

# Synopsis

International digest of children's palliative  
care research abstracts

Editors: Dr Satbir Singh Jassal, Dr Susie Lapwood,  
Dr Linda Maynard, Sue Langley Dr Nicky Harris,  
and Lizzie Chambers

**Editorial team:** Dr Satbir Singh Jassal, Dr Susie Lapwood, Dr Linda Maynard, Sue Langley, Dr Nicky Harris and Lizzie Chambers

**Synopsis, International digest of children's palliative care research abstracts**  
14th edition, Together for Short Lives, December 2020



**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.**

**Together for Short Lives**

New Bond House, Bond Street, Bristol, BS2 9AG

T: 0117 989 7820

E: [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)

**[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)**

Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is incorporated as a company limited by guarantee.

# Acknowledgements

Together for Short Lives would like to thank our editorial team who volunteer their time to produce Synopsis:

Dr Satbir Singh Jassal, Medical Director,  
Rainbow's Hospice for Children and Young People

Sue Langley, Library & Information Services Manager,  
East Anglia's Children's Hospices (EACH)

Dr Linda Maynard, Nurse Consultant Children's Palliative Care,  
East Anglia's Children's Hospices (EACH)

Dr Susie Lapwood, Head of Research and Professional Development and Senior Speciality Doctor  
Helen and Douglas House - Hospice care for children and young adults

Dr Nicky Harris, Palliative Care Paediatrician & Postgraduate Researcher and PhD Candidate, University of the West of England (Bristol)

## 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)

For information on membership, please contact: Sue Langley, Library and Information Services Manager [sue.langley@each.org.uk](mailto:sue.langley@each.org.uk); 01223 815103



# Contents

<a href="#"><u>Education, Professional &amp; Research</u></a>	P2
<a href="#"><u>Epidemiology &amp; Pathology</u></a>	P50
<a href="#"><u>Ethical &amp; Clinical Decision Making</u></a>	P74
<a href="#"><u>Outcomes &amp; Instruments</u></a>	P98
<a href="#"><u>Pain &amp; Symptom Control</u></a>	P149
<a href="#"><u>Psychosocial &amp; Family Issues</u></a>	P171
<a href="#"><u>Services for Children &amp; Young People</u></a>	P210

# Synopsis

Abstracts - 1/8/2019 – 31/07/2020

## Education, Professional & Research

Abdel Razeq, N. M., Alduraidi, H., Halasa, S. and Cuttini, M. (2020). "Clinicians' Self-Reported Practices Related to End-of-Life Care for Infants in NICUs in Jordan." *J Obstet Gynecol Neonatal Nurs* 49(1): 78-90.

**OBJECTIVE:** To examine how clinical decisions are made at the end of life for infants born with specific fatal and disabling conditions in NICUs in Jordan from the perspectives of neonatal health care providers. **DESIGN:** A cross-sectional survey of neonatal nurses and physicians. **SETTING:** Twenty-four NICUs in Jordan. **PARTICIPANTS:** Participants included 213 nurses and 75 physicians who provided direct care for infants in NICUs. **METHODS:** Using the EURONIC questionnaire, we asked participants to recall the last experiences of end-of-life decision making in which they were involved. The participants described factors and outcomes related to those experiences, and we used descriptive and inferential statistics to examine these factors. **RESULTS:** In 83% of the recalled situations, the physicians in charge of the infants' care or who were on duty were the primary decision makers. Parents, nurses, ethics committees, and NICU heads were less involved. The infants' primary diagnoses were significantly associated with the nature of decisions regarding end-of-life care ( $p < .001$ ). Age, importance of religion, having their own children, and involvement in research activities were factors that significantly predicted nurses' perceived levels of involvement in decision making ( $\chi^2(4) = 23.140, p < .001$ ). **CONCLUSION:** Our results suggest the need to improve clinical approaches to decision making regarding end-of-life care for infants in NICUs in Jordan to be more family focused and team based. This process should include parents, physicians, neonatal nurses, and ethics committees. <https://pubmed.ncbi.nlm.nih.gov/31811824/>

Akdeniz Kudubes, A. and Bektas, M. (2020). "The effect of web-based pediatric palliative care education on the palliative care knowledge level and practices of nursing students." *Perspect Psychiatr Care* 56(3): 533-540.

**PURPOSE:** This study is aimed to investigate the effect of web-based pediatric palliative care education on nursing students' knowledge level and practices related to palliative care. **METHODS:** The study was conducted with 265 nursing students including an intervention and a control group. The intervention group was given web-based pediatric palliative care education. **FINDINGS:** A statistically significant difference was found between the total and subscale pre-test and post-test scores of the students in the intervention and control groups regarding the palliative care knowledge level and self-reported palliative care practices. **PRACTICAL IMPLICATIONS:** The web-based pediatric palliative care education is an effective training model for nursing students to improve palliative care knowledge level and practices of the students. <https://pubmed.ncbi.nlm.nih.gov/31840260/>

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://pubmed.ncbi.nlm.nih.gov/31383701/>

Aljethaily, A., Al-Mutairi, T., Al-Harbi, K., Al-Khonezan, S., Aljethaily, A. and Al-Homaidhi, H. S. (2020). "Pediatricians' Perceptions Toward Do Not Resuscitate: A Survey in Saudi Arabia and Literature Review." *Adv Med Educ Pract* 11: 1-8.

**OBJECTIVE:** To explore the pediatricians' attitudes and perceptions toward do-not-resuscitate (DNR) orders in a specific region of the world not fully explored before. **METHODS:** A cross-sectional study was conducted between March 4 and May 30, 2018. Pediatricians from three public hospitals in the city of Riyadh were asked to respond to a questionnaire consisting of 22 questions designed to meet the objectives of our study. **RESULTS:** A total of 203 pediatricians (51.2% female) completed the questionnaire, both junior pediatricians (JPs) and senior pediatricians (SPs). A majority (58.9% of JPs and 61.4% of SPs) thought patients have the right to demand intensive care, despite their terminal illness. Half the participants in both groups thought that DNR is a physician's decision. Only 9.3% of JPs and 12.5% of SPs felt comfortable

discussing DNR with patients/families. Medical school was also a source of knowledge on DNR issues, mainly for JPs (40.2% of JPs vs 20.8% of SPs,  $P=0.005$ ). Half the participants felt that DNR is consistent with Islamic beliefs, while 57.9% of JPs vs 41.7% of SPs felt they are legally protected. Hospital policy was clear to 48.6% of JPs vs 66.7% of SPs, while procedure was clear to 35.5% of JPs vs 49% of SPs.

CONCLUSION: Several factors are present that may hinder DNR implementation, such as doubts concerning being legally protected, doubts concerning consistency with Islamic sharia, unclear policies and procedures, and lack of training and orientation on DNR issues. Policies may need to include patients as decision-makers.

<https://pubmed.ncbi.nlm.nih.gov/32021536/>

**Atout, M. (2019). "Experience of nurses who work with children with palliative care needs: A mixed-method systematic review." *Palliat Support Care*, 10.1017/s1478951519000956: 1-13.**

OBJECTIVE: The importance of palliative care education for nurses has been recognized worldwide. The study aims to explore the experiences of nurses working with children with palliative care needs and to identify any related educational needs.

METHODS: The electronic databases of CINAHL, Cochrane, PubMed, OVID, Social Care Online, Web of Science, Scopus, and ProQuest were searched for the period 2000-2015. RESULTS: Finding revealed that working with children with palliative care needs is an emotionally struggling job for nurses, especially when they try to manage the transition of pediatric patients from curative to palliative care. Staffing level and time constraints comprise a major obstacle in pediatric palliative care. Focusing on invasive treatment and technology in spite of the feelings that it will not improve patients' health status intensifies the feeling of guilt and helplessness for nurses. Finally, nurses asserted the importance of receiving pediatric palliative care education, especially how to communicate with children with palliative care needs and their families.

SIGNIFICANCE OF RESULTS: Further research is recommended with regard to nurses' experience in communication with children with palliative care needs. Nursing education in pediatric palliative care is significantly important, especially how to communicate with children with palliative care needs and their families.

<https://pubmed.ncbi.nlm.nih.gov/31774390/>

**Barnes, S., Jordan, Z. and Broom, M. (2020). "Health professionals' experiences of grief associated with the death of pediatric patients: a systematic review." *JBI Evid Synth* 18(3): 459-515.**

OBJECTIVE: The objective of this review was to synthesize the experiences of health professionals who have experienced grief as a result of a pediatric patient dying.

INTRODUCTION: There has been some research into health professionals' grief experiences associated with the death of pediatric patients, but there has not been a review that synthesizes the findings of these experiences. Other related reviews have focused on prenatal, perinatal or adult deaths or the coping strategies employed by health professionals. This review highlights the complexities of experiences faced by pediatric health professionals. INCLUSION CRITERIA: Qualitative studies involving pediatric health professionals working in any healthcare setting who had experienced grief from the death of a patient were considered for inclusion. Studies were conducted in any country, at any time and published in English. METHODS: The search was

conducted in PubMed, CINAHL, Embase, PsycINFO, Scopus and ProQuest Dissertations and Theses. The search was completed in January 2019. The review followed principles of meta-aggregation in line with the JBI approach. Methodological quality assessment was based on representation of participants' voices and congruence between research methodology and both research question and analysis of data. RESULTS: Meta-aggregation led to three synthesized findings from 12 qualitative studies that met the inclusion and methodological quality criteria. Studies predominantly included nurses working in a hospital, with sample sizes ranging from six to 25 participants. The synthesized findings were physical, behavioral, psychological or spiritual symptoms; compounding grief; and alleviating grief. Physical, behavioral, psychological, or spiritual symptoms highlighted the various characteristics of grief experiences by health professionals. Compounding grief was the largest synthesized finding and incorporated the various factors that contributed to a poorer experience of grief. Alleviating grief showed the limited identified factors that improved the experience of grief. Methodological quality led to synthesized findings receiving a ConQual rating of low or moderate. CONCLUSIONS: The synthesized findings from this review highlight the varied reported experiences of grief in health professionals. The methodological quality and reporting of studies, however, led to decreased confidence in the synthesized findings and recommendations arising from this review. Healthcare professionals should be aware of the potential for experiencing grief when a patient dies and the compounding and alleviating factors associated with this. Further research could expand participant and language limitations, and improve methodological quality and reporting.

<https://pubmed.ncbi.nlm.nih.gov/32197009/>

**Barr, P. (2020). "Burnout in neonatal intensive care unit nurses: relationships with moral distress, adult attachment insecurities, and proneness to guilt and shame." *J Perinat Med*, 10.1515/jpm-2019-0323.**

Background Informed by the person-environment transactional model of stress, the purpose of the study was to explore the relationships of environment-related moral distress and person-related anxious and avoidant adult attachment insecurities, and personality proneness to guilt and shame with burnout in neonatal intensive care unit (NICU) nurses. Methods This was a multicenter cross-sectional self-report questionnaire cohort study comprising 142 NICU nurses currently working on six Level 3-4 NICUs in New South Wales, Australia. Results Burnout was reported by 37% of NICU nurses. Moral distress, anxious and avoidant attachment, and guilt- and shame-proneness had moderate-large zero-order correlations with burnout. Overall, these predictor variables explained 40% of the variance in burnout. Moral distress ( $\beta = 0.40$ ,  $P < 0.001$ ), anxious attachment ( $\beta = 0.18$ ,  $P < 0.05$ ) and shame-proneness ( $\beta = 0.22$ ,  $P < 0.01$ ) were unique predictors of burnout. Shame-proneness partially mediated the effect of anxious attachment on burnout [indirect effect,  $B = 0.12$ , confidence interval (CI) (0.051-0.201)]. Conclusion The management of burnout in NICU nurses requires attention not only to environment-related moral distress but also to person-related anxious and avoidant adult attachment insecurities and personality proneness to guilt and shame.

<https://pubmed.ncbi.nlm.nih.gov/32112704/>

**Boss, R. D., Hirschfeld, R. S., Barone, S., Johnson, E. and Arnold, R. M. (2020). "Pediatric Chronic Critical Illness: Training Teams to Address the Communication Challenges of Patients With Repeated and Prolonged Hospitalizations." J Pain Symptom Manage, 10.1016/j.jpainsymman.2020.06.005.**

CONTEXT: Children with chronic critical illness (CCI) have repeated and prolonged hospitalizations. Discrete communication challenges characterize their inpatient care. OBJECTIVES: Develop, implement, and evaluate a communication training for inpatient clinicians managing pediatric CCI. METHODS: A one-day communication training for interdisciplinary clinicians, incorporating didactic sessions and simulated family and interdisciplinary team meetings. RESULTS: Learners had an average of 11 years' clinical experience. About 34% lacked prior communication training relevant to pediatric CCI. Mean baseline competence across communication skills was 2.6 (range 2.4-3.2), corresponding to less than somewhat prepared; after the training, this increased to a mean of 4.0 (range 3.5-4.5), corresponding to well prepared. Skills with greatest improvement included conducting a family meeting, delivering bad news, discussing stopping intensive care, and end-of-life communication. After one month, perceived competence was sustained for seven of 10 skills; for remaining skills, perceived competence scores decreased by 0.1-0.2. About 100% of learners would recommend the training to colleagues; 89% advocated it for all clinicians caring for children with CCI. CONCLUSION: Interdisciplinary communication training regarding long stay patients is feasible and valued by novice and seasoned clinicians. The novel integration of intrateam communication skills alongside team-family skills reflects the reality that the care of children with CCI challenges clinicians to communicate well with each other and families. Teaching interdisciplinary teams to share communication skills has the potential to overcome reported limitations of existing inpatient discussions, which can be dominated by one or two physicians and lack contributions from diverse team members.

<https://pubmed.ncbi.nlm.nih.gov/32540469/>

**Bowen, R., Lally, K. M., Pingitore, F. R., Tucker, R., McGowan, E. C. and Lechner, B. E. (2020). "A simulation based difficult conversations intervention for neonatal intensive care unit nurse practitioners: A randomized controlled trial." PLoS One 15(3): e0229895.**

BACKGROUND: Neonatal nurse practitioners are often the front line providers in discussing unexpected news with parents. This study seeks to evaluate whether a simulation based Difficult Conversations Workshop for neonatal nurse practitioners leads to improved skills in conducting difficult conversations. METHODS: We performed a randomized controlled study of a simulation based Difficult Conversations Workshop for neonatal nurse practitioners (n = 13) in a regional level IV neonatal intensive care unit to test the hypothesis that this intervention would improve communication skills. A simulated test conversation was performed after the workshop by the intervention group and before the workshop by the control group. Two independent blinded content experts scored each conversation using a quantitative communication skills performance checklist and by assigning an empathy score. Standard statistical analysis was performed. RESULTS: Randomization occurred as follows: n = 5 to the intervention group, n = 7 to the control group. All participants were

analyzed in each group. Participation in the simulation based Difficult Conversations Workshop increases participants' empathy score ( $p = 0.015$ ) and the use of communication skills ( $p = 0.013$ ) in a simulated clinical encounter. **CONCLUSIONS:** Our study demonstrates that a lecture and simulation based Difficult Conversations Workshop for neonatal nurse practitioners improves objective communication skills and empathy in conducting difficult conversations.

<https://pubmed.ncbi.nlm.nih.gov/32150584/>

**Boyle, F. M., Horey, D., Middleton, P. F. and Flenady, V. (2020). "Clinical practice guidelines for perinatal bereavement care - An overview." *Women Birth* 33(2): 107-110.**

**BACKGROUND:** High quality perinatal bereavement care is critical for women and families following stillbirth or newborn death. It is a challenging area of practice and a difficult area for guideline development due to a sparse and disparate evidence base. **AIM:** We present an overview of the newly updated Perinatal Society of Australia and New Zealand/Stillbirth Centre of Research Excellence guideline for perinatal bereavement care. The guideline aims to provide clear guidance for maternity health care providers and their services to support the provision of care that meets the needs of bereaved parents. **DISCUSSION:** The Guideline for Respectful and Supportive Perinatal Bereavement Care is underpinned by a review of current research combined with extensive stakeholder consultation that included parents and their organisations and clinicians from a variety of disciplines. The Guideline contains 49 recommendations that reflect five fundamental goals of care: good communication; shared decision-making; recognition of parenthood; effective support; and organisational response. **CONCLUSION:** Best available research, parents' lived experiences and maternity care providers' insights have contributed to a set of implementable recommendations that address the needs of bereaved parents.

<https://pubmed.ncbi.nlm.nih.gov/30885566/>

**Brimble, M. J., Anstey, S. and Davies, J. (2019). "Long-term nurse-parent relationships in paediatric palliative care: a narrative literature review." *Int J Palliat Nurs* 25(11): 542-550.**

**BACKGROUND:** Paediatric palliative care (PPC) is an active, total approach to the holistic care of the child and family. Close, long-lasting relationships between healthcare professionals and parents in paediatric palliative care enhance quality, provide emotional support and can influence how parents manage their role in the face of uncertainty. **AIM:** To present a narrative literature review of long-term relationships between children's nurses and parents in PPC settings. **METHODS:** Six databases (CINAHL, PsycINFO, ASSIA, Scopus, Medline and BNI) were searched, identifying 35 articles. A grey literature search produced seven additional relevant items. **FINDINGS:** Four themes were identified: bonds; attachments and trust; sharing the journey; going the extra mile; and boundaries and integrity. All themes revealed an element of tension between closeness and professionalism. **CONCLUSION:** Gaining a greater understanding of how closeness and professionalism are successfully managed by children's palliative care nurses could positively influence pre- and post-registration nurse education.

<https://pubmed.ncbi.nlm.nih.gov/31755830/>

Cooper, K., Kirkpatrick, P., Brand, C., Rolfe, A. and Florida-James, S. (2020). "Discussing sudden unexpected death in epilepsy with children and young people with epilepsy and their parents/carers: A mixed methods systematic review." *Seizure* 78: 159-167.

**PURPOSE:** To synthesise the quantitative and qualitative evidence on the views and experiences of children and young people with epilepsy (CYPwE), their family members/caregivers and healthcare professionals on conversations between healthcare professionals and CYPwE/caregivers about the possibility of sudden unexplained death in epilepsy (SUDEP). **METHODS:** Mixed methods systematic review in accordance with Joanna Briggs Institute methodology, PRISMA guidelines and guided by an a-priori protocol. **RESULTS:** 656 potentially relevant studies were identified, 11 of which fulfilled the inclusion criteria for the review: 6 quantitative studies, 4 qualitative studies and 1 opinion/text article. Data synthesis resulted in the following 2 integrated findings: (i) Caregivers, and where appropriate CYPwE, should be provided with information on SUDEP and how it relates to them; (ii) Information on SUDEP should be delivered face-to-face, with supporting written information, by a suitably knowledgeable healthcare professional whom the caregiver/CYPwE feels comfortable with, at an appropriate time at or close to diagnosis. **CONCLUSION:** This review confirms that healthcare professionals should discuss SUDEP with CYPwE and/or their caregivers at or around the time of diagnosis and that the discussion should include prevalence of SUDEP, risk factors and risk reduction methods relative to the individual concerned. Apart from delivering SUDEP information face-to-face, with written or online information provided to reinforce messages, there is a lack of evidence on "how" to impart this sensitive information. Further research exploring the most acceptable and effective methods of discussing SUDEP with CYPwE and their caregivers is therefore indicated.

<https://pubmed.ncbi.nlm.nih.gov/31813747/>

Cortezzo, D. E., Bowers, K. and Cameron Meyer, M. (2019). "Birth Planning in Uncertain or Life-Limiting Fetal Diagnoses: Perspectives of Physicians and Parents." *J Palliat Med* 22(11): 1337-1345.

