes. **METHODS AND RESULTS:** The study population consisted of all persons in Denmark aged 1-35 years in 2000-2009 and 36-49 years in 2007-2009, which equals 27.1 million person-years. All 14,294 deaths in the 10-year period were included and cause of death was established based on information from autopsy reports and death certificates. The Danish Register of Medicinal Product Statistics was used to identify persons with type 1 diabetes and type 2 diabetes. During the study period, which included 153,070 diabetic person-years, 669 (5% of all deceased) persons with diabetes mellitus died, of which 70% had type 1 and 30% had type 2 diabetes. Persons with diabetes mellitus had an all-cause mortality rate (ASMR) of 327 per 100,000 person-years compared with 74 per 100,000 person-years among persons without diabetes mellitus (ASMR ratio 4,  $p < 0.001$ ). The leading cause of death among persons with diabetes mellitus was cardiac diseases (  $n = 230$ , 34%) with an ASMR ratio of 8 (95% confidence interval 6-9). **CONCLUSIONS:** Young persons with diabetes mellitus had four-fold increased all-cause mortality and eight-fold increased cardiovascular mortality compared with

persons without diabetes mellitus. Focus on cardiovascular risk monitoring and management among young persons with diabetes mellitus is warranted to prevent premature death in diabetes mellitus.

<https://www.ncbi.nlm.nih.gov/pubmed/30862235>

**Webster, G., Olson, R., Schoppen, Z. J., Giancola, N., Balmert, L. C., Cherny, S. and George, A. L., Jr. (2019). "Cardiac Evaluation of Children With a Family History of Sudden Death." J Am Coll Cardiol 74(6): 759-770.**

**BACKGROUND:** After sudden death occurs in the young, first-degree family members should undergo clinical screening for occult cardiac disease, but the diagnostic yield from screening is not well-defined in the United States.

**OBJECTIVES:** The purpose of this study was to determine the clinical predictors of cardiac diagnosis in children referred for evaluation following a sudden death in the family. **METHODS:** Patients referred for a family history of sudden death were evaluated in a retrospective review from a tertiary pediatric referral center.

**RESULTS:** Among 419 pediatric relatives of 256 decedents, 27% of patients were diagnosed with a disease or had a clinical finding of uncertain significance. Patients were diagnosed with heritable cardiac disease in 39 cases (9.3%). Nonheritable cardiac disease was diagnosed in another 5.5% of patients. Clinical findings of uncertain significance were present in 52 patients (12.4%), including abnormal electrophysiological test results (41 of 52) or imaging test results (11 of 52). Among patients diagnosed with a heritable cardiac disease, the nearest affected relative was almost always a first-degree relative (37 of 39, 95%). The strongest predictors for a successful diagnosis in the patient were an abnormal electrocardiogram and a first-degree relationship to the nearest affected relative (odds ratios: 24.2 and 18.8, respectively). **CONCLUSIONS:** Children referred for a family history of sudden death receive cardiac disease diagnoses (14%), but clinical findings of uncertain significance increase the challenge of clinical management. The importance of a diagnosis in first-degree affected relatives supports the clinical practice of testing intervening family members first when patients are second- or higher-degree relatives to the decedent.

<https://www.ncbi.nlm.nih.gov/pubmed/31395126>

**Youngblut, J. M., Brooten, D., Del-Moral, T., Cantwell, G. P., Totapally, B. and Yoo, C. (2019). "Black, White, and Hispanic Children's Health and Function 2-13 Months After Sibling Intensive Care Unit Death." J Pediatr 210: 184-193.**

**OBJECTIVE:** To describe children's anxiety, depression, behaviors, and school performance at 2-13 months after sibling neonatal/pediatric intensive care unit (NICU/PICU) or emergency department (ED) death and compare these outcomes by child age, sex, race/ethnicity, whether the child saw their sibling in the NICU/PICU/ED, and attended the sibling's funeral. **STUDY DESIGN:** Children in 71 families were recruited for this longitudinal study from 4 children's hospitals and 14 other Florida hospitals. Children rated anxiety (Spence Children's Anxiety Scale) and depression (Children's Depression Inventory); parents rated child behaviors (Child Behavior Checklist) and reported school performance (detentions, suspensions, requested parent-teacher meetings) at 2, 4, 6, and 13 months post-sibling death. Analyses included repeated measures-ANOVA, t-tests, and 1-way ANOVA.

**RESULTS:** In total, 132 children and 96 parents participated. More children were

female (58%), black (50%), and school-age (72%). Of the children, 43% had elevated anxiety and 6% had elevated depression over 13 months post-sibling death. Child-rated anxiety was higher for girls and black vs white children. Child-rated anxiety and depression were lower if they saw their sibling in the NICU/PICU/ED before and/or after the death, and/or attended the funeral. Teens were more withdrawn than school-age children at all time points. Children who did not see their deceased sibling in the NICU/PICU/ED after death had more requests for parent-teacher conferences. CONCLUSIONS: Children's anxiety was more common than depression, especially in girls and black children. Children who saw their siblings in the NICU/PICU/ED before/after death and/or attended funeral services had lower anxiety and depression over the first 13 months after sibling death.

<https://www.ncbi.nlm.nih.gov/pubmed/31030947>

## ***Outcomes and Instruments***

**Aston, L., Shaw, R. and Knibb, R. (2019). "Preliminary development of proxy-rated quality-of-life scales for children and adults with Niemann-Pick type C." Qual Life Res 28(11): 3083-3092.**

**OBJECTIVES:** Niemann-Pick disease type C (NPC) is a rare life-limiting disease for which there is no cure. No scales currently exist to measure the impact of medication, physical therapy or clinical trials. The aim of this study was to develop age-appropriate Quality-of-Life (QoL) scales to measure the impact of NPC on children and adults. **DESIGN:** Scale development study using a phenomenological approach to data generation and analysis. **METHODS:** Fourteen interviews were conducted with people living with NPC and/or their parents/carers. Themes were generated and examined against an existential-phenomenological theory of wellbeing. A matrix was constructed to represent the phenomenological insight gained on participants' subjective experiences and a bank of items that were related to their QoL was developed. **RESULTS:** NPC quality-of-life questionnaires for children (NPCQLQ-C) and adults (NPCQLQ-A) proxy prototype scales were produced and completed by 23 parents/carers of children (child age mean = 8.61 years) and 20 parents/carers of adults (adult age = 33.4 years). Reliability analysis resulted in a 15-item NPCQLQ-C and a 30-item NPCQLQ-A, which showed excellent internal consistency, Cronbach's alpha = 0.925 and 0.947, respectively. **CONCLUSION:** The NPCQLQ-C and NPCQLQ-A are the first disease-specific QoL scales to be developed for people living with NPC. This novel approach to scale development values the experiential, real life impact of living with NPC and focused on the lived-experiences and impact on QoL. The scales will enable healthcare professionals and researchers to have a better understanding and quantifiable measurement of the impact of living with NPC on a patient's daily life.

<https://www.ncbi.nlm.nih.gov/pubmed/31227959>

**Baca, Q., Lin, C., O'Hare, K., Golianu, B. and Tsui, B. (2019). "Erector spinae plane block for pediatric palliative care." Paediatr Anaesth 29(4): 386-387.**

<https://www.ncbi.nlm.nih.gov/pubmed/30758119>

**Bardsley, M., Georghiou, T., Spence, R. and Billings, J. (2019). "Factors associated with variation in hospital use at the end of life in England." BMJ Support Palliat Care 9(2): 167-174.**

**OBJECTIVE:** To identify the relative importance of factors influencing hospital use at the end of life. **DESIGN:** Retrospective cohort study of person and health system effects on hospital use in the past 12 months modelling differences in admissions, bed days and whether a person died in hospital. **SETTING:** Residents in England for the period 2009/2010 to 2011/2012 using Hospital Episodes Statistics (HES) data from all acute care hospitals in England funded by the National Health Service (NHS). **PARTICIPANTS:** 1 223 859 people registered with a GP in England who died (decedents) in England (April 2009-March 2012) with a record of NHS hospital care. **MAIN OUTCOME MEASURES:** Hospital admissions, and hospital bed days and place of death (in or out of hospital) in the past 12 months of life. **RESULTS:** The mean number of admissions in the past 12 months of life averaged 2.28 occupying

30.05 bed days-excluding 9.8% of patients with no hospital history. A total of 50.8% of people died in hospital. Difference in hospital use was associated with a range of patient descriptors (age, gender and ethnicity). The variables with the greatest 'explanatory power' were those that described the diagnoses and causes of death. So, for example, 65% of the variability in the model of hospital admissions was explained by diagnoses. Only moderate levels of variation were explained by the hospital provider variables for admissions and deaths in hospital, though the impacts on total bed days was large. CONCLUSIONS: Comparative analyses of hospital utilisation should standardise for a range of patient specific variables. Though the models indicated some degree of variability associated with individual providers, the scale of this was not great for admissions and death in hospital but the variability associated with length of stay differences suggests that attempts to optimise hospital use should look at differences in lengths of stay and bed use. This study adds important new information about variability in admissions by diagnostic group, and variability in bed days by diagnostic group and eventual cause of death.

<https://www.ncbi.nlm.nih.gov/pubmed/27013618>

**Broomfield, A., Davison, J., Roberts, J., Stewart, C., Hensman, P., Beesley, C., Tylee, K., Rust, S., Schwahn, B., Jameson, E., Vijay, S., Santra, S., Sreekantam, S., Ramaswami, U., Chakrapani, A., Raiman, J., Cleary, M. A. and Jones, S. A. (2019). "Ten years of enzyme replacement therapy in paediatric onset mucopolysaccharidosis II in England." Mol Genet Metab, 10.1016/j.ymgme.2019.07.016.**

The outcome of 110 patients with paediatric onset mucopolysaccharidosis II (MPS II) since the commercial introduction of enzyme replacement therapy (ERT) in England in 2007 is reported. Median length of follow up was 10years 3months (range=1y 2m to 18years 6month). 78 patients were treated with ERT, 18 had no ERT or disease modifying treatment 7 had haematopoietic stem cell transplant, 4 experimental intrathecal therapy and 3 were lost to follow up. There is clear evidence of improved survival (median age of death of ERT treated (n=16)=15.13years (range=9.53 to 20.58y), and untreated (n=17)=11.43y (0.5 to 19.13y) p=.0005). Early introduction of ERT improved respiratory outcome at 16years, the median FVC (% predicted) of those in whom ERT initiated <8years=69% (range=34-86%) and 48% (25-108) (p=.045) in those started >8years. However, ERT appears to have minimal impact on hearing, carpal tunnel syndrome or progression of cardiac valvular disease. Cardiac valvular disease occurred in 18/46 (40%), with progression occurring most frequently in the aortic valve 13/46 (28%). The lack of requirement for neurosurgical intervention in the first 8years of life suggests that targeted imaging based on clinical symptomology would be safe in this age group after baseline assessments. There is also emerging evidence that the neurological phenotype is more nuanced than the previously recognized dichotomy of severe and attenuated phenotypes in patients presenting in early childhood.

<https://www.ncbi.nlm.nih.gov/pubmed/31383595>

**Cawley, P. and Chakkarapani, E. (2019). "Fifteen-minute consultation: Therapeutic hypothermia for infants with hypoxic ischaemic encephalopathy-translating jargon, prognosis and uncertainty for parents." Arch Dis Child Educ Pract Ed, 10.1136/archdischild-2017-314116.**

Hypoxic ischaemic encephalopathy may lead to death or severe long-term morbidity. Therapeutic hypothermia (TH) increases survival without impairments in childhood, but prognostic uncertainty may remain for years after birth. Clear and accurate communication is imperative but challenging. This article explores the predictive value of routinely performed assessments during TH, as well as the qualitative research relating to parental experience. This article will benefit paediatric trainees, consultants and nurse practitioners in providing: (1) the background information needed for initiating a conversation with parents regarding outcome and (2) optimising their communication with parents in translating jargon, prognosis and uncertainty.

<https://www.ncbi.nlm.nih.gov/pubmed/31292147>

**Eksi, M. S., Turgut, V. U., Ozcan-Eksi, E. E., Gungor, A., Tukul Turgut, F. N. and Pamir, M. N. (2019). "Serotonin Syndrome Following Tramadol and Gabapentin Use After Spine Surgery." World Neurosurg 126: 261-263.**

**BACKGROUND:** Serotonin syndrome (SS) is a common disease entity and could result in death if missed. The incidence of SS is underestimated due to misdiagnosis of many cases, especially the ones with less severe presentation. Many medications have been depicted as the source of SS. We present a case of SS in a patient who received intravenous tramadol and oral gabapentin as pain management after spine surgery. **CASE DESCRIPTION:** A 66-year-old man was admitted to our outpatient clinic with walking difficulties for 2 months. He was neurologically intact. However, he had neurologic claudication. He was on insulin, telmisartan-hydrochlorothiazide, amlodipine, and albuterol before the surgery, and these drugs were continued after the surgery. After he was diagnosed with lumbar spinal stenosis, he underwent total laminectomies of L3 and L4 and bilateral transpedicular screw placement from L1 to L5. He received tramadol 100 mg once daily intravenously and gabapentin 300 mg thrice daily orally after the spine surgery. He became confused, aggressive, and agitated during his stay in the hospital postoperatively. He became frustrated with even his children and wife. He started receiving haloperidol and quetiapine after psychiatry consultation. Because he worsened immediately after quetiapine and haloperidol, his medications were ceased in a step-by-step manner (first, tramadol and second, gabapentin). He became stable in a few hours, and his symptoms have improved since then. **CONCLUSIONS:** Physicians treating spine patients should be alert about SS in patients using both tramadol and gabapentin.

<https://www.ncbi.nlm.nih.gov/pubmed/30898741>

**Figueras-Coll, M., Canete-Abajo, N. and Betrian-Blasco, P. (2019). "[Percutaneous palliation in a child with scimitar syndrome]." An Pediatr (Barc), 10.1016/j.anpedi.2019.07.002.**

<https://www.ncbi.nlm.nih.gov/pubmed/31416712>

**Forbat, L., Mnatzaganian, G. and Barclay, S. (2019). "The Healthcare Conflict Scale: development, validation and reliability testing of a tool for use across clinical settings." J Interprof Care 33(6): 680-688.**

Despite the widespread incidence of conflict and its detrimental impact across a range of health-care settings, there is no validated tool with which to measure it. This paper describes the international innovation of a tool to measure staff-family conflict in pediatrics, intensive care, emergency, palliative care, and nursing homes. Sixty-two health-care workers contributed to focus group discussions to refine a draft tool developed from the literature. Subsequently, 101 health-care workers applied the tool to fictionalized vignettes. The psychometric properties (construct validity, internal consistency, repeatability, and reliability) were explored using principal component analysis, Cronbach's alpha, and intra-class correlation (ICC) tests. The initial 17-item tool was reduced to seven items within three factors that explained 70.2% of the total variance in overarching construct. The internal consistency of the final overall scale was good (Cronbach's alpha: 0.750); test-retest reliability of each item was excellent with ICCs  $\geq 0.9$ . This new tool can be used to identify and score conflict, making it a key reference point in healthcare conflict work across clinical specialties. Its development and testing across specialties and across countries means it can be used in a variety of contexts. The tool provides health-care professionals with a new way to identify and measure conflict, and consequently has the potential to transform health-care relationships across disciplines and settings.

<https://www.ncbi.nlm.nih.gov/pubmed/31006290>

**Foulks, M. G., Meyer, R. M. L., Gold, J. I., Herrington, C. S., Kallin, K. and Menteer, J. (2019). "Postoperative heart failure after stage 1 palliative surgery for single ventricle cardiac disease." *Pediatr Cardiol* 40(5): 943-949.**

Outcomes for patients with single ventricle congenital heart disease (SV-CHD) continue to improve over time. However, the prognosis for patients who develop heart failure immediately after surgery is poorly understood. We conducted a single-center, retrospective cohort study of patients with SV-CHD, who suffered postoperative heart failure. Of 1038 cardiac surgeries performed on 621 SV-CHD patients between 2004 and 2010, 125 patients met inclusion criteria, including non-septatable anatomy, stage 1 surgery, and verified low cardiac output or heart failure state per STS definition. Overall survival was 73.2% at 2 months, 64.9% at 1 year, 60.5% at 2 years, and 54.6% at 4 years. Inotrope dependence beyond 7 days post-op yielded 45% 2-year survival versus 68% for those who weaned from inotropes within 7 days ( $p = 0.02$ ). Atrioventricular valve regurgitation (AVVR) influenced survival, and patients who developed renal failure or required ECMO fared poorly, even when they survived their hospitalization. Patients with postoperative heart failure and low cardiac output syndrome constitute a high-risk population beyond the term of the initial hospitalization and have an overall mid-term survival of 55% at 4 years. Wean from inotropic therapy is not completely reassuring in this population, as they have ongoing elevated risk of cardiac failure and death in the medium term. Ventricular dysfunction, AVVR, renal failure, and need for ECMO are all important prognostic factors for mid-term mortality. Inotrope dependence for  $> 7$  days has important implications reaching beyond the hospitalization.

<https://www.ncbi.nlm.nih.gov/pubmed/30937501>

**Friedrichsdorf, S. J., Remke, S., Hauser, J., Foster, L., Postier, A., Kolste, A. and Wolfe, J. (2019). "Development of a Pediatric Palliative Care Curriculum and Dissemination Model: Education in Palliative and End-of-Life Care (EPEC) Pediatrics." *J Pain Symptom Manage* 58(4): 707-720.e703.**

**CONTEXT:** Most children living and dying with serious illnesses experience high burden of distressing symptoms. Many seriously ill children and their families do not have access to subspecialist pediatric palliative care (PPC) services nor to clinicians trained in primary PPC. Lack of PPC education appears to be a significant barrier to PPC implementation. **OBJECTIVES:** Description of the development and dissemination of Education in Palliative and End-of-Life Care (EPEC)-Pediatrics. **METHODS:** Funded through a U.S. \$1.6 million National Institutes of Health/National Cancer Institute grant 2010-2017, this 24-module curriculum was designed to teach primary palliative care. The target audience included interprofessional pediatric hematology/oncology providers and all other clinicians caring for seriously ill children. **RESULTS:** The curriculum is delivered in a combination of online learning and in-person, face-to-face sessions. In addition, a one-day Professional Development Workshop was developed to teach EPEC-Pediatrics graduates, future "Trainers," thus becoming "Master Facilitators." Between 2012-May 2019, a total of 867 EPEC-Pediatric Trainers and 75 Master Facilitators from 58 countries participated in 17 Become an EPEC-Pediatrics-Trainer conferences and three Professional Development Workshops. The curriculum has also been adapted for large-scale dissemination across Canada and Latin-America, with translation to French and Spanish. Participants overwhelmingly report improvements in their PPC knowledge, attitudes, and skills, including teaching. Trainers subsequently anticipated improvements in patient care for children with serious illness at their home institutions. **CONCLUSION:** EPEC-Pediatrics has developed into the most comprehensive PPC curriculum worldwide. It is highly adaptable for local settings, became self-sustaining and six conferences are offered around the world in 2019. <https://www.ncbi.nlm.nih.gov/pubmed/31220594>

**Gainza-Lein, M., Fernandez, I. S., Ulate-Campos, A., Loddenkemper, T. and Ostendorf, A. P. (2019). "Timing in the treatment of status epilepticus: From basics to the clinic." *Seizure* 68: 22-30.**

**OBJECTIVE:** Describe basic science, animal models and clinical data related to timing of treatment in status epilepticus (SE). **METHODS:** We summarized the results of 15 studies that reported time to treatment in SE, and reviewed basic and clinical literature. **RESULTS:** SE is a life-threatening and time-sensitive emergency that requires immediate treatment. Current guidelines recommend escalation of anti-seizure medications (ASM) within specified time frames. Prolonged seizures may lead to changes in the composition and location of gamma-aminobutyric acid A receptors (GABAAR) and N-Methyl-d-aspartic acid receptors (NMDAR), leading to loss of inhibition and increased excitation. These biochemical changes are apparent in specific animal models having progressive resistance to benzodiazepines (BZD) with longer seizures. Later treatments lead to decreased response to BZD, longer seizures, greater need of continuous infusions, potential brain injury and increased in-hospital mortality. Despite mounting evidence that early treatment of SE is more effective and safer, treatment and ASM escalation is often delayed compared to protocols. Literature review of 2212 patients with SE showed an average time to treatment of 42.4min and time to hospital arrival of 56min. Also, only 51.8% of patients received treatment by emergency medical services and 12.8% by their families, including patients with a previous diagnosis of epilepsy or with prior SE. **CONCLUSIONS:** Morbidity and mortality may be avoided with rapid, effective

treatment of SE. Treatment application and escalation remains delayed especially in outpatient settings, potentially leading to suboptimal outcomes. Implementation techniques and quality improvement methodologies may provide avenues for improving outcomes in SE.

<https://www.ncbi.nlm.nih.gov/pubmed/29884518>

**Glover Williams, A. and Finlay, F. (2019). "Can infant sleeping bags be recommended by medical professionals as protection against sudden infant death syndrome?" Arch Dis Child 104(3): 305-307.**

Clinical scenario: A mother brought her infant to the hospital with bronchiolitis and incidentally asked if I would recommend the use of infant sleeping bags to protect against Sudden Infant Death Syndrome as several of her friends use them.

Structured question: Can infant sleeping bags be recommended by medical professionals as protective against Sudden Infant Death Syndrome? Methods: A literature search was performed. Trials were included if they had an English version available and the papers examined the impact that sleeping bag use had on risk of SIDS or its risk factors. Cochrane Library search found eight trials, two of which were found to meet inclusion criteria. MEDLINE was searched using the search terms ((baby sleeping bag) OR infant sleeping bag) OR cotton sleeping sack. Forty-seven papers were found, two of which were found to meet the inclusion criteria, one of which had already been found in the Cochrane Library search. One further paper was found through searching citations of the papers included. Discussion: Sleeping bags are used in 48-95% of infants in the UK and advocated for by the Lullaby Trust for their safety in the prevention of SIDS. The case control studies included found that sleeping bags are as safe, if not safer than other bedding when examining SIDS as an outcome. For sleeping bags to be safe they must be well made and appropriately used, which includes the correct size, Tog, clothing and other bedding for bedroom temperature.

<https://www.ncbi.nlm.nih.gov/pubmed/30297442>

**Gogna, G., Broadbent, A. and Baade, I. (2019). "Comparison on expenditure between an inpatient palliative care unit, and tertiary adult medical and surgical wards for patients' at end of life - A retrospective chart analysis." Intern Med J, 10.1111/imj.14623.**

BACKGROUND AND AIMS: The highest healthcare expenditures occur towards end of life. Costs relate to hospital admissions and investigations to diagnose, prognosticate and direct treatment. This Australian study compared cost of investigations in the last 72 h of life between an inpatient palliative care unit (PCU) and a tertiary hospital. METHOD: We retrospectively reviewed fifty adult medical and surgical patients (admitted for >72 h and who died in hospital) from the PCU and referring tertiary centre, between March and July 2016. Patients in the emergency department, intensive care, medical assessment, paediatric and obstetric units were excluded. All patients had an acute resuscitation plan and were on the 'Care of the Dying' pathway. RESULTS: Expenditure was less if palliative care were the primary caregivers, with statistically significant differences in amount of imaging ( $p < 0.001$ ) and pathology ( $p < 0.001$ ) ordered. There was no difference in microbiology ( $p = 0.172$ ) and histology ( $p \sim 1$ ) ordered. Total cost of investigations for PCU patients was \$1340.60 (4 of 50 patients), compared with \$9467.78 (29 of 50 patients) in the

tertiary hospital. PCU patients had longer length of stays (15.54 days vs 11.06 days) but cost less per bed day (\$868.32 vs \$878.79 respectively). **CONCLUSION:** Inpatient PCUs are less likely to order investigations and are more cost-effective. A prospective study comparing an inpatient PCU, and patients at a tertiary centre, with and without consult liaison palliative care input, would be worthwhile to see if outcomes remain the same and if consult liaison palliative care affects the investigative burden. This article is protected by copyright. All rights reserved.  
<https://www.ncbi.nlm.nih.gov/pubmed/31449720>

**Gouton, M., Bical, O. M., Zoghbi, J., Roussin, R., Lucet, V. and Leca, F. (2019). "Surgery of single ventricles in humanitarian practice: surgery for which patients?" Cardiol Young 29(5): 583-588.**

**OBJECTIVES:** To analyse the feasibility and effectiveness in humanitarian practice of surgical management of children with single-ventricle heart condition. **METHODS:** Retrospective study of children with a single ventricle, managed by the association Mecenat-Chirurgie Cardiaque since 1996, with long-term follow-up after their return home. **RESULTS:** Of the 138 children in our cohort, 119 had one or more surgeries (180 procedures): palliative surgery alone (systemic-pulmonary anastomosis or banding), 41; partial cavo-pulmonary connection, 47; total cavo-pulmonary connection (mean age 8.5 years), 31. Operative mortality is 5.5%. After a mean follow-up of 5.6 years, 18 children (13%) were lost to follow-up. Survival at 10 years is 79% in children receiving surgery (palliative only, 72%; partial cavo-pulmonary connection, 77%; total cavo-pulmonary connection, 97%) versus 29% in children with no surgical intervention. The prognosis is better for tricuspid atresia and double-inlet left ventricle (86 and 83% survival at 10 years) than for double-outlet right ventricle or complete atrio-ventricular canal defect (64 and 68% at 5 years). **CONCLUSION:** The surgery of the single ventricle in humanitarian medicine allows a very satisfactory survival after one or more surgeries tending towards a total cavo-pulmonary connection as soon as possible.  
<https://www.ncbi.nlm.nih.gov/pubmed/31046854>

**Grade, M., Koenig, J., Qian, Y., Sandhu, N., Liu, Y., Turner, B., von Eyben, R., Knox, S. and Dudley, S. (2019). "Outcomes and Characteristics of Patients Treated with Emergent Palliative Radiation Therapy." Pract Radiat Oncol 9(2): e203-e209.**

**PURPOSE:** Emergent palliative radiation therapy (PRT) of symptomatic metastases can significantly increase the quality of life of patients with cancer. In some contexts, this treatment may be underused, but in others PRT may represent an excessively aggressive intervention. The characterization of the current use of emergent PRT is warranted for optimized value and patient-centered care. **METHODS AND MATERIALS:** This study is a cross-sectional retrospective analysis of all emergent PRT courses at a single academic tertiary institution across 1 year. **RESULTS:** A total of 214 patients received a total of 238 treatment courses. The most common indications were bone (39%) and brain (14%) metastases. Compared with outpatients, inpatients had lower mean survival rates (2 months vs 6 months;  $P < .001$ ), higher rates of stopping treatment early (19.1% vs 9.0%;  $P = .034$ ), and greater involvement of palliative care (44.8% vs 24.1%;  $P < .001$ ), but the same mean planned fractions (9.10 vs 9.40 fractions;  $P = .669$ ). In a multiple predictor

survival analysis, palliative care involvement ( $P = .025$ ), male sex ( $P = .001$ ), ending treatment early ( $P = .011$ ), and having 1 of 3 serious indications (airway compromise, leptomeningeal disease, and superior/inferior vena cava involvement;  $P = .007$ ) were significantly associated with worse overall survival. CONCLUSIONS: Survival is particularly poor in patients who receive emergent PRT, and patient characteristics such as functional status and indication should be considered when determining fractionation schedule and dosing. A multi-institutional study of practice patterns and outcomes is warranted.

<https://www.ncbi.nlm.nih.gov/pubmed/30529795>

**Graham, E. M., Martin, R. H., Buckley, J. R., Zyblewski, S. C., Kavarana, M. N., Bradley, S. M., Alsoufi, B., Mahle, W. T., Hassid, M. and Atz, A. M. (2019). "Corticosteroid Therapy in Neonates Undergoing Cardiopulmonary Bypass: Randomized Controlled Trial." J Am Coll Cardiol 74(5): 659-668.**

BACKGROUND: The efficacy of intraoperative corticosteroids to improve outcomes following congenital cardiac operations remains controversial. OBJECTIVES: The purpose of this study was to determine whether intraoperative methylprednisolone improves post-operative recovery in neonates undergoing cardiac surgery. METHODS: Neonates undergoing cardiac surgery with cardiopulmonary bypass at 2 centers were enrolled in a double-blind randomized controlled trial of methylprednisolone (30 mg/kg) or placebo after the induction of anesthesia. The primary outcome was a previously validated morbidity-mortality composite that included any of the following events following surgery before discharge: death, mechanical circulatory support, cardiac arrest, hepatic injury, renal injury, or rising lactate level ( $>5$  mmol/l). RESULTS: Of the 190 subjects enrolled, 176 ( $n = 81$  methylprednisolone,  $n = 95$  placebo) were included in this analysis. A total of 27 (33%) subjects in the methylprednisolone group and 40 (42%) in the placebo group reached the primary study endpoint (odds ratio [OR]: 0.63; 95% confidence interval [CI]: 0.31 to 1.3;  $p = 0.21$ ). Methylprednisolone was associated with reductions in vasoactive inotropic requirements and in the incidence of the composite endpoint in subjects undergoing palliative operations (OR: 0.38; 95% CI: 0.15 to 0.99;  $p = 0.048$ ). There was a significant interaction between treatment effect and center. In this analysis, methylprednisolone was protective at 1 center, with an OR: 0.35 (95% CI: 0.15 to 0.84;  $p = 0.02$ ), and not so at the other center, with OR: 5.13 (95% CI: 0.85 to 30.90;  $p = 0.07$ ). CONCLUSIONS: Intraoperative methylprednisolone failed to show an overall significant benefit on the incidence of the composite primary study endpoint. There was, however, a benefit in patients undergoing palliative procedures and a significant interaction between treatment effect and center, suggesting that there may be center or patient characteristics that make prophylactic methylprednisolone beneficial.

<https://www.ncbi.nlm.nih.gov/pubmed/30529795>

**Gulczynska, E., Szczapa, T., Hozejowski, R., Borszewska-Kornacka, M. K. and Rutkowska, M. (2019). "Fraction of Inspired Oxygen as a Predictor of CPAP Failure in Preterm Infants with Respiratory Distress Syndrome: A Prospective Multicenter Study." Neonatology 116(2): 171-178.**

INTRODUCTION: There are limited data available regarding the fraction of inspired oxygen ( $FiO_2$ ) predictive of the failure of continuous positive airway pressure (CPAP)

in preterm infants with respiratory distress syndrome (RDS). Therefore, we investigated factors predictive of CPAP failure in the first 72 h of life, with special attention to the prognostic role of FiO<sub>2</sub>. **METHODS:** This multicenter, prospective study enrolled infants <30 weeks gestation in whom CPAP was initiated within the first 15 min after birth. In the univariate and multivariate logistic regression models, demographic, perinatal, and respiratory parameters were analyzed. The FiO<sub>2</sub> threshold was determined with ROC curve analysis. **RESULTS:** Of 389 recruited newborns, CPAP failure occurred in 108 infants (27.8%). In the univariate model, each gestational week reduced the odds of CPAP failure by 19%, and each 100 g of birth weight reduced the odds by 16% (both  $p < 0.05$ ). The risk was increased by 4.2 and 7.5% for each 0.01 increase in FiO<sub>2</sub> in the first and second hours of life, respectively. In the final multivariate model, birth weight and FiO<sub>2</sub> in the second hour of life were the predictive measures. The prognostic threshold was FiO<sub>2</sub> = 0.29 in the second hour of life (AUC 0.7;  $p < 0.0001$ ), with a sensitivity of 73% and a specificity of 57%. CPAP failure implied a more than 20-fold higher risk of death and pneumothorax and a 2- to 5-fold higher risk of typical complications of prematurity, including bronchopulmonary dysplasia and severe intraventricular hemorrhage. **CONCLUSION:** FiO<sub>2</sub> in the second hour of life is a significant predictor of CPAP failure. The threshold of 0.29 best discriminates the CPAP outcome. Nonresponders to CPAP have a remarkably higher incidence of complications and a higher mortality rate.

<https://www.ncbi.nlm.nih.gov/pubmed/31112987>

**Harmoney, K., Mobley, E. M., Gilbertson-White, S., Brogden, N. K. and Benson, R. J. (2019). "Differences in Advance Care Planning and Circumstances of Death for Pediatric Patients Who Do and Do Not Receive Palliative Care Consults: A Single-Center Retrospective Review of All Pediatric Deaths from 2012 to 2016." *J Palliat Med* 22(12): 1506-1514.**

**Background:** Growing evidence suggests that pediatric palliative care (PPC) teams influence the care received by children and young adults with chronic, life-limiting illnesses. Little is known about how PPC involvement affects advance care planning (ACP) and circumstances of death in pediatric populations with a wide range of diagnoses. **Objective:** To determine the relationship between PPC involvement, ACP, and circumstances of death for pediatric patients. **Design:** A retrospective chart review of 558 pediatric patients who died between January 1, 2012 and December 31, 2016 was conducted. Descriptive statistics were used to characterize the sample. A multivariable logistic regression was used to obtain associations between PPC involvement and ACP. **Setting:** Large, multidisciplinary tertiary care center in a rural state. **Measurements:** Data abstracted for each patient included the following: demographic information, diagnosis, location of primary unit, hospice involvement, goals of care (GOC), code status, Physician Orders for Life-Sustaining Treatment (POLST) completion, and location of death. **Results:** Patients with PPC involvement were more likely to have had ACP addressed before death. After adjusting for covariates in the model, patients with PPC were more likely to have their GOC documented (odds ratio [OR] = 96.93), completion of POLST (OR = 24.06), do-not-resuscitate code status (OR = 7.71), and hospice involvement at the time of death (OR = 11.70) compared with those who did not receive PPC. **Conclusions:** Pediatric patients are more likely to have ACP addressed if they have PPC involvement. Patients with chronic complex conditions are most likely to receive palliative care.

<https://www.ncbi.nlm.nih.gov/pubmed/31233350>

**Hogan, N. S., Schmidt, L. A., Howard Sharp, K. M., Barrera, M., Compas, B. E., Davies, B., Fairclough, D. L., Gilmer, M. J., Vannatta, K. and Gerhardt, C. A. (2019). "Development and testing of the Hogan Inventory of Bereavement short form for children and adolescents." Death Stud, 10.1080/07481187.2019.1627034: 1-9.**

To reduce response burden for bereaved children and adolescents, we provide data on the development and psychometric testing of a short form of the Hogan Sibling Inventory of Bereavement (HSIB). The resulting measure of grief symptoms and personal growth was renamed the Hogan Inventory of Bereavement - Short Form (Children and Adolescents; HIB-SF-CA). Psychometric properties were evaluated in a sample of 86 bereaved siblings. Instrument development and validation research design methods were used. Evidence of strong reliability and convergent validity indicates that the 21-item HIB-SF-CA is comparable to the original 46-item HSIB in measuring grief and personal growth in this population.

<https://www.ncbi.nlm.nih.gov/pubmed/31274055>

**Hui, D., Paiva, C. E., Del Fabbro, E. G., Steer, C., Naberhuis, J., van de Wetering, M., Fernandez-Ortega, P., Morita, T., Suh, S. Y., Bruera, E. and Mori, M. (2019). "Prognostication in advanced cancer: update and directions for future research." Support Care Cancer 27(6): 1973-1984.**

The objective of this review is to provide an update on prognostication in patients with advanced cancer and to discuss future directions for research in this field. Accurate prognostication of survival for patients with advanced cancer is vital, as patient life expectancy informs many important personal and clinical decisions. The most common prognostic approach is clinician prediction of survival (CPS) using temporal, surprise, or probabilistic questions. The surprise and probabilistic questions may be more accurate than the temporal approach, partly by limiting the time frame of prediction. Prognostic models such as the Glasgow Prognostic Score (GPS), Palliative Performance Scale (PPS), Palliative Prognostic Score (PaP), Palliative Prognostic Index (PPI), or Prognosis in Palliative Care Study (PiPS) predictor model may augment CPS. However, care must be taken to select the appropriate tool since prognostic accuracy varies by patient population, setting, and time frame of prediction. In addition to life expectancy, patients and caregivers often desire that expected treatment outcomes and bodily changes be communicated to them in a sensible manner at an appropriate time. We propose the following 10 major themes for future prognostication research: (1) enhancing prognostic accuracy, (2) improving reliability and reproducibility of prognosis, (3) identifying the appropriate prognostic tool for a given setting, (4) predicting the risks and benefits of cancer therapies, (5) predicting survival for pediatric populations, (6) translating prognostic knowledge into practice, (7) understanding the impact of prognostic uncertainty, (8) communicating prognosis, (9) clarifying outcomes associated with delivery of prognostic information, and (10) standardizing prognostic terminology.

<https://www.ncbi.nlm.nih.gov/pubmed/30863893>

**Marcus, K. L., Santos, G., Ciapponi, A., Comande, D., Bilodeau, M., Wolfe, J. and Dussel, V. (2019). "Impact of Specialized Pediatric Palliative Care: A**

**Systematic Review." J Pain Symptom Manage,**  
10.1016/j.jpainsymman.2019.08.005.

CONTEXT: Specialized pediatric palliative care (SPPC) is increasingly involved in the care of seriously ill children, yet the evidence on its impact has not been comprehensively reviewed. OBJECTIVE: The objective of this study was to assess the effects of providing SPPC to seriously ill children on patient-, caregiver-, and systems-level outcomes. METHODS: We performed a Systematic Review following Cochrane methods. DATA SOURCES: Medline, Embase, PsycINFO, Global Health, The Cochrane Central Register of Controlled Trials, LILACS, and Web of Science were searched from January 1996 to June 2018. STUDY SELECTION/DATA EXTRACTION: We included randomized controlled, cohort, case-control, and before-after studies in which exposure to SPPC services was the intervention of interest. All outcomes reported in these studies were included. Two investigators independently selected articles, extracted data, and assessed risk of bias of included studies using standardized criteria. RESULTS: Twenty-four studies were included in qualitative synthesis: one nonrandomized controlled trial, 16 cohort studies, and seven before-after studies. Evidence certainty was low. Twenty-one studies had one or more area with high risk of bias, most commonly selection bias, low group comparability, risk for confounding, and inadequate statistical reporting. Studies analyzed 46 domains, operationalized as 136 distinct outcomes. SPPC was associated with better child quality of life scores in all four studies that assessed this outcome. No other outcome showed this consistency. CONCLUSION: Receiving SPPC was associated with better child quality of life. However, the paucity and low certainty of the evidence precluded any firm recommendations about SPPC practice. Larger collaborative networks and greater consensus regarding SPPC research standards are needed.

<https://www.ncbi.nlm.nih.gov/pubmed/31404638>

**Mitchell, S., Bennett, K., Morris, A., Slowther, A. M., Coad, J. and Dale, J. (2019). "Achieving beneficial outcomes for children with life-limiting and life-threatening conditions receiving palliative care and their families: A realist review." Palliat Med, 10.1177/0269216319870647: 269216319870647.**

BACKGROUND: Palliative care for children and young people is a growing global health concern with significant resource implications. Improved understanding of how palliative care provides benefits is necessary as the number of children with life-limiting and life-threatening conditions rises. AIM: The aim is to investigate beneficial outcomes in palliative care from the perspective of children and families and the contexts and hidden mechanisms through which these outcomes can be achieved. DESIGN: This is a systematic realist review following the RAMESES standards. A protocol has been published in PROSPERO (registration no: CRD42018090646). DATA SOURCES: An iterative literature search was conducted over 2 years (2015-2017). Empirical research and systematic reviews about the experiences of children and families in relation to palliative care were included. RESULTS: Sixty papers were included. Narrative synthesis and realist analysis led to the proposal of context-mechanism-outcome configurations in four conceptual areas: (1) family adaptation, (2) the child's situation, (3) relationships with healthcare professionals and (4) access to palliative care services. The presence of two interdependent contexts, the 'expert' child and family and established relationships with healthcare professionals, triggers

mechanisms, including advocacy and affirmation in decision-making, which lead to important outcomes including an ability to place the emphasis of care on lessening suffering. Important child and family outcomes underpin the delivery of palliative care. CONCLUSION: Palliative care is a complex, multifactorial intervention. This review provides in-depth understanding into important contexts in which child and family outcomes can be achieved so that they benefit from palliative care and should inform future service development and practice.

<https://www.ncbi.nlm.nih.gov/pubmed/31431129>

**Munoz-Bonet, J. I., Lopez-Prats, J. L., Flor-Macian, E. M., Cantavella, T., Dominguez, A., Vidal, Y. and Brines, J. (2019). "Medical complications in a telemedicine home care programme for paediatric ventilated patients." J Telemed Telecare, 10.1177/1357633x19843761: 1357633x19843761.**

INTRODUCTION: Advances in paediatric medicine have increased survival rates for patients with severe chronic illnesses, of which the most complex are ventilator-dependent children (VDCs). Although home care improves their quality of life, morbidity and mortality rates are high. Our aim was to study the medical complications (events) that occur at home and assess the usefulness of telemedicine in their detection and treatment. METHODS: A prospective clinical study (2007-2017) was performed for tracheotomised VDCs. We used a high-density data telemedicine monitoring system from our Paediatric Intensive Care Unit and analysed events during the first two years of home care to study how different variables inter-correlated with the four most common ones: hospital admissions, admissions avoided, event durations and life-threatening events (LTEs); the significance level was set at an alpha of 0.05 in all cases. RESULTS: All our VDCs were included (n = 12); there were 141 events, and these were homogeneously distributed over the study period. The incidence was higher in children who were ventilator dependent for more than 12 h a day (70.9%, p < 0.001) and the main cause was respiratory (69.5%, p < 0.001). Telemedicine was the main initial care and monitoring approach (86.5% and 90.1%, respectively, p < 0.001); 13 events were LTEs, nine were resolved telemedically, four required medicalised transfer to hospital and three resulted in a hospital admission. DISCUSSION: Clinical complications are frequent in VDCs receiving home care, and respiratory decompensation is the most frequent cause. Telemedicine facilitated diagnosis and early treatment, and was useful in managing LTEs.

<https://www.ncbi.nlm.nih.gov/pubmed/31023136>

**Nagoya, Y., Miyashita, M., Irie, W., Yotani, N. and Shiwaku, H. (2019). "Development of a Proxy Quality-of-Life Rating Scale for the End-of-Life Care of Pediatric Cancer Patients, Evaluated from a Nurse's Perspective." J Palliat Med, 10.1089/jpm.2018.0598.**

Background: Assessing the quality of life (QoL) of children receiving end-of-life (EoL) care through evaluations by the children and their bereaved families is challenging; presently, there is no QoL assessment measure that is appropriate for use in pediatric EoL and/or palliative care. Objective: To develop and test a proxy rating scale (the "Good Death Inventory for Pediatrics," GDI-P) for the QoL of pediatric cancer patients receiving EoL care, evaluated from the nurse's perspective, as well as a short version of the scale. Design, Setting, and Measurements: The GDI-P was

developed based on previous studies. After initial testing, it was distributed to hospitals across Japan, where nurses in charge of patients with childhood cancer receiving EoL care used the scale to evaluate a patient retrospectively. To examine inter-rater reliability, we encouraged two nurses to evaluate one patient. The GDI-P was modified on the basis of the responses, and the validity and reliability were measured. Results: In total, 85 questionnaires were completed, including 32 pairs of responses from two nurses evaluating one patient. In addition, 47 retest questionnaires were returned. The final, modified GDI-P comprised eight factors with 22 items and showed high convergent and discriminant validity, scaling success rates for each item and factor, and Cronbach's alpha values. A short version of GDI-P was prepared, comprising eight representative items. Conclusions: The final GDI-P was confirmed to have adequate reliability and validity. The QoL scale developed in this study should provide useful outcome evaluation criteria for assessing the EoL care of pediatric cancer patients.

<https://www.ncbi.nlm.nih.gov/pubmed/31355699>

**Piris Borregas, S., Torres Valdivieso, M. J., Martin-Arriscado, C., de la Cruz Bertolo, J., Sierra Garcia, P. and Pallas Alonso, C. R. (2019). "Model that predicted death or disabilities in premature infants was valid at seven years of age." *Acta Paediatr* 108(7): 1245-1249.**

AIM: Validated a model that used bronchopulmonary dysplasia (BPD), brain injuries measured using ultrasound and retinopathy of prematurity (ROP) to predict late death or disability in premature infants at seven years of age. METHODS: A retrospective study was performed at the 12 de Octubre Hospital neonatal unit in Madrid. A logistic model was applied to estimate the independent prognostic contribution of each morbidity, and the effect that the combination of morbidities had on the seven-year outcomes. The analysis was performed on the total cohort from 1991 to 2008 and on two subcohorts from 1991 to 1998 and 1999 to 2008. RESULTS: A total of 1001 children were included with a mean birth weight of 922 +/- 208 g. Severe ROP was strongly associated with poor neurodevelopment, with an odds ratio (OR) 3.17 and 95% confidence interval (CI) of 1.56-6.50, and so was BPD (OR 1.52, 95% CI: 1.03-2.2). The combination of two neonatal morbidities increased the risk of a poor outcome (OR 4.44, 95% CI: 1.51-7.86). The model behaved differently in the two subcohorts. CONCLUSION: The prognostic model predicted a poor outcome at seven years of age when the subjects had at least two of the three morbidities.

<https://www.ncbi.nlm.nih.gov/pubmed/30536707>

**Price, J. F., Younan, S., Cabrera, A. G., Denfield, S. W., Tunuguntla, H., Choudhry, S., Dreyer, W. J. and Akcan-Arikan, A. (2019). "Diuretic Responsiveness and Its Prognostic Significance in Children With Heart Failure." *J Card Fail*, 10.1016/j.cardfail.2019.03.019.**

BACKGROUND: Loop diuretics are considered first-line therapy for congestion in children with heart failure, although some patients remain volume overloaded during treatment. We sought to characterize loop diuretic responsiveness (DR) in children hospitalized with acute decompensated failure and to determine whether a decreased response was associated with worse outcomes. METHODS AND RESULTS: DR was calculated for 108 consecutive children <21 years of age who

were hospitalized with acute decompensated heart failure. DR was defined as net fluid (mL) output per 1 mg of furosemide equivalents during the first 72 hours of treatment with a loop diuretic. The primary outcome was the composite end point of inpatient death or use of mechanical circulatory support. The median DR was 6.0 mL/mg (interquartile range -2.4 to 15.7 mL/mg). Thirty-two percent of patients remained in a positive fluid balance after 72 hours of treatment with a loop diuretic. Death or use of mechanical circulatory support occurred in 29 patients (27%). Low DR was associated with the composite end point, even after adjusting for net urine output and loop diuretic dose indexed to weight (odds ratio 5.3; P=.003). Patients with low DR also experienced longer length of hospital stay than patients with greater DR (median 33 days vs 11 days; P=.002). **CONCLUSION:** In children hospitalized with acute decompensated heart failure, early diminished loop DR during decongestion therapy is common and portends a poor prognosis.

<https://www.ncbi.nlm.nih.gov/pubmed/30986498>

**Rao, A. D., Figueiredo, M. L. S., Yegya-Raman, N., Sehgal, S., Chen, Q., Alcorn, S. R., Chen, M. J., Ladra, M., Villar, R. and Terezakis, S. A. (2019). "Clinical practice and outcomes of palliative radiation therapy in pediatric oncology patients: An international comparison of experiences from two distinct countries and health care systems." Radiother Oncol 140: 1-5.**

**BACKGROUND AND PURPOSE:** This study describes clinical outcomes of palliative radiation therapy (RT) for children treated in distinct health-care environments-the US where there is advanced integration of palliative resources and Brazil, a country in the process of developing provisions for pediatric palliative care. **METHODS AND MATERIALS:** Palliative RT cases of pediatric oncology patients aged  $\leq 21$ -years from 2010 to 2016 in two Brazil-based and one US-based (Johns Hopkins Hospital, JHH) academic centers were reviewed in this study. **RESULTS:** Eighty-eight pediatric patients were treated to 131 lesions with palliative RT. Forty-nine patients from the JHH cohort comprised 84 cases and 39 patients from the Brazil cohort comprised 46 cases. The most common indication for palliative RT was pain (55% overall, 39% Brazil, 63% JHH). Sixty-seven percent of patients experienced a complete (CR) or partial response (PR) to palliative RT, 12% reported stable symptoms (SS), and 22% reported progressive symptoms (PS). The median survival from the end of palliative RT was 3.6months (95% confidence interval (CI), 2.3-4.8months). When treated with palliative RT for pain, 83% of patients experience CR/PR, facilitating reduction or discontinuation of opiates in 46% of these patients. **CONCLUSION:** Despite different practices, the clinical results using palliative RT for pediatric patients treated in two unique healthcare environments demonstrated it is an effective tool for pediatric oncology patients across systems.

<https://www.ncbi.nlm.nih.gov/pubmed/31174104>

**Revon-Riviere, G., Pauly, V., Baumstarck, K., Bernard, C., Andre, N., Gentet, J. C., Seyler, C., Fond, G., Orleans, V., Michel, G., Auquier, P. and Boyer, L. (2019). "High-intensity end-of-life care among children, adolescents, and young adults with cancer who die in the hospital: A population-based study from the French national hospital database." Cancer, 10.1002/cncr.32035.**

**BACKGROUND:** Efforts to improve the quality of end-of-life (EOL) care depend on better knowledge of the care that children, adolescents, and young adults with

cancer receive, including high-intensity EOL (HI-EOL) care. The objective was to assess the rates of HI-EOL care in this population and to determine patient- and hospital-related predictors of HI-EOL from the French national hospital database. METHODS: This was a population-based, retrospective study of a cohort of patients aged 0 to 25 years at the time of death who died at hospital as a result of cancer in France between 2014 and 2016. The primary outcome was HI-EOL care, defined as the occurrence of  $\geq 1$  chemotherapy session  $< 14$  days from death, receiving care in an intensive care unit  $\geq 1$  time,  $> 1$  emergency room admission, and  $> 1$  hospitalization in an acute care unit in the last 30 days of life. RESULTS: The study included 1899 individuals from 345 hospitals; 61.4% experienced HI-EOL care. HI-EOL was increased with social disadvantage (adjusted odds ratio [AOR], 1.30; 95% confidence interval [CI], 1.03-1.65;  $P = .028$ ), hematological malignancies (AOR, 2.09; 95% CI, 1.57-2.77;  $P < .001$ ), complex chronic conditions (AOR, 1.60; 95% CI, 1.23-2.09;  $P = .001$ ) and care delivered in a specialty center (AOR, 1.70; 95% CI, 1.22-2.36;  $P = .001$ ). HI-EOL was reduced in cases of palliative care (AOR, 0.31; 95% CI, 0.24-0.41;  $P < .001$ ). CONCLUSION: A majority of children, adolescents, and young adults experience HI-EOL care. Several features (eg, social disadvantage, cancer diagnosis, complex chronic conditions, and specialty center care) were associated with HI-EOL care. These findings should now be discussed with patients, families, and professionals to define the optimal EOL.