**Background:** Providers often use birth plans to document parents' wishes for their fetus with a life-limiting condition. **Objective:** The objective of the study was to (1) discover important components of a birth plan for parents and providers who carry them out, and (2) understand the experience of parents and providers with birth plans. **Methods:** The study design involves mixed-methods, descriptive, exploratory survey. This involves parents (n = 20) of a pregnancy complicated by a life-limiting diagnosis and providers who care for them (n = 116). The approach involves descriptive and univariate analyses for quantitative data and thematic analysis for qualitative data. **Results:** Consistent components for families and physicians were diagnosis and medical management of the infant. Families gave greater emphasis on memory-making preferences. Parents feel birth plans give them a sense of control. Themes emerged from parents' experience of creating a birth plan are as follows: sense of control, therapeutic, memory making, effective communication, feeling prepared, and unexpected events. Most physicians feel comfortable discussing goals of care with families but report insufficient time. The importance of components of birth plans and

perception of the parents' understanding of the prognosis varied by specialty. Discussion: Birth plans are beneficial and provide a greater sense of control for parents. Most physicians feel comfortable utilizing them. More than one-third of the physicians do not feel that they have time to complete a birth plan with parents. Communication between physicians and families about limitations of the plan and the potential trajectories could be improved. Communication between maternal and neonatal care providers regarding parent expectations and understanding could also be improved. <https://pubmed.ncbi.nlm.nih.gov/31063010/>

**Côté, A. J., Payot, A. and Gaucher, N. (2020). "Paediatric palliative care in practice: Perspectives between acute and long-term healthcare teams." *Acta Paediatr* 109(3): 613-619.**

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://pubmed.ncbi.nlm.nih.gov/31444801/>

**Cuviello, A., Raisanen, J. C., Donohue, P. K., Wiener, L. and Boss, R. D. (2020). "Initiating Palliative Care Referrals in Pediatric Oncology." *J Pain Symptom Manage*, 10.1016/j.jpainsymman.2020.07.008.**

CONTEXT: Early palliative care (PC) has been shown to improve the quality of life of children with cancer, yet referral practices by pediatric oncology providers remains inconsistent and few patients receive a formal PC consult. OBJECTIVES: We sought to describe patient characteristics used by oncologists for PC referral and identify ways to improve PC integration into the care for children with cancer. METHODS: This mixed-methods study used semistructured audiotaped interviews to explore the patient or disease characteristics used by pediatric oncology providers to trigger PC referral. Conventional content analysis was applied to interview transcripts. RESULTS: About 77 participants with diverse experience were interviewed. More than 75% of participants reported that PC was consulted too late and cited communication and systems issues as the top barriers. Most participants (85%) stated that a screening tool would be helpful to standardize referral practices to PC. Characteristics such as poor prognosis

(88%), symptom management (86%), comorbidities (65%), and psychosocial needs (65%) were commonly reported triggers that should initiate PC consultation. However, when presented with case scenarios that included these characteristics, participants did not consistently identify the PC triggers. Nearly 50% of participants stated they had received some formalized PC training; however, only one-third of these participants noted completing a PC rotation. CONCLUSION: Our findings suggest that pediatric oncologists are committed to improving the integration of PC for their patients and that standardization of referral practices, through the use of a screening tool, would be of benefit. Additional PC education might reinforce pediatric oncologists' recognition of PC triggers.

<https://pubmed.ncbi.nlm.nih.gov/32711123/>

**Cuviello, A., Raisanen, J. C., Donohue, P. K., Wiener, L. and Boss, R. D. (2020). "Defining the Boundaries of Palliative Care in Pediatric Oncology." J Pain Symptom Manage 59(5): 1033-1042.e1031.**

CONTEXT: Although palliative care (PC) continues to be integrated into pediatric oncological care, only a minority of patients with cancer receive a formal PC consult. OBJECTIVES: We sought to describe oncologists' current understanding of PC and how primary PC is provided for children with cancer. METHODS: This mixed-methods study explored pediatric oncology providers' definitions of PC and self-reported PC practices through semistructured audiotaped interviews. Conventional content analysis was applied to interview transcripts. RESULTS: Seventy-seven participants with diverse training backgrounds (30 attending physicians, 21 nurses, 18 fellows, five nurse practitioners, and two child life specialists) completed an interview. Approximately 75% provided a modern definition of PC (e.g., not limited to end-of-life care); all participants acknowledged primary PC skills as part of their daily clinical activities. However, participants expressed wide variation in the comfort and time spent performing primary PC tasks (i.e., symptom management, addressing mental health and psychosocial needs) and over half reported that patients' PC needs are not adequately met. In addition, some reported confusion about the benefits of PC consultation, despite acknowledging that PC needs to be better integrated into the care of pediatric oncology patients. CONCLUSION: Our findings demonstrate that although most pediatric oncologists accept a modern definition of PC in theory, how to integrate PC into pediatric oncology practice is less understood. Formalized training and standardization of practice surrounding identification of PC needs in patients who may require secondary or tertiary PC services may help to overcome current barriers for PC integration in pediatric oncology.

<https://pubmed.ncbi.nlm.nih.gov/31838131/>

**da Silva Knihs, N., Santos, J. D., Schuantes Paim, S. M., Pestana Magalhães, A. L., Erbs Pessoa, J. L., Ramos, S. F., Schirmer, J., Bittencourt, I., Albuquerque Bezerra, H. C., Reis Bellaguarda, M. L. D. and Lima da Silva, E. (2020). "Communication of Death in the Context of Infant-Child Donation: Best Practices for Creating Family Interview for Organ and Tissue Donation." Transplant Proc 52(5): 1216-1222.**

OBJECTIVE: To analyze evidence capable of supporting best practices available in the literature to create dialogues about organ and tissue donation with parents of deceased

children and adolescents. **METHODS:** An integrative literature review performed using Scopus, Cochrane, PsycINFO, PubMed/MEDLINE, Web of Science database, and SciELO electronic libraries from November of 2013 to November of 2018, using keyword syntax for each database. The categories were developed using the Alicante model. **RESULTS:** A total of 745 articles were identified, with 7 selected for analysis. The information obtained was grouped into 3 categories: death communication, which indicates the importance of using simple and clear words; emotional support, which reveals the need to respect family time and the importance of empathy and compassion; and donation information, which punctuates the importance of dissociating communication about the death from that regarding organ donation. **CONCLUSIONS:** Evidence shows that best practices are the use of simple language, respect for the family during the grieving process, and the importance of establishing different situations in which to communicate about the death and the donation process. <https://pubmed.ncbi.nlm.nih.gov/32199644/>

**DeMuth, M., Taggi-Pinto, A., Miller, E. G. and Alderfer, M. A. (2020). "Bereavement Accommodations in the Classroom: Experiences and Opinions of School Staff." *J Sch Health* 90(3): 165-171.**

**BACKGROUND:** Bereaved children often struggle in the school environment and school personnel often feel inadequately prepared to support them. This pilot study explored the experiences and opinions of school staff regarding approaches to addressing the needs of bereaved students in the classroom. **METHODS:** Teachers/school personnel (N = 29) completed written open-ended questions about their experiences with bereaved students and opinions regarding a bereavement-focused accommodation (ie, 504) plan. Responses were summarized using qualitative content analysis. **RESULTS:** Most participants (93%) reported interacting with bereaved students and: (1) providing emotional support; (2) making classroom accommodations; (3) collaborating with the family/community; and (4) referring the student for counseling. Many (72%) expressed interest in a templated bereavement plan (21% did not respond; 7% said no) with education/resources for school personnel and suggested accommodations for students. **CONCLUSIONS:** Teachers encountering grieving students would welcome a templated bereavement plan to help meet students' needs. Such a plan would allow staff to become more knowledgeable about grief and provide guidance for developing specific strategies to accommodate grieving students both emotionally and academically. <https://pubmed.ncbi.nlm.nih.gov/31957037/>

**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://pubmed.ncbi.nlm.nih.gov/31269799/>

Dombrecht, L., Deliëns, L., Chambaere, K., Baes, S., Cools, F., Goossens, L., Naulaers, G., Roets, E., Piette, V., Cohen, J. and Beernaert, K. (2020). "Neonatologists and neonatal nurses have positive attitudes towards perinatal end-of-life decisions, a nationwide survey." *Acta Paediatr* 109(3): 494-504.

AIM: Perinatal death is often preceded by an end-of-life decision (ELD). Disparate hospital policies, complex legal frameworks and ethically difficult cases make attitudes important. This study investigated attitudes of neonatologists and nurses towards perinatal ELDs. METHODS: A survey was handed out to all neonatologists and neonatal nurses in all eight neonatal intensive care units in Flanders, Belgium in May 2017. Respondents indicated agreement with statements regarding perinatal ELDs on a Likert-scale and sent back questionnaires via mail. RESULTS: The response rate was 49.5% (302/610). Most neonatologists and nurses found nontreatment decisions such as withholding or withdrawing treatment acceptable (90-100%). Termination of pregnancy when the foetus is viable in cases of severe or lethal foetal problems was considered highly acceptable in both groups (80-98%). Physicians and nurses do not find different ELDs equally acceptable, e.g. nurses more often than physicians (74% vs 60%,  $p = 0.017$ ) agree that it is acceptable in certain cases to administer medication with the explicit intention of hastening death. CONCLUSION: There was considerable support for both prenatal and neonatal ELDs, even for decisions that currently fall outside the Belgian legal framework. Differences between neonatologists' and nurses' attitudes indicate that both opinions should be heard during ELD-making.  
<https://pubmed.ncbi.nlm.nih.gov/30920064/>

Dombrecht, L., Piette, V., Deliëns, L., Cools, F., Chambaere, K., Goossens, L., Naulaers, G., Cornette, L., Beernaert, K. and Cohen, J. (2020). "Barriers to and Facilitators of End-of-Life Decision Making by Neonatologists and Neonatal Nurses in Neonates: A Qualitative Study." *J Pain Symptom Manage* 59(3): 599-608.e592.

CONTEXT: Making end-of-life decisions (ELDs) in neonates involves ethically difficult and distressing dilemmas for health care providers. Insight into which factors

complicate or facilitate this decision-making process could be a necessary first step in formulating recommendations to aid future practice. OBJECTIVES: This study aimed to identify barriers to and facilitators of the ELD-making process as perceived by neonatologists and nurses. METHODS: We conducted semistructured face-to-face interviews with 15 neonatologists and 15 neonatal nurses, recruited through four neonatal intensive care units in Flanders, Belgium. They were asked what factors had facilitated and complicated previous ELD-making processes. Two researchers independently analyzed the data, using thematic content analysis to extract and summarize barriers and facilitators. RESULTS: Barriers and facilitators were found at three distinct levels: the case-specific context (e.g., uncertainty of the diagnosis and specific characteristics of the child, parents, and health care providers, which make decision making more difficult), decision-making process (e.g., multidisciplinary consultations and advance care planning, which make decision making easier), and overarching structure (e.g., lack of privacy and complex legislation making decision making more challenging). CONCLUSION: Barriers and facilitators found in this study can lead to recommendations, some simpler to implement than others, to aid the complex ELD-making process. Recommendations include establishing regular multidisciplinary meetings to include all health care providers and reduce unnecessary uncertainty, routinely implementing advance care planning in severely ill neonates to make important decisions beforehand, creating privacy for bad-news conversations with parents, and reviewing the complex legal framework of perinatal ELD making. <https://pubmed.ncbi.nlm.nih.gov/31639496/>

Drach, L. L., Hansen, D. A., King, T. M. and Sibinga, E. M. S. (2020). "Communication between neonatologists and parents when prognosis is uncertain." *J Perinatol* 40(9): 1412-1422.

OBJECTIVE: When an infant's prognosis is uncertain, communication between neonatologists and parents surrounding goals of care and decision-making can be challenging. This qualitative study explored communication between neonatologists and parents to discover qualities which may enhance or impede parent-clinician partnership under such difficult circumstances. STUDY DESIGN: Guided by the National Cancer Institute (NCI) Patient Centered Communication framework, semi-structured individual interviews were conducted and analyzed regarding neonatologist and parent perceptions of their communication. Subjects consisted of nine dyads of neonatologists and English-speaking parents whose infant had an uncertain prognosis. RESULTS: Parents were overall satisfied with neonatologists' communications concerning their infant's uncertain trajectory. Nonetheless, both experienced challenges and distress during communication, impeding collaboration and engagement. CONCLUSIONS: Families and neonatologists value principles of patient centered communication but report challenges implementing this practice. Incorporating a multidisciplinary approach in settings of prognostic uncertainty to foster patient centered communication, may enhance communication surrounding NICU care. <https://pubmed.ncbi.nlm.nih.gov/32382115/>

Ehrlich, B. S., Movsisyan, N., Batmunkh, T., Kumirova, E., Borisevich, M. V., Kirgizov, K., Graetz, D. E., McNeil, M. J., Yakimkova, T., Vinitzky, A., Ferrara, G., Li, C., Lu, Z., Kaye, E. C., Baker, J. N. and Agulnik, A. (2020). "A multicountry

**assessment in Eurasia: Alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines." Cancer 126(16): 3777-3787.**

**BACKGROUND:** The World Health Organization (WHO) advocates for early integration of palliative care for all children with life-threatening illness. Provider awareness and misperceptions, however, can impede this imperative. In the Eurasian region, little is known about physician knowledge and perspectives on palliative care. **METHODS:** The Assessing Doctors' Attitudes on Palliative Treatment survey was developed as an evidence-based and culturally relevant assessment of physician perceptions on palliative care integration into childhood cancer care in Eurasia. Iteratively tested by American and Eurasian palliative care experts, the survey was culturally adapted, translated, and piloted in English, Russian, and Mongolian. The survey was distributed to physicians caring for children with cancer. Fifteen statements were scored in accordance with WHO guidelines to evaluate provider knowledge. The statistical analysis was complemented by a qualitative analysis of open-ended responses. **RESULTS:** This study received 424 responses from 11 countries in Eurasia. The mean alignment between provider perspectives and WHO recommendations was 70% (range, 7%-100%). Significant independent predictors of higher alignment included country, prior palliative care education, and greater experience with patient death. Respondents primarily described palliative care as end-of-life care and symptom management. Two-thirds of respondents (67%) reported not feeling confident about delivering at least 1 component of palliative care. **CONCLUSIONS:** This is the first study assessing physician perspectives and knowledge of palliative care in Eurasia and reveals wide variability in alignment with WHO guidelines and limited confidence in providing palliative care. Study findings will inform targeted educational interventions, which must be tailored to the local political, economic, and cultural context.  
<https://pubmed.ncbi.nlm.nih.gov/32530519/>

**Ekberg, S., Danby, S., Herbert, A., Bradford, N. K. and Yates, P. (2020). "Affording opportunities to discuss deterioration in paediatric palliative care consultations: a conversation analytic study." BMJ Support Palliat Care 10(2): e13.**

**OBJECTIVE:** Discussing the potential deterioration of a child who has a life-limiting condition has recognised benefits for future care, but can be challenging in a clinical context where uncertain illness trajectories are common. Existing research is restricted to indirect forms of evidence such as self-report data from clinicians and families. This study directly explores how discussions about deterioration are managed within actual paediatric palliative care consultations. **METHODS:** 9 consultations were video recorded in an Australian paediatric palliative care service. Each consultation involved the same paediatric palliative care specialist. Conversation analysis was used to identify and explore recurrent ways in which discussions about deterioration came to be realised. **FINDINGS:** The study identified two communicative practices used by a paediatric palliative care specialist that afforded opportunities to discuss deterioration: (1) soliciting the family's agenda for the consultation; (2) initiating and maintaining topics where discussing deterioration is a relevant possibility. Across these different practices, a common feature was indirect initiation of discussions about deterioration. This approach made such discussions possible, but without mandating or even suggesting that such discussion must occur. **CONCLUSIONS:** These communicative practices

balance the benefit of discussing deterioration against a recognised importance of allowing discussions to be directed by a child's family. This was achieved by creating opportunities for discussing deterioration, without making such discussions necessary. <https://pubmed.ncbi.nlm.nih.gov/28270396/>

**Ekberg, S., Herbert, A., Johns, K., Tarrant, G., Sansone, H., Yates, P., Danby, S. and Bradford, N. K. (2020). "Finding a way with words: Delphi study to develop a discussion prompt list for paediatric palliative care." *Palliat Med* 34(3): 291-299.**

**BACKGROUND:** Effective communication is a cornerstone of quality paediatric palliative care. Families report struggling, however, to know what to discuss, with whom, and when. Although question prompt lists exist for adult palliative care, they do not suit the unique circumstances of paediatric palliative care. **AIM:** To develop a prompt list suitable for paediatric palliative care. **DESIGN:** Underpinned by Delphi methodology, a six-phase procedure was adopted: (1) drafting items based on the findings of a literature review, (2) condensing the list of items based on group discussion, (3) refining items based on a survey of expert healthcare professionals, (4) additional refining of items based on another survey of professionals, (5) further refining of items based on cognitive interviews with family members, and (6) final review by healthcare professional and family member groups. **PARTICIPANTS:** Three participant groups were involved during various phases: (1) members of an Australasian paediatric palliative care national reference group, (2) healthcare professionals associated with a local paediatric palliative care service, and (3) family members who were users of the same local service. **RESULTS:** Through multi-phase consultation across participant groups, the draft question prompt list was refined progressively to 28 items, split across two booklets to allow end-of-life items to be provided separately, and reconceptualised as a discussion prompt list rather than a question prompt list. **CONCLUSION:** By involving representatives of major stakeholder groups, this study has facilitated the design of a prompt list suited to the circumstances of paediatric palliative care. Future research should trial the effectiveness of this resource. <https://pubmed.ncbi.nlm.nih.gov/31752593/>

**Engler, J., Gruber, D., Engler, F., Hach, M., Seipp, H., Kuss, K., Gerlach, F. M., Ulrich, L. R. and Erler, A. (2020). "Parents' Perspectives on Hospital Care for Children and Adolescents with Life-Limiting Conditions: A Grounded Theory Analysis of Narrative Interviews." *J Palliat Med* 23(4): 466-474.**

**Background:** Guidelines on pediatric palliative care recommend to provide care for children and adolescents with life-limiting conditions at home. Since 2007, in Germany, palliative home care can be provided by specialized outpatient palliative care teams. However, teams with specific expertise for children are not available all over the country. Families without this support need to use the hospital to get specialists' assistance. **Objective:** To explore how parents of children and adolescents with life-limiting conditions think about the hospital as place of care. **Design:** We conducted narrative interviews with parents and analyzed these by using a grounded theory approach. **Setting/Subjects:** We interviewed 13 parents (4 fathers and 9 mothers) of 9 children with life-limiting conditions receiving or having received pediatric specialized outpatient palliative care (SOPPC) in Germany. **Results:** Parents reported feelings of vulnerability, heteronomy, and disablement associated with hospital care and were

afraid that their children's needs were not adequately addressed. These perceptions resulted from hospitals' standardized care structures and over- and undertreatment, a lack of continuity of care, hospital pathogens, a lack of a palliative mindset, insensitive hospital staff, the exclusion of parents from the treatment and parental care of their children, the hospital stay as a permanent state of emergency, and a waste of limited life time. Conclusion: Pediatric hospital staff needs training in identifying and responding to palliative care needs. SOPPC structures should be expanded all over Germany to meet the needs of families of children with life-limiting conditions.

<https://pubmed.ncbi.nlm.nih.gov/31730390/>

**Erondy, M. U. and Mahoney, D. P. (2020). "Palliative care, resuscitation status, and end-of-life considerations in pediatric anesthesia." *Curr Opin Anaesthesiol* 33(3): 354-360.**

**PURPOSE OF REVIEW:** To familiarize pediatric anesthesiologists with primary palliative care procedural communication skills and recommendations for discussions involving complex medical decision-making or advance care planning, such as discussions about resuscitation status. **RECENT FINDINGS:** Recent publications highlight the benefits of pediatric palliative care (PPC) for seriously ill patients and their families, and how PPC principles might be applied to perioperative communication and decision-making. Both prospective and retrospective reports reveal improved quality of life, symptom management, and avoidance of unnecessary interventions when PPC is introduced early for a child with serious illness. **SUMMARY:** Pediatric anesthesiologists will, at some point, care for a child with serious illness who would benefit from PPC. It is important that all members of the perioperative care team are familiar with primary PPC procedural communication skills and models for approaching discussions about goals of care, shared decision-making, and advance care planning. Pediatric anesthesiologists should be incorporated as early as possible in team discussions about potential procedures requiring sedation for seriously ill children.

<https://pubmed.ncbi.nlm.nih.gov/32371634/>

**Evans, A. M., Jonas, M. and Lantos, J. (2020). "Pediatric Palliative Care in a Pandemic: Role Obligations, Moral Distress, and the Care You Can Give." *Pediatrics* 146(1).**

Many ethical issues arise concerning the care of critically ill and dying patients during the coronavirus disease 2019 (COVID-19) pandemic. In this issue's Ethics Rounds, we present 2 cases that highlight 2 different sorts of ethical issues. One is focused on the decisions that have to be made when the surge of patients with respiratory failure overwhelm ICUs. The other is focused on the psychological issues that arise for parents who are caring for a dying child when infection-control policies limit the number of visitors. Both of these situations raise challenges for caregivers who are trying to be honest, to deal with their own moral distress, and to provide compassionate palliative care.