<https://www.ncbi.nlm.nih.gov/pubmed/30913309>

**Rosfeld, Z. M., Miller, R., Fosselman, D. D., Ketner, A. R., Tumin, D., Tobias, J. D. and Humphrey, L. (2019). "Timing of Palliative Consultation for Children During a Fatal Illness." Hosp Pediatr 9(5): 373-378.**

BACKGROUND: The American Academy of Pediatrics recommends palliative care for children at the diagnosis of serious illness. Yet few children who die receive specialty palliative care consultation, and when it is provided, palliative care consultation tends to occur after  $> 75\%$  of the time from diagnosis until death. Focusing on the timing of palliative consultation in relation to the date of diagnosis, we evaluated factors predicting earlier receipt of pediatric palliative care in a cohort of decedents. METHODS: We retrospectively identified patients diagnosed with a life-limiting disease who died at our hospital in 2015-2017 after at least 1 inpatient palliative medicine consultation. Our primary outcome was time from palliative-qualifying diagnosis to earliest receipt of specialty palliative care. A survival analysis was used to describe factors associated with earlier receipt of palliative care. RESULTS: The analysis included 180 patients (median age at diagnosis  $< 1$  month [interquartile range (IQR): 0-77]). The median time to first palliative consultation was 7 days after diagnosis (IQR: 2-63), compared with a median of 50 days between diagnosis and death (IQR: 7-210). On the multivariable analysis, palliative consultation occurred earlier for patients who had cardiovascular diagnoses, had private insurance, and were of African American race. CONCLUSIONS: In a cohort of decedents at our institution, palliative consultation occurred much earlier than has been previously reported. We also identify factors associated with delayed receipt of palliative care among children who are dying that reveal further opportunities to improve access to specialty palliative care.

<https://www.ncbi.nlm.nih.gov/pubmed/30995995>

**Rossfeld, Z. M., Miller, R., Tumin, D., Tobias, J. D. and Humphrey, L. M. (2019). "Implications of Pediatric Palliative Consultation for Intensive Care Unit Stay." *J Palliat Med* 22(7): 790-796.**

**BACKGROUND:** The impact of specialty pediatric palliative care (PPC) on intensive care unit (ICU) length of stay for children is unclear. **Objective:** To estimate the impact of PPC consultation by analyzing ICU stay as a dynamic outcome over the course of hospitalization. **Patients and Methods:** Retrospective cohort study of children hospitalized with diagnoses suggested as referral triggers for PPC at a large academic children's hospital. We assessed ICU stay according to PPC consultation and, using a patient-day analysis, applied multivariable mixed effects logistic regression to predict the odds of being in the ICU on a given day. **Results:** The analytic sample included 777 admissions (11,954 hospital days), of which 100 admissions (13%) included PPC consultation. Principal patient demographics were age 8 +/- 6 years, 55% male sex, 71% white race, and 52% commercial insurance. Cardiac diagnoses were most frequent (29%) followed by gastrointestinal (22%) and malignant (20%) conditions. Although total ICU stay was longer for admissions, including PPC consultation (compared to admissions where PPC was not consulted), the odds of being in the ICU on a given day were reduced by 79% after PPC consultation (odds ratio [OR] = 0.21; 95% confidence interval [CI]: 0.13-0.34;  $p < 0.001$ ) for children with cancer and 85% (OR = 0.15; 95% CI: 0.08-0.26;  $p < 0.001$ ) for children with nononcologic conditions. **Conclusions:** Among children hospitalized with a diagnosis deemed eligible for specialty PPC, the likelihood of being in the ICU on a given day was strongly reduced after PPC consultation, supporting the value of PPC.

<https://www.ncbi.nlm.nih.gov/pubmed/30835155>

**Schulz, R., Bien, C. G. and May, T. W. (2019). "Decreasing SUDEP incidence in a tertiary epilepsy center between 1981 and 2016: Effects of better patient supervision." *Epilepsy Behav* 92: 1-4.**

**OBJECTIVE:** The objective of this study was to investigate the incidence of sudden unexpected death in epilepsy (SUDEP) in a tertiary epilepsy center in the years 1981-2016 with an emphasis on patient supervision and nursing intervention in different departments. **METHODS:** We identified 14 SUDEP cases (probable, definite, definite plus). Patient-years (PY) and incidence were calculated for the periods of six years for the general epileptology wards (adults and children) and, in addition, for the epilepsy monitoring unit (EMU) since 1990. **RESULTS:** The incidence of SUDEP showed a decreasing trend over time ( $r = -0.81$ ;  $p = 0.053$ , two-sided; Pearson correlation coefficient). This is especially true in children (no SUDEP occurred in pediatric general epileptology since 1992). Additionally, in the EMU (314PY since the start of 1990), no SUDEP occurred. Sudden unexpected death in epilepsy incidence was highest (6.8/1000PY) in the early time periods (1981-1992) and lowest (1.7/1000PY) in the later time periods (1999-2010). In the general epileptology wards (3579PY), the overall incidence was 3.9 per 1000PY (95% confidence interval (CI): 2.1-6.6). **CONCLUSIONS:** We assume that the decreased SUDEP incidence is an effect of better supervision by the use of technical means (e.g., video cameras, pulse oximeters, seizure detection systems) and rooming-in of parents or family.

<https://www.ncbi.nlm.nih.gov/pubmed/30580108>

**Shelmerdine, S. C., Davendralingam, N., Palm, L., Minden, T., Cary, N., Sebire, N. J. and Arthurs, O. J. (2019). "Diagnostic Accuracy of Postmortem CT of Children: A Retrospective Single-Center Study." AJR Am J Roentgenol, 10.2214/ajr.18.20534: 1-13.**

**OBJECTIVE:** The objective of our study was to determine the diagnostic accuracy of postmortem CT in children compared with standard autopsy. **MATERIALS AND METHODS:** This single-center retrospective study reviewed un-enhanced whole-body postmortem CT examinations of children less than 16 years old with corresponding autopsy reports irrespective of the clinical indication for referral for postmortem CT. Perinatal deaths were excluded. Postmortem CT was reported by experienced postmortem radiologists who were blinded to autopsy findings, with the primary outcome being concordance for the main pathologic diagnosis or findings leading to a cause of death. Autopsy performed by pediatric pathologists was the reference standard. **RESULTS:** One hundred thirty-six patients (74 [54.4%] male and 62 [45.6%] female patients) were included. The mean age of the 136 patients was 2 years 1 month (range, 2 days-14.7 years). A cause of death at autopsy was found for 77 of the 136 (56.6%) patients. Postmortem CT depicted a correct cause of death in 55 of 77 (71.4%) patients; (55/136 overall [40.4%]), with the majority attributable to traumatic brain or body injuries. For major pathologic findings, diagnostic accuracy rates were a sensitivity of 71.4% (95% CI, 60.5-80.3%), specificity of 81.4% (95% CI, 69.6-89.3%), positive predictive value of 83.3% (95% CI, 72.6-90.4%), negative predictive value of 68.6% (95% CI, 57.0-78.2%), and concordance rate of 75.7% (95% CI, 67.9-82.2%). The sensitivity of postmortem CT versus autopsy was highest for intracranial (75.6%; 95% CI, 60.7-86.2%) and musculoskeletal (98.4%; 95% CI, 91.4-99.7%) abnormalities and lowest for cardiac (31.3%; 95% CI, 14.2-55.6%) and abdominal (53.8%; 95% CI, 29.1-78.6%) findings. **CONCLUSION:** Postmortem CT gives an acceptable diagnostic concordance rate with autopsy of 71.4%, although identification of the cause of death overall was low at 40.4%. The highest accuracy rates were for intracranial and musculoskeletal abnormalities.

<https://www.ncbi.nlm.nih.gov/pubmed/30917029>

**Stenekes, S., Penner, J. L., Harlos, M., Proulx, M. C., Shepherd, E., Liben, S., Thompson, G., MacConnell, G., Gregoire, M. C. and Siden, H. H. (2019). "Development and Implementation of a Survey to Assess Health-Care Provider's Competency, Attitudes, and Knowledge About Perinatal Palliative Care." J Palliat Care 34(3): 151-159.**

Perinatal palliative care is an emerging area of health care. To date, no published tools assess health-care provider's knowledge and level of comfort in providing such care. A 2-phase study was undertaken to develop and implement a survey to evaluate the self-assessed competency, attitudes, and knowledge of health-care providers working in perinatal palliative care. Phase 1 included a review of the literature and appraisal of palliative and death-related instruments to inform the initial draft of the Perinatal Palliative Care Survey (PPCS). Twenty-four Canadian pediatric palliative care specialists critiqued the PPCS, establishing its face and content validity. Phase 2 involved administering the PPCS at 4 sites across Canada, resulting in 167 responses from nurses, physicians, and midwives. The majority of participants responded that they possessed a degree of comfort in providing

perinatal palliative care, particularly with assessing pain (76%), managing pain (69%), assessing other symptoms (85%), and managing other symptoms (78%). Two areas where participants level of confidence or extreme confidence was diminished included having conversations with families about the possibility of their infant dying (55%) and knowing and accessing community palliative care resources (32%). Responses in the knowledge section identified gaps related to opioid use, pharmacological interventions for breathlessness, pain behaviors, and tolerance developed to opioids and sedatives. Eighty-six percent of respondents stated that if education about palliative care was made available, they would participate with priority topics identified as communication with families (75%), managing symptoms (69%), pain management (69%), and ethical issues (66%). The PPCS provides a useful assessment to determine the educational needs of health-care providers delivering perinatal palliative care.

<https://www.ncbi.nlm.nih.gov/pubmed/30060727>

**Tucker Edmonds, B., Hoffman, S. M., Lynch, D., Jeffries, E., Jenkins, K., Wiehe, S., Bauer, N. and Kuppermann, M. (2019). "Creation of a Decision Support Tool for Expectant Parents Facing Threatened Periviable Delivery: Application of a User-Centered Design Approach." *Patient* 12(3): 327-337.**

**BACKGROUND:** Shared decision-making (SDM) is optimal in the context of periviable delivery, where the decision to pursue life-support measures or palliation is both preference sensitive and value laden. We sought to develop a decision support tool (DST) prototype to facilitate SDM by utilizing a user-centered design research approach. **METHODS:** We convened four patient and provider advisory boards with women and their partners who had experienced a surviving or non-surviving periviable delivery, pregnant women who had not experienced a prior preterm birth, and obstetric providers. Each 2-h session involved design research activities to generate ideas and facilitate sharing of values, goals, and attitudes. Participant feedback shaped the design of three prototypes (a tablet application, family story videos, and a virtual reality experience) to be tested in a final session. **RESULTS:** Ninety-five individuals (48 mothers/partners; 47 providers) from two hospitals participated. Most participants agreed that the prototypes should include factual, unbiased outcomes and probabilities. Mothers and support partners also desired comprehensive explanations of delivery and care options, while providers wanted a tool to ease communication, help elicit values, and share patient experiences. Participants ultimately favored the tablet application and suggested that it include family testimonial videos. **CONCLUSION:** Our results suggest that a DST that combines unbiased information and understandable outcomes with family testimonials would be meaningful for periviable SDM. User-centered design was found to be a useful method for creating a DST prototype that may lead to improved effectiveness, usability, uptake, and dissemination in the future, by leveraging the expertise of a wide range of stakeholders.

<https://www.ncbi.nlm.nih.gov/pubmed/30488236>

**Widger, K., Brennenstuhl, S., Duc, J., Tourangeau, A. and Rapoport, A. (2019). "Factor structure of the Quality of Children's Palliative Care Instrument (QCPCI) when complete by parents of children with cancer." *BMC Palliat Care* 18(1): 23.**

**BACKGROUND:** Currently available indicators of quality pediatric palliative care tend to focus on care provided during the end-of-life period rather than care provided throughout the disease trajectory. We adapted a previously developed instrument focused on mothers' perspectives on the quality of end-of-life care and assessed its psychometric properties with mothers and fathers of children with cancer at any stage of the illness. **METHODS:** Four subscales were included in the analysis: Connect with Families, Involve Parents, Share Information Among Health Professionals, Support Siblings. The number of items across the four subscales was reduced from 31 to 15. We conducted confirmatory factor analysis, composite reliability, internal consistency, and tests of correlation between the overall scale and subscale totals and a separate question inquiring about overall quality of care. Measurement invariance between mothers and fathers was assessed. **RESULTS:** A total of 533 mothers and fathers completed the survey. The four-factor model was confirmed and there were significant correlations between each subscale score and responses to the overall item on care quality. Cronbach's alpha was adequate for the scale as a whole and for each subscale ranging from 0.78 to 0.90. We also found the factor structure, means, and intercepts were similar across mothers and fathers, suggesting the tool can be used by both groups. **CONCLUSIONS:** There is evidence for a four-factor structure within a new Quality of Children's Palliative Care Instrument (QCPCI) with demonstrated reliability when used with mothers and fathers of children with cancer. Ongoing assessment of the psychometric properties is needed, including testing in additional populations. However, our initial findings suggest that the QCPCI may be a helpful tool for assessing the quality of palliative care for pediatric patients anywhere along the disease trajectory from the perspective of parents.

<https://www.ncbi.nlm.nih.gov/pubmed/30823877>

**Wilson, R. E., Rao, P. K., Cunningham, A. J., Dewey, E. N., Krishnaswami, S. and Hamilton, N. A. (2019). "A Natural History of Gastrojejunostomy Tubes in Children." J Surg Res 245: 461-466.**

**BACKGROUND:** Gastrojejunostomy (GJ) tubes are frequently used to provide nutrition in patients who do not tolerate gastric feeding. Despite their widespread use, there is little literature on the lifespan of GJ tubes, reasons for failure, and recommendations for optimal techniques and timing of replacement. We aimed to evaluate the natural history of GJ tubes in pediatric patients. **MATERIALS AND METHODS:** We reviewed all pediatric patients who underwent GJ tube placement or exchange at our institution from January 2012 to July 2018. Demographic data, time, and indication for replacement or removal of GJ tubes were collected. End points were permanent removal of GJ tube or mortality. **RESULTS:** Seventy-nine patients underwent 205 GJ tube procedures with a median of 2 GJ tubes per patient. Median GJ tube lifespan was 98 d (interquartile range = 54-166). The two most common indications for tube exchange were structural or mechanical problems (43.1%) and GJ tube dislodgement (34.6%). Although most GJ tube exchanges (66%) were performed under general anesthesia or with moderate sedation, 34% of exchanges were done without sedation. During the study period, 12 patients (15.2%) died from their primary disease, nine patients (11.4%) required subsequent fundoplication, one (1.3%) underwent a jejunostomy, and 23 (29.1%) progressed to gastric feeds without fundoplication at a median time of 208 d. **CONCLUSIONS:** GJ tubes offer a safe and effective feeding option in patients intolerant of gastric feeding. GJ tubes fail most

commonly from intrinsic structural or mechanical issues, and many patients ultimately tolerate gastric feeds without need for further intervention. Exchange of tubes without anesthesia is a viable option.

<https://www.ncbi.nlm.nih.gov/pubmed/31446187>

**Yieh, L., Dukhovny, D., Zhou, C. G., Gievers, L. and Caughey, A. B. (2019). "Cost Effectiveness of Neonatal Resuscitation at 22 Weeks of Gestation." *Obstet Gynecol* 133(6): 1199-1207.**

**OBJECTIVE:** To evaluate the cost effectiveness of three different approaches to the care of neonates born at 22 weeks of gestation: universal resuscitation, selective resuscitation, or no resuscitation. **METHODS:** We constructed a decision-analytic model using TreeAge to compare the outcomes of death and survival with and without neurodevelopmental impairment in a theoretical cohort of 5,176 neonates (an estimate of the annual number of deliveries that occur in the 22nd week of gestation in the United States). We took a societal perspective using a lifetime horizon, and all costs were expressed in 2017 U.S. dollars. Effectiveness was based on combined maternal and neonatal quality-adjusted life years (QALYs). The incremental cost-effectiveness ratio was determined (cost/QALY) for each additional survivor. The willingness to pay threshold was set at \$100,000/QALY. All model inputs were derived from the literature. Deterministic and probabilistic sensitivity analyses were performed to interrogate model assumptions. **RESULTS:** Universal resuscitation would result in 373 survivors, 123 of whom would have severe disability. Selective resuscitation would produce 78 survivors with 26 affected by severe impairments. No resuscitation would result in only eight survivors and three neonates with severe sequelae. Selective resuscitation was eliminated by extended dominance because this strategy had a higher incremental cost-effectiveness ratio than universal resuscitation, which was a more effective intervention. The incremental cost-effectiveness ratio of universal resuscitation compared with no resuscitation was not cost effective at \$106,691/QALY. Monte Carlo simulations demonstrated that universal resuscitation is more effective but also more expensive compared with no resuscitation, with only 35% of simulations below the willingness to pay threshold. **CONCLUSION:** In our model, neither selective nor universal resuscitation of 22-week neonates is a cost-effective strategy compared with no resuscitation.

<https://www.ncbi.nlm.nih.gov/pubmed/31135735>

## ***Pain and Symptom Control***

**Anghelescu, D. L. and Tesney, J. M. (2019). "Neuropathic Pain in Pediatric Oncology: A Clinical Decision Algorithm." Paediatr Drugs 21(2): 59-70.**

Neuropathic pain in pediatric oncology can be caused by distinct lesions or disease processes affecting the somatosensory system, including chemotherapy-related neuronal injury, solid tumor-related involvement of neural structures, post-surgical neuropathic pain-including phantom limb pain and pain after limb-sparing surgery-and the complex circumstances of neuropathic pain at the end of life. Treatment algorithms reflect the general treatment principles applied for adult neuropathic pain, but the dose regimens applied in children are modest and rarely escalated to the maximum doses to optimize analgesic efficacy. Pharmacological management of neuropathic pain should be based on a stepwise intervention strategy, as combinations of medications are the most effective approach. Gabapentinoids and tricyclic antidepressants are recommended as first-line therapy. Methadone, ketamine, and lidocaine may be useful adjuvants in selected patients. Prospective studies extended over a substantial length of time are recommended because of the nature of neuropathic pain as persistent, chronic pain and based on the need for sufficient time to escalate medication dose regimens to full analgesic efficacy.

<https://www.ncbi.nlm.nih.gov/pubmed/30761460>

**Collins, A., Mannion, R., Broderick, A., Hussey, S., Devins, M. and Bourke, B. (2019). "Gabapentin for the treatment of pain manifestations in children with severe neurological impairment: a single-centre retrospective review." BMJ Paediatr Open 3(1): e000467.**

Pain, irritability and feeding intolerance are common symptoms affecting quality of life in children with severe neurological impairment (SNI). We performed a retrospective study to explore the use of gabapentinoid medications for symptom control in children with SNI. Patients attending the palliative care or gastroenterology department being treated with gabapentin for irritability, vomiting or pain of unknown origin were included. Information was gathered retrospectively from medical documentation. Irritability was reduced in 30 of the 42 patients included. Gabapentin was discontinued in 15 children, 12 of whom then received pregabalin. Three children had a good response to pregabalin, six a minimal improvement and three no improvement. These results support the use of gabapentinoids in this patient cohort.

<https://www.ncbi.nlm.nih.gov/pubmed/31414063>

**Egeli, D., Bainbridge, L., Miller, T. and Potts, J. (2019). "Interdisciplinary Perspectives on the Value of Massage Therapy in a Pediatric Hospice." J Hosp Palliat Nurs 21(4): 319-325.**

Canuck Place Children's Hospice in Vancouver, Canada, has been hosting a massage therapy practicum within the hospice since 2011. The practicum is delivered by upper-level massage therapy students who are supervised by a registered massage therapist and clinical instructor through West Coast College of Massage Therapy. This study aimed to explore clinicians' perspectives on the value of providing massage therapy to support children in hospice care, their families, and staff. The research participants (n = 6) comprised Canuck Place clinicians who have

experience with the massage therapy practicum. In this descriptive phenomenological inquiry, semistructured interviews and thematic analysis were used. The findings demonstrated that Canuck Place clinicians valued the massage therapy practicum for its practical support in terms of creating access to massage therapy and self-care in the hospice. Massage therapy was also valued for supporting physical wellness (injury prevention/maintenance and symptom management) and psychosocial wellness (supporting dignity, interconnection, intraconnection, and rest/relaxation and providing a source of comfort/nurturing). This study is the first to explore clinicians' perceptions of massage therapy within a pediatric hospice and contributes to understanding massage therapy's potential role in the support of children, families, and staff within a hospice setting.  
<https://www.ncbi.nlm.nih.gov/pubmed/31149941>

**Eisdorfer, S. and Galinkin, J. (2019). "Opioid Use Disorder in Children and Adolescents: Risk Factors, Detection, and Treatment." Clin J Pain 35(6): 521-524.**

Opioid medications are an important tool in the management of pain and have been used in clinical practice for centuries. However, due to the highly addictive nature of this class of medications coupled with the life-threatening side effect of respiratory depression, opioid misuse has become a significant public health crisis worldwide. Children and adolescents are at risk for opioid misuse, and early detection is imperative to facilitate treatment and improve outcomes. This review will address the current state of opioid misuse and treatment in children and adolescents in the United States.  
<https://www.ncbi.nlm.nih.gov/pubmed/30985401>

**EIMokhallati, Y., Woodhouse, N., Farragher, T. and Bennett, M. I. (2019). "Specialist palliative care support is associated with improved pain relief at home during the last 3 months of life in patients with advanced disease: analysis of 5-year data from the national survey of bereaved people (VOICES)." BMC Med 17(1): 50.**

**BACKGROUND:** Studies have shown that more than half of patients with advanced progressive diseases approaching the end-of-life report pain and that pain relief for these patients is poorest at home compared to other care settings such as acute care facilities and hospice. Although home is the most common preferred place of death, the majority of deaths occur outside the home. Specialist palliative care is associated with improved quality of life, but systematic reviews of RCTs have failed to show a consistent association with better pain relief. The aim of this study was to examine the factors associated with good pain relief at home in the last 3 months of life for people with advanced progressive disease. **METHODS:** Data were obtained from the National Bereavement Survey in England, a cross-sectional post-bereavement survey of a stratified random sample of 246,763 deaths which were registered in England from 2011 to 2015. From 110,311 completed surveys (45% response rate), the analysis was based on individual-level data from 43,509 decedents who were cared for at home before death. **RESULTS:** Decedents who experienced good pain relief at home before death were significantly more likely to have received specialist palliative care (adjusted OR = 2.67; 95% CI, 2.62 to 2.72) and to have a recorded preferred place of death (adjusted OR = 1.87; 95% CI, 1.84

to 1.90) compared to those who did not. Good pain relief was more likely to be reported by a spouse or partner of the decedents compared to reports from their son or daughter (adjusted OR = 1.50, 95% CI, 1.47 to 1.53). **CONCLUSION:** This study indicates that patients at home who are approaching the end-of-life experience substantially better pain relief if they receive specialist palliative care and their preferred place of death is recorded regardless of their disease aetiology.

<https://www.ncbi.nlm.nih.gov/pubmed/30898162>

**Friedman, D., French, J. A. and Maccarrone, M. (2019). "Safety, efficacy, and mechanisms of action of cannabinoids in neurological disorders." Lancet Neurol 18(5): 504-512.**

In the past two decades, there has been an increasing interest in the therapeutic potential of cannabinoids for neurological disorders such as epilepsy, multiple sclerosis, pain, and neurodegenerative diseases. Cannabis-based treatments for pain and spasticity in patients with multiple sclerosis have been approved in some countries. Randomised controlled trials of plant-derived cannabidiol for treatment of Lennox-Gastaut syndrome and Dravet syndrome, two severe childhood-onset epilepsies, provide evidence of anti-seizure effects. However, small clinical trials of cannabinoids in other neurological disorders such as Huntington's disease, attention deficit hyperactivity disorder, and dementia, have not found any effect. Despite positive results in these two severe epilepsy syndromes, further studies are needed to determine if the anti-seizure effects of cannabidiol extend to other forms of epilepsy, to overcome pharmacokinetic challenges with oral cannabinoids, and to uncover the exact mechanisms by which cannabidiol or other exogenous and endogenous cannabinoids exert their therapeutic effects.

<https://www.ncbi.nlm.nih.gov/pubmed/30910443>

**Friedrichsdorf, S. J. (2019). "From Tramadol to Methadone: Opioids in the Treatment of Pain and Dyspnea in Pediatric Palliative Care." Clin J Pain 35(6): 501-508.**

**BACKGROUND:** More than 15,000 children die annually in the United States due to an underlying life-limiting disease and the majority of those children experience distressing symptoms, which are not adequately relieved, such as pain and dyspnea. Multimodal analgesia, that is multiple agents, interventions, rehabilitation, psychological modalities, and integrative (nonpharmacologic) therapies, act synergistically for more effective pediatric pain and symptom control with fewer side effects than a single analgesic or modality. However, opioids, such as morphine, fentanyl, hydromorphone, oxycodone, and methadone (in the United Kingdom: diamorphine) remain the mainstay medication to effectively treat pain and dyspnea in children with serious illness. **METHODS:** This article reviews commonly used opioids in Pediatric Palliative Care, which a special emphasis on 2 potentially particularly effective multimechanistic opioids: tramadol and methadone. **RESULTS:** Methadone, due to its multimechanistic action profile, is possibly among the most effective and most underutilized opioid analgesics in children with severe unrelieved pain at end of life. However, methadone should not be prescribed by those unfamiliar with its use: Its effects should be closely monitored for several days, particularly when it is first started and after any dose changes. **CONCLUSIONS:** Tramadol appears to play a key role in treating episodes of inconsolability in children with progressive neurologic,

metabolic, or chromosomally based condition with impairment of the central nervous system. However, the recent 2017 United States Food and Drug Administration (FDA) warning against pediatric use of tramadol does not seem to be based on clinical evidence, and therefore puts children at risk for unrelieved pain or increased respiratory depression.

<https://www.ncbi.nlm.nih.gov/pubmed/30985399>

**Garten, L. and Buhrer, C. (2019). "Pain and distress management in palliative neonatal care." Semin Fetal Neonatal Med 24(4): 101008.**

Palliative care concentrates on preventing and relieving suffering by reducing the severity of disease symptoms. Consistent treatment of pain and distress must therefore be an integral component of every palliative care concept. In this review non-pharmacological and pharmacological measures for pain and distress management in the context of palliative neonatal care are summarised. Furthermore, recommendations are given focusing on two special palliative neonatal care settings: compassionate extubation and withdrawing artificial nutrition and hydration.