<https://pubmed.ncbi.nlm.nih.gov/32461261/>

**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://pubmed.ncbi.nlm.nih.gov/30724688/>

Fahner, J. C., Thölking, T. W., Rietjens, J. A. C., van der Heide, A., van Delden, J. J. M. and Kars, M. C. (2020). "Towards advance care planning in pediatrics: a qualitative study on envisioning the future as parents of a seriously ill child." *Eur J Pediatr* 179(9): 1461-1468.

Advance care planning enables parents to discuss goals and preferences for future care and treatment of their seriously ill child. Although clinicians report parental factors as common barriers for advance care planning, parental views on reflecting on their child's future have had limited exploration. A clear understanding of their perspectives might help clinicians to implement advance care planning tailored to parental needs. This interpretive qualitative study using thematic analysis aims to identify how parents envision the future when caring for their seriously ill child. Single interviews and two focus groups were attended by 20 parents of 17 seriously ill children. Parents reported to focus on the near future of their child. However, their actions and deeper thoughts showed perspectives towards a further future. Future perspectives initial focused on practical, disease-related themes, but more existential elaborations, reflecting underlying life values, were also identified. Parents needed acknowledgement of their challenging situation, care tasks, and expertise as a precondition for sharing their deepest thoughts regarding the future of their child. Conclusion: When envisioning the future of their seriously ill child, parents tend to stay in the near future, whereas they value the opportunity to share further thoughts within a compassionate relationship with clinicians.

What is Known:

- Parents prefer open and honest information about their child's illness and prognosis and they value the concept of advance care planning, while they emphasize the need for an individualized approach.
- Health care professionals see parental factors like unease and emotional burden as key barriers for advance care planning.

What is New:

- When envisioning the future of their seriously ill child, parents tended to stay close to the near future initially, with a focus on disease-related, practical themes. Ongoing conversations uncovered deeper, value-based elaborations towards the future. To engage parents in advance care planning, the future needs to be discussed in relation to the present and the past.
- There is "no sharing without caring". Parents who felt cared for and acknowledged in their challenging context by clinicians, were open to share their perspectives on the future of their seriously ill child. To share deeper motives and values underlying goals and preferences for future care and treatment, parents need a stimulating attitude of listening and encouragement from clinicians to express their feelings.

<https://pubmed.ncbi.nlm.nih.gov/32193658/>

**Ferraz, S. L., O'Connor, M. and Mazzucchelli, T. G. (2020). "Exploring Compassion from the Perspective of Health Care Professionals Working in Palliative Care." *J Palliat Med*, 10.1089/jpm.2019.0682.**

Background: Despite the body of literature regarding the varying definition of compassion, there appears a lack of literature pertaining to the meaning of compassion from the perspective of health care professionals working in palliative care settings.

Objective: The study aimed to explore how health care professionals working in palliative care settings view and/or understand the construct of compassion. Methods:

A qualitative approach using semistructured interviews was used. Interviews were conducted with eighteen health care professionals working in pediatric, adult, and aged palliative care settings. Interviews transcripts were thematically analyzed. Results:

Thematic analysis identified four main interrelated themes and supplementary subthemes. Health care professionals working in palliative care settings identified their perception of the (1) meaning of compassion, (2) importance of providing compassionate care, (3) barriers to providing compassionate care, and (4) facilitating compassionate care. Conclusions: This study presents a novel understanding of the components of compassion from the perspective of health care professionals working in palliative care. While there is need for future research, important areas of improvement include increased resourcing, reducing time pressures, and education within palliative care settings. This will enable the fostering of compassionate care to patients, as well as enhanced well-being both professionally and personally for health care providers delivering such care.

<https://pubmed.ncbi.nlm.nih.gov/32293968/>

**Ferrell, B., Thaxton, C. A. and Murphy, H. (2020). "Preparing Nurses for Palliative Care in the NICU." *Adv Neonatal Care* 20(2): 142-150.**

BACKGROUND: Neonatal intensive care unit (NICU) nurses require knowledge and skill to meet the unique needs of infants and families. Increasingly, principles of palliative

care are being integrated into the NICU setting to improve the quality of care. **PURPOSE:** The purpose of this article is to describe the efforts of the End-of-Life Nursing Education Consortium (ELNEC) project and its Pediatric Curriculum, which began in 2003 to provide this education, and to also describe efforts by nurses to implement the training into their practice settings. **METHODS:** The ELNEC Pediatric Palliative Care (ELNEC-PPC) project is a train-the-trainer educational program and evidence-based curriculum. **FINDINGS/RESULTS:** Participants attend a course or receive online training and then apply the education to implement improved practices in areas such as symptom management, care at the time of death, and bereavement support for families. **IMPLICATIONS FOR RESEARCH:** Experiences with ELNEC-PPC have demonstrated that nurses can implement the curriculum to improve care. **IMPLICATIONS FOR PRACTICE:** Continued attention to palliative care in this setting is needed, and future research is needed to evaluate the outcomes of this education and practice change.

<https://pubmed.ncbi.nlm.nih.gov/32053525/>

**Flanders, S., Hampton, D., Missi, P., Ipsan, C. and Gruebbel, C. (2020). "Effectiveness of a Staff Resilience Program in a Pediatric Intensive Care Unit." *J Pediatr Nurs* 50: 1-4.**

**BACKGROUND:** Compassion fatigue (CF) and secondary traumatic stress (STS) is prevalent in intensive care nurses, especially in pediatric intensive care nurses (PICU). CF, which includes STS and burnout, leads to reduced employee engagement and nursing turnover. **PURPOSE:** The purpose of this project was to evaluate the impact of a staff resilience program on nursing turnover, employee engagement and compassion satisfaction among nurses in a PICU. **DESIGN AND METHODS:** A retrospective pre-test and post-test design was used to evaluate the impact of a staff resilience program on turnover, engagement, and Professional Quality of Life (ProQOL), which measured compassion satisfaction and compassion fatigue. **RESULTS:** RN turnover was reduced and employee engagement was improved, although the differences were not statistically significant. The aggregate scores of the ProQOL indicated the RN's had low levels of CF with high levels of compassion satisfaction post implementation of the resilience program. Years of work experience was positively associated with compassion satisfaction and work engagement. **CONCLUSIONS:** Education regarding the prevention of CF and burnout coupled with interventions designed to promote resilience can be effective in reducing CF and in building compassion satisfaction. **PRACTICE IMPLICATIONS:** Doing an assessment of compassion fatigue and following up with the implementation of interventions to build staff resilience and promote psychological health can lead to positive outcomes, as demonstrated by the increase in work engagement and compassion satisfaction when burnout and CF decreased.

<https://pubmed.ncbi.nlm.nih.gov/31669724/>

**Forman, K. R. and Thompson-Branch, A. (2020). "Educational Perspectives: Palliative Care Education in Neonatal-Perinatal Medicine Fellowship." *Neoreviews* 21(2): e72-e79.**

The neonatal period from birth to less than or equal to 28 days is one of increased risk of death. Congenital anomalies and prematurity are 2 of the most common risk factors for death at this early age. Many of these neonates will die in an intensive care unit,

some with full resuscitative efforts being undertaken despite the understanding that these actions are highly unlikely to yield an outcome different from death. Palliative care allows curative therapies to be provided alongside supportive techniques such as enhanced family communication, attention to spirituality and the psychosocial health of the family, management of symptoms other than those specific to the underlying disease process, and enhancing comfort. The American Academy of Pediatrics has set forth recommendations related to pediatric palliative care for the various pediatric subspecialties; however, much of the focus is on disease processes and curing or mitigating various illnesses. Given the high preponderance of death in the neonatal period, neonatal-perinatal medicine training programs should be tasked with generating formal palliative care training. Such training should be geared to providing better care for neonatal patients with a life-limiting or life-altering illness, and better equipping future neonatologists with the tools needed to provide truly comprehensive care for their sickest patients at risk for death and disability. This article serves to review the concept of palliative care in neonates, discuss the paucity of formal education in palliative care, explore the general trend in palliative care education, review various ways in which palliative care education can be formalized, and define metrics of a successful educational program.

<https://pubmed.ncbi.nlm.nih.gov/32005717/>

**Fortney, C. A. (2019). "Palliative and End-of-Life Care for Infants and Their Families in the NICU: Building a Program of Research." *J Pediatr Nurs* 49: 104-105.**

This article is a brief report on the building of a program of research to support palliative and end-of-life care for infants and their families in the neonatal intensive care unit.

<https://pubmed.ncbi.nlm.nih.gov/31668673/>

**Fraser, J., Sleaf, V. and Sidebotham, P. (2020). "National child death review statutory and operational guidance: Key concepts for practising paediatricians." *Arch Dis Child Educ Pract Ed* 105(4): 244-250.**

In October 2018, National Health Service England published new operational guidance for reviewing child deaths, which covers all children who die less than 18 years of age regardless of the cause of death. The Guidance is for all healthcare professionals caring for children as well as senior leaders who commission, provide or regulate children's services. It does not aim to be prescriptive but instead sets out a framework of expectations that intends to be flexible and proportionate. Its essential building blocks will be familiar to practising paediatricians: notification, investigation, review and reporting. It should be regarded as a key pillar in the hospital's governance program.

<https://pubmed.ncbi.nlm.nih.gov/31558573/>

**Fraser, J., Sleaf, V. and Sidebotham, P. (2020). "Child death review statutory and operational guidance: maximising learning from child deaths." *Arch Dis Child* 105(4): 315-318.**

<https://pubmed.ncbi.nlm.nih.gov/31492660/>

**Fraser, L. K., Bluebond-Langner, M. and Ling, J. (2020). "Advances and Challenges in European Paediatric Palliative Care." *Med Sci (Basel)* 8(2).**

Advances in both public health and medical interventions have resulted in a reduction in childhood mortality worldwide over the last few decades; however, children still have life-threatening conditions that require palliative care. Children's palliative care is a specialty that differs from palliative care for adults in many ways. This paper discusses some of the challenges, and some of the recent advances in paediatric palliative care. Developing responsive services requires good epidemiological data, as well as a clarity on services currently available and a robust definition of the group of children who would benefit from palliative care. Once a child is diagnosed with a life-limiting condition or life-limiting illness, parents face a number of complex and difficult decisions; not only about care and treatment, but also about the place of care and ultimately, place of death. The best way to address the needs of children requiring palliative care and their families is complex and requires further research and the routine collection of high-quality data. Although research in children's palliative care has dramatically increased, there is still a dearth of evidence on key components of palliative care notably decision making, communication and pain and symptom management specifically as it relates to children. This evidence is required in order to ensure that the care that these children and their families require is delivered.

<https://pubmed.ncbi.nlm.nih.gov/32316401/>

**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://pubmed.ncbi.nlm.nih.gov/31220594/>

Güthlin, C., Bartsch, H. H., Joos, S., Längler, A., Lampert, C., Ritter, C., Schildmann, J., Weis, J., Wilhelm, M., Witt, C. M. and Horneber, M. (2020). "KOKON: A Germany-Wide Collaborative Research Project to Identify Needs, Provide Information, Foster Communication and Support Decision-Making about Complementary and Alternative Medicine in Oncology." Complement Med Res 27(2): 105-111.

BACKGROUND: The German Cancer Aid set up a priority research programme with the intention to generate high-quality information based on evidence and to make this information easily accessible for health-care professionals and advisors, researchers, patients, and the general public. SUMMARY: The Kompetenznetz Komplementärmedizin in der Onkologie (KOKON) received 2 funding periods within this programme. During the first funding period, KOKON assessed patients' and health-care professionals' informational needs, developed a consulting manual for physicians, developed an education programme for self-help groups, set up a knowledge database, and developed a pilot information website for patients. Funding period 2 continues with work that allows cancer patients and health-care professionals to make informed decisions about complementary and alternative medicine (CAM). For this aim, KOKON evaluates training programmes for physicians (oncology physicians, paediatric oncologists, and general practitioners) and for self-help groups. All training programmes integrate results from an analysis of the ethical, psychological, and medical challenges of CAM in the medical encounter, and the knowledge database is being extended with issues related to CAM for supportive and palliative care. Key Message: A Germany-wide collaborative research project to identify needs, provide information, foster communication, and support decision-making about CAM in oncology is being set up. <https://pubmed.ncbi.nlm.nih.gov/31722354/>

Harris, N., Blackburn, M., Noyes, J., Aldridge, J., Lapwood, S., Dunbar, H., Price, J., Mitchell, S., Chambers, L. and Bluebond-Langner, M. (2019). "Undertaking doctoral research with children and young people with life-limiting or life-threatening conditions." J Adv Nurs 75(12): 3183-3185. <https://pubmed.ncbi.nlm.nih.gov/31144341/>

Henao-Castaño Á, M. and Quiñonez-Mora, M. A. (2019). "How nurses cope with death in the Paediatric Intensive Care Unit." Enferm Intensiva 30(4): 163-169.

The death of a child in the Paediatric Intensive Care Unit (PICU) is difficult, the loss generates feelings of sadness and pain; this study highlights the different coping strategies used by nurses to manage this situation and find the strength to provide care at the end of life. OBJECTIVE: Explore the strategies used by nurses in the PICU in coping with death. METHODS: Study conducted in the city of Manizales, Colombia, during the months of October, November and December. A qualitative, hermeneutical phenomenological approach was used. The method of intentional sampling for the selection of participating nurses (n=10) working in PICU, in-depth interviews were conducted for the construction of the information and the data were analyzed according to the procedures proposed by Cohen, Kahn and Steeves. RESULTS: Nurses use coping strategies focused on emotions: they inhibit their feelings towards the patient and their family; they use communication and prayer with the patient, as

well as accompaniment to alleviate the suffering of the family. CONCLUSION: UCIP nurses develop coping strategies for end-of-life care using spiritual resources and communication with the family who require ongoing support, reflecting on death and accompanying the child in its transcendence.

<https://pubmed.ncbi.nlm.nih.gov/30509877/>

Hill, D. L., Walter, J. K., Szymczak, J. E., DiDomenico, C., Parikh, S. and Feudtner, C. (2020). "Seven Types of Uncertainty When Clinicians Care for Pediatric Patients With Advanced Cancer." *J Pain Symptom Manage* 59(1): 86-94.

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 semi-structured 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://pubmed.ncbi.nlm.nih.gov/31425822/>

Janvier, A., Farlow, B., Barrington, K. J., Bourque, C. J., Brazg, T. and Wilfond, B. (2020). "Building trust and improving communication with parents of children with Trisomy 13 and 18: A mixed-methods study." *Palliat Med* 34(3): 262-271.

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://pubmed.ncbi.nlm.nih.gov/31280664/>

Johnston, E. E. and Rosenberg, A. R. (2020). "Better Understanding the Importance of Palliative Care for Pediatric Patients." *JAMA Oncol* 6(6): 817-818.

<https://pubmed.ncbi.nlm.nih.gov/32239199/>

Kaye, E. C., Applegarth, J., Gattas, M., Kiefer, A., Reynolds, J., Zalud, K. and Baker, J. N. (2020). "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* 34(3): 403-412.

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://pubmed.ncbi.nlm.nih.gov/31347446/>

Kim, S., Savage, T. A., Song, M. K., Vincent, C., Park, C. G., Ferrans, C. E. and Kavanaugh, K. (2019). "Nurses' roles and challenges in providing end-of-life care in neonatal intensive care units in South Korea." Appl Nurs Res 50: 151204.

BACKGROUND: Neonatal Intensive Care Unit (NICU) nurses in Korea often experience challenges in providing care for dying infants and their families. However, there is limited understanding about what contributes to the challenges related to end-of-life care. PURPOSE: To describe NICU nurses' perceived roles and challenges faced while providing end-of-life care in South Korea. METHODS: A qualitative descriptive study was conducted with 20 NICU nurses in South Korea using semi-structured interviews. Participants were recruited from two NICUs in Seoul, where infant mortality is the highest in South Korea. Transcribed interviews were coded by two research personnel, and subsequently, a developed coding book was translated by three research personnel. The codes developed were categorized and peer-reviewed to develop themes using conventional content analysis. RESULTS: Nurses' roles during end-of-life care were grouped into four categories: providing information and support, enhancing attachment between the parents and infants, providing direct care to the infant, and completing documentation. Nurses' perceived challenges during end-of-life care included providing end-of-life care without adequate experience and knowledge, environmental constraints on end-of-life care, and conflicted situations during end-of-life care. CONCLUSION: Although the nurses provided the best care they could, their end-of-life care practice was hindered for various reasons. To enhance NICU nurses' ability to provide and make them more capable of providing high quality EOL care, hospitals need to support nurse education and improve staffing level, and create in NICUs an environment that is favorable for providing EOL care.

<https://pubmed.ncbi.nlm.nih.gov/31669082/>

Knighting, K., Kirton, J., Silverio, S. A. and Shaw, B. N. J. (2019). "A Network Approach to Neonatal Palliative Care Education: Impact on Knowledge, Efficacy, and Clinical Practice." J Perinat Neonatal Nurs 33(4): 350-360.

More than 80 000 babies are admitted to specialist neonatal units in the United Kingdom every year, with approximately 2109 neonatal deaths a year; 98% in hospital. A common element in guidance and pathways to facilitate the provision of palliative care to infants and their families is the importance of good education and training to develop high-quality staff and services. This article presents a mixed-methods, sequential, explanatory design evaluation of 1 day palliative care education workshops delivered using a network-wide approach to multidisciplinary professionals. Workshops were delivered by healthcare professionals and bereaved parents and evaluated using questionnaires, adapted for neonatal staff from standardized measures, and follow-up interviews. The workshop content and shared learning approach resulted in significant improvements in participant's knowledge, attitude, self-beliefs and confidence in neonatal palliative care, enhanced awareness of services, and improved links between professionals. Participants cascaded their learning to their teams and provided examples of changes in their clinical practice following the workshop. Parent stories were identified as a very powerful component of the training, with lasting impact on participants. Formal, integrated palliative care education programs for perinatal and neonatal staff and longitudinal research into the impact on practice and the experience received by families are needed.

<https://pubmed.ncbi.nlm.nih.gov/31651629/>

Kobler, K., Bell, C., Kavanaugh, K., Gallo, A. M., Corte, C. and Vincent, C. (2020). "Health Care Professionals' Awareness of a Child's Impending Death." Qual Health Res 30(9): 1314-1325.

Health care professionals' (HCPs) experiences during early pediatric end-of-life care were explored using a theory-building case study approach. Multiple data collection methods including observation, electronic medical record review, and semi-structured interviews were collected with 15 interdisciplinary HCPs across four cases. Within- and across-case analyses resulted in an emerging theory. HCPs' initial awareness of a child's impending death is fluid, ongoing, and informed through both relational and internal dimensions. Initial cognitive awareness is followed by a deeper focus on the child through time-oriented attention to the past, present, and future. HCPs engage in a "delicate dance of figuring out" key issues. Awareness was exemplified through four themes: professional responsibility, staying connected, grounded uncertainty, and holding in. The emerging theoretical model provides a framework for HCPs to assess their ongoing awareness, identify personal assumptions, and inform gaps in understanding when facilitating early end-of-life care discussions with families.

<https://pubmed.ncbi.nlm.nih.gov/32249703/>

Kolmar, A., Hueckel, R. M., Kamal, A. and Dickerman, M. (2019). "Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children in Neonatal and Pediatric Intensive Care Units." J Palliat Med 22(9): 1149-1153.

Over the past several years, pediatric critical care units increasingly count on the expert advisement of palliative care specialists. Given the limited availability of pediatric palliative care specialists, all palliative care clinicians may be required to care for pediatric patients and their families. Special considerations in caring for these patients include the relative importance of prognosis, involvement of child life, music and pet therapy, incorporation of parents in end-of-life rituals, care for siblings, use of medical technology, and prolonged duration of stay. The following top 10 tips provide recommendations for caring for seriously ill infants, children, adolescents, and the families of these critically ill pediatric patients. They are written by pediatric intensive care providers to address common issues around palliative care in intensive care units.

<https://pubmed.ncbi.nlm.nih.gov/31498731/>

Kyc, S. J., Bruno, C. J., Shabanova, V. and Montgomery, A. M. (2020). "Perceptions of Neonatal Palliative Care: Similarities and Differences between Medical and Nursing Staff in a Level IV Neonatal Intensive Care Unit." J Palliat Med 23(5): 662-669.