<https://www.ncbi.nlm.nih.gov/pubmed/31056417>

**Greenfield, K., Holley, S., Schoth, D. E., Harrop, E., Howard, R., Bayliss, J., Brook, L., Jassal, S., Johnson, M., Wong, I. and Liossi, C. (2019). "Barriers and facilitators experienced by patients, carers and healthcare professionals when managing symptoms in infants, children and young people at end-of-life: a mixed methods systematic review protocol." BMJ Open 9(7): e030566.**

**INTRODUCTION:** This protocol describes the objective and methods of a systematic review of barriers and facilitators experienced by patients, carers and healthcare professionals when managing symptoms in infants, children and young people (ICYP) at end-of-life. **METHODS AND ANALYSIS:** The Cochrane Library, PROSPERO, CINAHL, MEDLINE, PsycINFO, Web of Science Core Collection, ProQuest Dissertations & Theses Database, Evidence Search and OpenGrey will be electronically searched. Reference screening of relevant articles and inquiries to researchers in the field will be undertaken. Studies will be selected if they apply qualitative, quantitative or mixed-methods designs to explore barriers and facilitators experienced by patients, carers and healthcare professionals when managing symptoms in ICYP at end-of-life. Articles will be screened by title and abstract by one reviewer with a second reviewer assessing 10% of the articles. Both reviewers will read and screen all remaining potentially relevant articles. For included articles, one reviewer will extract study characteristics and one will check this. Both reviewers will undertake independent quality assessments of included studies using established and appropriate checklists including The Critical Appraisal Skills Programme Qualitative Checklist; The evaluative criteria of credibility, transferability, dependability and confirmability; The Quality Assessment Tool for Quantitative Studies, and The Mixed Methods Appraisal Tool. Data synthesis methods will be decided after data extraction and assessment. **ETHICS AND DISSEMINATION:** This review will inform our understanding of symptom management in ICYP at end-of-life. The findings will be reported in a peer-reviewed journal and presented at conferences. The study raises no ethical issues. **PROSPERO REGISTRATION NUMBER:** CRD42019124797.

<https://www.ncbi.nlm.nih.gov/pubmed/31352426>

**Huizenga, M. N., Sepulveda-Rodriguez, A. and Forcelli, P. A. (2019). "Preclinical safety and efficacy of cannabidivarin for early life seizures." Neuropharmacology 148: 189-198.**

A significant proportion of neonatal and childhood seizures are poorly controlled by existing anti-seizure drugs (ASDs), likely due to prominent differences in ionic homeostasis and network connectivity between the immature and mature brain. In addition to the poor efficacy of current ASDs, many induce apoptosis, impair synaptic development, and produce behavioral deficits when given during early postnatal development. There is growing interest in new targets, such as cannabidiol (CBD) and its propyl analog cannabidivarin (CBDV) for early life indications. While CBD was recently approved for treatment of refractory childhood epilepsies, little is known about the efficacy or safety of CBDV. Here, we addressed this gap through a systematic evaluation of CBDV against multiple seizure models in postnatal day (P) 10 and 20 animals. We also evaluated the impact of CBDV on acute neurotoxicity in immature rats. CBDV (50-200mg/kg) displayed an age and model-specific profile of anticonvulsant action. In P10 rats, CBDV suppressed seizures only in the pentylenetetrazole model. In P20 rats, CBDV suppressed seizures in the pentylenetetrazole, DMCM, and maximal electroshock models. Between P10 and P20, we identified significant increases in mRNA expression of TRPV1 in multiple brain regions; when CBDV was tested in P20 TRPV1 knockout mice, anticonvulsant effects were attenuated. Finally, CBDV treatment generally avoided induction of neuronal degeneration in immature rats. Together, the efficacy and safety profile of CBDV suggest it may have therapeutic value for early life seizures.

<https://www.ncbi.nlm.nih.gov/pubmed/30633929>

**Kendrick, L. M., Hudgell, D., Hellman, A. and Weaver, M. S. (2019). "Attending to Total Pain in Juvenile Huntington Disease: A Case Report Informed by Narrative Review of the Literature." J Palliat Care 34(3): 205-207.**

**OBJECTIVES:** To consider the impact of juvenile Huntington disease (JHD) from a biomedical, symptom burden, and total pain palliative care perspective. **METHODS:** This case report was informed by a narrative review of the literature with inclusion of expert opinion from pediatric palliative care, an adult and pediatric neurologist, and a child psychiatrist. Audio-recorded qualitative interview and coauthorship with the pediatric patient's primary caregiver (his mother). **RESULTS:** The JHD impacts all domains of child and family function. **SIGNIFICANCE OF RESULTS:** Application of the concept of total pain to JHD informs and guides care for this complex, challenging condition.

<https://www.ncbi.nlm.nih.gov/pubmed/30950323>

**Madden, K., Jo, E., Williams, J. L., Liu, D. and Bruera, E. (2019). "Corrected QT Interval Prolongation in Pediatric and Young Adult Patients on Methadone for Cancer-Related Pain." J Pain Symptom Manage 58(4): 678-684.**

**CONTEXT:** Methadone has been reported to prolong the corrected QT (QTc) interval and increase the risk of torsades de pointes. **OBJECTIVES:** Our study examined the frequency of QTc prolongation among pediatric and young adult patients starting methadone for cancer pain. **METHODS:** All patients followed a standardized

protocol. Electrocardiograms (ECGs) were obtained at baseline (methadone starting day to 14 days prior), 1-2 weeks, and 4-6 weeks later. QTc values were manually calculated using the Bazett formula. QTc prolongation was defined as  $\geq 460$  milliseconds (ms) for prepubertal children,  $\geq 470$  ms for pubertal males, and  $\geq 480$  ms for pubertal females. RESULTS: Baseline ECGs were completed in 42 patients. Follow-up ECGs were completed in 38 of 42 (91%) and 31 of 42 (74%) patients at 1-2 weeks and 4-6 weeks, respectively. No patients had prolongation of the QTc at baseline, and 1 of 38 (3%) patients had a prolonged QTc at weeks 1-2. This patient had a history of prolonged QTc that the family did not initially report. No patients had prolongation of the QTc at weeks 4-6. No patients had torsades de pointes or ventricular fibrillation, and none died suddenly. Median (interquartile range [IQR]) baseline QTc was 391 (377-400) ms; median (IQR) 1-2 week follow-up QTc was 399 (374-411) ms ( $P = .05$ ), and median (IQR) 4-6 week follow-up QTc was 393 (379-423) ms ( $P = .01$ ). CONCLUSION: Clinically significant prolongation of the QTc interval occurred only in one patient who had a history of prolonged QTc. Prolonged QTc is rare in this population.

<https://www.ncbi.nlm.nih.gov/pubmed/31195079>

**Madden, K., Magno Charone, M., Mills, S., Dibaj, S., Williams, J. L., Liu, D. and Bruera, E. (2019). "Systematic Symptom Reporting by Pediatric Palliative Care Patients with Cancer: A Preliminary Report." J Palliat Med 22(8): 894-901.**

Background: Systematic symptom assessment is not a standard of care in children with cancer. Many well-known symptom assessment tools are lengthy or difficult to integrate into a daily pediatric palliative care practice. We created a series of brief and simple questions to be systematically given to children and their caregivers. Objective: The primary objective was to determine the percentage of eligible children and caregivers exposed to the questions that were able to complete the assessment. Secondary objectives included documenting the symptom burden at the time of consultation, evaluating the level of agreement in symptom reporting between children and caregivers, as well as between children/caregivers and the referring medical team. Design: A series of systematic questions were presented to all caregivers (if present) and children who were seven years of age or older at the time of initial consultation with pediatric palliative care. Results: One hundred twenty-two consecutive children/caregiver dyads were given the survey. One hundred seven of 108 (99%) eligible caregivers and 83 of 97 (86%) eligible children completed the survey. Lack of appetite (child-72/83, 87%; caregiver-89/107, 83%) and pain (child-71/83, 86%; caregiver-86/107, 80%) were the most commonly reported symptoms. Caregivers reported irritability ( $p = 0.005$ ) and nervousness ( $p < 0.001$ ) more frequently than children. Referring medical teams significantly underdiagnosed psychological and other less clinically evident symptoms such as lack of appetite, fatigue, and sleep disturbance ( $p < 0.001$ ). Conclusions: Our series of questions is easy to complete by children and caregivers. Systematic symptom assessment of children with cancer referred to palliative care should become a true standard of care.

<https://www.ncbi.nlm.nih.gov/pubmed/30759031>

**Miele, E., Mastronuzzi, A., Cefalo, M. G., Del Bufalo, F., De Pasquale, M. D., Serra, A., Spinelli, G. P. and De Sio, L. (2019). "Propofol-based palliative**

**sedation in terminally ill children with solid tumors: A case series." Medicine (Baltimore) 98(21): e15615.**

**RATIONALE:** The palliative sedation therapy is defined as the intentional reduction of the alert state, using pharmacological tools. Propofol is a short-acting general anesthetic agent, widely used for induction and maintenance of general anesthesia and rarely employed in palliative care. **PATIENT CONCERNS AND DIAGNOSES:** This case series describes 5 pediatric oncology inpatients affected by relapsed/refractory solid tumors received palliative sedation using propofol alone or in combination with opioids and benzodiazepines. **INTERVENTIONS AND OUTCOMES:** Five terminally ill children affected by solid tumors received propofol-based palliative sedation. All patients were previously treated with opioids and some of them reduced the consumption of these drugs after propofol starting. In all cases the progressive increase of the level of sedation until the death has been the only effective measure of control of refractory symptoms related to disease progression and psychological suffering. **LESSONS:** We evaluated the quality of propofol-based palliative sedation in a series of pediatric oncology patients with solid tumors at the end of their life. We concluded that propofol represents an effective and tolerable adjuvant drug for the management of intractable suffering and a practicable strategy for palliative sedation in pediatric oncology patients at the end of their life.

<https://www.ncbi.nlm.nih.gov/pubmed/31124940>

**Ofir, R., Bar-Sela, G., Weyl Ben-Arush, M. and Postovsky, S. (2019). "Medical marijuana use for pediatric oncology patients: single institution experience." Pediatr Hematol Oncol 36(5): 255-266.**

Medical marijuana (MM) is widespread in many medical fields, including oncology, with limited use in pediatric oncology where research is scarce and often shows conflicting results. This research focuses on alleviating side effects of anticancer treatment as an integral part of supportive and palliative care of children with cancer. We report our experience with MM treatment in 50 children, adolescents, and young adults with different types of cancer during 2010-2017. The main indications for prescriptions were nausea and vomiting, decreased mood, disturbed sleep, and pain. The medication was supplied to 30 patients via oil drops (60%) and 11 via smoking (22%), followed by vaporization, capsules, or combinations of various routes. Positive effects were reported by verbal children and parents in 80% of cases. MM was generally well tolerated with few patients reporting toxicity, with the most common adverse reactions being burning in the throat and anxiety attacks in subjects who chose to smoke the product. We conclude that MM may serve as a potentially useful complementary therapy to conventional supportive treatment of children suffering from cancer at the end of life. Further research is needed on the safety and efficacy and the consequences of prolonged use in pediatric populations.

<https://www.ncbi.nlm.nih.gov/pubmed/31424297>

**Onder, S. S., Gergin, O. and Karabulut, B. (2019). "A Life Threatening Subglottic and Mediastinal Hemangioma in an Infant." J Craniofac Surg, 10.1097/scs.0000000000005340.**

Subglottic and mediastinal hemangioma are rare benign vascular tumors of childhood. They cause potentially life threatening condition which requires

intervention. Several therapeutic options have been described in the literature with varying degrees of success and complications. We report a case of a stridulous 2-month old female infant with mediastinal and subglottic hemangioma. The child was treated with propranolol without the need for tracheostomy or any other surgical intervention, and with no reported side effects. Propranolol is an effective, non-invasive treatment for life threatening infantile hemangiomas compressing the airway, should be used as a firstline treatment for subglottic hemangiomas when intervention is required.

<https://www.ncbi.nlm.nih.gov/pubmed/31299792>

**Simonyan, T., Papyan, R., Danielyan, S., Sargsyan, L., Grigoryan, V., Topchyan, H., Azaryan, A., Tananyan, A., Muradyan, A. and Tamamyian, G. (2019). "Availability of Essential Medicines for Pediatric Oncology in Armenia." Asian Pac J Cancer Prev 20(4): 991-994.**

Background: One of the main contributors in low survival rate in LMIC is the lack of availability of cancer medications for curative, supportive and palliative care. In many developing countries access to cytotoxic medicine is a major challenge. The information about the availability of essential medicines for pediatric cancer in the country is not known. The main objective of this study was to determine whether the medications used during the treatment of pediatric cancer are available in Armenia. Methods: In summer 2016 we conducted a survey in the 3 main pharmacies in Yerevan, which import pediatric cancer medications to Armenia to evaluate whether medications used during cancer treatment are officially registered and available in the country. In addition, the information on official registration was cross-checked with the Ministry of Health of the Republic of Armenia (MOH). Simultaneously, detailed information about the drugs, on type of produced drug company, doses and price intervals was confined from the price lists of the national drug importer companies. Results: The survey included 64 agents in three classes of medication: anti-neoplastics, anti-microbials, and drugs used in supportive care. All of these medications were included in the recent version of the WHO model list of essential medicines. From 30 anti-neoplastic medications on the essential medicines list 22 (73%) were officially registered in Armenia; from 19 anti-microbial drugs all were registered except caspofungin and from 15 supportive care agents 13 (87%) were registered. From registered anti-neoplastic drugs 18% and from antimicrobial drugs 33% were not available in the drug stores. Conclusion: This study showed that not all the drugs from the SIOP PODC Essential Medication list for pediatric oncology are officially registered and available in Armenia, and effective drug regulation focusing on the childhood cancer care medicine is needed for improving the situation in the country.

<https://www.ncbi.nlm.nih.gov/pubmed/31030465>

**Stachelek, G. C., Terezakis, S. A. and Ermoian, R. (2019). "Palliative radiation oncology in pediatric patients." Ann Palliat Med 8(3): 285-292.**

Radiation therapy (RT) provides an effective and often rapid means to alleviate symptomatic progression in pediatric patients with advanced or metastatic cancer. As part of a comprehensive, multimodality approach to pediatric palliative care, RT can be a useful tool to manage pain, spinal cord compression, dyspnea, neurologic compromise, bleeding, and bowel or urinary obstruction. Whether such symptoms

present earlier in the disease course or in children and adolescents approaching the end of life, they can significantly impact the quality of life of patients and caregivers. Control of symptoms is therefore an important aspect in maximizing end of life care. Outcomes for palliative RT in both children and adults are favorable. While RT has been widely adopted as a component of palliative oncologic care for many adult malignancies, it remains infrequently utilized in pediatric patients despite the relative radiosensitivity of many pediatric tumors. Potential barriers to palliative radiation for pediatric patients include insufficient understanding by care providers regarding the utility of RT for a given symptom, lack of comfort in discussing a transition away from definitive management, concern over radiation-related side effects, and hesitancy toward radiation treatment on the part of parents and caregivers. Delivery of palliative RT can also be impeded by logistical obstacles including lack of on-site radiation facilities, unavailability of radiation oncologists comfortable with pediatric treatments, and the potential need for specialized medical care such as pediatric anesthesia. The aim of this review is to foster a more complete understanding of the benefits and limitations of palliative RT in the pediatric oncology setting, including common symptoms experienced by children and adolescents with cancer that may be indications for the integration of RT into palliative care paradigms, as well as the expected efficacy of treatment. We describe the logistics, delivery, common doses for palliative radiation regimens, and management of potential side effects. While palliative RT is generally well tolerated in the pediatric population, we also discuss potential side effects of RT to various body sites and approaches for prevention or mitigation.

<https://www.ncbi.nlm.nih.gov/pubmed/31280578>

**Weaver, M. S., White, A. G. and Robinson, J. (2019). "Crossing the Line: Care of a Pediatric Patient with Intractable Seizures and Severe Neuropathic Pain in Absence of Access to Medical Marijuana." *J Palliat Med* 22(10): 1232-1235.**

Background: A reality of the current political and legal environment is that while marijuana and cannabis-based products remain not approved for human consumption at the federal level in the United States, several states have authorized use for constituents. While state lines represent meaningful cultural and geographical identity markers, the reality is that patients and families readily cross state lines to access medical interventions and care. Methods: We present the case of a six-year-old child with intractable seizures and severe neuropathic pain managed on medical marijuana (MM) in her home state of Colorado; where medicinal use of marijuana is authorized at the state level; traveling across state lines to access surgical care in Nebraska where MM is prohibited. Conclusion: The case report shares the communication and creativity invested in adequate symptom management for this child weaned off of MM perioperatively. The case recognizes the unique complexities of shared symptom management goals within state-specific care models.

<https://www.ncbi.nlm.nih.gov/pubmed/31184974>

**Zernikow, B., Szybalski, K., Hubner-Mohler, B., Wager, J., Paulussen, M., Lassay, L., Jorch, N., Weber, C., Schneider, D. T., Janssen, G., Oommen, P. T., Kuhlen, M., Brune, T., Wieland, R., Schundeln, M., Kremens, B., Langler, A., Prokop, A., Kiener, R., Niehues, T., Rose, M., Baumann-Kohler, M., Poppelmann, M., Thorer, H., Irrnich, M., Sinha, K., Wolfe, J. and Schmidt, P.**

(2019). "Specialized pediatric palliative care services for children dying from cancer: A repeated cohort study on the developments of symptom management and quality of care over a 10-year period." Palliat Med 33(3): 381-391.

<https://www.ncbi.nlm.nih.gov/pubmed/30537890>

## ***Psychological and Family Issues***

**Agrawal, J. (2019). "What Do Preschool Children in India Understand About Death?: An Exploratory Study." Omega (Westport), 10.1177/0030222819852834: 30222819852834.**

Most people avoid talking about death with children even when required, as they are unsure at what age children start understanding the concept of death. Although this question has been researched in the west, it has not been answered in the Indian context. Therefore, this study was conducted in India with 25 children (14 females, 11 males; 3-5 years), using play and joint story construction method, along with semistructured interviews. Results indicated that majority of the children understood that everyone has to die, including significant people like their own parents (i.e., universality) and also, many children understood that death is final (i.e., irreversibility). However, only few children understood that all cognitive/behavioral functions cease at death (i.e., nonfunctionality). In conclusion, only a small proportion of preschoolers seems to have had a mature concept of death.  
<https://www.ncbi.nlm.nih.gov/pubmed/31138008>

**Al Mutair, A., Al Ammary, M., Brooks, L. A. and Bloomer, M. J. (2019). "Supporting Muslim families before and after a death in neonatal and paediatric intensive care units." Nurs Crit Care 24(4): 192-200.**

**BACKGROUND:** The death of a child is regarded as one of the most devastating events for a family. Families are reliant on nurses to not only provide end-of-life care but also to support and care for grieving families in a way that is sensitive to their cultural and religious needs and preferences. **AIMS:** The aim of this study was to explore the perceived impact and influence of cultural diversity on how neonatal and paediatric intensive care nurses care for Muslim families before and after the death of infants/children. **DESIGN:** A qualitative descriptive approach was used in this study, conducted in Saudi Arabia. **METHODS:** Semi-structured interviews were used to gather data from a convenience sample of registered nurses working in neonatal and paediatric intensive care, with experience in providing end-of-life care. Interviews were conducted between July and November, 2018. Interviews were audio-recorded and transcribed for analysis. **RESULTS:** Thirteen registered nurses participated; all were born overseas, identified with various faiths and spoke English in the workplace. A respect for diversity and care of the family was prioritized yet impacted by communication challenges. Caring and respect was demonstrated by facilitating important cultural and religious practices important in the Muslim faith. Self-care was identified as important, transcending the culturally diverse nature of the nursing workforce. **CONCLUSIONS:** Significant challenges exist for a culturally diverse nursing workforce in providing care to a Saudi Muslim population of infants/children and families, before and after a death. Their overriding commitment to respect for others, and an openness to cultural diversity and difference, aided in overcoming the inherent challenges in providing culturally sensitive end-of-life care that meets the needs of Muslim families. These findings provide valuable insights for intensive care clinicians in other countries to address challenges associated with cultural diversity.  
<https://www.ncbi.nlm.nih.gov/pubmed/31124208>

**Barker, M. M., Beresford, B., Bland, M. and Fraser, L. K. (2019). "Prevalence and Incidence of Anxiety and Depression Among Children, Adolescents, and Young Adults With Life-Limiting Conditions: A Systematic Review and Meta-analysis." JAMA Pediatr, 10.1001/jamapediatrics.2019.1712.**

Importance: Children, adolescents, and young adults with life-limiting conditions experience various challenges that may make them more vulnerable to mental health problems, such as anxiety and depression. However, the prevalence and incidence of anxiety and depression among this population appears to be unknown. Objective: To conduct a systematic review and meta-analysis to estimate the prevalence and/or incidence of anxiety and depression in children, adolescents, and young adults with life-limiting conditions. Data Sources: Searches of MEDLINE (PubMed), PsycInfo, and Embase were conducted to identify studies published between January 2000 and January 2018. Study Selection: Studies were eligible for this review if they provided primary data of anxiety or depression prevalence and/or incidence, included participants aged 5 to 25 years with a life-limiting condition, were conducted in an Organisation for Economic Co-operation and Development country, and were available in English. Data Extraction and Synthesis: Random-effects meta-analyses were generated to provide anxiety and depression prevalence estimates. Meta-regression was conducted to analyze associations between study characteristics and each prevalence estimate. Main Outcomes and Measures: Prevalence of anxiety and depression. Results: A total of 14866 nonduplicate articles were screened, of which 37 were included in the review. Of these, 19 studies reported anxiety prevalence, and 36 studies reported depression prevalence. The mean (range) age of participants was 15.4 (6-25) years. The meta-analysis of anxiety prevalence (n = 4547 participants) generated a pooled prevalence estimate of 19.1% (95% CI, 14.1%-24.6%). Meta-regression analysis found statistically significant differences in anxiety prevalence by assessment tool; diagnostic interviews were associated with higher anxiety prevalence (28.5% [95% CI, 13.2%-46.8%]) than self-reported or parent-reported measures (14.9% [95% CI, 10.9%-19.4%]). The depression meta-analysis (n = 5934 participants) found a pooled prevalence estimate of 14.3% (95% CI, 10.5%-18.6%). Meta-regression analysis revealed statistically significant differences in depression prevalence by the mean age of the sample (beta = 0.02 [95% CI, 0.01-0.03]; P = .001). Conclusions and Relevance: In this systematic review and meta-analysis, the prevalence of anxiety and depression among children, adolescents, and young adults with life-limiting conditions was high, highlighting the need for increased psychological assessment and monitoring. Further research is required to determine the prevalence and incidence of anxiety and depression in a larger sample of children, adolescents, and young adults with a broader range of life-limiting conditions.  
<https://www.ncbi.nlm.nih.gov/pubmed/31282938>

**Bartel, B. T. (2019). "Families grieving together: Integrating the loss of a child through ongoing relational connections." Death Stud, 10.1080/07481187.2019.1586794: 1-12.**

This study explored the relational dimensions of grieving within the family unit. Three families bereaved of a child, participated. Using the Qualitative Action-Project Method, individual and joint interviews were conducted with family members. Data analysis illuminated family grieving processes and demonstrated that grieving was

an interactive process with individual, dyadic, multi-adic, and community levels of processing. The family grieving process included intentionality in grieving together and separately, recognition of differing grieving styles, and meaning came through the incorporation of ongoing rituals and remembrances. A finding emerged of family connection facilitated through an ongoing, shared, continuing bond with the deceased child.

<https://www.ncbi.nlm.nih.gov/pubmed/30907697>

**Bennett, R. A. and LeBaron, V. T. (2019). "Parental Perspectives on Roles in End-of-Life Decision Making in the Pediatric Intensive Care Unit: An Integrative Review." J Pediatr Nurs 46: 18-25.**

**PROBLEM:** Little is known about how parents perceive their role or the role of health care providers (HCPs) during end-of-life decision making (EOL DM) in the context of the pediatric intensive care unit (PICU). **ELIGIBILITY CRITERIA:** The authors searched CINAHL, PubMed, Ovid Medline, Web of Science, Social Science Database, PsycINFO, and Google scholar for English language studies performed in the United States related to parental perception of parental or HCP roles in EOL DM in the PICU since 2008. **SAMPLE:** Eleven studies of parents and health care providers (HCPs) of critically ill children in the PICU and/or receiving inpatient pediatric palliative care, and bereaved parents of PICU patients. **RESULTS:** Most parents reported belief that EOL DM is within the domain of parental role, a minority felt it was a physician's responsibility. Parental EOL DM is rooted more firmly in emotion and perception and a desire to be a 'good parent' to a child at EOL in the way they see fit than HCP recommendations or 'medical facts'. Parents need HCPs to treat them as allies, communicate well, and be trustworthy. **CONCLUSIONS:** Role conflict may exist between parents and HCPs who are prioritizing different attributes of the parental role. The role of the nurse in support of parental role in the PICU is not well-elucidated in the extant literature. **IMPLICATIONS:** Future research should focus on what parents need from HCPs, especially nurses, to support their parental role, and factors that facilitate the development of trust and good communication.

<https://www.ncbi.nlm.nih.gov/pubmed/30831448>

**Brooten, D., Youngblut, J. M., Roche, R. M., Caicedo, C., Del-Moral, T., Cantwell, G. P. and Totapally, B. R. (2019). "Acute Illnesses, Use of Health Services, and Changes in Medication Among Parents After Infant or Child Death." Am J Crit Care 28(3): 193-201.**

**BACKGROUND:** The death of an infant or child has been described as the most stressful life event, but few reports exist on the effects on parents' physical health in the year after the death. **OBJECTIVE:** To examine acute illnesses, use of health services, and medication changes among parents from 3 racial/ethnic groups 1 to 13 months after the death of an infant or child in the neonatal intensive care unit or pediatric intensive care unit. **METHODS:** In a longitudinal study, 96 parents (41% black, 32% Hispanic, 27% white) of deceased infants or children were recruited from 4 children's hospitals and death records. Parents reported demographic information, acute illnesses, health services used, and medication changes 1 to 13 months after the death. Descriptive statistics and 1-way analysis of variance were used to analyze the data. **RESULTS:** Seventy mothers (age, mean [SD], 35.9 [7.13] years) and 26 fathers (age, 39.0 [7.37] years) participated; 56% of mothers and 42% of fathers had

preexisting health problems before the death. Morbidity was greatest in the first 6 months, was relatively quiescent in months 7 through 10, and increased in months 11 through 13. Mothers reported 363 acute illnesses, 16 hospitalizations, and 124 medication changes. Morbidity rates and medication changes for fathers followed similar patterns but with lower frequency. **CONCLUSION:** After the death of an infant or child, interventions for parents, especially parents with chronic health problems, are best targeted on illness prevention and mental health in months 1 to 6 and 11 to 13 following the death.

<https://www.ncbi.nlm.nih.gov/pubmed/31043399>

**Clabburn, O., Knighting, K., Jack, B. A. and O'Brien, M. R. (2019). "Continuing Bonds With Children and Bereaved Young People: A Narrative Review." Omega (Westport), 10.1177/0030222819853195: 30222819853195.**

**BACKGROUND:** Finding alternative ways to reconnect with the deceased is a common feature of bereavement. However, it is currently unclear how bereaved children or young people establish and develop a "continuing bond" with deceased family members. **AIM:** To investigate how bereaved young people continue bonds with deceased family members. **DESIGN:** A systematically conducted narrative review was conducted using six electronic databases: CINAHL, Medline, EMBASE, PsycINFO, PubMed, and BNI. Limiters were applied to peer-reviewed articles published in English. Studies were assessed for methodological quality using the Joanna Briggs Institute Critical Appraisal Tools. **RESULTS:** Twenty articles were included in the review. Three overarching themes were generated: unintended connections, intended connections, and internalized connections. **CONCLUSION:** Bereaved young people establish a sense of connection with deceased family members through various means (e.g., unprovoked or spontaneous reminders, physical mementos, internalized memories). Some connections are unintended and occur spontaneously. However, other young people will specifically seek ways to remember the deceased to provide a sense of enduring connection.

<https://www.ncbi.nlm.nih.gov/pubmed/31166136>

**Clabburn, O., Knighting, K., Jack, B. A. and O'Brien, M. R. (2019). "The use of digital legacies with people affected by motor neurone disease for continuing bonds: An interpretative phenomenological analysis study." Palliat Med 33(7): 812-822.**

**BACKGROUND:** Motor neurone disease is a progressive neurodegenerative disease without cure. Little is known about how young people are affected when a family member has the illness and subsequently dies, resulting in a gap in understanding of how best to support them. One psychotherapeutic approach involves creating a legacy to pass onto the young person, but little research has investigated the use of an emerging format, digital legacies, where videos document a person's life, memories and achievements. **AIM:** To investigate the views, perceptions and experiences of digital legacies with people affected by motor neurone disease. **DESIGN:** A qualitative study underpinned by interpretative phenomenological analysis. **SETTING/PARTICIPANTS:** People living with motor neurone disease (n = 4) and bereaved young people (n = 3) in the United Kingdom. Open-ended interviews were conducted in person. Ethical approval was granted by a University ethics committee. **RESULTS:** Five key themes emerged exemplifying mutual

challenges and benefits for people with motor neurone disease and bereaved young people. Creating a digital legacy provides a sense of purpose for people with motor neurone disease and a way to convey personality and life experiences. Bereaved young people can modify disease-related memories of the person and gain comfort from hearing and seeing videos. CONCLUSION: This study expands the existing continuing bonds model of grief to include an 'autobiographical chapter', creating 'The Model of Reciprocal Bonds Formation'.

<https://www.ncbi.nlm.nih.gov/pubmed/31023181>

**Clayton, M. and Aldridge, J. (2019). "Fifteen-minute consultation: Not the whole story-considering children's spirituality and advance care planning." Arch Dis Child Educ Pract Ed 104(4): 170-172.**

In a society of diverse views, faiths and beliefs, what can paediatric palliative care contribute to our understanding of children's spirituality? By failing to recognise and respond to their spirituality in this work, we risk missing something of profound importance to children and their families. We overlook their search for wholeness in the absence of cure and fall short of offering truly holistic care. This paper explores how developments in advance care planning and related documentation are addressing these issues. Since children's spirituality is elusive and rarely explored in practice, it aims to clarify our understanding of it with a variety of examples and contains suggestions for hearing the voice of the child amid the needs of parents and professionals.

<https://www.ncbi.nlm.nih.gov/pubmed/30266773>

**Constantinou, G., Garcia, R., Cook, E. and Randhawa, G. (2019). "Children's unmet palliative care needs: a scoping review of parents' perspectives." BMJ Support Palliat Care 9(4): 439-450.**

BACKGROUND: Children with life-limiting conditions often have complex needs, making it challenging for services to provide satisfactory care. Few studies consider whether services actually meet families' needs by exploring and identifying the parents' perspectives of unmet needs. AIM: To identify what published evidence is available on the unmet needs of children with life-limiting conditions and their families, from the perspective of parents, internationally. ELIGIBILITY CRITERIA: Inclusion criteria: papers from the perspective of parents of children aged 0-19 years, who have a life-limiting condition and are receiving palliative care. Exclusion criteria: those papers not written in English, not reporting primary research and discussing children who died from stillbirth, accidental or unexpected circumstance. CHARTING METHODS: A scoping review was conducted in accordance with the methods of Arksey and O'Malley. SOURCES OF EVIDENCE: The electronic databases PubMed, MEDLINE, CINAHL and PsycINFO were searched. Key terms included: parent, needs, met/unmet/satisfaction, palliative/supportive/end of life care, life-limiting/life-threatening illness, infants/children/young people. RESULTS: Total hit indicated 5975 papers for screening. Fifty-five papers met the scoping review criteria. The majority used mixed-methods approaches inclusive of: questionnaires, self-report measures, in-depth interviews, focus groups, case record analysis and art-based workshops. Unmet needs included: respite care, coordination and organisation of care, psychological support and professional communication skills. CONCLUSIONS: The findings suggest many unmet needs from the parent's

perspective, across several aspects of the Quality Standards and Children's Palliative Care Frameworks. Further research is needed which explores the parent's unmet needs in palliative care services.

<https://www.ncbi.nlm.nih.gov/pubmed/31324615>

**Darlington, A. S., Long-Sutehall, T., Randall, D., Wakefield, C., Robinson, V. and Brierley, J. (2019). "Parents' experiences of requests for organ and tissue donation: the value of asking." Arch Dis Child 104(9): 837-843.**

OBJECTIVE: A proportion of children die, making them potentially eligible to be organ/tissue donors. Not all are approached for donation, and experiences of those parents are not well understood. The objective was to investigate to what extent organ and tissue donation (OTD) is discussed as part of end-of-life care and to explore parents' and healthcare professionals' (HCPs) experiences. DESIGN: A retrospective qualitative study. SETTING: Multicentre study with participants recruited through two neonatal intensive care units (ICUs), two paediatric ICUs, a cardiac ICU and a children's hospice. PATIENTS: Bereaved parents, parents of a child with a long-term condition (LTC) and HCPs. INTERVENTIONS: None. MAIN OUTCOMES AND MEASURES: Parents' and HCPs' views and experiences of discussions about OTD. RESULTS: 24 parents of 20 children were interviewed: 21 bereaved parents and 3 parents of a child with a LTC. Seven parents were asked about donation (13 not asked), four agreed and two donated. 41 HCPs were interviewed. Themes: complexity of donation process, OTD as a coping strategy, the importance of asking, difficulty of raising the topic, and parents' assumptions about health of organs (when donation is not discussed). CONCLUSIONS: The findings add new knowledge about parents' assumptions about the value of their child's organs when discussions about OTD are not raised, and that HCPs do not routinely ask, are sometimes hesitant to ask in fear of damaging relationships, and the reality of the complexity of the donation process. Given the current levels of awareness around OTD, the topic should be raised.

<https://www.ncbi.nlm.nih.gov/pubmed/31079074>

**Das, K., Khanna, T., Arora, A. and Agrawal, N. (2020). "Parents' acceptance and regret about end of life care for children who died due to malignancy." Support Care Cancer 28(1): 303-308.**

PURPOSE: To analyse the preference of end of life care place in paediatric oncology patients, and to understand the end of life care needs and regrets among the care givers. METHOD: This was an observational qualitative study. Parents of incurable paediatric malignancy patients who died during the years 2016-2018 were interviewed using a pre-formed open-ended questionnaire. Fears during the last phase of child's life, most disturbing symptoms, choice of end of life care plan, regret of care givers and reasons for such choices were noted and analysed. RESULT: Twenty six families were interviewed. A median of 3 months of discordance was noted between declaration of in-curability and acceptance of the same by the family. During terminal months, pain (84.62%) was described as the most bothersome symptom followed by respiratory distress (73.08%). Eighteen families (69%) opted for home-based terminal care, 8 (31%) for hospital-based terminal care. Regret of choice was noted in 62.5% families of the hospital-based care group (separation from home environment being the main reason) and 38.89% of the home-based care

group (lack of access to health care personnel and pain medication being the main reasons). CONCLUSION: Home-based care is the preferred option for end of life care by the care givers. Lack of community-based terminal care support system and availability of analgesics are the main areas to work on in India.

<https://www.ncbi.nlm.nih.gov/pubmed/31044306>

**Dias, N., Hendricks-Ferguson, V. L., Wei, H., Boring, E., Sewell, K. and Haase, J. E. (2019). "A Systematic Literature Review of the Current State of Knowledge Related to Interventions for Bereaved Parents." Am J Hosp Palliat Care 36(12): 1124-1133.**

AIMS: The purpose of this systematic literature review is to describe the interventions for bereaved parents, evaluate intervention effectiveness through study methodology rigor, replicability, and theoretical foundations. METHODS: We searched MEDLINE via PubMed (1966-2018), CINAHL (1937-present), PsycINFO (1887-present), and Embase (1947-present) using various search words and MeSH terms related to the study purpose. A blinded screening of title/abstract was performed, with conflicting inclusion decisions resolved through group discussions. Matrices for remaining articles were created and discussed among the team. The levels of evidence of the 9 records were rated from very low to high based on the Grading of Recommendations Assessment, Development, and Evaluation guidelines. RESULTS: Our initial pool included 1025 articles. After the screening of titles/abstracts, 63 articles were retained for full-text reviews. Evaluated based on the inclusion/exclusion criteria, 9 records met the review criteria. Of the 9 records, 1 was graded as very low, 3 low, and 5 low to moderate. The interventions for bereaved parents varied from using single-model interventions such as expressive arts therapy and telephone support to multimodal interventions that combined resources (ie, peer support, resource packets, and health-care support). Only 1 study explicitly illustrated how its bereavement intervention was designed based on the proposed theoretical model. CONCLUSIONS: This review highlights the need for individualized, well-tested, and effective bereavement care interventions to support bereaved parents. In summary, the state of the science on interventions for bereaved parents is poor and much work needs to be done to effectively address the needs of bereaved parents, including both their physical and emotional health needs.

<https://www.ncbi.nlm.nih.gov/pubmed/31269799>

**Doumit, M. A. A., Rahi, A. C., Saab, R. and Majdalani, M. (2019). "Spirituality among parents of children with cancer in a Middle Eastern country." Eur J Oncol Nurs 39: 21-27.**

PURPOSE: Family caregivers of children with cancer face emotional, psychological, and spiritual challenges coping with their child's illness. For ensuring comprehensive multidisciplinary pediatric care, there is a need to understand and define what spirituality means for them in relation to their child's illness. The purpose of this study is to understand the meaning of spirituality for parents of cancer patients in Lebanon. METHODS: This qualitative study followed the Heideggerian interpretive phenomenological method. Through purposeful sampling, 11 parents (mother or father) of children with cancer receiving treatment at a tertiary care center in Beirut, Lebanon were interviewed. Data were analyzed following the hermeneutical process as described by Diekelmann and Ironside (1998). RESULTS: A constitutive pattern

and overarching theme, "spirituality is a two-level relationship. It is a relation with God and with people. It is the act of receiving and giving back" and five major themes emerged from the data. These were "Being there for me; " "Connectedness with other parents is a blessing and a torment; " "The power of knowing; " "Communication with Unknown" and "Spirituality is not religiosity". **CONCLUSION:** Lebanese parents of children with cancer defined the elements of their own spirituality. Relational aspects dominated and communication was an important factor. **IMPLICATIONS FOR PRACTICE:** This is the first study in the Middle East to address the meaning of spirituality in this population, and would pave the way for a customized palliative care program and integrative approach to patient care. <https://www.ncbi.nlm.nih.gov/pubmed/30850134>

**Edwards, J. D., Panitch, H. B., Nelson, J. E., Miller, R. L. and Morris, M. C. (2019). "Decisions for long-term ventilation for children: perspectives of family members." Ann Am Thorac Soc, 10.1513/AnnalsATS.201903-271OC.**

**RATIONALE:** The decision of whether to initiate or forgo long-term ventilation for children can be difficult and impactful. However, little has been published on the information and decisional needs of families facing this decision. **OBJECTIVES:** To assess what families with children with chronic respiratory failure and life-limiting conditions need and want for informed decision-making. **METHODS:** English- and Spanish-speaking parents who were facing (contemporaneous decision-makers) or previously faced (former decision-makers) a decision regarding invasive or noninvasive long-term ventilation for their child were recruited using convenience sampling. Patients who were older and cognitively-capable also were invited to participate. We performed semi-structured interviews using an open-ended interview guide developed de novo to assess parents' decisional needs and experiences. Qualitative data analysis used a thematic approach based on framework analysis, and thematic saturation was a goal. **RESULTS:** A sample of 44 parents and 2 patients from 43 families was interviewed. All contemporaneous decision-makers (n=28) favored or felt that they would choose long-term ventilation. Fifteen of 16 former decision-makers chose long-term ventilation. Thematic saturation was achieved from the perspective of parents who favored or chose long-term ventilation. Four domains were identified: parents' emotional and psychological experience with decision-making, parents' informational needs, parents' communication and decision-support needs, and parents' views on the option not to initiate long-term ventilation. For most parents, making a decision regarding long-term ventilation was stressful, even though they articulated goals and values that could/did guide their decision-making. In general, parents wanted comprehensive information, including what life would be like at home for the child and the family. They wanted their medical providers to be honest, tactful, patient, and supportive. Parents reported that they felt being presented with the option to not initiate was acceptable. **CONCLUSIONS:** In this study, we identified specific informational and decision-making needs regarding long-term ventilation that parents facing decisions feel important. These data suggest that providers should present families with comprehensive, balanced information on the impact of long-term ventilation and, when the child has a profoundly serious and life-limiting condition, explore the option not to initiate long-term ventilation. <https://www.ncbi.nlm.nih.gov/pubmed/31437013>

**Fearnley, R. and Boland, J. W. (2019). "Parental Life-Limiting Illness: What Do We Tell the Children?" Healthcare (Basel) 7(1).**

Being diagnosed with and having a life-limiting illness is a stressful experience which is compounded when the patient has dependent children. An important aspect of the patient's psychosocial care should include recognition that their children are also likely to experience severe stress because of the illness. However, children's needs are often overlooked during the illness. These needs include information about the illness. Health care professionals have a significant role in supporting patients to communicate with their children. This study aims to increase our understanding of children's experiences when a parent has a life-limiting illness by exploring bereaved children's experiences of the support they received when their parent had a life-limiting illness, and professionals' perspectives of the support offered to children. 7 children (aged between 9 and 24), and 16 health care professionals were interviewed about communication during parental illness. Children report needing open, clear and age appropriate conversations with parents and health care professionals to help them begin to obtain some meaning from the situation. The importance of communication is discussed, with particular reference to the role health care professionals have in supporting these conversations.

<https://www.ncbi.nlm.nih.gov/pubmed/30897857>

**Haley, J. M. (2019). "Parental Strengths in Caring for Their Dying Child: Long-Term Follow-up in Kenya." J Hosp Palliat Nurs 21(2): 144-151.**

Research conducted using the Haley Transcultural Strengths Assessment Interview Guide used in several studies has identified 11 sources of strength routinely utilized by parents caring for their child with intensive needs and child in hospice/palliative care. Results of past studies demonstrated this Strengths Guide (SG) interview to be an intervention bringing a heightened realization of the importance and utilization of one's inner strengths. The purpose of this study was to assess the long-term impact of this SG with a population of parents who participated in a previous study using the SG. This descriptive study was conducted using a quantitative tool, the Personal Strength Rating Scale, comparing the post-SG interview results with those results obtained 3 years later. Participants in this study were parents caring for a child receiving palliative/hospice care at home in Kenya. Results revealed the long-term retention of strengths following the SG interview 3 years previously was, for most sources of strength, equal to or greater than those obtained immediately following the SG.

<https://www.ncbi.nlm.nih.gov/pubmed/30688801>

**Hendricks-Ferguson, V. L. and Haase, J. E. (2019). "Parent Perspectives of Receiving Early Information About Palliative and End-of-Life Care Options From Their Child's Pediatric Providers." Cancer Nurs 42(4): E22-e30.**

**BACKGROUND:** Parents of children diagnosed with cancer may experience decision regret about cancer treatment decisions and dissatisfaction with the perceived clarity in information received from their child's providers. **OBJECTIVE:** The aim of this study was to describe parental perspectives about receiving an early palliative care and end-of-life (PC/EOL) communication intervention titled "Communication Plan:

Early through End of Life Intervention" (COMPLETE) from an interprofessional team of physician and registered nurse providers. METHODS: Ten parents participated in semistructured interviews after receiving the COMPLETE intervention. The COMPLETE intervention included 3 sessions delivered shortly after diagnosis and at the next 2 cancer treatment evaluations. Sessions of COMPLETE focused on early PC/EOL care discussions at diagnosis and after tumor response evaluations with their child's providers. RESULTS: Results included 2 theme categories: (1) COMPLETE nurtures realistic hope and meaningful dialogue by parents connecting with healthcare providers as a dyad, and (2) benefits of COMPLETE helped parents to make informed decisions. In addition, there were offered suggestions to improve COMPLETE. CONCLUSION: The COMPLETE intervention provided a unique mechanism to foster early discussions about PC/EOL options between parents and an interprofessional team during the first 6 months of the child's cancer treatment. Future study is needed using a randomized clinical control-group design to evaluate COMPLETE with a large sample of parents. IMPLICATIONS FOR PRACTICE: Findings provide promising evidence of parents' preference and receptivity to receive early information about PC/EOL care options for a child with a brain tumor with a poor prognosis. The COMPLETE intervention provided a mechanism to help encourage parental consideration of realistic hoped-for goals for their child's condition and care.

<https://www.ncbi.nlm.nih.gov/pubmed/29620556>

**Hirano, H., Shimizu, C., Kawachi, A., Ozawa, M., Higuchi, A., Yoshida, S., Shimizu, K., Tatara, R. and Horibe, K. (2019). "Preferences Regarding End-of-Life Care Among Adolescents and Young Adults With Cancer: Results From a Comprehensive Multicenter Survey in Japan." J Pain Symptom Manage 58(2): 235-243.e231.**

CONTEXT: Patient preferences influence end-of-life (EOL) care which patients receive. However, preferences regarding EOL care among adolescent and young adult (AYA) cancer population remain unclear. OBJECTIVES: The objective of the study was to evaluate preferences regarding EOL care among AYA cancer population. METHODS: We evaluated preferences regarding EOL care as a part of a comprehensive multicenter questionnaire study investigating the experience and needs of Japanese AYA cancer population. RESULTS: A total of 349 AYA cancer population (213 AYA cancer patients and 136 AYA cancer survivors) were evaluated. Eighty-six percent (296/344), 53% (180/338), 88% (301/341), and 61% (207/342) of participants with valid response preferred to have prognostic disclosure, receive palliative chemotherapy for incurable cancer with limited efficacy at the expense of considerable toxicity, actively use palliative care, and stay home at EOL, respectively. In multivariate analysis, the preference regarding prognostic disclosure was associated positively with no child status (odds ratio [OR] = 3.05, P = 0.003) and negatively with history of chemotherapy (OR = 0.23, P = 0.009), the preference regarding palliative chemotherapy for incurable cancer with limited efficacy at the expense of considerable toxicity was associated positively with status under active cancer treatment (OR = 1.74, P = 0.03), and the preference of staying home at EOL was positively associated with anxiety (OR = 1.72, P = 0.04). CONCLUSION: This study elucidated preferences regarding EOL care among Japanese AYA cancer population. These findings may help health care practitioners to have better understanding of preferences regarding EOL care among this population.

<https://www.ncbi.nlm.nih.gov/pubmed/31077783>

**Jones, K., Robb, M., Murphy, S. and Davies, A. (2019). "New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: A scoping review." Midwifery 79: 102531.**

**OBJECTIVE:** To report on research conducted on men's experiences of grief and loss following stillbirth and neonatal death in high-income, Western countries. **DESIGN:** This review was guided by the following research questions: 1. The impact of perinatal death for men 2. The meaning of the loss for a father's sense of identity 3. The extent to which men were able to express grief while supporting their partners and, 4. how men's experience of grief was mediated by the support and care received by health professionals. **DATA SOURCES:** We searched the following databases: Medline; PsychINFO; CINAHL to identify relevant articles published from the year 2000 onwards. The searches were run between 1/04/2018 and 8/4/2018. **REVIEW METHODS:** A scoping review was conducted of nursing, psychological, medical and social science databases using these key words: fathers' grief, men's grief, perinatal loss and death, stillbirth and neonatal death. **RESULTS:** Studies indicated that men reported less intense and enduring levels of psychological outcomes than women but were more likely to engage in avoidance and coping behaviours such as increased alcohol consumption. Men felt that their role was primarily as a 'supportive partner' and that they were overlooked by health professionals. **CONCLUSIONS:** Further research is needed on men's experience of grief following perinatal death, especially on their physical and mental well-being. **IMPACT:** This review addressed the problem of the lack of knowledge around paternal needs following perinatal death and highlighted areas which researchers could usefully investigate with the eventual aim of improving care for fathers. <https://www.ncbi.nlm.nih.gov/pubmed/31493675>

**Kim, M. A., Yi, J., Sang, J. and Jung, D. (2019). "A photovoice study on the bereavement experience of mothers after the death of a child." Death Stud, 10.1080/07481187.2019.1648333: 1-15.**

This study explored the bereavement experience of mothers after losing a child to cancer in Korea, using photovoice. The mothers took photos reflecting five subject areas they selected: (a) if I had one more day with my child, (b) memories with my child, (c) dreaming of my child's healthy future, (d) what gave me strength, and (e) fulfilling my child's wishes for the future. The findings show that mothers who lost a child to cancer need bereavement care to promote well-being. This study can help pediatric oncology providers develop bereavement interventions that address parental grief and improve quality of life. <https://www.ncbi.nlm.nih.gov/pubmed/31418648>

**Kim, S., Savage, T. A., Hershberger, P. E. and Kavanaugh, K. (2019). "End-of-Life Care in Neonatal Intensive Care Units from an Asian Perspective: An Integrative Review of the Research Literature." J Palliat Med 22(7): 848-857.**

**Background:** End-of-life (EOL) care in neonatal intensive care units (NICUs) can vary depending on religious beliefs of health care providers and families as well as the sociocultural environment. Although guidelines exist for EOL care in NICUs, most

are based on Western studies, and little is known about such care in Asian countries, which have different religious and social background. Objective: This review synthesized empirical research to reveal the state of the science on infant EOL care in Asian countries. Design: This was an integrative review. Setting/Subjects: Data were collected from studies identified in CINAHL, Embase, PsycINFO, and PubMed. The search was limited to current empirical studies involving infant EOL care in Asian countries and published in English between 2007 and 2016. Results: Of 286 studies initially identified, 11 empirical studies conducted in Hong Kong, India, Israel, Japan, Mongolia, Taiwan, and Turkey were included in the review. Four themes were captured: factors influencing decision making, trends in decision making, practical aspects of EOL care, and health care providers' preparation. In most NICUs, health care providers controlled decisions regarding use of life-sustaining treatment, with parents participating in decision making no more than 60% of the time. Although care decisions were gradually changing from "do everything" for patient survival to a more palliative approach, comfort care at the EOL was chosen no more than 63% of the time. Conclusion: While infant EOL care practice and research vary by country, few articles address these matters in Asia. This integrative review characterizes infant EOL care in Asia and explores cultural influences on such care.

<https://www.ncbi.nlm.nih.gov/pubmed/30632880>

**Kuchemba-Hunter, J. (2019). "Compassion and Community in Perinatal Palliative Care: Understanding the Necessity of the Patient Perspective Through Narrative Illustration." J Palliat Care 34(3): 160-163.**

Advancing technology in reproductive medicine has led to more frequent perinatal diagnoses of fatal or life-limiting anomaly. For those parents who choose to continue pregnancies while facing such a diagnosis, compassionate and communal perinatal palliative care provides beneficial physical and psycho-socio-emotional support for these families, so that they may preserve and acknowledge the relationship with their child, no matter how brief his/her life.

<https://www.ncbi.nlm.nih.gov/pubmed/30776963>

**Kuhn, E., Schalley, S., Potthoff, M. and Weaver, M. S. (2019). "The Arc of Generational Care: A Case Series Considering Grandparent Roles and Care Needs in Pediatric Palliative Care()." J Soc Work End Life Palliat Care 15(2-3): 99-110.**

Children receiving palliative care services are held within the context of a family and often within multiple-generational arms. The purpose of this case series paper is to recognize grandparents' roles in their family system from a personal, cultural, and anthropological perspective; to explore emotions and experiences as applies to grandparents of children receiving palliative care; and to provide tangible insight into caring well for families across the generational arc.