Background: A significant number of newborns are affected by life-limiting or life-threatening conditions. Despite this prevalence, there are inconsistencies in attitudes toward, and delivery of, neonatal palliative care. Implementing neonatal palliative care practice requires a multidisciplinary, collaborative effort. Objective: To examine institutional and individual barriers to and facilitators of neonatal palliative care from both medical and nursing perspectives. Design/Setting/Subjects: A prospective cross-

sectional study design was used to collect data using the Neonatal Palliative Care Attitude Scale (NiPCAS) survey from medical providers and nurses in a 64-bed level IV neonatal intensive care unit in the United States. The response rate was 67%. Measurements: The NiPCAS survey included 26 attitudinal questions on a Likert scale. The instrument included three subscales: organization, resources, and clinician, in addition to other questions. Results: Six facilitators to neonatal palliative care were identified: (1) support of palliative care by the health care team, (2) support of palliative care by medical and nursing practice, (3) agreement that palliative care is as important as curative care, (4) parental involvement in decision making, (5) recognition of the importance of palliative care education, and (6) prioritizing pain relief. Three barriers to neonatal palliative care were highlighted: (1) a physical environment that is not conducive to providing palliative care, (2) technological obligations and parental demands, and (3) the societal belief that babies should not die. In addition, there were differences between medical and nursing staffs' attitudes on several topics. Conclusions: Several facilitators and barriers of neonatal palliative care were identified. There were similarities and differences in perceptions of neonatal palliative care between medical and nursing staff. Future work should be done to strengthen facilitators and to mitigate barriers.

<https://pubmed.ncbi.nlm.nih.gov/31808706/>

**Lafond, D. A., Bowling, S., Fortkiewicz, J. M., Reggio, C. and Hinds, P. S. (2019). "Integrating the Comfort Theory™ Into Pediatric Primary Palliative Care to Improve Access to Care." *J Hosp Palliat Nurs* 21(5): 382-389.**

Primary palliative care improves access to symptom control and quality-of-life care for children and families and can reduce moral distress in clinicians. This article describes the application of a nursing theory framework for an evidence-based practice/quality improvement project that embedded pediatric primary palliative care into a hospital-based setting using unit-specific projects. An evidence-based practice/quality improvement project, guided by the Comfort Theory™, provided primary palliative care education and mentorship to improve knowledge, skills, and attitudes of direct care clinicians. Training consisted of didactic and self-directed learning, mentoring, and completion of unit-based projects to establish meaning and impact best practices and policies. A total of 149 direct care clinicians, comprising 3 cohorts, enrolled in the program. Improvements in interdisciplinary collaboration in care were demonstrated through 21 unit-based projects, the development of triggers for specialty palliative care consults in several high-risk populations, and the development of institutional guidelines for end-of-life care. The Comfort Theory™ guided integration of palliative care for children with serious illness and their families. This project empowered direct care clinicians in caring for patients, providing support to clinical staff, and in developing best practices.

<https://pubmed.ncbi.nlm.nih.gov/30920492/>

**Lazzarin, P., Avagnina, I., Divisic, A., Agosto, C., Giacomelli, L. and Benini, F. (2020). "Management strategies adopted by a paediatric palliative care network in northern Italy during the COVID-19 pandemic." *Acta Paediatr* 109(9): 1897-1898.**

The Veneto region of northern Italy, which has about 5 million inhabitants, was the second area of the country, after Lombardy, to face the spread of COVID-19. After the

first case on 21 February 2020, the number of cases increased exponentially, and lockdown was enforced. The regional healthcare system was forced to implement appropriate measures to protect patients and healthcare providers from the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, which causes COVID-19, while ensuring continued care.

<https://pubmed.ncbi.nlm.nih.gov/32533863/>

**Lee, J., Clarke, S. and Lynn, F. (2020). "Understanding the Causes of Work-Related Stress among Registered Nurses Working with Children at Home: An Integrative Literature Review." Compr Child Adolesc Nurs, 10.1080/24694193.2020.1745325: 1-32.**

Work-related stress in nursing is widely acknowledged. This integrative review was undertaken to systematically identify and appraise the causes of work-related stress experienced by registered nurses working with children at home. Ten studies were included, eight of which focused solely on the experiences of nurses providing palliative and end of life care at home for children. One study focused on the experiences of newly qualified nurses and one on the experiences of nurses caring for sick children at home at different stages within their care trajectory. Stress was experienced by nurses caring for children at home and identified and acknowledged within all included studies. Recurrent themes reported in the literature that contributed to work-related stress were, provision of out of hours care, challenge of developing and maintaining skills (clinical and non-clinical), ambiguity of roles and relationships (professional team and child and family), lack of resources, emotional toll, and lack of staff support. The causes of work-related stress highlighted in this review need to be proactively addressed; thus, providing an opportunity to improve the working experiences of nurses improve job satisfaction and overall wellbeing. A recommendation from this integrative review is for workplaces to identify and invest in effective strategies to prevent or reduce work-related stress.

<https://pubmed.ncbi.nlm.nih.gov/32324438/>

**Lee, R. J. and Steer, P. J. (2020). "Miscarriage, stillbirth, and neonatal death - the words we use are important but holistic care requires both practical improvements and appropriately trained staff." Bjog 127(7): 875.**

<https://pubmed.ncbi.nlm.nih.gov/32017409/>

**Lemaster, P. and Moyer, E. (2020). "A Matter of Life and Death: Teaching Undergraduates About the End of Life." Int J Aging Hum Dev, 10.1177/0091415020909488: 91415020909488.**

As the population ages, the number of careers that intersect with aging is expected to grow. However, many young people lack an interest in working with aging populations. As previous work has shown, though, students' interest in aging careers may be stimulated by coursework and experiential activities related to aging. Despite being a normative developmental process, anxiety about death and dying may be particular barriers to students developing interest in aging, and these topics may be particularly difficult subjects to teach in the college classroom. Here, strategies and activities for teaching the end of life are offered.

<https://pubmed.ncbi.nlm.nih.gov/32122148/>

Lewis, S. L. (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): 250-256.

End-of-life care in the neonatal intensive care unit (NICU) is one of the most challenging practices for nurses. Negative emotions associated with moral distress often cause care to be incomplete or nurse disengagement. Emotional intelligence in nurses holds potential to address this issue, while improving patient outcomes. The purpose of this study was to critically appraise the evidence about emotional intelligence in nursing and to explore the relationship between emotional intelligence, moral distress in NICU nurses, end-of-life care, and other priority nurse and patient outcomes. A PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses)-structured integrative review was conducted, and CINAHL, Ovid, PubMed, and other databases were searched. Twelve studies were identified as relevant to this review after exclusion criteria were applied. Evidence supports the efficacy of emotional intelligence in bedside nurses as a method of improving key nurse and patient outcomes. Additionally, research suggests that emotional intelligence can be improved by training interventions. Clinical educators should integrate emotional intelligence concepts and strategies into staff training. Further research is recommended to validate previous findings in the NICU setting. Exploration of the relationship between emotional intelligence and moral distress in NICU nurses would provide a foundation for experimental designs to evaluate the effectiveness of emotional intelligence training interventions.

<https://pubmed.ncbi.nlm.nih.gov/31268970/>

Liddiard, K., Whitney, S., Evans, K., Watts, L., Vogelmann, E., Spurr, R., Aimes, C., Runswick-Cole, K. and Goodley, D. (2019). "Working the edges of Posthuman disability studies: theorising with disabled young people with life-limiting impairments." *Sociol Health Illn* 41(8): 1473-1487.

This paper is built upon an assumption: that social theory can be generated through a meaningful engagement with a co-researcher group of disabled young people. Our co-researchers are theoretical provocateurs and theorists in their own right who, through their activism and writing, are challenging us to reconsider the meaning of life, death and disability. Their work on our funded Economic and Social Research Council (ESRC) project has enabled us to consider the promise and potential of humanist and posthuman epistemologies, theories, methodologies, interventions and activism. The paper introduces the research, the authors of this paper (academics and co-researchers) and then explores three layers of analysis that work the edges of posthuman thinking; sovereign and assembled selves; affects and desires; mourning and affirmation. We conclude by asserting that as a research team we are engaging with a DisHuman approach to theory and activism: one that blends the pragmatics of humanism with posthuman possibilities.

<https://pubmed.ncbi.nlm.nih.gov/31173378/>

Lindley, L. C., Keim-Malpass, J., Svyrenko, R., Cozad, M. J., Mack, J. W. and Hinds, P. S. (2020). "Pediatric Concurrent Hospice Care: A Scoping Review and Directions for Future Nursing Research." *J Hosp Palliat Nurs* 22(3): 238-245.

In 2010, forgoing curative therapies were removed as a hospice eligibility criterion for children through section 2302 of the Patient Protection and Affordable Care Act called Concurrent Care for Children. Given that concurrent care is a federally mandated option for children and their families, no review of the science has been conducted. The purpose of this study was to systematically collect the evidence on concurrent hospice care, critically appraise the evidence, and identify areas for future nursing research. Of the 186 articles identified for review, 14 met the inclusion and exclusion criteria. Studies in this review described concurrent hospice care from a variety of perspectives: policy, legal, and ethics. However, only 1 article evaluated the impact of concurrent hospice care on outcomes, whereas several studies explained clinical and state-level implementation. There is a need for further studies that move beyond conceptualization and generate baseline and outcomes data. Understanding the effectiveness of concurrent hospice care might provide important information for future nursing research. The approaches used to disseminate and implement concurrent hospice care at state, provider, and family levels should be explored.

<https://pubmed.ncbi.nlm.nih.gov/32282559/>

Linebarger, J. and Moreno, M. A. (2019). "Pediatric Palliative Care." JAMA Pediatr, 10.1001/jamapediatrics.2019.3327.

<https://pubmed.ncbi.nlm.nih.gov/31566678/>

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

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

Lowenstein, S., Macauley, R., Perko, K. and Ronai, C. (2020). "Provider perspective on the role of palliative care in hypoplastic left heart syndrome." Cardiol Young 30(3): 377-382.

**OBJECTIVE:** Hypoplastic left heart syndrome is a single ventricle defect. While staged surgical palliative treatments have revolutionised care, patients with hypoplastic left heart syndrome continue to have significant morbidity and mortality. In 2017, the National Pediatric Cardiology Quality Improvement Collaborative recommended all single ventricle patients to receive a prenatal palliative care consult. This study aimed to elucidate provider perspectives on the implementation of prenatal palliative care consults for families expecting a child with hypoplastic left heart syndrome. **METHODS:** An online survey was administered to obstetric and paediatric providers of relevant disciplines to assess their experience with palliative care involvement in hypoplastic left heart syndrome cases. **RESULTS:** Nearly, all physicians (97%) and most registered nurses (79%) agreed that the initial palliative care consult for patients with hypoplastic left heart syndrome should occur during the prenatal period. Respondents also indicated that prenatal palliative care consults should also be offered in a variety of other CHD conditions. Participants believed positive aspects of this new referral protocol included an expanded support network for families, decreased family stress during the postnatal period, increased patient education about what to expect during the postnatal period, and continuity of care. **CONCLUSION:** Multidisciplinary healthcare professionals believe that prenatal palliative care consults provide a variety of benefits for patients and families with hypoplastic left heart syndrome. Additional, multi-centre

research is necessary to evaluate whether prenatal palliative care consults should become standard of care for families expecting a child with a single ventricle defect. <https://pubmed.ncbi.nlm.nih.gov/32146916/>

**Macauley, R. (2019). "The Selfishness of Pediatric Palliative Care." J Palliat Med 22(11): 1473-1474.**  
<https://pubmed.ncbi.nlm.nih.gov/31661384/>

**Malcolm, C. and McGirr, D. (2020). "Educational needs and preferred learning approaches of the paediatric palliative care workforce: A qualitative exploratory study." Nurse Educ Today 89: 104417.**

Background: Delivering effective palliative care requires a workforce equipped to meet the complex and changing needs of children with life-shortening conditions (LSC). The current evidence base suggests gaps in educational provision for generalist and specialist staff delivering paediatric palliative care. Aim: This study aimed to explore the education requirements and preferred learning approaches of the paediatric palliative care workforce in Scotland. Design: Qualitative exploratory design using focus groups. Results: 61 participants representing health and social care, children's hospices, education services and the voluntary sector participated in a focus group. There was a clear commitment and enthusiasm for enhancing educational opportunities in the field. Perceived unmet learning needs included advance care planning, provision of end of life care and bereavement support, management of rare and complex symptoms, spirituality, faith and culturally sensitive care, ethics and ethical decision making, communication skills, managing parental expectations and self-care and support mechanisms. Participants value opportunities for experiential learning, inter-disciplinary learning and learning from the stories and unique perspectives of children and families. Conclusions: Education, learning and continuing professional development are core to promoting and maintaining a workforce competent in delivering quality palliative care. This paper identified comparable learning needs and preferred educational approaches amongst those delivering paediatric palliative care across a range of different services and settings. The evidence generated will inform the development of innovative and effective approaches to address educational needs. Additionally, action at a national level is required to ensure consistent, accessible and standardised approaches to education for all those who come into contact with children with palliative care needs.

<https://pubmed.ncbi.nlm.nih.gov/32320847/>

**McManus, K. and Robinson, P. S. (2020). "A thematic analysis of the effects of compassion rounds on clinicians and the families of NICU patients." J Health Care Chaplain, 10.1080/08854726.2020.1745489: 1-12.**

The correlation between spiritual wellness and clinical outcomes is widely established in the literature. This thematic analysis illuminates the experiences of clinicians, chaplains, and parents of Neo-natal Intensive Care Unit (NICU) patients who participated in Compassion Rounds, spiritual care interventions that focus solely on emotional and spiritual well-being, rather than physical diagnoses. Clinicians and families participated in semi-structured interviews and focus groups. The results showed that Compassion

Rounds had positive effects on spiritual wellness for NICU parents and their health care providers, while also allowing chaplains to model and provide spiritual care for physicians. Compassion Rounds enabled physicians to learn from chaplains and deliver effective spiritual wellness interventions within their limited available time. Compassion Rounds had a restorative effect on caregivers and have the potential to prevent or overcome burnout, return meaning to the work of clinicians, and create trust within multidisciplinary care teams.

<https://pubmed.ncbi.nlm.nih.gov/32228290/>

**Morell, E., Thompson, J., Rajagopal, S., Blume, E. D. and May, R. (2019). "Congenital Cardiothoracic Surgeons and Palliative Care: A National Survey Study." *J Palliat Care*, 10.1177/0825859719874765: 825859719874765.**

**BACKGROUND:** The majority of children with advanced heart disease in the inpatient setting die in an intensive care unit under 1 year of age following multiple interventions. While pediatric cardiology and palliative care provider attitudes have been described, little is known about pediatric cardiothoracic surgeon attitudes toward palliative care in children with advanced heart disease. **OBJECTIVE:** To describe perspectives of pediatric cardiothoracic surgeons regarding palliative care in pediatric heart disease. **DESIGN:** Cross-sectional web-based national survey. **RESULTS:** Of the 220 surgeons who were e-mailed the survey, 36 opened the survey and 5 did not meet inclusion criteria (n = 31). Median years of practice was 23.5 (range: 12-41 years), and 87.1% were male. Almost all (90%) reported that they had experience consulting palliative care. While 68% felt palliative care consultation was initiated at the appropriate time, 29% felt it occurred too late. When asked the appropriate timing for palliative care consultation in hypoplastic left heart syndrome, 45% selected "at time of prenatal diagnosis" and 30% selected "when surgical and transcatheter options have been exhausted." Common barriers to palliative care involvement included the perception of "giving up" (40%) and concern for undermining parental hope (36%). **CONCLUSIONS:** While a majority of pediatric cardiothoracic surgeons are familiar with palliative care, there is variation in perception of appropriate timing of consultation. Significant barriers to consultation still exist, including concern that parents will think they are "giving" up, undermining parental hope, and influence of palliative care on the medical care team's approach.

<https://pubmed.ncbi.nlm.nih.gov/31597507/>

**Mott, C., Herbert, A., Malcolm, K., Sansone, H. and Agar, M. (2020). "Emergencies in Pediatric Palliative Care: A Survey of Ambulance Officers to Understand the Interface between Families and Ambulance Services." *J Palliat Med*, 10.1089/jpm.2019.0299.**

**Background:** Pediatric palliative care occurs across contexts through the child's illness trajectory, including within the child or young person's community. Interactions with the ambulance service may occur with a child's deterioration, crisis, or when needing transfer, but there is little research on this interaction. **Aim:** To explore the experiences and attitudes of ambulance officers in managing pediatric patients with palliative care needs. **Design:** A targeted e-mail survey was sent exploring perceptions of the involvement with these patients including exposure, comfort, resuscitation topics, and supports available. **Setting/Participants:** Participants were Queensland ambulance

officers known to have had an interaction with one of the last 50 pediatric palliative care referrals across Queensland. Results: Twenty-two survey responses were received. Most of the palliative group accessed ambulances for the 13-month study period. Most ambulance officers did not easily identify patients as receiving palliative care. Many participants felt these cases were challenging, confidence levels varied, and staff counselling services were felt to be relevant. Ambulance officers were most likely to use correspondence provided by the family from their usual team as a guide for emergency management. Half of the participants felt patients receiving pediatric palliative care should have a "not for resuscitation" order. Respondents suggested officer support could be improved through increased patient documentation and promotion of existing officer supports. Conclusions: These findings demonstrate challenges experienced by ambulance officers and suggest practical ways in which pediatric palliative care services can better support emergency services.

<https://pubmed.ncbi.nlm.nih.gov/32176562/>

**Moya-Dionisio, V. (2020). "Knowledge of primary care pediatricians about pediatric palliative care in the Principality of Asturias, Spain." *Bol Med Hosp Infant Mex* 77(4): 195-201.**

BACKGROUND: To know and assess the experience and knowledge among primary care pediatricians about pediatric palliative care in the Principality of Asturias (Spain). METHODS: A descriptive and cross-sectional analysis was conducted using a survey among primary care pediatricians in the Principality of Asturias between May and June 2018. RESULTS: The majority of participants (77%) did not receive previous training, and 100% considered that their knowledge on the subject was insufficient, although 37% had occasionally attended to palliative care patients. Almost all participants (97%) considered that a pediatric palliative care unit is necessary. CONCLUSIONS: The knowledge of primary care pediatricians about pediatric palliative care is deficient in the Principality of Asturias, a region where no exclusive pediatric unit exists. It would be interesting to seize the opportunity to improve the training of these pediatricians, given their great willingness, and to incorporating the subject into colleges and medical intern formation as well.

<https://pubmed.ncbi.nlm.nih.gov/32713952/>

**Mroz, E., Bluck, S. and Smith, K. (2020). "Young adults' perspectives on advance care planning: Evaluating the Death over Dinner initiative." *Death Stud*, 10.1080/07481187.2020.1731015: 1-10.**

We investigated how death attitudes and experience relate to perspectives on advance care planning (ACP) in young adulthood, and whether attending a Death over Dinner event affects perspectives on ACP. Participants (N = 109) were assigned to a Death over Dinner or waitlist control condition, completing pretest and post-test measures. Higher Death Rejection and having more Experience with Death predicted Reservations about ACP. Participation in a Death over Dinner decreased Reservations toward ACP compared to the control group. Death over Dinner appears to be useful in ameliorating reservations toward ACP without shortening individuals' sense of their time left to live.

<https://pubmed.ncbi.nlm.nih.gov/32098575/>

Muskat, B., Greenblatt, A., Anthony, S., Beaune, L., Hubley, P., Newman, C., Brownstone, D. and Rapoport, A. (2020). "The experiences of physicians, nurses, and social workers providing end-of-life care in a pediatric acute-care hospital." Death Stud 44(2): 105-116.

This qualitative study explored the experiences of social workers, nurses, and physicians providing end-of-life care to children in a pediatric acute-care hospital setting. Findings demonstrated that participants experienced both professional and personal impacts of their work and employed various coping strategies under each of these domains. The acute-care setting was found to create unique challenges in providing end-of-life care. Implications for policy and practice include promotion of both individual and institutional-level coping strategies and supports that meet the various needs of staff. Implications for future research include a nuanced examination of differences in experiences among nurses, social workers, and physicians.

<https://pubmed.ncbi.nlm.nih.gov/30832553/>

Negrete, T. N. and Tariman, J. D. (2019). "Pediatric Palliative Care: A Literature Review of Best Practices in Oncology Nursing Education Programs." Clin J Oncol Nurs 23(6): 565-568.

Palliative care as a foundation for patient-centered care is not adequately covered in nursing curricula. This gap in education means that pediatric oncology nurses may lack necessary palliative care competencies to provide comprehensive care to patients. A literature review was performed to determine if nurses believe that they are prepared to provide clinical palliative care to pediatric patients and how pediatric palliative care best practices can be better integrated into nursing education programs. According to the literature review, studies suggest that providing pediatric palliative care education in nursing programs can build nurses' confidence and better prepare them to competently care for patients and families.