<https://www.ncbi.nlm.nih.gov/pubmed/31230584>

**Lykke, C., Ekholm, O., Schmiegelow, K., Olsen, M. and Sjogren, P. (2019). "End-of-life communication: a nationwide study of bereaved parents' perceptions." BMJ Support Palliat Care, 10.1136/bmjspcare-2018-001709.**

**OBJECTIVE:** To investigate bereaved parents' perception of end-of-life communication with healthcare professionals after losing a child due to life-limiting diagnoses. **METHODS:** A national register identified the causes of death of 951 children aged 0-18 years during the period 2012-2014. A previously described classification of life-limiting diagnoses identified 402 children. A modified version of the self-administered questionnaire 'To Lose a Child' was distributed to the parents of these 402 children, capturing their perceptions of communication with the healthcare professionals throughout the child's disease trajectory and imminent death. **RESULTS:** A total of 193 bereaved parents, representing 38% of the identified children, participated in the study. Overall, 98% of the parents expressed the view that physicians should immediately disclose when curatively intended treatment options were exhausted. Some 79% of parents reported that information about their child's incurable illness was given in an appropriate manner; however, 42% said that information about the child's imminent death was given too late. Finally, 31% felt deprived of the option to say goodbye to their child in their preferred manner, and 56% said that their child's death was "a shock". **CONCLUSIONS:** Parents request accurate and timely information. However, a substantial number of the parents surveyed reported that healthcare professionals communicated too late about palliative care and end-of-life issues. Even though healthcare professionals strive to communicate effectively with dying children and their parents, barriers were identified that may hinder even the best of intentions. National guidelines addressing communication issues and improved education of healthcare professionals should form part of any future agenda.

<https://www.ncbi.nlm.nih.gov/pubmed/31427305>

**Lykke, C., Ekholm, O., Schmiegelow, K., Olsen, M. and Sjogren, P. (2019). "Anxiety and Depression in Bereaved Parents After Losing a Child due to Life-Limiting Diagnoses: A Danish Nationwide Questionnaire Survey." J Pain Symptom Manage 58(4): 596-604.**

**CONTEXT:** Losing a child is the most burdensome event parents can experience involving risks of developing anxiety and depression. **OBJECTIVES:** To investigate anxiety and depression in bereaved parents during their child's life-limiting illness and imminent death and three to five years after the loss to target future interventions. **METHODS:** A Danish nationwide cross-sectional questionnaire survey. From 2012 to 2014, a register-based study identified causes of deaths of 951 children aged zero to 18 years. Potential palliative diagnoses were classified according to previously used classification. A total of 402 families were included. A modified version of the self-administered questionnaire "To lose a child" was used. Non-response surveys identified reasons for lack of response. **RESULTS:** In all, 136 mothers and 57 fathers completed a questionnaire, representing parents of 152 children (38%). Sixty-five percent of mothers and 63% of fathers reported moderate-to-severe anxiety during the child's illness. However, three to five years after their loss anxiety had decreased markedly. Thirty-five percent of mothers and 39% of fathers reported moderate-to-severe depression during the child's illness; three to five years after the loss they were suffering equivalently from depression. The Center for Epidemiologic Studies Depression Scale indicated that severe depression was significantly associated with lower education and being unmarried. **CONCLUSION:** The reporting of anxiety during the child's illness and prolonged depression in bereaved parents three to five years after the loss indicates a potential need for

psychological interventions. In the process of implementing specialized pediatric palliative care in Denmark, our findings should be considered for future treatment programs.

<https://www.ncbi.nlm.nih.gov/pubmed/31276811>

**Lyon, M. E., Thompkins, J. D., Fratantoni, K., Fraser, J. L., Schellinger, S. E., Briggs, L., Friebert, S., Aoun, S., Cheng, Y. I. and Wang, J. (2019). "Family caregivers of children and adolescents with rare diseases: a novel palliative care intervention." BMJ Support Palliat Care, 10.1136/bmjspcare-2019-001766.**

**OBJECTIVE:** To develop and pilot test a palliative care intervention for family caregivers of children with rare diseases (FAMILY-CENTERED pediatric Advance Care Planning-Rare (FACE-Rare)). **METHODS:** FACE-Rare development involved an iterative, family-guided process including review by a Patient and Family Advisory Council, semistructured family interviews and adaptation of two evidence-based person-centred approaches and pilot testing their integration. Eligible families were enrolled in FACE-Rare (the Carer Support Needs Assessment Tool (CSNAT) Approach Paediatric sessions 1 and 2; plus Respecting Choices Next Steps pACP intervention sessions 3 and 4). Satisfaction, quality of communication and caregiver appraisal were assessed. **RESULTS:** Parents were mean age 40 years, and children 7 years. Children's diseases were rare enough that description would identify patients. All children were technology dependent. Telemedicine, used with four of seven families, was an effective engagement strategy and decreased subject burden. Families found FACE-Rare valuable following a strategy that first elicited palliative care needs and a support plan. Eight families were approached for pilot testing. Of the seven mothers who agreed to participate, six began session 1, and of those, 100% completed: all four FACE-Rare sessions, baseline and 2-week postintervention assessments, and a written pACP which described their preferences for medical decision-making to share with their providers. 100% reported FACE-Rare was helpful. The top three CSNAT concerns were: knowing what to expect in the future, having enough time for yourself and financial issues. Benchmarks were achieved and questionnaires were acceptable to parents and thus feasible to use in a larger trial. **CONCLUSIONS:** FACE-Rare provides an innovative, structured approach for clinicians to deliver person-centred care.

<https://www.ncbi.nlm.nih.gov/pubmed/31345846>

**Pene, C. T. H. and Kissane, D. (2019). "Communication in cancer: its impact on the experience of cancer care: communicating with the angry patient and the patient in denial." Curr Opin Support Palliat Care 13(1): 46-52.**

**PURPOSE OF REVIEW:** This review aims to describe the recent literature on communication between cancer care clinicians and angry patients and patients in denial. **RECENT FINDINGS:** Clinicians had improved perceived self-efficacy in responding to patient anger after completing anger management training, with a focus on reframing anger as a normative response to unmet needs. Psychosocial and mindfulness programmes for cancer patients were found to be useful for modifying anger response to stressors. Existing clinician communication guidelines may not meet the complex needs of adolescents and individuals with anger-prone personality expressing anger. The detrimental effects of avoiding communication about cancer and dying in patients and families include increased stress and

emotional burden, patient depression and anxiety and regret in bereaved family members. Further understanding of the complex interplay between the expression of instrumental and emotional concerns of patients may lead to improved clinician communication. SUMMARY: Anger and maladaptive denial in patients with cancer have detrimental effects that can be seen across a wide range of cultural contexts, in not only the patient but also in their families and the involved clinicians. Training interventions for both patients and clinicians can benefit patient emotional response and perceived clinician self-efficacy.

<https://www.ncbi.nlm.nih.gov/pubmed/30632988>

**Pohlkamp, L., Kreicbergs, U. and Sveen, J. (2019). "Bereaved mothers' and fathers' prolonged grief and psychological health 1 to 5 years after loss-A nationwide study." Psychooncology 28(7): 1530-1536.**

OBJECTIVE: To assess differences in prolonged grief, depression, posttraumatic stress, and sleep disturbances in bereaved parents across years since loss (1-5 years) and by gender and to assess potential interactive effects of time since loss and gender on bereavement outcomes. METHODS: This study examined symptom levels of prolonged grief disorder, depression, posttraumatic stress, and insomnia in bereaved parents. A sample, including 133 mothers and 92 fathers who had lost a child to cancer 1 to 5 years previously, subdivided to five subsamples, one for each year since loss. Analysis of variance (ANOVA) was used to assess differences in symptom levels, related to years since loss, and gender. RESULTS: Regardless of how many years had passed since the loss, symptom levels of prolonged grief, depression, posttraumatic stress symptoms, and insomnia were elevated in all subsamples. Mothers showed higher symptom levels of prolonged grief, depression, and posttraumatic stress than fathers. However, no significant interaction effects were found between years since loss and gender on any of the symptom levels. CONCLUSIONS: Cancer-bereaved mothers and fathers are vulnerable to prolonged grief and psychological symptoms up to 5 years after the death of their child. Findings highlight that bereaved parents may need long-term support, and the results deserve further attention in research and clinical care.

<https://www.ncbi.nlm.nih.gov/pubmed/31108000>

**Pollock, D., Pearson, E., Cooper, M., Ziaian, T., Foord, C. and Warland, J. (2019). "Voices of the unheard: A qualitative survey exploring bereaved parents experiences of stillbirth stigma." Women Birth, 10.1016/j.wombi.2019.03.002.**

BACKGROUND: Every year, 2.6 million babies are stillborn worldwide. Despite these figures, stillbirth remains a relatively ignored public health issue. The wider literature suggests that this is due to the stigma associated with stillbirth. The stigma of stillbirth is seen as possibly one of the greatest barriers in reducing stagnant stillbirth rates and supporting bereaved parents. However, empirical evidence on the extent, type, and experiences of stillbirth stigma remain scarce. AIM: This study aimed to explore the stigma experiences of bereaved parents who have endured a stillbirth. METHODS: An online survey of closed and open-questions with 817 participants (n=796 female; n=17 male) was conducted in high-income countries. FINDINGS: Based on self-perception, 38% of bereaved parents believed they had been stigmatised due to their stillbirth. Thematic data analysis revealed several themes consistent with Link and Phelan's stigma theory- labelling, stereotyping,

status loss and discrimination, separation, and power. One more theme outside of this theory- bereaved parents as agents of change was also discovered.

**CONCLUSION:** Bereaved parents after stillbirth may experience stigma. Common experiences included feelings of shame, blame, devaluation of motherhood and discrimination. Bereaved parents also reported the silence of stillbirth occurred during their antenatal care with many health care providers not informing them about the possibility of stillbirth. Further research needs to be undertaken to explore further the extent and type of stigma felt by bereaved parents after stillbirth, and how stigma is impacting the health care professional disseminating and distributing resources to pregnant women.

<https://www.ncbi.nlm.nih.gov/pubmed/31005574>

**Rostila, M., Berg, L., Saarela, J., Kawachi, I. and Hjern, A. (2019). "Experience of sibling death in childhood and risk of psychiatric care in adulthood: a national cohort study from Sweden." Eur Child Adolesc Psychiatry 28(12): 1581-1588.**

Studies have found that sibling loss is associated with an increased risk of death from external causes (i.e. suicides, accidents and homicides). Increased psychiatric health problems following bereavement could underlie such an association. We studied the influence of sibling loss during childhood on psychiatric care in young adulthood, adjusting for psychosocial covariates shared by siblings in childhood. A national cohort born in Sweden in 1973-1982 (N = 701,270) was followed prospectively until 2013. Cox proportional hazards models were used to analyse the association between sibling loss during childhood and psychiatric inpatient and outpatient care identified by the Hospital Discharge Register. After adjustment for confounders, the HRs of psychiatric care in men who experienced sibling loss were 1.17 (95% CI 1.07-1.27) while the associations turned non-significant in women after adjustment for family-related psychosocial covariates, HR 1.07 (95% CI 0.99-1.16). An increased risk was found in men bereaved in early childhood (1.22 95% CI 1.07-1.38) and adolescence (1.27 95% CI 1.08-1.48). Among women, loss of a sibling during adolescence was significantly associated with psychiatric care (1.19 95% CI 1.03-1.36). Increased psychiatric health problems following bereavement could underlie the previously found association between sibling loss and mortality from external causes. Family-related psychosocial conditions shared by siblings in childhood may account for the association between sibling death and psychiatric care in adulthood.

<https://www.ncbi.nlm.nih.gov/pubmed/30937545>

**Salloum, A., Bjoerke, A. and Johnco, C. (2019). "The Associations of Complicated Grief, Depression, Posttraumatic Growth, and Hope Among Bereaved Youth." Omega (Westport) 79(2): 157-173.**

Research on the association between complicated grief (CG), hope, and posttraumatic growth (PTG) among bereaved youth is limited. Measures of CG, depression, hope, and PTG were completed by 85 youth (aged 7-18 years). Results indicated a strong positive relationship between CG and depressive symptoms, an inverse relationship between hope and depressive symptoms, and a moderate positive relationship between hope and PTG. There was no significant association between CG and hope or between CG and PTG. Higher levels of CG and lower

levels of hope independently predicted greater depressive symptoms, but PTG did not. Results have implications for assessing positive outcomes in bereaved youth.  
<https://www.ncbi.nlm.nih.gov/pubmed/28705039>

**Sansom-Daly, U. M. (2019). "Cancer, Sex, Drugs and Death: A Guide for the Psychological Management of Young People with Cancer by Dr. Toni Lindsay." J Adolesc Young Adult Oncol, 10.1089/jayao.2019.0066.**  
<https://www.ncbi.nlm.nih.gov/pubmed/31314642>

**Schaefer, M. R., Spencer, S. K., Barnett, M., Reynolds, N. C. and Madan-Swain, A. (2019). "Legacy Artwork in Pediatric Oncology: The Impact on Bereaved Caregivers' Psychological Functioning and Grief." J Palliat Med 22(9): 1124-1128.**

Background: Legacy-making (i.e., a way for patients with terminal illness to create or do something for others as a means of remembrance) is rising in popularity in palliative medicine, although only one study has examined its impact in a pediatric population. Objective: In response to the gaps in literature, this study (1) examines the impact of legacy artwork on bereaved caregivers' psychological functioning and grief and (2) compares caregivers' perceptions of support provided by the hospital throughout their child's cancer journey between the intervention and control groups. Methods: Forty-four caregivers whose children died of cancer completed a demographic questionnaire specifically created for this study, the Brief Symptom Inventory-18, and the Prolonged Grief Disorder-13. They also answered questions regarding supportive services provided to them toward the end of the child's life, at the time of death, and after the child's death. Those caregivers who endorsed participating in legacy artwork were identified as the intervention group, whereas those who did not were classified as the control group. Results: There were no significant differences in psychological functioning among caregivers who participated in legacy artwork versus those who did not participate. However, caregivers who created legacy artwork with their child reported significantly less symptoms of prolonged grief and a greater perception of support from health care providers compared with caregivers who did not engage in this activity. Conclusion: Although preliminary, these findings suggest that legacy artwork may have the potential to improve grief and overall satisfaction of support from the hospital in bereaved caregivers.

<https://www.ncbi.nlm.nih.gov/pubmed/30892150>

**Stuart, B., Danaher, T., Awdish, R. and Berry, L. (2019). "Finding Hope and Healing When Cure Is Not Possible." Mayo Clin Proc 94(4): 677-685.**

Traditional medical training focused on curing disease may not prepare clinicians to provide comfort and solace to their patients facing life-limiting illness. But dying patients and their families still need healing, and clinicians can actively facilitate it. We explore the clinician's role in the healing journey through the lens of pediatric brain cancer. Specifically, we examine how clinicians can help affected families find their way from "focused hope" (which centers on cure) to "intrinsic hope," which offers a more realistic and resilient emotional foundation as the child's death approaches and letting go becomes essential. Drawing on their clinical experience and medical knowledge, clinicians can help families comprehend the lessons that

their seriously ill child's body has to teach, highlighting the importance of cherishing the present and creating new memories that outlast the disease. Clinicians can avoid the mindset of "nothing more can be done," emphasizing that there is plenty to do in providing physical, emotional, and spiritual comfort. Clinicians can learn how to be "unconditionally present" for patients and families without immersing themselves in anguish and, eventually, how to help the family find freedom from despair and a full life that still honors the child's memory.

<https://www.ncbi.nlm.nih.gov/pubmed/30922692>

**Tatterton, M. J. and Walshe, C. (2019). "Understanding the bereavement experience of grandparents following the death of a grandchild from a life-limiting condition: A meta-ethnography." *J Adv Nurs* 75(7): 1406-1417.**

AIM: To increase understanding of grandparental grief following the death of a grandchild from a life-limiting condition. DESIGN: Meta-ethnography. DATA SOURCES: Academic Search Complete CINHALL, Embase, psycINFO, PubMed and Web of Science, supplemented by manual search strategies (in 2015, updated 2018). REVIEW METHODS: Studies were appraised and synthesized using the principles of meta-ethnography. FINDINGS: Three superordinate themes were identified: 'influence of the relationship with their grandchild', 'influence of the relationship with the grandchild's family' and 'pain'. The simultaneous, multigenerational position of grandparents meant individuals experience emotional pain from witnessing the experience of family members. CONCLUSION: Many factors that contribute to the bereavement experience of grandparents are outside of their control. The roles, positions, and support needs of grandparents need to be acknowledged to better meet their needs as parents, grandparents, and individuals who have experienced a child death.

<https://www.ncbi.nlm.nih.gov/pubmed/30536458>

**The, L. (2019). "Centring the invisible mother." *Lancet* 393(10185): 2010.**

<https://www.ncbi.nlm.nih.gov/pubmed/31106732>

**Toly, V. B., Blanchette, J. E., Alhamed, A. and Musil, C. M. (2019). "Mothers' Voices Related to Caregiving: The Transition of a Technology-Dependent Infant from the NICU to Home." *Neonatal Netw* 38(2): 69-79.**

PURPOSE: The transition from the NICU to home is a complicated, challenging process for mothers of infants dependent on lifesaving medical technology, such as feeding tubes, supplemental oxygen, tracheostomies, and mechanical ventilation. The study purpose was to explore how these mothers perceive their transition experiences just prior to and during the first three months after initial NICU discharge. DESIGN: A qualitative, descriptive, longitudinal design was employed. SAMPLE: Nineteen mothers of infants dependent on lifesaving technology were recruited from a large Midwest NICU. MAIN OUTCOME VARIABLE: Description of mothers' transition experience. RESULTS: Three themes were identified pretransition: negative emotions, positive cognitive-behavioral efforts, and preparation for life at home. Two post transition themes were negative and positive transition experiences. Throughout the transition, the mothers expressed heightened anxiety, fear, and stress about life-threatening situations that did not abate over time despite the discharge education received.

<https://www.ncbi.nlm.nih.gov/pubmed/31470369>

**Vegsund, H. K., Reinfjell, T., Moksnes, U. K., Wallin, A. E., Hjemdal, O. and Eilertsen, M. B. (2019). "Resilience as a predictive factor towards a healthy adjustment to grief after the loss of a child to cancer." PLoS One 14(3): e0214138.**

INTRODUCTION: Grief among bereaved parents is known to cause psychological distress and physical illness, but knowledge concerning factors that can contribute to health promotion after bereavement is scarce. Childhood cancer remains the most common non-accidental cause of death among children in Norway. The aim of the present study was to explore if resilience factors among cancer-bereaved parents could predict whether they will be able to come to terms with their grief 2-8 years following the loss. METHODS: A Norwegian cross-sectional national survey was conducted among 161 cancer-bereaved parents using a study-specific questionnaire. Logistic regression was used to explore whether resilience factors predicted parents' grief outcome 2-8 years after their loss. RESULTS: On the Resilience Scale for Adults (RSA), three of the resilience factors contributed significantly in predicting whether the parents in the present study would come to terms with their grief 2-8 years after the loss their child: "Perception of self" (OR 2.08,  $p = .048$ ), "Social resources" (OR 2.83,  $p = .008$ ) and "Family cohesion" (OR .41,  $p = .025$ ). The results showed a negative relationship between time since loss (2-6 years) and whether the parents answered that they had come to terms with their grief ( $p < .05$ ). The loss of a parent (OR .30,  $p = .030$ ) combined with the loss of their child had a negative and significant effect on whether they indicated that they had processed their grief. CONCLUSION: The total score of RSA and three of the six resilient factors contributed significantly in predicting whether cancer-bereaved parents in the present study indicated that they had come to terms with their grief to a great extent. The present study supports hypotheses that regard resilience as an important contribution in predicting healthy outcomes in people exposed to adverse life events.

<https://www.ncbi.nlm.nih.gov/pubmed/30897157>

**Velasco-Whetsell, M. and Baumann, S. L. (2019). "Special Sorrow: Terminally Ill Children's Experience of Their Parent's Distress." Nurs Sci Q 32(2): 135-139.**

The authors of this paper explore the distress that terminally ill children experience when they see the suffering their illness and dying is causing their parents. The authors refer to this experience as special sorrow. The conceptual framework that guides this reflection of the terminally ill child's experience is the Roy adaptation model. The goal of this paper is to explore the concept of special sorrow as lived, so as to help nurses be with such children and their parents in a way that eases sorrow through effective adaptation and transcendence.

<https://www.ncbi.nlm.nih.gov/pubmed/30888290>

**Verberne, L. M., Kars, M. C., Schouten-van Meeteren, A. Y. N., van den Bergh, E. M. M., Bosman, D. K., Colenbrander, D. A., Grootenhuis, M. A. and van Delden, J. J. M. (2019). "Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study." Eur J Pediatr 178(7): 1075-1085.**

Parenting and providing extensive care to a child with a life-limiting or life-threatening disease while being aware of the future loss of the child are among the most stressful parental experiences. Due to technical and medical improvements, children are living longer and are increasingly cared for at home. To align healthcare professionals' support with the needs of parents, a clear understanding of prominent experiences and main coping strategies of parents caring for a child in need of palliative care is needed. An interpretative qualitative study using thematic analysis was performed. Single or repeated interviews were undertaken with 42 parents of 24 children with malignant or non-malignant diseases receiving palliative care. Prominent reported parental experiences were daily anxiety of child loss, confrontation with loss and related grief, ambiguity towards uncertainty, preservation of a meaningful relationship with their child, tension regarding end-of-life decisions and engagement with professionals. Four closely related coping strategies were identified: suppressing emotions by keeping the loss of their child at bay, seeking support, taking control to arrange optimal childcare and adapting to and accepting the ongoing change(s). Conclusion: Parents need healthcare professionals who understand and carefully handle their worries, losses, parent-child relationship and coping strategies. What is Known: \* In paediatric palliative care, parents have a daunting task in fulfilling all caregiving tasks while striving for control of their child's symptoms, a life worth living and a family balance. What is New: \* Prominent experiences were: continuous management of anxiety of child loss, feelings of uncertainty, tension with end-of-life decision making and engagement with professionals. Parents experienced unique significance to their child, reinforcing a meaningful parent-child relationship. \* Relevant coping strategies were: suppressing emotions, seeking support, taking control to arrange optimal care and adapting to the ongoing changes. \* To provide tailored support, professionals need to understand parents' perceptions, relationship with their child and coping strategies.

<https://www.ncbi.nlm.nih.gov/pubmed/31104108>

**Verkissen, M. N., Leemans, K., Van den Block, L., Deliens, L. and Cohen, J. (2019). "Information provision as evaluated by people with cancer and bereaved relatives: A cross-sectional survey of 34 specialist palliative care teams." Patient Educ Couns 102(4): 768-775.**

**OBJECTIVE:** To explore how individuals with cancer and bereaved relatives evaluate information provision by specialist palliative care services (PCSs). **METHODS:** A cross-sectional survey was conducted within four multidisciplinary palliative homecare teams (HCTs), 17 hospital-based palliative care units (PCUs) and 13 hospital-based mobile palliative support teams (PSTs) in Belgium. During four measurement periods, structured questionnaires were administered to people being guided by PCSs and relatives of patients who had died while under the care of PCSs. **RESULTS:** In total, 628 patients (80%) and 980 relatives (55%) responded; 73-82% and 75-77% respectively reported having received the right amount of information. Compared with those receiving care within a PCU, those being supported by a PST were more likely to report suboptimal information provision and decision-making. Relatives of those who had died while under the guidance of a PST were also more likely to report suboptimal information provision than their PCU counterparts. **CONCLUSION:** Although information provision to cancer patients and relatives being supported by PCSs is generally evaluated positively, evaluations

depend on the type of service. PRACTICE IMPLICATIONS: Information provided within PCUs offering highly personalised, continuous care appears to both groups more satisfactory than that provided by palliative care teams mainly supporting care staff.

<https://www.ncbi.nlm.nih.gov/pubmed/30503640>

**Wallin, A. E., Udo, C., Kreicbergs, U. and Lovgren, M. (2019). "Cancer-bereaved siblings' advice to peers - A nationwide follow-up survey." Death Stud, 10.1080/07481187.2019.1595220: 1-8.**

The aim of this nationwide survey was to explore, based on an open-ended question, cancer-bereaved siblings' advice to peers with a brother or sister with cancer. Half of the advice related to being with the ill sibling and cherishing the time together. Other advice related to the value of communicating about the situation, letting go of guilt, and living life as usual. The results highlight the importance of health care professionals, family, and others facilitating for siblings to spend time together and communicate openly.

<https://www.ncbi.nlm.nih.gov/pubmed/30985264>

**Wang, S. C., Wu, L. M., Yang, Y. M. and Sheen, J. M. (2019). "The experience of parents living with a child with cancer at the end of life." Eur J Cancer Care (Engl) 28(4): e13061.**

The study was to describe the essence of the lived experience of parents with a child with incurable cancer at the end of life (EOL). A descriptive phenomenological study was conducted with ten parents of children with incurable cancer in a medical centre in Taiwan. Data were collected from in-depth interviews and were analysed according to the method of Giorgi. Two major themes emerged: (a) immersion in the struggling and suffering, which included conflicts and arguments, witnessing their child suffering, denying their child being at EOL and waiting for a miracle; and (b) acceptance of death, which included an end to suffering, living in the moment, discussion of death and letting go. Parents had difficulty adapting to a palliative care perspective due to their misconception that this meant giving up on their child. In addition, religion and belief played varied and important roles in the lived experience of these parents with a child with incurable cancer. Healthcare providers must address the core value of palliative care and help parents accept the reality of their child's situation at an earlier stage in order to provide a better quality of life for the child.

<https://www.ncbi.nlm.nih.gov/pubmed/31016821>

**Watson, J., Simmonds, A., La Fontaine, M. and Fockler, M. E. (2019). "Pregnancy and infant loss: a survey of families' experiences in Ontario Canada." BMC Pregnancy Childbirth 19(1): 129.**

BACKGROUND: Pregnancy and infant loss has a pervasive impact on families, health systems, and communities. During and after loss, compassionate, individualized, and skilled support from professionals and organizations is important, but often lacking. Historically, little has been known about how families in Ontario access existing care and supports around the time of their loss and their experiences of receiving such care. METHODS: An online cross-sectional survey, including both

closed-ended multiple choice questions and one open-ended question, was completed by 596 people in Ontario, Canada relating to their experiences of care and support following pregnancy loss and infant death. Quantitative data were analyzed descriptively using frequency distributions. Responses to the one open-ended question were thematically analyzed using a qualitative inductive approach. RESULTS: The majority of families told us that around the time of their loss, they felt they were not adequately informed, supported and cared for by healthcare professionals, and that their healthcare provider lacked the skills needed to care for them. Almost half of respondents reported experiencing stigma from providers, exacerbating their experience of loss. Positive encounters with care providers were marked by timely, individualized, and compassionate care. Families indicated that improvements in care could be made by providing information and explanations, discharge and follow-up instructions, and through discussions about available supports. CONCLUSIONS: Healthcare professionals can make a positive difference in how loss is experienced and in overall well-being by recognizing the impact of the loss, minimizing uncertainty and isolation, and by thoughtfully working within physical environments often not designed for the experience of loss. Ongoing supports are needed and should be tailored to parents' changing needs. Prioritizing access to specialized education for professionals providing services and care to this population may help to reduce the stigma experienced by bereaved families.

<https://www.ncbi.nlm.nih.gov/pubmed/30991981>

## **Services for Children and Families**

**Arias, N., Garralda, E., De Lima, L., Rhee, J. Y. and Centeno, C. (2019). "Global Palliative Care and Cross-National Comparison: How Is Palliative Care Development Assessed?" J Palliat Med 22(5): 580-590.**

Background: Indicators assessing national-level palliative care (PC) development used for cross-national comparison depict progress on this field. There is current interest on its inclusion in global monitoring frameworks. Objective: Identify and conceptualize those most frequently used for international PC development reporting. Design: Systematic review. Data Sources: PubMed, CINAHL, Google Scholar, and Google targeting national-level development indicators used for cross-national comparison. Additional search requesting experts' suggestions on key studies and "snow-balling" on reference section of all included studies. Identified indicators were listed and categorized in dimensions: services, use of medicines, policy, and education. Results: Fifty-four studies were included. Development has been evaluated using 480 different formulations of 165 indicators, 38 were highly reported. Thirty-two fell into proposed dimensions, 11 for use of medicines, 9 for policy, 7 for services, and 5 for education. Six into complementary dimensions: research, professional activity, and international cooperation. Six were the most frequently used indicators: number of PC services per population (40 reports), existence of PC national plan, strategy, or program (25), existence of palliative medicine specialization (22), availability and allocation of funds for PC (13), medical schools, including PC, in undergraduate curricula (13), and total use of opioids-morphine equivalents (11). Conclusion: There is a clear pattern for national-level PC development evaluation repeatedly using a small number of indicators. Indicators addressing generalistic provision, integration into health systems, and specific fields such as pediatric lack. This study invites international discussion on a global consensus on PC-development assessment.  
[ncbi.nlm.nih.gov/pubmed/30615544](https://pubmed.ncbi.nlm.nih.gov/30615544)

**Basak, R. B., Momaya, R., Guo, J. and Rathi, P. (2019). "Role of Child Life Specialists in Pediatric Palliative Care." J Pain Symptom Manage 58(4): 735-737.**

<https://www.ncbi.nlm.nih.gov/pubmed/31195077>

**Brock, K. E., Snaman, J. M., Kaye, E. C., Bower, K. A., Weaver, M. S., Baker, J. N., Wolfe, J. and Ullrich, C. (2019). "Models of Pediatric Palliative Oncology Outpatient Care-Benefits, Challenges, and Opportunities." J Oncol Pract 15(9): 476-487.**

PURPOSE: Although the bulk of current pediatric palliative care (PPC) services are concentrated in inpatient settings, the vast majority of clinical care, symptom assessment and management, decision-making, and advance care planning occurs in the outpatient and home settings. As integrated PPC/pediatric oncology becomes the standard of care, novel pediatric palliative oncology (PPO) outpatient models are emerging. The optimal PPO model is unknown and likely varies on the basis of institutional culture, resources, space, and personnel. METHODS: We review five institutions' unique outpatient PPO clinical models with their respective benefits and challenges. This review offers pragmatic guidance regarding PPO clinic

development, implementation, and resource allocation. RESULTS: Specific examples include a floating clinic model, embedded disease-specific PPC experts, embedded consultative or trigger-based supportive care clinics, and telehealth clinics. CONCLUSION: Organizations that have overcome personnel, funding, and logistical challenges can serve as role models for centers developing PPO clinic models. In the absence of a one-size-fits-all model, pediatric oncology and PPC groups can select, tailor, and implement the model that best suits their respective personnel, needs, and capacities. Emerging PPO clinics must balance the challenges and opportunities unique to their organization, with the goal of providing high-quality PPC for children with cancer and their families.

<https://www.ncbi.nlm.nih.gov/pubmed/31322987>

**Chirico, J., Donnelly, J. P., Gupton, A., Cromwell, P., Miller, M., Dawson, C. and Korones, D. N. (2019). "Costs of Care and Location of Death in Community-Based Pediatric Palliative Care." *J Palliat Med* 22(5): 517-521.**

Background: Children with complex chronic conditions (CCCs) are dying at home with increased frequency, yet the number of studies on the financial feasibility of community-based pediatric palliative care is limited. Objective: The objectives of this study were to (1) describe characteristics of patients who died in a community-based palliative care program and (2) evaluate cost differences associated with participant characteristics and location of death. Design: A retrospective cohort analysis of administrative and electronic medical record data was employed. Setting/Subjects: Children enrolled in the community-based pediatric palliative care program, CompassionNet, who died between 2008 and 2015 were included (N = 224). Measurements: Demographic data, program expense, and paid claims were extracted from an insurance provider database and clinical data from the electronic medical record. Results: Sixty-six (29%) of the children were <1 year old at death; 80 (36%) were 1-9 years old, and 78 (35%) were 10-22 years old. Malignancy was the most common primary CCC diagnosis for the 158 children/adolescents (n = 89, 56%), whereas neuromuscular conditions (n = 20, 30%) were most frequent for infants. Death at home occurred 21% of the time for infants, 48% for children of ages 1-9 years, and 46% for children of ages 10-22 years. The mean total cost in the final year of life for pediatric patients was significantly related to location of death, a malignancy diagnosis, and participation in Medicaid. The largest estimated difference was between costs of care associated with death at home (\$121,111) versus death in the hospital (\$200,050). Conclusions: Multidisciplinary community-based pediatric palliative care teams provide the opportunity for a home death to be realized as desired. Significant cost differences associated with location of death may support program replication and sustainability.

<https://www.ncbi.nlm.nih.gov/pubmed/30730239>

**Cote, A. J., Payot, A. and Gaucher, N. (2019). "Palliative Care in the Pediatric Emergency Department: Findings From a Qualitative Study." *Ann Emerg Med* 74(4): 481-490.**

STUDY OBJECTIVE: Children with medical complexity represent a fragile population and account for the majority of patients followed in pediatric palliative care. Little is known in regard to the role of the emergency department (ED) in caring for the families of children with medical complexity. METHODS: Semistructured focus

groups were held with health care professionals from pediatric emergency medicine, palliative care, complex care, and intensive care to explore their perspective on pediatric palliative care in the ED. Data were transcribed and analyzed with NVivo software, and thematic analysis and theoretic sampling were performed. RESULTS: From January to October 2016, 58 participants were interviewed. Difficulties providing pediatric palliative care in the ED are related on the one hand to characteristics specific to the ED, such as its culture and its health care professionals' strong emotional responses when caring for children with medical complexity, and on the other hand to factors extrinsic to the ED; mainly, lack of continuity of care. For critically ill children with unknown goals of care and potential for end of life, professionals in the ED should evaluate the clinical situation, contact known health care teams, remain open to families' preferences, alleviate distressing symptoms, and create a caring environment. Communication between teams is targeted by health care professionals to facilitate and improve patient flow and care. CONCLUSION: Although perspectives differ in regard to how to provide care for pediatric palliative care patients in the ED, several barriers to providing high-quality emergency pediatric palliative care can be overcome.

<https://www.ncbi.nlm.nih.gov/pubmed/31060745>

**Diffin, J., Byrne, B., Kerr, H., Price, J., Abbott, A., McLaughlin, D. and O'Halloran, P. (2019). "The usefulness and acceptability of a personal health record to children and young people living with a complex health condition: A realist review of the literature." Child Care Health Dev 45(3): 313-332.**

BACKGROUND: There are a growing number of children and young people (CYP) with chronic health needs or complex disabilities. Increasingly, CYP with life-limiting or life-threatening conditions are surviving into adulthood. Communication between CYP, their family, and health professionals can be challenging. The use of a personal health record (PHR) is one potential strategy for improving communication by promoting CYP's health advocacy skills. However, PHR implementation has proved difficult due to technical, organisational, and professional barriers. The aim of this realist review is to identify the factors, which help or hinder the use of PHRs with CYP living with a complex health condition. METHODS: Systematic realist review. Literature was sourced from six databases: Medline, Embase, CINAHL, PsychInfo, The Cochrane Library, and Science Direct (from 1946 to August Week 3 2018). The web was searched to identify grey literature. Articles were sourced from reference lists of included studies. Data were extracted using a standardised data extraction form. Two reviewers completed data extraction and synthesis. Methodological rigor was assessed using the relevant Critical Appraisal Skills Programme tool. RESULTS: Nine articles were included. Contextual factors, which helped implementation, included the CYP having a high perception of need for a PHR and a high level of desire for self-management. Service providers and CYP need knowledge about the purpose and benefits of the PHR, and organisations need a dedicated person to facilitate PHR use. Mechanisms triggered by the PHR included improved understanding and knowledge of health care condition(s) for CYP, an increased feeling of control over condition(s), and more active engagement in their health care. Outcomes for CYP included improved self-advocacy and communication. CONCLUSION: Clearer definitions of which young people would benefit from using a PHR must be established to inform which organisations and service providers would be best suited to PHR implementation.

<https://www.ncbi.nlm.nih.gov/pubmed/30817012>

**Edwin, F., Elgamal, M. A., Dorra, A., Reddy, D., Entsua-Mensah, K., Adzamli, I., Yao, N. A., Tettey, M., Tamatey, M., Vosloo, S. and Kinsley, R. (2019). "Challenges of Caring for Functionally Single Ventricle Patients in Africa." World J Pediatr Congenit Heart Surg 10(3): 338-342.**

Surgical palliation has remarkably improved survival of functionally single ventricle (FSV) patients born in developed nations but such outcomes have not occurred in Africa. The poor care coverage for FSV patients in Africa exists within the larger sphere of deficient health care for children born with congenital heart defects (CHDs) in Africa generally. This review takes the position that to improve health-care coverage for CHD patients on the continent, political priority is paramount. This can be attained with cohesive leadership for the CHD agenda, a guiding institution, and the mobilization of civil society to drive advocacy at national and international levels.  
<https://www.ncbi.nlm.nih.gov/pubmed/31084309>

**Ghesquiere, A., Bagaajav, A., Metzendorf, M., Bookbinder, M. and Gardner, D. S. (2019). "Hospice Bereavement Service Delivery to Family Members and Friends With Bereavement-Related Mental Health Symptoms." Am J Hosp Palliat Care 36(5): 370-378.**

**OBJECTIVES:** A sizable minority of those who lose a loved one in hospice will experience symptoms of bereavement-related mental health disorders. Though hospices offer services to bereaved informal caregivers (family members or friends) of patients, little is known about services offered or interest in them. Therefore, we sought to assess services offered by hospice staff and interest expressed by bereaved informal caregivers with symptoms of depression, anxiety, or complicated grief (CG). **METHODS:** De-identified electronic bereavement care charts of 3561 informal caregivers who lost someone in a large urban metropolitan hospice from October 1, 2015, to June 30, 2016, were reviewed. **RESULTS:** Of bereaved informal caregivers in the sample, 9.4% (n = 333) were positive for symptoms of depression, anxiety, or CG. The symptom-positive family members/friends were more likely than other family members/friends to be offered mailings, one-to-one counseling, telephone calls, and reference material. However, interest in most services by symptom-positive caregivers was low, with only 6% interested in one-to-one counseling and 7% interested in outside referral. **DISCUSSION:** The findings suggest that hospices offer a range of services to family members or friends with symptoms of anxiety, depression, and CG, but that there can be a gap between what is offered and in the interest levels of the bereaved. Engagement with symptomatic family members and friends could be enhanced in future work.  
<https://www.ncbi.nlm.nih.gov/pubmed/30428680>

**Goymour, K. L., Heaton, M., Coombs, S., Kelk, N., Estreich, K., Sarraf, S., Trethewie, S. and Jaaniste, T. (2019). "Developing the Comfort Care Case: An End-of-Life Resource for Pediatric Patients, Their Families, and Health Professionals." J Palliat Care 34(3): 197-204.**

Caring for a child in hospital who is approaching death, in the terminal phase, requires a focus on caring for the physical, emotional, and spiritual needs of the child

and family. Health professionals caring for these children and families may need to shift their focus from a treatment-focused approach aimed at cure or maintaining life to a comfort-focused approach. The Comfort Care Case (CCC) is a collection of resources designed for use in hospital to ease suffering and facilitate comfort within a pediatric end-of-life (EOL) context. The resources are intended to support the child, the family, and the health professionals involved in EOL care. This article describes the development, implementation, and education associated with the CCC in a tertiary pediatric hospital.

<https://www.ncbi.nlm.nih.gov/pubmed/30168359>

**Hain, R. D. W. (2019). "Hospices and palliative care for children: converging stories." Br Med Bull 130(1): 81-88.**

**INTRODUCTION:** Children's hospices offer support to children and their families according to a model that is quite different from adult hospices and has evolved in parallel with specialist paediatric palliative medicine services. **SOURCES OF DATA:** Published research, Together for Short Lives. **AREAS OF AGREEMENT:** The services hospices offer are highly valued by families. **AREAS OF CONTROVERSY:** It is not always clear that hospices can be described as 'specialist', which can make it difficult for hospices to negotiate appropriate commissioning arrangements with the statutory sector. **GROWING POINTS:** Children's palliative care generally is poorly developed compared with the adult specialty, and local providers should work with hospices to help redress the inequity that children face in accessing specialist palliative care. **AREAS TIMELY FOR DEVELOPING RESEARCH:** If hospices are to continue to be important providers of palliative care in children they must develop robust and fair relationships with local healthcare providers. That would be facilitated by development of a funding formula for children that properly acknowledges the part hospices already play in palliative care.

<https://www.ncbi.nlm.nih.gov/pubmed/31222265>

**Johnston, E. E., Bogetz, J., Saynina, O., Chamberlain, L. J., Bhatia, S. and Sanders, L. (2019). "Disparities in Inpatient Intensity of End-of-Life Care for Complex Chronic Conditions." Pediatrics 143(5).**

**BACKGROUND:** Children with complex chronic conditions (CCCs) require a disproportionate share of health care services and have high mortality rates, but little is known about their end-of-life care. **METHODS:** We performed a retrospective population-based analysis using a California State administrative database of children aged 1 to 21 years with a CCC who died of disease-related causes between 2000 and 2013. Rates of and sociodemographic and clinical factors associated with previously defined inpatient end-of-life intensity indicators were determined. The intensity indicators included: (1) hospital death, (2) receipt of a medically intense intervention within 30 days of death (ICU admission, cardiopulmonary resuscitation, hemodialysis, and/or intubation), and (3) having  $\geq 2$  intensity markers (including hospital death). **RESULTS:** There were 8654 children in the study population with a mean death age of 11.8 years (SD 6.8). The 3 most common CCC categories were neuromuscular (47%), malignancy (43%), and cardiovascular (42%). Sixty-six percent of the children died in the hospital, 36% had a medically intense intervention in the last 30 days of life, and 35% had  $\geq 2$  intensity markers. Living in a low-income neighborhood was associated with increased odds of hospital death, a

medically intense intervention, and  $\geq 2$  intensity markers. Hispanic and "other" race and/or ethnicity were associated with hospital death and  $\geq 2$  intensity markers. Age 15 to 21 years was associated with hospital death, a medically intense intervention, and  $\geq 2$  intensity markers. CONCLUSIONS: Sociodemographic disparities in the intensity of end-of-life care for children with CCCs raise concerns about whether all children are receiving high-quality and goal-concordant end-of-life care.

<https://www.ncbi.nlm.nih.gov/pubmed/30971431>

**Kamrath, H. J., Osterholm, E., Stover-Haney, R., George, T., O'Connor-Von, S. and Needle, J. (2019). "Lasting Legacy: Maternal Perspectives of Perinatal Palliative Care." J Palliat Med 22(3): 310-315.**

BACKGROUND: Many of the leading causes of infant mortality are diagnosed prenatally, presenting providers with the ability to present perinatal palliative care planning as an option. OBJECTIVE: Our study adds to the literature both by describing infant interaction with the health care system and by gaining deeper understanding of the maternal experience after being offered perinatal palliative care. METHODS: The study was conducted at a public university-based medical center in the Midwest. Phase 1 consisted of a retrospective review of electronic medical records of 27 mother-infant pairs offered perinatal palliative care, 18 of whom elected to develop a perinatal palliative care. Phase 2 consisted of a focus group and interviews of seven of the mothers. RESULTS: In the initial phase of this study, results revealed differences regarding the infant's end-of-life trajectory, including location of death, number of invasive procedures, and death in the setting of withholding versus withdrawing life-sustaining treatment. Highlighting that without a perinatal palliative care plan in place, the default treatment for infants with prenatally diagnosed life-limiting conditions is likely to be invasive and painful with often times minimal likelihood of long-term survival. Analysis of interview and focus group data revealed three themes: care, choice, and legacy. CONCLUSION: The authors used their experience with the health care system to draw implications for practice from the focus group and interview data, which care can serve to promote women feeling cared for and cared about, as well as promote opportunities for hope during a fragile pregnancy.

<https://www.ncbi.nlm.nih.gov/pubmed/30388063>

**Kerr, H., Price, J. and O'Halloran, P. (2019). "A cross-sectional survey of services for young adults with life-limiting conditions making the transition from children's to adult services in Ireland." Ir J Med Sci, 10.1007/s11845-019-02054-z.**

BACKGROUND: Increasing numbers of young adults with life-limiting conditions are living into adulthood and consequently making the transition from children's to adult services. A poorly planned transition is associated with adverse outcomes such as non-adherence to treatment and loss to follow-up, together with negative social and emotional outcomes. However, there is little descriptive data on how organisations are currently managing transition. AIM: To obtain an overview of organisational approaches to transition on the island of Ireland, and to explore important organisational factors that may influence the effectiveness of the process. METHODS: A cross-sectional questionnaire survey. One of the four Health Services Executive areas in the Republic of Ireland and the whole of Northern Ireland.

Participants were service providers in statutory and non-statutory organisations providing transition services to young adults with life-limiting conditions. **RESULTS:** The survey was distributed to 55 organisations. The overall response rate was 29/55 (53%). The approach to transition most commonly used focused on interagency communication and collaboration. Key factors in an effective transition were reported as: early commencement; effective communication between the young adult, their family, and services; the availability of appropriate adult services; and effective preparation through collaboration with the young adult and their family. However, implementation of these processes was inconsistent. **CONCLUSIONS:** The findings demonstrate that caring for young adults with life-limiting conditions presents a considerable challenge to organisations and that transition from children's to adult services is an important part of this challenge.

<https://www.ncbi.nlm.nih.gov/pubmed/31273561>

**Levy, K., Grant, P. C., Depner, R. M., Tenzek, K. E., Pailer, M. E., Beaupin, L. K., Breier, J. M. and Byrwa, D. J. (2019). "The Photographs of Meaning Program for Pediatric Palliative Caregivers: Feasibility of a Novel Meaning-Making Intervention." Am J Hosp Palliat Care 36(7): 557-563.**

**BACKGROUND:** Research indicates that informal caregiving can have intense physical and mental impact on the individual. Relative to caregivers of adults, pediatric palliative caregivers appear less in literature despite experiencing greater mental, physical, financial, and social strain. There is limited research on the creation and evaluation of interventions specifically for this population despite clear need. **OBJECTIVE:** This study aims to evaluate the feasibility and engagement of the Photographs of Meaning Program, a modified meaning-making intervention for pediatric palliative caregivers. **DESIGN:** Participants completed a pre-post intervention meaning-in-life measure. Over a 9-week period, participants followed a meaning-making curriculum whereby they created and shared photo narratives via social media. As part of the intervention, a community photo exhibition was held featuring these photo narratives. Exit interviews were also conducted at study close. **SETTING/PARTICIPANTS:** Nine individuals providing informal care to children in a pediatric palliative care program participated in the intervention. All participants were female and are older than 18 years. Settings for research include participant homes and at The Center for Hospice and Palliative Care in Cheektowaga, New York. **RESULTS:** Participants posted 95 photographs and 96 narratives during the intervention, posting on average once each week. Statistical analysis within the small sample indicated an increased presence of meaning in the lives of participants (  $P = .022$ ). Exit interviews conveyed satisfaction with the intervention. **CONCLUSIONS:** Findings suggest that the Photographs of Meaning Program is a practical intervention with life-enhancing potential for pediatric palliative. Future research should aim to collect additional evidence of the intervention's effectiveness.

<https://www.ncbi.nlm.nih.gov/pubmed/30665322>

**Martin, A. E. and Beringer, A. J. (2019). "Advanced care planning 5 years on: An observational study of multi-centred service development for children with life-limiting conditions." Child Care Health Dev 45(2): 234-240.**

**AIM:** The purpose of this study was to compare how planning has developed over the 5 years across a range of children's health care services in a single U.K. city.

**BACKGROUND:** Advanced planning for end of life care (EOLC) is an essential component of care for children with life-limiting and life-threatening (LLLT) conditions. We report the findings of a follow-up study (R2) completed 5 years after the initial review (R1). Documented advanced care planning (ACP) was measured against published children's palliative care standards. **METHOD:** We used a manual retrospective review of health care records, using focused data collection. Inclusion criteria were children who died before the age of 18 years, as a consequence of an LLLT condition, over an 18-month period and had lived locally to a regional children's hospital. **RESULTS:** The first review (R1) included 48 patients with 114 health care records: median age at death 0 years (range 0 to 18 years). The follow-up review (R2) included 47 patients, with 80 health care records: median age at death 2 years (range 0 to 17 years). The proportion of records containing evidence of a prognostic discussion had risen from 73% (R1) to 91% (R2),  $p < 0.005$ . The proportion of health care records with ACP was consistent between R1 and R2 (75% and 72%, respectively). An ACP tool was found to be in regular use in R2 compared with no examples in R1. The acute hospital trust plans were more detailed in R2 than R1. The proportion of cases where preferred location of death matched actual location was stable, around half. **CONCLUSIONS:** EOLC conversations increased over the 5 years studied. In the acute hospital trust, there is evidence of a better quality ACP although quantity is stable: enabled by the implementation of an ACP tool and education programme. Challenges remain in engaging children and young people in advanced planning.

<https://www.ncbi.nlm.nih.gov/pubmed/30693557>

**Morell, E., Moynihan, K., Wolfe, J. and Blume, E. D. (2019). "Palliative care and paediatric cardiology: current evidence and future directions." Lancet Child Adolesc Health 3(7): 502-510.**

Although outcomes for children with heart disease have improved substantially over the past several decades, heart disease remains one of the leading causes of paediatric mortality. For children who progress to advanced heart disease, disease morbidity is high, with many children requiring multiple surgical interventions and long-term intensive care hospitalisations. Care for children with advanced heart disease requires a multidisciplinary approach, and opportunities for earlier integration of palliative care are being explored. This Viewpoint summarises the relevant literature over the past decade. We also identify gaps in parent and provider understanding of prognosis and communication, propose indications for palliative care consultation in paediatric advanced heart disease, and summarise attitudes and perceived barriers to palliative care consultation. Areas for additional research that we identify include paediatric cardiologist education, parental distress, socioeconomic disparities, and patient-reported outcomes. Interdisciplinary clinical and research efforts are required to further advance the field and improve integration of palliative care in the care of children with heart disease.

<https://www.ncbi.nlm.nih.gov/pubmed/31126897>

**Morton, K. E., Richardson, A., Coombs, M. A. and Darlington, A. E. (2019). "Transferring critically ill babies and children home to die from intensive care." Nurs Crit Care 24(4): 222-228.**

**BACKGROUND:** A significant proportion of hospital deaths occur in intensive care units (ICU) and often follow a decision to limit or withdraw life-sustaining treatment. Facilitating the preferred choice in place of death for babies/children is increasingly being advocated, although the literature on a home death is often limited to case reports. **AIMS AND OBJECTIVES:** To examine (a) health care professionals' (HCPs) views and experience of transferring babies/children home to die from intensive care, (b) patient clinical characteristics that HCPs would consider transferring home and (c) barriers to transferring home. **DESIGN:** A cross-sectional descriptive web-based survey. **METHODS:** A total of 900 HCPs from paediatric and neonatal ICU across the United Kingdom were invited to participate. **RESULTS:** A total of 191 (22%) respondents completed the survey; 135 (70.7%) reported being involved in transferring home to die. However, most (58.4%) had just transferred one or two patients in the last 3 years. Overall, respondents held positive views towards transfer, although there was some evidence of divided opinion. Patients identified as unsuitable for transfer included unstable patients (57.6%) and those in need of cardiovascular support (56%). There was statistically significant difference in views between those with and without experience, in that those with experience had more positive views. The most significant barrier was the lack of access to care in the community. **CONCLUSIONS:** HCPs view the concept of transferring critically ill babies/children home to die positively but have infrequent experience. Views held about transfers are influenced by previous experience. The clinical instability of patients and access to community care are central to decision-making. **RELEVANCE TO CLINICAL PRACTICE:** A home death for critically ill babies/children is occurring in the United Kingdom but infrequently. Experience of a transfer home positively influences views and increases confidence. Improved multi-organizational collaboration between ICU and community care teams would assist decision-making and facilitation for a transfer home.