<https://pubmed.ncbi.nlm.nih.gov/31730610/>

Neilson, S., Gibson, F., Jeffares, S. and Greenfield, S. M. (2020). "GPs and paediatric oncology palliative care: a Q methodological study." BMJ Support Palliat Care 10(2): e11.

**OBJECTIVE:** This mixed-methods study set in the West Midlands region of the UK demonstrates the effectiveness of Q methodology in examining general practitioners' (GPs') perception of their role in children's oncology palliative care. **METHODS:** Using data obtained from the analysis of semistructured interviews with GPs who had cared for a child receiving palliative care at home and bereaved parents, 50 statements were identified as representative of the analysis findings. 32 GPs with a non-palliative child with cancer on their caseload were asked to rank the statements according to their level of agreement/disagreement on a grid. They were then asked to reflect and comment on the statements they most and least agreed with. The data were analysed using a dedicated statistical software package for Q analysis PQMethod V.2.20 (Schmolck 2012). A centroid factor analysis was undertaken initially with 7 factors then repeated for factors 1-6. Varimax and manual flagging was then completed. **RESULTS:** 4 shared viewpoints were identified denoting different GP roles: the GP, the compassionate practitioner, the team player practitioner and the pragmatic practitioner.

In addition consensus (time pressures, knowledge deficits, emotional toll) and disagreement (psychological support, role, experiential learning, prior relationships) between the viewpoints were identified and examined. CONCLUSIONS: Q methodology, used for the first time in this arena, identified 4 novel and distinct viewpoints reflecting a diverse range of GP perspectives. Appropriately timed and targeted GP education, training, support, in conjunction with collaborative multiprofessional working, have the potential to inform their role and practice across specialities.

<https://pubmed.ncbi.nlm.nih.gov/28432088/>

**Newton, K. and Sebbens, D. (2020). "The Impact of Provider Education on Pediatric Palliative Care Referral." J Pediatr Health Care 34(2): 99-108.**

INTRODUCTION: Palliative care can significantly benefit children managing a life-limiting illness; unfortunately, services are still generally reserved for end of life. The aim of this project was to demonstrate how established guidelines and provider education could impact referrals. METHODS: Educational sessions outlining national referral recommendations were offered to providers in the neonatal intensive care unit, pediatric intensive care unit, and Center for Cancer and Blood Disorders at a tertiary care facility. Presurveys and postsurveys were administered at the time of the intervention, and referral rates for the organization were collected for 2 months before and 2 months after the intervention. RESULTS: While there was a clinically significant increase in hospital-wide referral rates, most important was the statistically significant ( $p < .1$ ) increase in provider comfortability with established guidelines. DISCUSSION: Palliative care is essential for optimizing quality of life. Provider knowledge of referral criteria ensures that patients receive this service early in their disease trajectory and can benefit from its inclusion within their care team.

<https://pubmed.ncbi.nlm.nih.gov/31590995/>

**Nicholas, D., Beaune, L., Belletrutti, M., Blumberg, J., Ing, S., Rapoport, A. and Barrera, M. (2020). "Engaging Fathers in Pediatric Palliative Care Research." J Soc Work End Life Palliat Care 16(1): 42-56.**

Fathers are under-represented in pediatric palliative care research despite frequently playing a key role in the lives of their children. The purpose of this study was to identify factors that affected paternal study invitation and participation. A secondary mixed-methods evaluation design guided examination of interview and focus group data as well as field notes from a qualitative study that examined the experiences and support needs of fathers of children with a life-limiting illness. Facilitators of paternal participation in the study consisted of: fathers' desire to gain from study participation either for themselves or others, perception of the study's importance, sense of appreciation for the study's focus on fathers and an established relationship with recruiting health care providers. Barriers to study participation included: recruiting health care providers' appraisal of fathers' lack of well-being, bereaved fathers' self-reported poor coping and the inability to locate and contact fathers, particularly after a child's death. Strategies for improving the engagement of fathers into research entailed: educating recruitment personnel, designing "father-focused" studies, communicating the value of the research to recruitment personnel and potential participants, and ensuring that child health records are accurate and include fathers' contact information.

<https://pubmed.ncbi.nlm.nih.gov/31951504/>

Niehaus, J. Z., Palmer, M. M., Slaven, J., Hatton, A., Scanlon, C. and Hill, A. B. (2020). "Neonatal palliative care: perception differences between providers." J Perinatol, 10.1038/s41372-020-0714-1.

OBJECTIVE: The purpose of this study was to describe differences and identify education gaps in the perception of palliative care (PC) between neonatal care providers in a Level IV Neonatal intensive care unit. STUDY DESIGN: This is a descriptive survey mixed methods study. Email surveys were sent to social workers, pharmacists, dieticians, nurses, respiratory therapists, fellows and faculty in November of 2018. Total number of respondents was 181 with a response rate of 56%.

RESULTS: Statistically significant differences between faculty and non-faculty were found in regards to benefits of early PC consults, need for automatic consults for certain diagnosis and the frequency of PC consults. CONCLUSION: The perception of PC differs greatly between faculty and non-faculty. Educational initiatives surrounding PC and communication along with instituting automatic consults for certain diagnosis could help bridge this difference in perception and educational gap.

<https://pubmed.ncbi.nlm.nih.gov/32661367/>

Nilsson, S., Ohlen, J., Hessman, E. and Brännström, M. (2020). "Paediatric palliative care: a systematic review." BMJ Support Palliat Care 10(2): 157-163.

OBJECTIVES: To review literature relating to evidence, context and facilitation to describe knowledge translation in paediatric palliative care. Paediatric palliative care requires competences including both paediatric specialists as well as services that are developed for this purpose, and there is a need to facilitate paediatric palliative care knowledge translation. Promoting Action on Research Implementation in the Health Services (PARIHS) is a framework for knowledge translation, which highlights the relationships between evidence, context and facilitation. PARIHS framework has been revised and updated in a new version called i-PARIHS. METHODS: The electronic databases AgeLine, CINAHL, The Cochrane Library, PsycINFO, PubMed and Scopus were searched. Papers included were limited to English and Swedish publications and restricted to publications dated between 1993 and August 2019. All types of observational and experimental studies using any research design were included.

RESULTS AND CONCLUSIONS: Thirty-eight articles were included and there was a common vision about how and when palliative care should be offered to children. The i-PARIHS was used as a lens to describe the knowledge translation in paediatric palliative care. Symptom relief was the most commonly described evidence-based strategy, and the hospital environment was the most commonly described context. Different types of education were the most commonly used strategies to facilitate knowledge translation. The results mainly focused on increasing knowledge of palliative care in paediatric care. To sum up, the results report strategies to achieve knowledge translation of paediatric palliative care, and these can be interpreted as a guideline for how this process can be facilitated. TRIAL REGISTRATION NUMBER: CRD42018100663.

<https://pubmed.ncbi.nlm.nih.gov/31836595/>

Paulsen, K., Wu, D. S. and Mehta, A. K. (2020). "Primary Palliative Care Education for Trainees in U.S. Medical Residencies and Fellowships: A Scoping Review." J Palliat Med, 10.1089/jpm.2020.0293.

Background: The medical profession increasingly recognizes the growing need to educate nonpalliative physicians in palliative care. Objective: This study aims to provide a scoping review of the primary palliative care (PPC) education currently available to graduate medical trainees in primary and specialty tracks. Design: Studies of PPC interventions in U.S. residency or fellowship programs of all subspecialties published in English and listed on MEDLINE, CINAHL, and EMBASE through January 2020 were included. To meet admission criteria, studies had to describe the content, delivery methods, and evaluation instruments of a PPC educational intervention. Results: Of 233 eligible full texts, 85 studies were included for assessment, of which 66 were novel PPC educational interventions and 19 were standard education. Total number of publications evaluating PPC education increased from 8 (2000-2004) to 36 (2015-2019), across 11 residency and 10 fellowship specialties. Residency specialties representing the majority of publications were emergency medicine, general surgery, internal medicine, and pediatric/medicine-pediatrics. PPC content domains most taught in residencies were communication and symptom management; the primary delivery method was didactics, and the outcome assessed was attitudes. Fellowship specialties representing the majority of publications were pediatric subspecialties, nephrology, and oncology. The PPC content domain most taught in fellowships was communication; the primary delivery method was didactics and the outcome evaluated was attitudes. Conclusions: While PPC education has increased, it remains varied in content, delivery method, and intervention evaluations. Future studies should include more widespread evaluation of behavioral outcomes, longitudinal persistence of use, and clinical impact.

<https://pubmed.ncbi.nlm.nih.gov/32640863/>

Prentice, T. M., Gillam, L., Janvier, A. and Davis, P. G. (2020). "How should neonatal clinicians act in the presence of moral distress?" Arch Dis Child Fetal Neonatal Ed 105(4): 348-349.

<https://pubmed.ncbi.nlm.nih.gov/31969459/>

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://pubmed.ncbi.nlm.nih.gov/31706207/>

**Ratislavová, K., Bužgová, R. and Vejvodová, 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 pre-graduate education for midwives and neonatal nurses. Other research is vital for finding out the effectiveness of this education for pre-graduate 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://pubmed.ncbi.nlm.nih.gov/31442632/>

**Rosenberg, A. R., Junkins, C. C., Sherr, N., Scott, S., Klein, V., Barton, K. S. and Yi-Frazier, J. P. (2019). "Conducting Psychosocial Intervention Research among Adolescents and Young Adults with Cancer: Lessons from the PRISM Randomized Clinical Trial." *Children (Basel)* 6(11).**

**BACKGROUND:** Adolescents and young adults (AYAs) with cancer have poor psychosocial outcomes, in part because their limited participation in clinical trials precludes intervention-testing. We previously reported results of a successful randomized trial testing an AYA-targeted psychosocial intervention. Here, we aimed to describe strategies learned during the trial's conduct. **METHODS:** We summarized data from the medical record and staff field notes regarding reasons for participation/non-participation. We conducted two focus groups with study staff; directed content analyses identified strategies for success. **RESULTS:** 92 AYAs enrolled (77% of approached; n = 50 Usual Care (control), n = 49 PRISM (intervention)). In eligible families who declined participation (n = 22 AYAs, n = 8 parents), the AYAs more commonly had advanced cancer (n = 11 (37%) declined vs. n = 25 (26%) enrolled).

AYA reasons for non-enrollment were predominantly "not interested"; parents worried participation was "too burdensome." Staff strategies for accrual included having significant time to introduce the study and underscoring a desire to learn from the patient. After enrollment, AYAs who discontinued participation were more commonly assigned to control (n = 5 (10%) control vs. n = 2 (4%) intervention). Only n = 1 AYA chose to discontinue participation after receiving the intervention. CONCLUSIONS: Efforts to engage AYAs prior to and during studies may help with accrual and retention. <https://pubmed.ncbi.nlm.nih.gov/31652895/>

Sansom-Daly, U. M., Wakefield, C. E., Patterson, P., Cohn, R. J., Rosenberg, A. R., Wiener, L. and Fardell, J. E. (2020). "End-of-Life Communication Needs for Adolescents and Young Adults with Cancer: Recommendations for Research and Practice." J Adolesc Young Adult Oncol 9(2): 157-165.

A growing evidence base highlights the negative impact of poor psychosocial care at end-of-life. Adolescents and young adults (AYAs) 15-39 years of age with cancer face unique medical and psychosocial challenges that make them especially vulnerable when treatment is not successful. Although the importance of age-appropriate medical and psychosocial care is internationally recognized for AYAs across the cancer trajectory, there is little guidance on best-practice care and communication practices with AYAs as they approach the end-of-life. We conducted a narrative review and found evidence points to the potential benefits of introducing palliative care teams early in the care trajectory. Research undertaken to date emphasizes the importance of exploring AYAs' preferences around end-of-life issues in a repeated, consistent manner, and highlighted that AYAs may have strong preferences on a range of issues such as being able to stay in their own home, being comfortable and free from pain, and expressing their wishes to loved ones. We highlight a number of best-practice recommendations to guide clinicians around the critical elements of when, who, what, and how end-of-life conversations may be best facilitated with AYAs. Gaps in the evidence base remain, including research focusing on better understanding barriers and facilitators to timely, age-appropriate end-of-life communication for AYAs with different diagnoses, where discordance between AYA-parent preferences exists, and when AYAs die at home versus in hospital. We have proposed a new model to support clinicians and researchers to better conceptualize how interacting individual, familial, and sociocultural factors impact end-of-life communication with AYAs in clinical settings.

<https://pubmed.ncbi.nlm.nih.gov/31660768/>

Şener Taplak, A., Gürol, A. and Polat, S. (2020). "Nurses' Perceptions of the Palliative Care Needs of Neonates With Multiple Congenital Anomalies." J Hosp Palliat Nurs 22(2): 137-144.

This study was conducted to determine neonatal intensive care unit (NICU) nurses' opinions about the palliative care needs of neonates with multiple congenital anomalies. The study sample consisted of the 20 nurses who agreed to participate in the study and worked in the NICU between November and December 2017. A one-to-one interview method was utilized using a semi-structured interview form. Written consent was obtained from participants and reconfirmed verbally prior to data collection. In the study, most of the nurses stated that the therapeutic medical treatment should not be

started for dying neonates with multiple congenital anomalies. It was also found that nurses did not have enough palliative care knowledge for neonates. The palliative care needs of the neonates with multiple congenital anomalies in NICUs were found to be pain management, infection care, enhancing quality of life by avoiding unnecessary medical practices, skin care, the care of the baby in the ventilator, timely application of the treatment of neonates, and supporting family.

**Shanks, S. D. (2019). "Sharing Bad News." Arch Dis Child Educ Pract Ed, 10.1136/archdischild-2019-317847. <https://pubmed.ncbi.nlm.nih.gov/31990852/>**

**Silberberg, A., Herich, L. C., Croci, I., Cuttini, M., Villar, M. J. and Requena Meana, P. (2020). "Limitation of life-sustaining treatment in NICU: Physicians' beliefs and attitudes in the Buenos Aires region." Early Hum Dev 142: 104955.**

**OBJECTIVE:** To explore the ethical beliefs and attitudes of Argentinean neonatologists regarding limitation of life-sustaining treatment (LST) for very sick infants. **METHODS:** We used an anonymous questionnaire including direct questions and hypothetical clinical cases (inevitable demise and anticipated survival with severe long-term disability). Multivariable analysis was carried out to assess the relation between type of clinical case and physicians' LST attitudes. **RESULTS:** Overall, 315 neonatologists in 34 units in the Buenos Aires region participated (response rate 54%). Most responders would agree with decisions to start or continue LST. In both clinical cases, continuing current treatment with no therapeutic escalation was the only form of LST limitation acceptable to a substantial proportion (about 60%) of neonatologists. Agreement with LST limitation was slightly but significantly more likely when death was inevitable. **CONCLUSION:** Argentinean neonatologists showed a conservative attitude regarding LST limitation. Patient prognosis and options of non-treatment decision significantly influenced their choices.

<https://pubmed.ncbi.nlm.nih.gov/32006786/>

**Silva, E. M. B., Silva, M. J. M. and Silva, D. M. (2019). "Perception of health professionals about neonatal palliative care." Rev Bras Enferm 72(6): 1707-1714.**

**OBJECTIVE:** To identify the perception of health professionals about neonatal palliative care. **METHOD:** A phenomenological qualitative study, a non-probabilistic sample, of 15 health professionals from a neonatal intensive care unit in northern Portugal. Content analysis was performed. **RESULTS:** Despite their lack of training in palliative care, the health professionals showed concern for the dignity, quality of life and comfort of the newborn and family. They expressed emotional and relational difficulties in following the trajectories of serious illness and death and in the ethical decisions regarding the end-of-life. **CONCLUSION:** It is emphasized that professionals are sensitive to pain and suffering and reveal dedicated and committed in the care of the newborn and family. They are available to train and embrace the current challenges posed by the constitution of pediatric palliative care teams and to help achieve an organizational culture that advances in such care.

<https://pubmed.ncbi.nlm.nih.gov/31644764/>

Sinigaglia, V., Pomicino, L., Candotti, C., Ait Oumghar, H., Bertuol, M. and Buchini, S. (2020). "[Experiences and coping strategies of nurses in the face of death in pediatric hematology: qualitative study]." Prof Inferm 73(1): 42-52.

**INTRODUCTION:** The death of a pediatric patient causes personal, social and work-related repercussions on nursing staff who have witnessed it. The objective of this qualitative study is to investigate the experiences and the coping strategies of nurses working in pediatric oncoematology before the deaths of assisted children/adolescents. **METHOD:** It has been placed in the Pediatric Oncoematology Clinic - Padua Hospital. Nurses without considering sex, age, training or years of activity at the clinic were interviewed using a socio-demographic data collection board and a semi-structured interview. **RESULTS:** 36 (72%) nurses (between 24 and 57 years) were interviewed. The death of a patient causes emotions and feelings: impotence, anger, identification with parents, sadness and disorientation for the inability to find explanation for the death of the child. Among the coping strategies used prevail the will to vent. **CONCLUSION:** Death in pediatric oncology is an event whose repercussions on nursing staff should not be underestimated as they are a source of emotional stress due to lack of adequate support and adequate training.

<https://pubmed.ncbi.nlm.nih.gov/32594679/>

Sisk, B. A. and Baker, J. N. (2019). "The Underappreciated Influence of Elisabeth Kübler-Ross on the Development of Palliative Care for Children." Am J Bioeth 19(12): 70-72.

<https://pubmed.ncbi.nlm.nih.gov/31746709/>

Sisk, B. A., Feudtner, C., Bluebond-Langner, M., Sourkes, B., Hinds, P. S. and Wolfe, J. (2020). "Response to Suffering of the Seriously Ill Child: A History of Palliative Care for Children." Pediatrics 145(1).

Most pediatric clinicians aspire to promote the physical, emotional, and developmental well-being of children, hoping to bestow a long and healthy life. Yet, some infants, children, and adolescents confront life-threatening illnesses and life-shortening conditions. Over the past 70 years, the clinician's response to the suffering of these children has evolved from veritable neglect to the development of pediatric palliative care as a subspecialty devoted to their care. In this article, we review the history of how clinicians have understood and responded to the suffering of children with serious illnesses, highlighting how an initially narrow focus on anxiety eventually transformed into a holistic, multidimensional awareness of suffering. Through this transition, and influenced by the adult hospice movement, pediatric palliative care emerged as a new discipline. Becoming a discipline, however, has not been a panacea. We conclude by highlighting challenges remaining for the next generation of pediatric palliative care professionals to address.

<https://pubmed.ncbi.nlm.nih.gov/31806669/>

Smith, P., Vasileiou, K. and Jordan, A. (2020). "Healthcare professionals' perceptions and experiences of using a cold cot following the loss of a baby: a qualitative study in maternity and neonatal units in the UK." BMC Pregnancy Childbirth 20(1): 175.

**BACKGROUND:** Best practice in perinatal bereavement care suggests offering parents the opportunity to spend time with their baby. Cold cots facilitate this purpose by reducing the deterioration of the body and evidence indicates their wide availability in maternity and neonatal units in the UK. This study aimed to examine healthcare professionals' perceptions and experiences of using a cold cot following the loss of a baby. **METHODS:** A qualitative cross-sectional study was designed. In-depth, semi-structured interviews were conducted with 33 maternity and neonatal unit healthcare professionals who worked across three UK hospital settings. Data were analysed using inductive reflexive thematic analysis. **RESULTS:** Findings revealed that staff had predominantly positive views about, and experiences of, using a cold cot. The technology was highly valued because it facilitated parents to spend time with their baby and participants reported that it was generally easy to use and smoothly embedded into the clinical environment. Cold cots were deemed useful when mothers were medically unwell and needed time to recover, when parents struggled to say goodbye to their baby, wished to take the baby home, or wanted their baby to stay in the unit instead of going straight to the mortuary. The use of technology was further perceived to be relevant in scenarios of unexpected loss, post-mortem examination and with babies of late gestations or neonates. Despite staff expressing comfort with the delay of visual and olfactory body changes, the coldness of the baby's body that was accelerated with the use of a cold cot was a major concern as it connoted and possibly exacerbated the reality of death. **CONCLUSIONS:** Cold cots allow the materialisation of modern bereavement care practices that recognise the importance of continuing bonds with the deceased that is made possible through the creation of memories within an extremely restricted timeframe. Simultaneously, the body coldness concentrates the ambivalence toward an inherently paradoxical death, that of a baby. Training in perinatal bereavement care, including the use of cold cots, would help staff support bereaved parents whilst acknowledging dilemmas and managing contradictions encompassed in death at the time or near the time of birth.