<https://www.ncbi.nlm.nih.gov/pubmed/31126897>

**Moynihan, K. M., Snaman, J. M., Kaye, E. C., Morrison, W. E., DeWitt, A. G., Sacks, L. D., Thompson, J. L., Hwang, J. M., Bailey, V., Lafond, D. A., Wolfe, J. and Blume, E. D. (2019). "Integration of Pediatric Palliative Care Into Cardiac Intensive Care: A Champion-Based Model." *Pediatrics* 144(2).**

Integration of pediatric palliative care (PPC) into management of children with serious illness and their families is endorsed as the standard of care. Despite this, timely referral to and integration of PPC into the traditionally cure-oriented cardiac ICU (CICU) remains variable. Despite dramatic declines in mortality in pediatric cardiac disease, key challenges confront the CICU community. Given increasing comorbidities, technological dependence, lengthy recurrent hospitalizations, and interventions risking significant morbidity, many patients in the CICU would benefit from PPC involvement across the illness trajectory. Current PPC delivery models have inherent disadvantages, insufficiently address the unique aspects of the CICU setting, place significant burden on subspecialty PPC teams, and fail to use CICU clinician skill sets. We therefore propose a novel conceptual framework for PPC-CICU integration based on literature review and expert interdisciplinary, multi-institutional consensus-building. This model uses interdisciplinary CICU-based champions who receive additional PPC training through courses and subspecialty rotations. PPC champions strengthen CICU PPC provision by (1) leading PPC-

specific educational training of CICU staff; (2) liaising between CICU and PPC, improving use of support staff and encouraging earlier subspecialty PPC involvement in complex patients' management; and (3) developing and implementing quality improvement initiatives and CICU-specific PPC protocols. Our PPC-CICU integration model is designed for adaptability within institutional, cultural, financial, and logistic constraints, with potential applications in other pediatric settings, including ICUs. Although the PPC champion framework offers several unique advantages, barriers to implementation are anticipated and additional research is needed to investigate the model's feasibility, acceptability, and efficacy.

<https://www.ncbi.nlm.nih.gov/pubmed/31366685>

**Mullin, J., Wolfe, J., Bluebond-Langner, M. and Craig, F. (2019). "Experiences of children with trisomy 18 referred to pediatric palliative care services on two continents." Am J Med Genet A 179(6): 903-907.**

Children with trisomy 18 that survive beyond the neonatal period have multiple congenital anomalies, neurodevelopmental disability, and high mortality rates. The experience of children with trisomy 18 who receive pediatric palliative care services is largely unknown. We conducted a retrospective review of children with trisomy 18 receiving pediatric palliative care services at both Boston Children's Hospital, USA and Great Ormond Street Hospital, UK from January 1, 2004 to January 1, 2015. Fifty-eight children with trisomy 18 were referred to pediatric palliative care, 38 in the United Kingdom, 20 in the United States. Median age at referral was 19 days (2-89) in the United Kingdom, and 25 days (1-463) in the United States. Median length of time being followed by pediatric palliative care was 32 days (1-1,637) in the United Kingdom and 67 days (3-2,442) in the United States. The only significant difference in the two cohorts ( $p = .001$ ) was in likelihood of receiving cardiac surgical intervention-37% in the United States, 0% the United Kingdom. Children with trisomy 18 receive pediatric palliative care services, with variable age at referral and for a variable length of time. Further research is needed to understand the experience of children with trisomy 18 and their families receiving pediatric palliative care services.

<https://www.ncbi.nlm.nih.gov/pubmed/30932336>

**Patel, A. D., Glynn, P., Falke, A. M., Reynolds, M., Hoyt, R., Hoynes, A., Moore-Clingenpeel, M., Salvator, A. and Moreland, J. J. (2019). "Impact of a Make-A-Wish experience on healthcare utilization." Pediatr Res 85(5): 634-638.**

**OBJECTIVES:** To evaluate the impact of receiving a wish from the Make-A-Wish(R) Foundation on (1) patient healthcare utilization and (2) savings benefit measures. **STUDY DESIGN:** Make-A-Wish(R) arranges experiences, or "wishes," to children with progressive, life-threatening, or life-limiting illness. A retrospective, case-control analysis was performed comparing patients who received or did not receive a wish and associated impact on healthcare utilization and costs across 2 years. Healthcare utilization was defined as visits to primary, urgent, emergent care, and planned/unplanned inpatient hospitalizations. We defined wish savings benefit as a decline in the cost of care from years 1 to 2, which exceeded the average cost of a wish in 2016, \$10,130. **RESULTS:** From 2011 to 2016, 496 Nationwide Children's Hospital patients received a wish. We matched these patients to 496 controls based on age, gender, disease category, and disease complexity. Patients who received a wish were 2.5 and 1.9 times more likely to have fewer unplanned hospital

admissions and emergency department visits, respectively. These decreases were associated with a higher likelihood (2.3-fold and 2.2-fold greater odds) of the wish achieving a savings benefit compared to hospital charges. CONCLUSIONS: Participation in the Make-A-Wish(R) program may provide children quality of life relief while reducing hospital visits and healthcare expenditures.

<https://www.ncbi.nlm.nih.gov/pubmed/30385853>

**Pilkington, G., Knighting, K., Bray, L., Downing, J., Jack, B. A., Maden, M., Mateus, C., Noyes, J., O'Brien, M. R., Roe, B., Tsang, A. and Spencer, S. (2019). "The specification, acceptability and effectiveness of respite care and short breaks for young adults with complex healthcare needs: protocol for a mixed-methods systematic review." BMJ Open 9(6): e030470.**

INTRODUCTION: The number of young adults with complex healthcare needs due to life-limiting conditions/complex physical disability has risen significantly as children with complex conditions survive into adulthood. Respite care and short breaks are an essential service, however, needs often go unmet after the transition to adult services, leading to a significant impact on the life expectancy and quality of life for this population. We aim to identify, appraise and synthesise relevant evidence to explore respite care and short breaks provision for this population, and to develop a conceptual framework for understanding service models. METHODS AND ANALYSIS: A mixed-methods systematic review conducted in two stages: (1) knowledge map and (2) evidence review. We will comprehensively search multiple electronic databases; use the Citations, Lead authors, Unpublished materials, Google Scholar, Theories, Early examples, and Related projects (CLUSTER) approach, search relevant websites and circulate a 'call for evidence'. Using the setting, perspective, intervention/phenomenon of interest, comparison and evaluation framework, two reviewers will independently select evidence for inclusion into a knowledge map and subsequent evidence review, extract data relating to study and population characteristics, methods and outcomes; and assess the quality of evidence. A third reviewer will arbitrate where necessary. Evidence will be synthesised using the following approaches: quantitative (narratively/conducting meta-analyses where appropriate); qualitative (framework approach); policy and guidelines (documentary analysis informed approach). An overall, integrated synthesis will be created using a modified framework approach. We will use Grading of Recommendations Assessment, Development and Evaluation (GRADE)/GRADE-Confidence in the Evidence from Reviews of Qualitative Research to assess the strength and confidence of the synthesised evidence. Throughout, we will develop a conceptual framework to articulate how service models work in relation to context and setting. ETHICS AND DISSEMINATION: Ethical approval is not required as this is a systematic review. We will present our work in academic journals, at appropriate conferences; we will disseminate findings across networks using a range of media. Steering and advisory groups were established to ensure findings are shared widely and in accessible formats. PROSPERO REGISTRATION NUMBER: CRD42018088780.

<https://www.ncbi.nlm.nih.gov/pubmed/31213455>

**Plaza Fornieles, M., Garcia-Marcos Barbero, P., Galera Minarro, A. M., Barbieri, G., Bellavia, N., Bermudez Cortes, M. D. M. and Navarro Mingorance, A. (2019).**

**"[Efficacy of the Paediatrics Palliative Care Team of Murcia according to the experience of the parents]." An Pediatr (Barc), 10.1016/j.anpedi.2019.07.001.**

**INTRODUCTION:** The care at the end of children's lives must be sensitive to the needs of the child and their family. An understanding of the illness is required from the perspective of parents faced with the death of their child, in order to improve quality and guide the development of end-of-life care in Paediatrics. **METHOD:** A retrospective observational study was conducted between June 2014 and June 2017 using a questionnaire, to assess the needs, experiences, and satisfaction with the care received, from a sample of parents who lost a child due to a foreseeable cause. Three different study groups were formed based on the team responsible for end-of-life care, and an analysis was carried out on the differences between the group treated by the paediatric palliative care team, the group attended by non-palliative paediatricians, and the neonatal group. **RESULTS:** Of the 80 eligible families, 64 could be contacted, and 28 (43.8%) finally completed the questionnaire. Our study shows positive experiences and high satisfaction of parents with the care received at the end of their child's life. The highest scores in experiences and satisfaction were given by the parents of the children served by the paediatric palliative care team, with statistically significant differences in family support, communication, shared decision making, and bereavement support ( $P < .05$ ). **CONCLUSIONS:** Parents are satisfied with the care received at the end of their children's lives, but the intervention of a specific paediatric palliative care team improves the quality of care at the end of life in paediatrics.

<https://www.ncbi.nlm.nih.gov/pubmed/31427213>

**Raed, M., Grossoehme, D. H., Brown, M. and Friebert, S. (2019). "Hospital to home transport at end of life: Survey of clinician experience." Palliat Med, 10.1177/0269216319870641: 269216319870641.**

**BACKGROUND:** Palliative transport is transport home of patients requiring critical care transport support with expectation of imminent death. Many parents prefer their child's death at home; evidence suggests death in the preferred location improves bereavement outcomes. Little is known about the clinical and demographic diversity of patients receiving palliative transport or the perspectives of participating staff. **AIM:** The objectives of the present study were to (1) characterize demographic and clinical factors involved in palliative transport, (2) identify challenges encountered, and (3) ascertain staff perspectives. **DESIGN:** Ten-year retrospective chart review and cross-sectional staff survey using study-specific questionnaire.

**SETTING/PARTICIPANTS:** Twenty-three patients had palliative transport from a tertiary pediatric hospital from 2004 to 2013, of which 12 met inclusion criteria. Survey responses from 22 participating staff were received. **RESULTS:** The cohort of 12 patients was 58% female, with a mean (range) age of 5.5 (0.01-22) years; racial composition was not significantly different than the palliative care clinical census over the same time period. Distances under 30 miles accounted for 50% of palliative transports. The majority of patients (75%) died within 2 days of palliative transport. Six unanticipated events are described. Staff reported palliative transport as a positive experience, regarding it as an important job component. However, 63% were dissatisfied or undecided about the plan should the patient die enroute, and 48% experienced some level of dissatisfaction with communication. **CONCLUSION:**

Palliative transport is a feasible option for some patients. Staff experienced palliative transport as valuable, although process concerns were noted. This study underscores the importance of preparedness, training, and education for palliative transports.

<https://www.ncbi.nlm.nih.gov/pubmed/31431157>

**Ramirez, F. D., Bogetz, J. F., Kufeld, M. and Yee, L. M. (2019). "Professional Bereavement Photography in the Setting of Perinatal Loss: A Qualitative Analysis." Glob Pediatr Health 6: 2333794x19854941.**

Perinatal loss, including fetal and infant death, is a devastating experience for parents, resulting in long-term adverse physical and psychosocial outcomes. However, little is known about what services might best support grieving parents. We aimed to understand the role of professional bereavement photography in assisting the grieving process of parents who have lost a fetus or infant, by examining the perspectives of bereaved parents, professional photographers, and health care professionals. Twenty semistructured interviews were conducted, and interview transcripts were analyzed using modified grounded theory. Twenty-three individuals participated, including 6 bereaved parents, 8 photographers, and 9 health care professionals. Analyses generated 5 major themes describing ways in which the photographs were valuable to parents: validation of the experience, permission to share, creation of a permanent and tangible legacy, creation of positive memories, and moving forward after the loss. Hospitals should consider incorporation of professional bereavement photography services into palliative care and bereavement programs.

<https://www.ncbi.nlm.nih.gov/pubmed/31236429>

**Rico-Mena, P., Palacios-Cena, D., Martino-Alba, R., Chocarro-Gonzalez, L. and Gueita-Rodriguez, J. (2019). "The impact of home-based physical rehabilitation program on parents' experience with children in palliative care: a qualitative study." Eur J Phys Rehabil Med 55(4): 494-504.**

**BACKGROUND:** Pediatric palliative care programs aim to improve the quality of life of children with severe life-threatening illnesses, and that of their families. Although rehabilitation and physical therapy provides a valuable tool for the control of symptoms, it has been poorly researched to date. Since the family represents such a fundamental support in these cases, it is important to deepen our understanding regarding the value of implementing rehabilitation programs from the parents' perspective. **AIM:** The aim of this paper was to explore parents' experiences regarding the implementation of a physical rehabilitation program in pediatric palliative care. **DESIGN:** A qualitative methodology was chosen. **SETTING:** The unit of pediatric palliative care at the Hospital Nino Jesus (Madrid, Spain). **POPULATION:** The inclusion criteria were: 1) parents of children, irrespective of their diagnosis; 2) integrated within the program of palliative care at the time of study; 3) aged between 0-18 years; 4) must be receiving Home-Based Rehabilitation Program by the Pediatric Palliative Care team. Fourteen parents were included. **METHODS:** Purposeful sampling method was implemented. Data collection consisted of unstructured and semi-structured interviews. A thematic analysis was performed to interpret transcripts. Guidelines for conducting qualitative studies established by the

Consolidated Criteria for Reporting Qualitative Research were followed. RESULTS: Three main themes were identified: 1) the meaning of physical rehabilitation to parents; 2) physical rehabilitation as an opportunity for patients to stay in their home environment; and 3) home-based physical rehabilitation as part of the families' social environment. CONCLUSIONS: The main needs of a home physical rehabilitation program are to decrease pain and suffering, together with improving family education and training. CLINICAL REHABILITATION IMPACT: The experience of rehabilitation programs at home is essential in order to improve both the quality of life and the quality of care of affected children and parents.

<https://www.ncbi.nlm.nih.gov/pubmed/30781934>

**Robert, R., Stavinoha, P., Jones, B. L., Robinson, J., Larson, K., Hicklen, R., Smith, B., Perko, K., Koch, K., Findley, S. and Weaver, M. S. (2019). "Spiritual assessment and spiritual care offerings as a standard of care in pediatric oncology: A recommendation informed by a systematic review of the literature." Pediatr Blood Cancer 66(9): e27764.**

Children with cancer and their families experience shifts in spiritual wellness from diagnosis through treatment and survivorship or bereavement. An interdisciplinary team conducted a systematic review of quantitative and qualitative research on spiritual assessments, interventions, and outcomes in childhood cancer following PRISMA guidelines using a PROSPERO registered protocol. Thirty-nine well-designed studies were included in the final analysis. The findings from this systematic review indicate the need for early spiritual assessment with offering of continued support for the spiritual functioning of children with cancer and their families as a standard of care.

<https://www.ncbi.nlm.nih.gov/pubmed/31033210>

**Rogers, M., Meier, D. E., Heitner, R., Aldridge, M., Hill Spragens, L., Kelley, A., Nemec, S. R. and Morrison, R. S. (2019). "The National Palliative Care Registry: A Decade of Supporting Growth and Sustainability of Palliative Care Programs." J Palliat Med 22(9): 1026-1031.**

Background: Palliative care program service delivery is variable, and programs often lack data to support and guide program development and growth. Objective: To review the development and key features of the National Palliative Care Registry ("the Registry") and describe recent findings from its surveys on hospital palliative care. Description: Established in 2008, the Registry data elements align with National Consensus Project (NCP) guidelines related to palliative care program structures and operations. The Registry provides longitudinal and comparative data that palliative care programs can use to support programmatic growth. Results: As of 2018, >1000 hospitals and 120 community sites have submitted data on their palliative care programs to the Registry. Over the past decade, the percentage of hospital admissions seen by palliative care teams (penetration) has increased from 2.5% to 5.3%. Higher penetration is correlated with teaching hospital status, having a palliative care trigger, and hospital size ( $p < 0.05$ ). Although overall staffing has expanded, only 42% of Registry programs include the recommended four key disciplines: physician, advanced practice or other registered nurse, social worker, and chaplain. Compliance with NCP guidelines on key structures and processes vary across adult and pediatric programs. Conclusions: The Registry allows palliative care

programs to optimize core structures and processes and understand their performance relative to their peers.

<https://www.ncbi.nlm.nih.gov/pubmed/31329016>

**Rusalen, F., Cavicchiolo, M. E., Lago, P., Salvadori, S. and Benini, F. (2019). "Perinatal palliative care: a dedicated care pathway." BMJ Support Palliat Care, 10.1136/bmjspcare-2019-001849.**

**OBJECTIVE:** Ensure access to perinatal palliative care (PnPC) to all eligible fetuses/infants/parents. **DESIGN:** During 12 meetings in 2016, a multidisciplinary work-group (WG) performed literature review (Grading of Recommendations, Assessment, Development and Evaluation (GRADE) method was applied), including the ethical and legal references, in order to propose shared care pathway. **SETTING:** Maternal-Infant Department of Padua's University Hospital. **PATIENTS:** PnPC eligible population has been divided into three main groups: extremely preterm newborns (first group), newborns with prenatal/postnatal diagnosis of life-limiting and/or life-threatening disease and poor prognosis (second group) and newborns for whom a shift to PnPC is appropriate after the initial intensive care (third group). **INTERVENTIONS:** The multidisciplinary WG has shared care pathway for these three groups and defined roles and responsibilities. **MAIN OUTCOME MEASURES:** Prenatal and postnatal management, symptom's treatment, end-of-life care. **RESULTS:** The best care setting and the best practice for PnPC have been defined, as well as the indications for family support, corpse management and postmortem counselling, as well suggestion for conflicts' mediation. **CONCLUSIONS:** PnPC represents an emerging field within the paediatric palliative care and calls for the development of dedicated shared pathways, in order to ensure accessibility and quality of care to this specific population of newborns.

<https://www.ncbi.nlm.nih.gov/pubmed/31324614>

**Smith, M. G. W., LaFond, D. A., Keim-Malpass, J., Lindley, L. C. and Matzo, M. (2019). "A New Era in Pediatric Hospice Care for Military Families." Am J Nurs 119(8): 66-69.**

: This series on palliative care is developed in collaboration with the Hospice and Palliative Nurses Association (HPNA; <https://advancingexpertcare.org>). The HPNA aims to guide nurses in preventing and relieving suffering and in giving the best possible care to patients and families, regardless of the stage of disease or the need for other therapies. The HPNA offers education, certification, advocacy, leadership, and research.

<https://www.ncbi.nlm.nih.gov/pubmed/31356337>

**Spraker-Perlman, H. L., Tam, R. P., Bardsley, T., Wilkes, J., Farley, L., Moore, D., Sheetz, J. and Baker, J. N. (2019). "The Impact of Pediatric Palliative Care Involvement in the Care of Critically Ill Patients without Complex Chronic Conditions." J Palliat Med 22(5): 553-556.**

**Background:** The impact of pediatric palliative care (PPC) is well established for children with chronic complex diseases. However, PPC likely also benefits previously healthy children with acute life-threatening conditions. **Objective:** To determine the incidence and impact of PPC for previously healthy patients who died in a pediatric

hospital. Design: Retrospective chart review of all pediatric deaths over four years. Setting/Subjects: Patients were 0 to 25 years old, died during an inpatient stay at an academic pediatric hospital  $\geq 48$  hours after admission, and had no complex chronic conditions (CCCs) before admission. Measurements: One hundred sixty-seven patients met the eligibility criteria. Most died in intensive care settings ( $n = 149, 89\%$ ), and few ( $n = 34, 20\%$ ) received PPC consultations or services. Results: Patients who received PPC services were more likely to receive a multidisciplinary care conference than did patients without PPC support (70.5% vs. 39.9%;  $p = 0.001$ ), which also occurred earlier for patients who received PPC services (seven days vs. two days before death;  $p = 0.04$ ). Most patients had documented end-of-life planning in their medical records; however, this occurred earlier for patients who received PPC consultation (9.5 days before death) than for those who did not (two days before death;  $p < 0.0001$ ). Patients receiving PPC support (67.7%) were also more likely to have a do-not-resuscitate/intubate order before death than those who did not (39.9%;  $p = 0.004$ ). Conclusions: Pediatric patients without known CCCs who subsequently die as inpatients benefit from PPC in terms of goals of care discussions and documentation of end-of-life care preferences.

<https://www.ncbi.nlm.nih.gov/pubmed/30589623>

**Tatterton, M. J., Summers, R. and Brennan, C. Y. (2019). "A qualitative descriptive analysis of nurses' perceptions of hospice care for deceased children following organ donation in hospice cool rooms." *Int J Palliat Nurs* 25(4): 166-175.**

**BACKGROUND:** Following organ donation, bodies of children are generally cared for in hospital mortuaries or by funeral directors, and their families are offered little routine bereavement support. A partnership between an organ donation nursing team and regional children's hospice trialled an initiative where families were offered bereavement support from the hospice, and their child's body was cared for in a 'cool room' after death. Hospice services are usually restricted to children with life-limiting conditions, and their families. **OBJECTIVE:** To explore the perceptions and experience of nursing staff who are involved in supporting families of children and young people who have been cared for in children's hospice cool rooms after death, following organ donation. **DESIGN:** A qualitative exploratory study consisting of a focus group interview with registered nurses from the children's hospice and organ donation teams. **METHOD:** A purposeful sample of nurses was recruited. Data were collected in a digitally-recorded focus group interview during March 2018. The interview was transcribed and analysed using a qualitative content approach. **RESULTS:** Six nurses participated in the focus group. Analysis revealed five themes that characterised the perceptions of nurses: (i) barriers to care, (ii) bereavement care for families, (iii) impact on families and staff, (iv) influencers and enablers of change, and (v) sustainability of new practices. **CONCLUSION:** Nurses perceived the long-term, responsive and family-centred approach to bereavement support as a strength of the hospice model, reducing the experience of moral distress in organ donation nurses.

<https://www.ncbi.nlm.nih.gov/pubmed/31013194>

**Thorvilson, M. J., Manahan, A. J., Schiltz, B. M. and Collura, C. A. (2019). "Homeward Bound: A Case Series of Cross-Cultural Care at End of Life, Enhanced by Pediatric Palliative Transport." J Palliat Med 22(4): 464-467.**

For most families, the preferred location of death for their child is home, yet most children still die in the hospital. Many children with life-threatening and life-limiting illness are medically dependent on technology, and palliative transport can serve as a bridge from the intensive care unit to the family's home to achieve family-centered goals of care. Palliative transport may also present an opportunity to prioritize cultural care and rituals at end of life which cannot be provided in the hospital. We describe a case series of pediatric patients from communities espousing markedly diverse cross-cultural values and limited financial resources. Specific cultural considerations at end of life for these children included optimizing the presence of the shared community or tribe, the centrality of healing rituals, and varied attitudes toward withdrawal of life-sustaining medical treatment. By addressing each of these components, we were able to coordinate palliative transport to enhance cross-cultural care and meaning at end of life for children with life-limiting illness.

<https://www.ncbi.nlm.nih.gov/pubmed/30513050>

**Thumfart, J., Bethe, D., Wagner, S., Pommer, W., Rheinlander, C. and Muller, D. (2019). "A survey demonstrates limited palliative care structures in paediatric nephrology from the perspective of a multidisciplinary healthcare team." Acta Paediatr 108(7): 1350-1356.**

AIM: Children and adolescents with end-stage renal disease face a high morbidity and mortality. Palliative care provides a multidisciplinary approach to reduce disease burden and improve quality of life. This study evaluated concepts and current structures of palliative care from the perspective of a multidisciplinary paediatric nephrology team including physicians, nurses and psychosocial health professionals. METHODS: Evaluation was done by an online survey sent to the members of the German Society of Nephrology and to the nurse managers of German paediatric dialysis centres between April 9, 2018 and May 31, 2018. RESULTS: Out of the 52 respondents, 54% were physicians, 21% nurses and 25% psychosocial health professionals. The quality of actual palliative care service was rated as moderate (3.3 on a scale from one to six). Specialised palliative care teams (54%) and the caring paediatric nephrologist (50%) were considered as primarily responsible for palliative care. Two thirds wished for training in palliative care. In only 15% of the respondents' centres, palliative care specialisation existed. CONCLUSION: Palliative care structures in paediatric nephrology were not sufficient in the view of the multidisciplinary healthcare team. Therefore, efforts should be taken to integrate palliative care into the routine treatment of children and adolescents with chronic kidney diseases.

<https://www.ncbi.nlm.nih.gov/pubmed/30536480>

**Yu, J. A., Schenker, Y., Maurer, S. H., Cook, S. C., Kavlieratos, D. and Houtrow, A. (2019). "Pediatric palliative care in the medical neighborhood for children with medical complexity." Fam Syst Health 37(2): 107-119.**

Children with medical complexity (CMC) are a medically fragile pediatric population that experience severe chronic illnesses resulting in significant health care needs, functional limitations, and health care utilization, and are at the highest risk for

morbidity and mortality among all children. Furthermore, families and parents of CMC experience significant caregiver hardships and diminished quality of life. The field of pediatric palliative care has grown in recent years, in part to address the physical and psychosocial issues inherent to the care of these chronically ill children. However, as the prevalence and long-term survival of CMC increases with medical advancements, the demand for pediatric palliative care will likely exceed the capacity of current and future pediatric palliative care specialists. Therefore, alternative strategies to ensure access to essential aspects of palliative care must be considered. This article focuses on why and how high-quality palliative care should be integrated into the patient- and family-centered medical home, the ideal care delivery model for CMC and their families. We first discuss how palliative care principles naturally align with and complement the goals of the CMC medical home. Next, we detail what actions pediatric palliative care specialists can take to best support the CMC medical home as "medical neighbors." Lastly, we describe the fundamental aspects of pediatric palliative care that all clinicians caring for CMC should be able to provide, referred to as "primary pediatric palliative care."

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