<https://pubmed.ncbi.nlm.nih.gov/32188415/>

**Sreedhar, S. S., Kraft, C. and Friebert, S. (2020). "Primary palliative care: Skills for all clinicians." *Curr Probl Pediatr Adolesc Health Care* 50(6): 100814.**

The number of children with life-threatening and life-limiting conditions is increasing, requiring an individualized approach and additional supportive care. The American Academy of Pediatrics has called for pediatric palliative care to be available to all children who would benefit.(1),(2) High quality pediatric palliative care is essential for these children. Collaborative team-based methods focused on improving quality of life have shown to improve outcomes in physical, emotional, and cognitive domains.(3) Palliative care involvement at the time of diagnosis rather than just at the end of life has moved coordinated care upstream. All clinicians can and should deliver palliative care. The Joint Commission recommends having patient-centered palliative care services available for children, and the Centers for Medicare and Medicaid Services is reimbursing clinicians for this coordinated care. This article details how all pediatric clinicians can positively influence the care of seriously ill children by incorporating palliative care principles into their daily care, resulting in better outcomes for their patients and families.

<https://pubmed.ncbi.nlm.nih.gov/32616444/>

Steen, S. E. (2019). "Raising the bar: development of a perinatal bereavement programme." Int J Palliat Nurs 25(12): 578-586.

The care a family receives at the time of perinatal loss can have a significant and lasting impact, hence it is important for healthcare providers to offer quality care that will meet the family's needs. Our hospital embarked on a journey to develop a perinatal bereavement programme that would give compassionate and excellent care to all families who experienced perinatal loss at any time during their pregnancy.

Components of our bereavement programme include leadership, administrative and financial support, communication, well-educated and supported staff, and a process for individualised care. A perinatal bereavement programme can help institutions, large or small, to provide quality care for bereaved families and help them through this difficult experience. The purpose of this article is to discuss hospital-wide bereavement care, both on a large scale, detailing the specifics of programme development, and on a smaller scale, individualised care for families.

<https://pubmed.ncbi.nlm.nih.gov/31855519/>

Swanson, T. M., Patel, A., Baxter, A. J., Morris, S. A., Maskatia, S. A. and Lantos, J. D. (2020). "Pediatric Cardiology Specialist's Opinions Toward the Acceptability of Comfort Care for Congenital Heart Disease." Pediatr Cardiol 41(6): 1160-1165.

In order to evaluate physicians' willingness to seek legal action to mandate surgery when parents refuse surgery for various congenital heart lesions, we surveyed pediatric cardiologists and cardiovascular surgeons at 4 children's hospitals. We asked whether physicians would support parental refusal of surgery for specific heart defects and, if not, whether they would seek legal action to mandate surgery. We then analyzed associations between physicians' willingness to mandate surgery and national operative mortality rates for each lesion. We surveyed 126 cardiologists and 9 cardiac surgeons at four tertiary referral centers. Overall response rate was 77%. Greater than 70% of physicians would seek legal action and mandate surgery for the following lesions: ventricular septal defect, coarctation of the aorta, complete atrioventricular canal, transposition of the great arteries, tetralogy of Fallot, and unobstructed total anomalous pulmonary venous return. Surgery for all of these lesions has reported mortality rates of < 5%. Physicians were less likely to seek legal action when parents refused surgery for Shone complex, any single ventricle lesion, or any congenital heart disease accompanied by Trisomy 13 or Trisomy 18. Among experts in pediatric cardiology, there is widespread agreement about the appropriate response to parental refusal of surgery for most congenital heart lesions, and these lesions tended to be heart defects with lower surgical mortality rates. Lesions for which there was greater consensus among experts were those with the best outcomes. There was less consensus for lesions with higher mortality rates. Such surveys, revealing disagreement among expert professionals, can provide an operational definition of the current professional "gray zone" in which parental preferences should determine treatment.

<https://pubmed.ncbi.nlm.nih.gov/32419096/>

Taylor, M. R., Barton, K. S., Kingsley, J. M., Heunis, J. and Rosenberg, A. R. (2020). "Defining a "Good Death" in Pediatric Oncology: A Mixed Methods Study of Healthcare Providers." Children (Basel) 7(8).

Delivering optimal end-of-life (EOL) care to children and adolescents is a healthcare priority, yet relatively little is known about what patients, families, and healthcare providers (HCPs) consider "best" practices. The objective of this study was to identify factors that pediatric oncology HCPs consider important for EOL care. This was a cross-sectional mixed methods study. Participants were multidisciplinary pediatric oncology staff who completed surveys and participated in semi-structured qualitative interviews. Interviews were analyzed using a modified grounded theory approach. Provider statements were compared based on years of experience ( $\leq 10$  or  $> 10$  years) and discipline (non-physician or physician). A total of  $n = 19$  staff (74% female) enrolled, including physicians ( $n = 8$ ), advanced practice providers ( $n = 4$ ), nurses ( $n = 2$ ), music/art therapists ( $n = 2$ ), physical therapists ( $n = 1$ ), educators ( $n = 1$ ), and chaplains ( $n = 1$ ). Most HCPs identified communication, symptom control, and acceptance as features of a "good" death. Compared to physicians, non-physicians focused on relationships (67% vs. 33%,  $p = 0.007$ ); HCPs with  $\leq 10$  years of experience ( $n = 11$ ) more frequently identified the benefits of a multidisciplinary team (74% vs. 26%,  $p = 0.004$ ). This study identified many common HCP-defined components of "good" pediatric EOL care in addition to some differing perspectives depending on discipline and experience. Incorporating diverse HCP perspectives with those of the patient and family can guide contemporary high-quality pediatric EOL clinical care and education. <https://pubmed.ncbi.nlm.nih.gov/32751891/>

Teoli, D. and Kalish, V. B. (2020). Palliative Care. StatPearls. Treasure Island (FL), StatPearls Publishing  
Copyright © 2020, StatPearls Publishing LLC.

The World Health Organization characterizes the field of palliative care as a form of specialized medical care which aims to optimize the quality of life and alleviate the suffering of patients. One of the primary ways to achieve this is through early identification and treatment of new symptoms along with the management of those that prove refractory. Palliative care addresses the physical, psychosocial, and spiritual aspects of patients with a life-threatening disease by employing an interprofessional team approach. A palliative team is comprised of a wide array of professionals, including the palliative physician, nurse, social worker, chaplain, and pharmacist. Of note, palliation consists of comprehensive care provided to patients with life-limiting illnesses and should not be considered an alternative to failed life-prolonging care. The physicians who specialize in palliative care have often completed a fellowship in hospice and palliative medicine (HPM). As an official subspecialty recognized by the American Board of Medical Specialties (ABMS), completion of a fellowship is needed to sit for the ABMS or American Osteopathic Association (AOA) board certification examinations. Currently, the following specialties are pathways to completing an HPM fellowship: internal medicine, family medicine, emergency medicine, psychiatry, neurology, surgery, pediatrics, radiology, OBGYN, anesthesiology, and physical medicine and rehabilitation. Therefore, palliative care physicians most often have underlying formal training in at least one of these specialties. Of note, almost always pediatric palliative care physicians have completed a residency in pediatrics before subspecializing.

<https://pubmed.ncbi.nlm.nih.gov/30725798/>

Trowbridge, A., Bamat, T., Griffis, H., McConathey, E., Feudtner, C. and Walter, J. K. (2020). "Pediatric Resident Experience Caring for Children at the End of Life in a Children's Hospital." *Acad Pediatr* 20(1): 81-88.

**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://pubmed.ncbi.nlm.nih.gov/31376579/>

Udo, C., Kreicbergs, U., Axelsson, B., Björk, O. and Lövgren, 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://pubmed.ncbi.nlm.nih.gov/31206784/>

Vente, T. M. (2020). "The Impact of Gun Violence on Those Already Dying: Perspectives From a Palliative Care Physician." *Pediatrics* 145(2).  
<https://pubmed.ncbi.nlm.nih.gov/31896549/>

Walter, J. K., Hill, D. L., DiDomenico, C., Parikh, S. and Feudtner, C. (2019). "A conceptual model of barriers and facilitators to primary clinical teams requesting pediatric palliative care consultation based upon a narrative review." *BMC Palliat Care* 18(1): 116.

BACKGROUND: Despite evidence that referral to pediatric palliative care reduces suffering and improves quality of life for patients and families, many clinicians delay referral until the end of life. The purpose of this article is to provide a conceptual model for why clinical teams delay discussing palliative care with parents. DISCUSSION: Building on a prior model of parent regoaling and relevant research literature, we argue for a conceptual model of the challenges and facilitators a clinical team might face in shifting from a restorative-focused treatment plan to a plan that includes palliative aspects, resulting in a subspecialty palliative care referral. Like patients and families, clinicians and clinical teams may recognize that a seriously ill patient would benefit from palliative care and shift from a restorative mindset to a palliative approach. We call this transition "clinician regoaling". Clinicians may experience inhibitors and facilitators to this transition at both the individual and team level which influence the clinicians' willingness to consult subspecialty palliative care. The 8 inhibitors to team level regoaling include: 1) team challenges due to hierarchy, 2) avoidance of criticizing colleagues, 3) structural communication challenges, 4) group norms in favor of restorative goals, 5) diffusion of responsibility, 6) inhibited expression of sorrow, 7) lack of social support, 8) reinforcement of labeling and conflict. The 6 facilitators of team regoaling include: 1) processes to build a shared mental model, 2) mutual trust to encourage dissent, 3) anticipating conflict and team problem solving, 4) processes for reevaluation of goals, 5) sharing serious news as a team, 6) team flexibility. CONCLUSIONS: Recognizing potential team level inhibitors to transitioning to palliative care can help clinicians develop strategies for making the transition more effectively when appropriate.

<https://pubmed.ncbi.nlm.nih.gov/31896549/>

Wan, A., Weingarten, K. and Rapoport, A. (2020). "Palliative Care?! But This Child's Not Dying: The Burgeoning Partnership Between Pediatric Cardiology and Palliative Care." *Can J Cardiol* 36(7): 1041-1049.

The field of pediatric cardiology has witnessed major changes over the past few decades that have considerably altered patient outcomes, including decreasing mortality rates for many previously untreatable conditions. Despite this, some pediatric cardiology programs are increasingly choosing to partner with their institutional palliative care teams. Why is this? The field of palliative care also has experienced significant shifts over a similar period of time. Today's palliative care is focused on improving quality of life for any patient with a serious or life-threatening condition, regardless of where they might be on their disease trajectory. Research has clearly demonstrated that improved outcomes can be achieved for a variety of patient cohorts through early integration of palliative care; recent evidence suggests that the same may be true in pediatric cardiology. All pediatric cardiologists need to be aware of what pediatric

palliative care has to offer their patients, especially those who are not actively dying. This manuscript reviews the evolution of palliative care and provides a rationale for its integration into the care of children with advanced heart disease. Readers will gain a sense of how and when to introduce palliative care to their families, as well as insight into what pediatric palliative care teams have to offer. Additional research is required to better delineate optimal partnerships between palliative care and pediatric cardiology so that we may promote maximal quality of life for patients concurrently with continued efforts to push the boundaries of quantity of life.

<https://pubmed.ncbi.nlm.nih.gov/32437731/>

Weaver, M. S., Jenkins, R., Wichman, C., Robinson, J. E., Potthoff, M. R., Menicucci, T. and Vail, C. A. (2019). "Sowing Across a State: Development and Delivery of a Grassroots Pediatric Palliative Care Nursing Curriculum." *J Palliat Care*, 10.1177/0825859719889700: 825859719889700.

**BACKGROUND:** Rural pediatricians and adult-trained hospice teams report feeling ill-prepared to care for children at end of life, resulting in geographies in which children are not able to access home-based services. **OBJECTIVES:** To develop a pediatric palliative care curriculum for inpatient nurses and adult-trained hospice teams caring for children in a rural region. **METHODS:** Curriculum design and delivery was informed by local culture through an interdisciplinary, iterative development approach with confidence, intention, and support measured pre-, post-, and 4 months after delivery. A needs assessment was completed by pediatric nurses caring for children receiving palliative or end-of-life care to inform curricular content (phase 1). A curriculum was designed by an interdisciplinary pediatric palliative care team and piloted with nursing cohorts annually through educational conferences with monthly discussion series for 3 consecutive years (phase 2). Curricular content was then provided for 31 rural hospice team members (phase 3). **RESULTS:** Self-reported confidence in caring for children increased by 1.1/10 points for adult-trained hospice team members. Mean score for intention to care for children increased by 5.2 points (sustained 5.1 points above baseline at 4 months). Perception of support in caring for children increased by 5 points (mean sustained 5.4 points above baseline at 4 months). Family needs, care goals, and symptom management were prioritized learning topics. Rural hospices previously unwilling to accept children enrolled pediatric patients in the 4 months following the conference. **CONCLUSION:** Grassroots curricular initiatives and ongoing educational mentorship can grow pediatric palliative and hospice services in rural regions.

<https://pubmed.ncbi.nlm.nih.gov/31771423/>

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://pubmed.ncbi.nlm.nih.gov/30835596/>

**Wheless, J. W., Fulton, S. P. and Mudigoudar, B. D. (2020). "Dravet Syndrome: A Review of Current Management." *Pediatr Neurol* 107: 28-40.**

Dravet syndrome is a debilitating epileptic encephalopathy of childhood with few treatment options available in the United States before 2018. In the modern era, new genetic testing options will allow diagnosis closer to disease onset. Three new medicines-stiripentol, cannabidiol, and fenfluramine-have documented efficacy and safety as adjunctive therapies for treating pharmacoresistant Dravet syndrome. Early diagnosis resulting in earlier treatment with these and other medications may improve prognosis of long-term outcomes, including less severity of cognitive, motor, and behavioral impairments. New rescue medication formulations can now manage acute seizures and help prevent status epilepticus via intranasal, buccal, and intramuscular routes as opposed to rectal administration. Preventing status epilepticus and generalized tonic-clonic seizures could potentially lower the risk of sudden unexpected death in epilepsy. With this changing landscape in diagnostic and treatment options comes questions and controversies for the practicing clinician, especially as diagnostic techniques outpace clinical treatment strategies. Critical decision points include when to start treatment, what pharmacotherapy combinations to try first, which rescue medication to recommend, and how to advise parents on controversial topics (e.g., immunizations). Given that most patients require polypharmacy, clinicians must be cognizant of drug-drug interactions between new medicines, existing anti-epileptic drugs, and other medications to manage comorbidities and must have an understanding of available therapeutic drug monitoring strategies and pharmacokinetic parameters. This review places new diagnostic, treatment and acute care options into the modern era and provides an overview of the challenges and opportunities facing the pediatric epileptologist in this rapidly changing landscape.

<https://pubmed.ncbi.nlm.nih.gov/32165031/>

Whitla, L., Devins, M., Molloy, E. J., Twomey, M., O'Reilly, M. and Balfe, J. (2020). "Children's Palliative Care; the identified Learning Needs of Paediatricians." *Ir Med J* 113(6): 95.

**Aim** To determine baseline learning needs of Paediatricians in Ireland when caring for children with palliative care needs. **Methods** A questionnaire based online survey was conducted. **Results** One hundred and fourteen paediatricians responded to the survey, the majority were Specialist Registrars but almost half were consultant paediatricians (46% n=52). Most had never had formal education in the paediatric palliative care (57% n=48). Areas of future training that were ranked as important or highly important (percentage of respondents) included: pain management (98% n=81), management of the dying child (96% n=80), palliative care resources (95% n=79), advanced care planning (95% n=79) and communication skills (86% n=71). Those surveyed were asked to comment on the challenges of recent clinical interactions, on analysis three overarching themes emerged; best interests of the child, inadequate training and confidence and co-ordinating care. **Conclusion** This survey highlights the learning needs of paediatricians and will inform the development of meaningful education sessions for doctors.

<https://pubmed.ncbi.nlm.nih.gov/32816430/>

Wolfe, J. and Bluebond-Langner, M. (2020). "Paediatric palliative care research has come of age." *Palliat Med* 34(3): 259-261.

Yu, J., Song, I. G., Kim, C. H., Moon, Y. J., Shin, H. Y. and Kim, M. S. (2020). "Perceptions of Pediatric Palliative Care among Physicians Who Care for Pediatric Patients in South Korea." *J Palliat Med* 23(3): 346-352.

**Background:** Despite advances in medical technology, resources for pediatric palliative care (PPC) for children with serious illnesses are limited in South Korea. Physicians' awareness of and willingness to provide general palliative care and refer to specialized palliative care are key elements for providing PPC. **Objective:** The aim of this study was to explore physicians' perceptions of PPC and the differences therein between nononcologists and oncologists. **Design:** A nationwide survey was conducted among physicians caring for children in 45 tertiary hospitals in South Korea. **Measurements:** A questionnaire was developed to identify the confidence in and need for PPC, appropriate timing for PPC referrals, and perceived barriers to PPC. **Results:** Overall, 141 physicians responded (response rate: 10.4%). Physicians' confidence in PPC was low, although most reported a high need for PPC. Lack of workforce and facilities specialized in PPC (60.2%) and patients' or caregivers' negative recognition (55.9%) were reported as the main barriers to PPC implementation. Specialized PPC services in children's hospitals were preferred as the model of care (84.2%). Compared with nononcologists, oncologists showed higher confidence levels in decision making and communication with patients and families with poor prognosis ( $p = 0.041$ ) and education and providing end-of-life care ( $p < 0.001$ ). Furthermore, oncologists preferred earlier referrals than did nononcologists. **Conclusions:** To promote PPC provision and improve the quality of life of pediatric patients and their families, it is important to introduce PPC early into disease-modifying treatment at any level of health care.

Developing education and training curricula regarding PPC for health care providers caring for children with severe illnesses is crucial.

<https://pubmed.ncbi.nlm.nih.gov/32164500/>

Zsák, É. and Hegedűs, K. (2020). "[Possibilities and challenges of perinatal hospice-palliative care]." *Orv Hetil* 161(12): 452-457.

Perinatal hospice care is a special form of paediatric palliative care, with a focus on prenatally diagnosed malformation, providing physical, psychological and mental support with a holistic approach for the families. Our aim was to analyse how perinatal hospice-palliative care can be implemented and what opportunities it may provide on the basis of available professional guidelines. We introduce study and analysis of the professional guidelines and protocols, mainly from Anglo-Saxon countries, and describe some examples of best practices. Perinatal hospice is a specially demanding care regarding professional and personal challenges. Standardised guidelines based on consensus can serve as starting points, describing proper care and its conditions. Moreover, they can facilitate communication and coordinative processes between the collaborating specialists. Challenging conditions and possible solutions to them can be identified during supportive formative courses. Continuous formation means competency development in palliative care as well as in adequate communication. *Orv Hetil*. 2020; 161(12): 452-457.

<https://pubmed.ncbi.nlm.nih.gov/32172586/>

## Epidemiology & Pathology

Abdel-Mannan, O., Hughes, E. and Dunkley, C. (2020). "Epilepsy deaths in children: Improvements driven by data and surveillance in pediatrics." *Epilepsy Behav* 103(Pt B): 106493.

Epilepsy-related death in children and young people deserves understanding and intervention along with epilepsy-related deaths in adults. Risk of death from epilepsy varies at different ages, and the specific calculations of risk remains complex and varies between studies. There have been several UK studies examining factors associated with epilepsy-related deaths. A UK national audit with other national initiatives has evidenced improving quality of care and more recently allowed service provision factors associated with reduced epilepsy-related death to be evidenced. A national program of health education, formalized epilepsy networks, commissioned surgical pathways, and patient information resources around risk and participation are examples of quality improvement initiatives. Epilepsy-related death is a key outcome, and there remains many difficulties and opportunities at local, regional, and national level to better understand and improve this outcome for children and young people and the adults that they should become. This paper is for the Special Issue: Prevent 21: SUDEP Summit - Time to Listen.

<https://pubmed.ncbi.nlm.nih.gov/31526647/>

Abdel-Mannan, O. and Sutcliffe, A. G. (2020). "A national surveillance study of childhood epilepsy mortality in the UK and Ireland." *Eur J Neurol* 27(2): 327-333.

**BACKGROUND AND PURPOSE:** Patients with epilepsy are significantly more likely to die prematurely than the general population, with causes ranging from associated comorbidities to sudden unexpected death in epilepsy (SUDEP). The aim was to estimate the UK and Ireland incidence of childhood epilepsy deaths and to describe case demographics and clinical characteristics. **METHODS:** This was a prospective, population-based surveillance study using established active surveillance methodology designed by the British Paediatric Surveillance Unit. **RESULTS:** Eighty-eight confirmed cases were reported with an overall annual incidence of 0.65 per 100 000 children aged <16 years (95% confidence interval 0.52-0.81). More cases were male (65%) and cases fell across all age groups, with more deaths reported in older children. Twenty-five per cent of deaths were epilepsy-related (including SUDEP); 75% of deaths were non-epilepsy-related. SUDEP was the most common cause of seizure-related deaths, accounting for 13 out of 17 children (76%). An underlying epilepsy syndrome was present in 36% of deaths, and 88% had global developmental delay. In addition, 90% of the children had comorbid conditions in addition to epilepsy. **CONCLUSIONS:** In this study, it has been demonstrated that death in children diagnosed with epilepsy occurs mainly in 'complicated epilepsy' secondary to factors associated with neurodisability, consolidating previous data. SUDEP is also a significant cause of paediatric epilepsy mortality that needs further attention. There is a clear need to better understand and reduce the number of epilepsy deaths in children in the UK, and national surveillance of SUDEP is warranted to better understand this entity in paediatric populations.

<https://pubmed.ncbi.nlm.nih.gov/31502743/>

**Almli, L. M., Ely, D. M., Ailes, E. C., Abouk, R., Grosse, S. D., Isenburg, J. L., Waldron, D. B. and Reefhuis, J. (2020). "Infant Mortality Attributable to Birth Defects - United States, 2003-2017." *MMWR Morb Mortal Wkly Rep* 69(2): 25-29.**

Birth defects are a leading cause of infant mortality in the United States, accounting for 20.6% of infant deaths in 2017 (1). Rates of infant mortality attributable to birth defects (IMBD) have generally declined since the 1970s (1-3). U.S. linked birth/infant death data from 2003-2017 were used to assess trends in IMBD. Overall, rates declined 10% during 2003-2017, but decreases varied by maternal and infant characteristics. During 2003-2017, IMBD rates decreased 4% for infants of Hispanic mothers, 11% for infants of non-Hispanic black (black) mothers, and 12% for infants of non-Hispanic white (white) mothers. In 2017, these rates were highest among infants of black mothers (13.3 per 10,000 live births) and were lowest among infants of white mothers (9.9). During 2003-2017, IMBD rates for infants who were born extremely preterm (20-27 completed gestational weeks), full term (39-40 weeks), and late term/postterm (41-44 weeks) declined 20%-29%; rates for moderate (32-33 weeks) and late preterm (34-36 weeks) infants increased 17%. Continued tracking of IMBD rates can help identify areas where efforts to reduce IMBD are needed, such as among infants born to black and Hispanic mothers and those born moderate and late preterm (32-36 weeks).

<https://pubmed.ncbi.nlm.nih.gov/31945037/>

**Anderson, M., Revie, C. W., Stryhn, H., Neudorf, C., Rosehart, Y., Li, W., Osman, M., Buckeridge, D. L., Rosella, L. C. and Wodchis, W. P. (2019). "Defining 'actionable' high- cost health care use: results using the Canadian Institute for**

Health Information population grouping methodology." *Int J Equity Health* 18(1): 171.

**BACKGROUND:** A small proportion of the population consumes the majority of health care resources. High-cost health care users are a heterogeneous group. We aim to segment a provincial population into relevant homogenous sub-groups to provide actionable information on risk factors associated with high-cost health care use within sub-populations. **METHODS:** The Canadian Institute for Health Information (CIHI) Population Grouping methodology was used to define mutually exclusive and clinically relevant health profile sub-groups. High-cost users ( $\geq$  90th percentile of health care spending) were defined within each sub-group. Univariate analyses explored demographic, socio-economic status, health status and health care utilization variables associated with high-cost use. Multivariable logistic regression models were constructed for the costliest health profile groups. **RESULTS:** From 2015 to 2017, 1,175,147 individuals were identified for study. High-cost users consumed 41% of total health care resources. Average annual health care spending for individuals not high-cost were \$642; high-cost users were \$16,316. The costliest health profile groups were 'long-term care', 'palliative', 'major acute', 'major chronic', 'major cancer', 'major newborn', 'major mental health' and 'moderate chronic'. Both 'major acute' and 'major cancer' health profile groups were largely explained by measures of health care utilization and multi-morbidity. In the remaining costliest health profile groups modelled, 'major chronic', 'moderate chronic', 'major newborn' and 'other mental health', a measure of socio-economic status, low neighbourhood income, was statistically significantly associated with high-cost use. **INTERPRETATION:** Model results point to specific, actionable information within clinically meaningful subgroups to reduce high-cost health care use. Health equity, specifically low socio-economic status, was statistically significantly associated with high-cost use in the majority of health profile sub-groups. Population segmentation methods, and more specifically, the CIHI Population Grouping Methodology, provide specificity to high-cost health care use; informing interventions aimed at reducing health care costs and improving population health. <https://pubmed.ncbi.nlm.nih.gov/31707981/>

Annunziato, L., Secondo, A., Pignataro, G., Scorziello, A. and Molinaro, P. (2020). "New perspectives for selective NCX activators in neurodegenerative diseases." *Cell Calcium* 87: 102170.

The Na<sup>(+)</sup>/Ca<sup>(2+)</sup> exchanger plays a relevant role in several neurological disorders, thus the pharmacological modulation of its isoforms might represent a promising strategy to ameliorate the course of some neurological pathologies including stroke, neonatal hypoxia, multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Alzheimer Disease (AD), and spinal muscular atrophy (SMA). This review will summarize heterocyclic, peptidergic, genetic and epigenetic compounds activating or inhibiting the expression/activity of each NCX isoform. In addition, we will focus our attention on the development of new strategies aimed to ameliorate the pathophysiological conditions in which NCX isoform changes are found.

<https://pubmed.ncbi.nlm.nih.gov/32106022/>

Arias López, M. D. P., Fernández, A. L., Figuepron, K., Meregalli, C., Ratto, M. E. and Siaba Serrate, A. (2020). "Prevalence of Children With Complex Chronic

**Conditions in PICUs of Argentina: A Prospective Multicenter Study." Pediatr Crit Care Med 21(3): e143-e151.**

**OBJECTIVES:** To determine the prevalence of children with complex chronic conditions in PICUs in Argentina. To describe the demographic profile, clinical course and outcomes in PICU of children with complex chronic condition in comparison to previously healthy children. **DESIGN:** Prospective, observational multicenter study. **SETTING:** Nineteen PICUs located in Argentina belonging to public and private institutions. **PATIENTS:** All children admitted to the participating PICUs between March 1, 2015, and February 28, 2016. **INTERVENTIONS:** None. **MEASUREMENT AND MAIN RESULTS:** We analyzed 3,483 PICU admissions. The prevalence of complex chronic condition was 48.06% (95% CI, 46.39-49.72). Cardiovascular complex chronic condition was predominant (22.24% [421/1,893]), followed by neuromuscular complex chronic condition (18.75% [355/1,893]) and malignant disease 17.7% (335/1,893). Technologic dependence was present in 22.22% of the patients (372 of 1,674). Predominant admission diagnosis was postoperative (36.6%) and respiratory disease (28.32%). Children with complex chronic condition had higher mortality than previously healthy patients (odds ratio, 2.74; 95% CI, 2.01-3.73). The risk of prolonged stay ( $\geq 26$  d) was also higher (odds ratio, 1.44; 95% CI, 1.10-1.89). Rate utilization of the following devices was higher in patients with complex chronic condition: mechanical ventilation (odds ratio, 1.35; 95% CI, 1.12-1.63), central venous catheter (odds ratio, 1.24; 95% CI, 1.04-1.48), and arterial monitoring (odds ratio, 1.33; 95% CI, 1.09-1.63). **CONCLUSIONS:** We observed a high prevalence of patients with complex chronic condition in this sample of argentine PICUs. These patients presented higher mortality and resource use than previously healthy children. This information is valuable to understand the impact that patients with complex chronic condition have on PICU performance and enables proper planning of care.

<https://pubmed.ncbi.nlm.nih.gov/31851126/>

**Arias-Casais, N., Garralda, E., Pons, J. J., Marston, J., Chambers, L., Downing, J., Ling, J., Rhee, J. Y., de Lima, L. and Centeno, C. (2020). "Mapping Pediatric Palliative Care Development in the WHO-European Region: Children Living in Low-to-Middle-Income Countries Are Less Likely to Access It." J Pain Symptom Manage, 10.1016/j.jpainsymman.2020.04.028.**

**CONTEXT:** Approximately 170,000 children in need of palliative care die every year in Europe without access to it. This field remains an evolving specialty with unexplored development. **OBJECTIVES:** To conduct the first regional assessment of pediatric palliative care (PPC) development and provision using data from the European Association for Palliative Care atlas of palliative care 2019. **METHODS:** Two surveys were conducted. The first one included a single question regarding PPC service provision and was addressed by European Association for Palliative Care atlas informants. The second one included 10 specific indicators derived from an open-ended interview and rating process; a specific network of informants was enabled and used as respondents. Data were analyzed and presented in the map of the figure. **RESULTS:** Data on PPC service provision were gathered from 51 of 54 (94%) European countries. Additional data were collected in 34 of 54 (62%) countries. A total of 680 PPC services were identified including 133 hospices, 385 home care services, and 162 hospital services. Nineteen countries had specific standards and norms for the

provision of PPC. Twenty-two countries had a national association, and 14 countries offered education for either pediatric doctors or nurses. In seven countries, specific neonatal palliative care referral services were identified. CONCLUSION: PPC provision is flourishing across the region; however, development is less accentuated in low-to-middle-income countries. Efforts need to be devoted to the conceptualization and definition of the models of care used to respond to the unmet need of PPC in Europe. The question whether specialized services are required or not should be further explored. Strategies to regulate and cover patients in need should be adapted to each national health system.

<https://pubmed.ncbi.nlm.nih.gov/32437945/>

**Audigé, M., Gillam, L. and Stark, Z. (2020). "Treatment limitation and advance planning: Hospital-wide audit of paediatric death." *J Paediatr Child Health* 56(6): 893-899.**

AIM: To examine paediatric deaths following withdrawal or withholding of medical treatment (WWMT) from a hospital-wide perspective and identify changes over a 10 year period. METHODS: A retrospective review of medical records was conducted for all paediatric inpatient deaths at the Royal Children's Hospital, Melbourne from April 2015 to April 2016, and results were compared to 2007 data from our centre.  $\chi^2$  tests were used for comparisons. RESULTS: A total of 101 deaths occurred in the inpatient setting in 2015-2016. Most deaths followed WWMT (88/101, 87%) and occurred in children with pre-existing chronic conditions (85/101, 85%). There was a shift to earlier discussions with parents regarding WWMT compared to 10 years prior. Cases where discussions began prior to the last admission increased from 4 to 19% ( $P = 0.004$ ). There was increased paediatric palliative care (PPC) involvement (10 vs. 37%,  $P < 0.001$ ), and a slightly greater proportion of children died outside of intensive care (16 vs. 22%,  $P = 0.25$ ). In 2015-2016, subgroup analysis showed that children who died as inpatients but outside of intensive care were 76% more likely to have PPC involved than those who died in intensive care ( $P < 0.001$ ). Their families were 51% more likely to have discussed WWMT with medical staff before the last admission ( $P < 0.001$ ). CONCLUSIONS: The last decade has seen an increase in PPC involvement and advance discussions around WWMT at our centre. Both of these are associated with death outside of intensive care.

<https://pubmed.ncbi.nlm.nih.gov/31898378/>

**Becker, C., Graf, N., Grabow, D., Creutzig, U., Reinhardt, D., Weyer-Elberich, V., Spix, C. and Kaatsch, P. (2020). "Early deaths from childhood cancer in Germany 1980-2016." *Cancer Epidemiol* 65: 101669.**

BACKGROUND: Even though the survival of childhood cancer has improved over the last decades, there are still children dying shortly after diagnosis. The aim of the study is to add to understanding of the reasons for deaths shortly after date of diagnosis. METHODS: Using data of the population-based German Childhood Cancer Registry (cancer below 15 years of age diagnosed between 1980 and 2016), we compared characteristics of 671 children with cancer who died within 30 days of diagnosis to 53,649 patients with childhood cancer who survived longer. In addition to a descriptive analysis, we used logistic regression with multivariable fractional polynomials to describe the relationship between early death with age at diagnosis and year of

diagnosis. RESULTS: The number of early death cases and the risk of early death have decreased considerably since 1980 (2.6% of study population in 1980-89 to 0.6% in 2010-16). Children under one year of age were at highest early death risk (odds ratio = 4.10, 95% confidence interval: 3.32-5.05 compared to 7-year-old patients). These results are similar to results from other studies. Moreover, children with acute myeloid leukemia and hepatic tumors had a higher early death risk, children with acute lymphoid leukemia a lower risk compared to patients with central nervous system tumors used as a reference group. CONCLUSION: Even though the risk for early death has declined overall with advances in diagnosis and therapy, special attention needs to be paid to infants and children with AML and hepatic tumors, who are especially at risk. <https://pubmed.ncbi.nlm.nih.gov/31955037/>

**Bordini, B. J., Kliegman, R. M., Basel, D. and Nocton, J. J. (2020). "Undiagnosed and Rare Diseases in Perinatal Medicine: Lessons in Context and Cognitive Diagnostic Error." *Clin Perinatol* 47(1): 1-14.**

Critically ill neonates experience high rates of morbidity and mortality. Major diagnostic errors are identified in up to 20% of autopsied neonatal intensive care unit deaths. Neonates with undiagnosed or rare congenital disorders may mimic critically ill neonates with more common acquired conditions. The context of the diagnostic evaluation can introduce unique biases that increase the likelihood of diagnostic error. Herein is presented a framework for understanding diagnostic errors in perinatal medicine, and individual, team, and systems-based solutions for improving diagnosis learned through the implementation and administration of an undiagnosed and rare disease program.

<https://pubmed.ncbi.nlm.nih.gov/32000918/>

**Chabrol, B. (2020). "[Disabled child, care and ethical aspects]." *Rev Prat* 70(2): 222-226.**

Disabled child, care and ethical aspects. The child's doctor occupies a privileged place in the life of a child with a disability. At all times, he must be an adviser, favouring a global approach and support to ensure optimal autonomy. Discovery of a neurodevelopmental disorder justifies a systematic search for the various causes known to date. Identification and knowledge of a precise diagnosis is an essential element in constructing the life plan for a disabled child. The announcement of the diagnosis is an integral part of the care system, it only makes sense when combined with tailor-made and step by step support. This requires that the doctor has a good knowledge of the main childcare structures, guidance agencies, and available financial aid. Multidisciplinary consultations enable a global approach to support a child with a disability. More children with disabilities become adults as medical care progresses. Transition from "children" to "adult" consultations represents a major challenge. However, some cases could be life-threatening. The decision on whether to continue the various therapies have to be considered and discussed with the child and his family, with reference to the notion of "unreasonable obstinacy". Drafting an individual certificate of "remarkable patient" will best help the implementation of end-of-life support measures.

<https://pubmed.ncbi.nlm.nih.gov/32877146/>

Chapman, J. and Arnold, J. K. (2020). Reye Syndrome. StatPearls. Treasure Island (FL), StatPearls Publishing  
Copyright © 2020, StatPearls Publishing LLC.

Reye syndrome is a rare and potentially fatal pediatric illness defined as acute noninflammatory encephalopathy with fatty liver failure. Australian pathologist R.D.K. Reye first described this syndrome in 1963. National surveillance of Reye syndrome began in the United States in the early 1970s and led to strict warnings regarding aspirin use in children. Reye syndrome typically presents in children as vomiting and confusion with rapid progression to coma and death. This syndrome often begins in the days following recovery from a viral illness during which aspirin was administered. Inborn errors of metabolism (especially fatty acid metabolism), medication reactions and toxins may also predispose or cause the development of Reye syndrome. This diagnosis is based on clinical signs as well as laboratory testing. However, there is no test specific to Reye syndrome.

<https://pubmed.ncbi.nlm.nih.gov/30252357/>

Collins, K. L. and Pollack, I. F. (2020). "Pediatric Low-Grade Gliomas." Cancers (Basel) 12(5).

Brain tumors constitute the largest source of oncologic mortality in children and low-grade gliomas are among most common pediatric central nervous system tumors. Pediatric low-grade gliomas differ from their counterparts in the adult population in their histopathology, genetics, and standard of care. Over the past decade, an increasingly detailed understanding of the molecular and genetic characteristics of pediatric brain tumors led to tailored therapy directed by integrated phenotypic and genotypic parameters and the availability of an increasing array of molecular-directed therapies. Advances in neuroimaging, conformal radiation therapy, and conventional chemotherapy further improved treatment outcomes. This article reviews the current classification of pediatric low-grade gliomas, their histopathologic and radiographic features, state-of-the-art surgical and adjuvant therapies, and emerging therapies currently under study in clinical trials.

<https://pubmed.ncbi.nlm.nih.gov/32375301/>

Dangel, T., Kmieć, T., Januszaniec, A. and Ważny, B. (2020). "Palliative care in 9 children with neurodegeneration with brain iron accumulation." Neurol Sci 41(3): 653-660.

AIM: Evaluation of pediatric palliative home care of families with children suffering from neurodegeneration with brain iron accumulation (NBIA) and their parents. MATERIAL AND METHODS: The children were treated at home by a multidisciplinary team. Densitometry was used to evaluate the condition of the skeletal system. Botulinum toxin was injected into the muscles in doses between 22 and 50 units/kg. The quality of palliative care was assessed on the basis of a specially designed questionnaire for parents. RESULTS: The observations were performed on a group of 9 patients with NBIA. On admission, the median age of patients was 9 years (7-14). The average time of palliative home care was 1569 days (34 days-17 years). The median age at death (6 patients) was 11 years (7-15). The botulinum toxin injections gave the following results: reduction of spasticity and dystonia, reduction of spine and chest deformation, relief of

pain and suffering, facilitation of rehabilitation and nursing, prevention of permanent contractures, and reduction of excessive salivation. Bone mineral density and bone strength index were reduced. Two patients experienced pathological fracture of the femur. The body mass index at admission varied between 9.8 and 14.9. In 7 cases, introduction of a ketogenic diet resulted in the increase of body mass and height. The ketogenic diet did not worsen the neurological symptoms. The parents positively evaluated the quality of care. CONCLUSION: Palliative home care is the optimal form of treatment for children with NBIA.

<https://pubmed.ncbi.nlm.nih.gov/31758347/>

**Dongarwar, D., Aggarwal, A., Barning, K. and Salihu, H. M. (2020). "Stillbirths among Advanced Maternal Age Women in the United States: 2003-2017." *Int J MCH AIDS* 9(1): 153-156.**

The aim of the study was to evaluate the association between fetal stillbirth and advanced maternal age in the United States (US). This was a population-based study using the Natality and Fetal Death datasets for the years 2003-2017. We built Cox proportional regression models to examine the likelihood of stillbirth among women aged  $\geq 40$  years. Out of a total of 57,273,305 births, stillbirth was observed in 302,522, yielding a stillbirth rate of 5 per 1000. After adjusting for confounders, women of advanced age ( $\geq 40$  years) had a 40-50% greater risk of stillbirth compared to women 20-29 years of age.

<https://pubmed.ncbi.nlm.nih.gov/32123639/>

**Donnelly, R., Umberson, D., Hummer, R. A. and Garcia, M. A. (2020). "Race, death of a child, and mortality risk among aging parents in the United States." *Soc Sci Med* 249: 112853.**

The death of a child is a stressful and traumatic life event that has been linked to increased mortality risk among parents. Tragically, black parents are significantly more likely than white parents to lose a child in the United States; however, prior research has not addressed this racial disadvantage in relation to parents' mortality risk. In this study, we focus on the racial context of the United States to suggest that black parents already face higher mortality rates compared to white parents, and the unequal burden of child death adds to their mortality risk. Using discrete-time event history models, we consider whether the death of a child by midlife is associated with increased mortality risk for black parents and for white parents in mid- to later-life using longitudinal data from the Health and Retirement Study (HRS; 1996-2016). Descriptive results show that by midlife, black parents, especially black mothers, experience substantially higher child mortality compared with white parents. At the same time, we find that losing a child prior to midlife is associated with heightened mortality risk for aging black mothers and white mothers. Controlling for educational attainment explains the association between child death and parental mortality risk among white mothers, whereas heightened biopsychosocial and behavioral risk factors explain the association for black mothers. Overall, the death of a child is associated with increased mortality risk for black mothers and for white mothers, but the processes linking child death to parental mortality seem to differ for black and white parents. These findings have implications for policies and interventions that address increased mortality risk for parents following the death of a child.

<https://pubmed.ncbi.nlm.nih.gov/32088513/>

Foster, K. D., Chuzi, S., Beaumont, J. L., Kircher, S., Smith, M., Sanford, S. and Mohindra, N. (2019). "Palliative Care Usage in Young Adult Oncology Population." *J Palliat Med* 22(11): 1425-1429.

Context: Early integration of palliative care (PC) into adult oncology practice has been shown to improve quality of life and health care utilization; however, little is known about PC in young adults with cancer. Objectives: Our primary objective was to determine rates and timing of PC consultation in young adult patients with advanced solid tumor cancer at a single institution. Methods: We conducted a retrospective analysis of young adults of age 18-39 years with advanced solid tumor malignancy at an urban academic medical center between June 1, 2014 and June 30, 2015. Results: Of 129 patients identified, 70 of 129 (54%) had a PC consult and 34 of 70 were inpatient-only consults. PC consults occurred for a median of 104 days before death, and for those with inpatient-only consults, PC consults occurred for a median of 18 days. Patients with worse recent Eastern Cooperative Oncology Group (ECOG) performance status were more likely to have had a PC consult ( $p < 0.001$ ). Of the patients who died during the study period, patients with PC consults were more likely to have been hospitalized (72% vs. 47%), in the intensive care unit (21% vs. 0%), in the emergency room (ER) (72% vs. 47%), and have received chemotherapy (17% vs. 0%) within 30 days of death compared with those who did not have a consult; however, these differences were not statistically significant. Conclusion: In this analysis, over half of young adults with advanced solid tumors received PC consults. PC consult typically occurred for one year after diagnosis and about three months before death. Additional research is needed to identify how to better integrate PC early in this patient population and assess the resulting impact.

<https://pubmed.ncbi.nlm.nih.gov/30907695/>

Fry, J. T., Matoba, N., Datta, A., DiGeronimo, R., Coghil, C. H., Natarajan, G., Brozanski, B., Leuthner, S. R., Niehaus, J. Z., Schlegel, A. B., Shah, A., Zaniletti, I., Bartman, T., Murthy, K. and Sullivan, K. M. (2020). "Center, Gestational Age, and Race Impact End-of-Life Care Practices at Regional Neonatal Intensive Care Units." *J Pediatr* 217: 86-91.e81.

OBJECTIVE: To assess the impact of intercenter variation and patient factors on end-of-life care practices for infants who die in regional neonatal intensive care units (NICUs). STUDY DESIGN: We conducted a retrospective cohort analysis using the Children's Hospital Neonatal Database during 2010-2016. A total of 6299 nonsurviving infants cared for in 32 participating regional NICUs were included to examine intercenter variation and the effects of gestational age, race, and cause of death on 3 end-of-life care practices: do not attempt resuscitation orders (DNR), cardiopulmonary resuscitation within 6 hours of death (CPR), and withdrawal of life-sustaining therapies (WLST). Factors associated with these practices were used to develop a multivariable equation. RESULTS: Dying infants in the cohort underwent DNR (55%), CPR (21%), and WLST (73%). Gestational age, cause of death, and race were significantly and differently associated with each practice: younger gestational age (<28 weeks) was associated with CPR (OR 1.7, 95% CI 1.5-2.1) but not with DNR or WLST, and central nervous system injury was associated with DNR (1.6, 1.3-1.9) and WLST (4.8, 3.7-6.2).

Black race was associated with decreased odds of WLST (0.7, 0.6-0.8). Between centers, practices varied widely at different gestational ages, race, and causes of death. CONCLUSIONS: From the available data on end-of-life care practices for regional NICU patients, variability appears to be either individualized or without consistency.

<https://pubmed.ncbi.nlm.nih.gov/31831163/>

Gubbels, C. S., VanNoy, G. E., Madden, J. A., Copenheaver, D., Yang, S., Wojcik, M. H., Gold, N. B., Genetti, C. A., Stoler, J., Parad, R. B., Roumiantsev, S., Bodamer, O., Beggs, A. H., Juusola, J., Agrawal, P. B. and Yu, T. W. (2020). "Prospective, phenotype-driven selection of critically ill neonates for rapid exome sequencing is associated with high diagnostic yield." *Genet Med* 22(4): 736-744.

PURPOSE: To investigate the impact of rapid-turnaround exome sequencing in critically ill neonates using phenotype-based subject selection criteria. METHODS: Intensive care unit babies aged <6 months with hypotonia, seizures, a complex metabolic phenotype, and/or multiple congenital malformations were prospectively enrolled for rapid (<7 day) trio-based exome sequencing. Genomic variants relevant to the presenting phenotype were returned to the medical team. RESULTS: A genetic diagnosis was attained in 29 of 50 (58%) sequenced cases. Twenty-seven (54%) patients received a molecular diagnosis involving known disease genes; two additional cases (4%) were solved with pathogenic variants found in novel disease genes. In 24 of the solved cases, diagnosis had impact on patient management and/or family members. Management changes included shift to palliative care, medication changes, involvement of additional specialties, and the consideration of new experimental therapies. CONCLUSION: Phenotype-based patient selection is effective at identifying critically ill neonates with a high likelihood of receiving a molecular diagnosis via rapid-turnaround exome sequencing, leading to faster and more accurate diagnoses, reducing unnecessary testing and procedures, and informing medical care.

<https://pubmed.ncbi.nlm.nih.gov/31780822/>

Gupta, A., Sasidharan, J. and Bhargava, A. (2020). "Case Series on Four Treated Cases of Embryonal Rhabdomyosarcoma in Children." *Indian J Otolaryngol Head Neck Surg* 72(2): 214-220.

We report four cases of embryonal rhabdomyosarcoma treated successfully with multimodality therapy which included surgery, chemotherapy and radiotherapy. Our first case was a 2 year old who admitted with the chief complaint of swelling of the upper lip. Biopsy was taken, which showed embryonal rhabdomyosarcoma. It was followed by a CT scan (face + neck), MRI face, USG abdomen and bone scan of the patient. Pre operatively chemotherapy was given. After completion of chemotherapy regimen, wide local excision of the lesion along with a reverse fan flap and bilateral modified radical neck dissection type 3 was done. This was followed by post operative chemotherapy and radiotherapy. There was no recurrence at 6 months post operatively. The second patient was 6 years old with similar complaints, after undertaking all the investigations as in the previous case, patient was given neoadjuvant chemotherapy following which wide local excision of the lesion along with reconstruction with the help of bilateral nasolabial flap was done. This was followed by post operative chemotherapy. No recurrence was present 6 months post operatively. The third patient was a 17 year old

male presenting with complaints of left sided nasal obstruction and left nasal swelling. Examination revealed left sided nasal mass which on biopsy turned out to be embryonal rhabdomyosarcoma. The patient underwent surgery followed by chemoradiation. At 6 months the patient had no evidence of recurrence. The fourth patient was 16-year-old male who presented with complaints of right sided nasal swelling and nasal obstruction. Radiological investigation showed the tumor involving the right sinonasal cavity with extension to anterior cranial fossa and with neck nodes. Patient was given concurrent chemoradiation. Patient was followed up for 6 months when the patient presented with recurrence of disease with distant metastasis. Patient is currently on palliative chemotherapy. To summarise, embryonal rhabdomyosarcoma in young children when treated aggressively with surgery and chemotherapy has better prognosis than with chemo-radiation alone.

<https://pubmed.ncbi.nlm.nih.gov/32551280/>

Gyngell, C., Stark, Z. and Savulescu, J. (2020). "Drugs, genes and screens: The ethics of preventing and treating spinal muscular atrophy." *Bioethics* 34(5): 493-501.

Spinal muscular atrophy (SMA) is the most common genetic disease that causes infant mortality. Its treatment and prevention represent the paradigmatic example of the ethical dilemmas of 21st-century medicine. New therapies (nusinersen and AVXS-101) hold the promise of being able to treat, but not cure, the condition. Alternatively, genomic analysis could identify carriers, and carriers could be offered in vitro fertilization and preimplantation genetic diagnosis. In the future, gene editing could prevent the condition at the embryonic stage. How should these different options be evaluated and compared within a health system? In this paper, we discuss the ethical considerations that bear on the question of how to prioritize the different treatments and preventive options for SMA, at a policy level. We argue that despite the tremendous value of what we call 'ex-post' approaches to treating SMA (such as using pharmacological agents or gene therapy), there is a moral imperative to pursue 'ex-ante' interventions (such as carrier screening in combination with prenatal testing and preimplantation genetic diagnosis, or gene editing) to reduce the incidence of SMA. There are moral reasons relating to autonomy, beneficence and justice to prioritize ex-ante methods over ex-post methods.

<https://pubmed.ncbi.nlm.nih.gov/31770817/>

Hampel, K. G., Rocamora Zuñiga, R. and Quesada, C. M. (2019). "Unravelling the mysteries of sudden unexpected death in epilepsy." *Neurologia* 34(8): 527-535.

**INTRODUCTION:** Sudden unexpected death in epilepsy (SUDEP) is the most frequent cause of premature death in epileptic patients. Most SUDEP events occur at night and frequently go unnoticed; the exact pathophysiological mechanisms of this phenomenon therefore remain undetermined. Nevertheless, most cases of SUDEP are attributed to an infrequent yet extremely severe complication of epileptic seizures. **DEVELOPMENT:** We conducted a systematic literature search on PubMed. Our review article summarises scientific evidence on the classification, pathophysiological mechanisms, risk factors, biomarkers, and prevention of SUDEP. Likewise, we propose new lines of research and critically analyse findings that are relevant to clinical practice. **CONCLUSIONS:** Current knowledge suggests that SUDEP is a heterogeneous

phenomenon caused by multiple factors. In most cases, however, SUDEP is thought to be due to postictal cardiorespiratory failure triggered by generalised tonic-clonic seizures and ultimately leading to cardiac arrest. The underlying pathophysiological mechanism involves multiple factors, ranging from genetic predisposition to environmental factors. Risk of SUDEP is higher in young adults with uncontrolled generalised tonic-clonic seizures. However, patients apparently at lower risk may also experience SUDEP. Current research focuses on identifying genetic and neuroimaging biomarkers that may help determine which patients are at high risk for SUDEP. Antiepileptic treatment is the only preventive measure proven effective to date. Night-time monitoring together with early resuscitation may reduce the risk of SUDEP.  
<https://pubmed.ncbi.nlm.nih.gov/28431832/>

**Helps, A., Leitao, S., Greene, R. and O'Donoghue, K. (2020). "Perinatal mortality audits and reviews: Past, present and the way forward." *Eur J Obstet Gynecol Reprod Biol* 250: 24-30.**

Perinatal deaths are devastating for families and staff involved. Failure to examine perinatal deaths for substandard care prevents learning and may lead to recurrence of events, as well as prolonged morbidity in bereaved families and hospital staff. Perinatal mortality reviews can identify factors contributing to suboptimal care. An integrative literature review was carried out to study the different types of perinatal mortality reviews currently being done internationally, establishing a comparison and examining promising new developments. We start by outlining issues with the classification of perinatal deaths and the different types of perinatal mortality reviews carried out in high-income countries. We reflect on the challenges that are encountered in the current processes and we then comment on how these may be overcome. Current literature shows that differences in classifications of perinatal deaths continue to impede important international comparisons. National perinatal mortality audits can provide reliable high-quality data to facilitate national and international benchmarking. Confidential enquiries give expert assessment on anonymised information to initiate system-wide improvements, but to provide local information on perinatal deaths unit-based multi-disciplinary team reviews are required. Additionally, there is a need to shift from a blame-culture to a focus on achieving best practice by learning from mistakes. Review tools and processes have been implemented in some countries to standardize perinatal mortality reviews, but there is still more work to be done. Involving the bereaved parents in the perinatal mortality review process is important and ways to achieve this are progressing. A structured approach to the perinatal mortality review process should be developed to facilitate sharing of experiences and challenges at national (or international) level. To achieve a reduction in the number of stillbirths and neonatal deaths, it is crucial to ensure that the perinatal mortality audit and review cycle is completed with implementation and re-evaluation of recommended changes in maternity services.

<https://pubmed.ncbi.nlm.nih.gov/32371247/>

**Hoell, J. I., Weber, H., Warfsmann, J., Trocan, L., Gagnon, G., Danneberg, M., Balzer, S., Keller, T., Janßen, G. and Kuhlen, M. (2019). "Facing the large variety of life-limiting conditions in children." *Eur J Pediatr* 178(12): 1893-1902.**

Life-limiting conditions in children in specialized pediatric palliative care (PPC) are manifold. The "Together for Short Lives" (TfSL) association established four disease categories, which represent the most common illness trajectories. Better understanding the palliative care needs and symptoms of children within these TfSL groups will result in improved anticipation of clinical problems and tailored care. During this retrospective single-center cohort study, 198 children, adolescents, and young adults (CAYAs) were in PPC. Mean age at referral was 8.7 years (range 0.0-25.0), mean duration of care 355 days (range 1-2754). One hundred six (53.5%) CAYAs died during the study period. Sixty-five (32.8%) CAYAs were assigned to TfSL-1, 13 (6.6%) to TfSL-2, 49 (24.7%) to TfSL-3, and 71 (35.9%) to TfSL-4. Home visits were conducted on average every 9.6 days in TfSL-1, 18.9 days in TfSL-2, 31.7 days in TfSL-3, and 31.8 days in TfSL-4 ( $p$  value < 0.01). Conclusions: Intensity of palliative care significantly differed between the TfSL groups. Neurological and gastrointestinal symptoms were most prominent across all TfSL groups. Symptom cluster analysis showed distinct clusters in TfSL-1 (cluster 1, fatigue/lack of appetite/nausea/somnolence; cluster 2, dyspnea/fear/myoclonus/seizures/spasticity) and TfSL-3/4 (cluster 1, spasticity; cluster 2, all other symptoms).

What is Known:

- The four TfSL (together for short lives) groups represent the four most common illness trajectories of pediatric palliative care patients.
- Better understanding the palliative care needs and symptoms of children within these four TfSL groups will result in improved anticipation of clinical problems and tailored care.

What is New:

- In our study, TfSL-1 represented the largest individual group of patients, also requiring the most intensive care (defined by the number of visits per days of care).
- Symptom cluster analysis revealed distinct symptom clusters in TfSL-1 and TfSL-3/4, which can be used to anticipate clinically common challenges in these patients.

<https://pubmed.ncbi.nlm.nih.gov/31624947/>

Hoffmann, C., Schultz, L. F., Vaichulonis, C. G., do Nascimento, I. B., João, C. G., Borges, D. C. and Silva, J. C. (2020). "Perinatal mortality: epidemiological profile, causes and avoidable factors at a reference public maternity hospital in the State of Santa Catarina, Brazil, 2011-2015." *J Perinat Med* 48(2): 162-167.

**Background** This study aimed to identify the perinatal mortality coefficient, the epidemiological profile, causes and avoidable factors at a reference public maternity hospital in southern Brazil. **Methods** In this cross-sectional study, 334 medical records of postpartum women and newborns were evaluated between January 1st, 2011 and December 31st, 2015. The Expanded Wigglesworth Classification was used to assess the causes of perinatal mortality and the International Statistical Classification of Diseases and Related Health Problems (ICD-10/SEADE Foundation) was used for the preventable perinatal mortality analysis. Absolute numbers and percentages were used for data analysis. The perinatal mortality formula was used to calculate the perinatal mortality rate. **Results** The perinatal mortality rate was 13.2/1000 total births, with a predominance of white race/color; mothers were 21-30 years of age, had experienced their first pregnancy and had completed their high school education. **Conclusion** The main factors associated with perinatal death were antepartum fetal death in 182

(54.49%) cases, and avoidable death through appropriate prenatal care in 234 (70.05%) cases.

<https://pubmed.ncbi.nlm.nih.gov/31874101/>

Hulsey, E. G., Hill, R. M., Layne, C. M., Gaffney, D. A. and Kaplow, J. B. (2020). "Calculating the incidence rate of sibling bereavement among children and adolescents across the United States: A proposed method." *Death Stud* 44(5): 303-311.

This study proposes a method for calculating the annual incidence rate of sibling bereavement among US youth using national epidemiological data. The proposed model combines data on family household size with national death statistics to calculate the number of siblings affected by the death of a child annually. From 2012 to 2015, an average of 61,389 children per year experienced the death of a sibling, resulting in an estimate of 0.0832% of children bereaved by the death of a sibling annually. Data indicate a need for greater awareness and dialog concerning the frequency with which children experience the death of a sibling.

<https://pubmed.ncbi.nlm.nih.gov/30513272/>

Jędrzejowska, M. and Kostera-Pruszczyk, A. (2020). "Spinal muscular atrophy - new therapies, new challenges." *Neurol Neurochir Pol* 54(1): 8-13.

Spinal muscular atrophy (SMA) is a progressive neurodegenerative disease with an autosomal recessive trait of inheritance and great variability of its clinical course - from the lethal congenital type (SMA0) to the adult-onset form (SMA4). The disease is associated with a deficiency of SMN protein, which is encoded by two genes SMN1 and SMN2. Clinical symptoms depend on mutations in the SMN1 gene. The number of copies of twin similar SMN2 gene, which produces small amounts of SMN protein, is the main phenotype modifier, which determines the clinical severity of the disease. Until recently, it was considered that spinal cord motoneurons undergo selective loss. Recent studies have shown the role of SMN protein in various cellular processes and the multisystemic character of SMA. The aim of the therapeutic strategies developed so far has been to increase the expression of SMN protein by modifying the splicing of SMN2 gene (intrathecally administered antisense oligonucleotide - nusinersen; orally available small molecules: RG7916 and LMI070 or SMN1 gene replacement therapy (AAV9-SMN). The first SMN2-directed antisense oligonucleotide (nusinersen) has demonstrated in clinical trials high efficiency, and it has now been registered. The best effects were obtained in patients who were introduced to the drug in the pre symptomatic period. Studies on other substances are ongoing. The great advances in SMA therapy and increased understanding of the pathogenesis of the disease raise hopes for changes to the natural history of the disease. Simultaneously, it increases awareness of the need to improve the standard of patient care and early diagnosis (newborn screening). Many questions (e.g. emerging phenotypes, combined therapies, systemic vs. intrathecal administration, long-term consequences, and complications of the therapy) will require further studies and observations.

<https://pubmed.ncbi.nlm.nih.gov/31922583/>

Kim, C. H., Song, I. G., Kim, M. S., Lee, J. Y., Lim, N. G. and Shin, H. Y. (2020). "Healthcare utilization among children and young people with life-limiting

conditions: Exploring palliative care needs using National Health Insurance claims data." Sci Rep 10(1): 2692.

Paediatric palliative care (PPC) is regarded as standard care for children and young people (CYP) with life-limiting conditions (LLCs). There is a lack of knowledge about the rate of CYP with LLCs, hampering the development of PPC. This retrospective study aimed to examine population-based statistics of South Korean CYP with LLCs and the pattern of healthcare use and costs in their last year of life, analysing the National Health Insurance Service claims database for the period 2013-2015. In 2015, the number of CYP ( $\leq 24$  years old) living with LLCs was 133,177, with those who died accounting for 1,032. Prevalence of LLC and mortality rate per 100,000 were highest among under-1-age group (2,151.7 and 82.7, respectively). In the last year of life, 91.8% of deceased CYP with LLCs were hospitalized at least once and the average length of stay was 101.2 days (standard deviation = 104.1). Deceased CYP with cancer spent more on healthcare than non-cancer CYP (64,266 vs. 40,694 US dollar,  $p < 0.001$ ). The average relevance index for CYP death related to LLCs was 55.9%. Our results provide baseline information on healthcare utilization and expenditure among CYP with LLCs, which is crucial data for designing evidence-based PPC policy and services.

<https://pubmed.ncbi.nlm.nih.gov/32060337/>

Lähteenmäki, P. (2020). "Late morbidity and mortality in young survivors of cancer." Lancet Oncol 21(3): 327-329.

<https://pubmed.ncbi.nlm.nih.gov/32066544/>

Lau, N., Bradford, M. C., Steineck, A., Scott, S., Bona, K., Yi-Frazier, J. P., McCauley, E. and Rosenberg, A. R. (2020). "Examining key sociodemographic characteristics of adolescents and young adults with cancer: A post hoc analysis of the Promoting Resilience in Stress Management randomized clinical trial." Palliat Med 34(3): 336-348.

**BACKGROUND:** The "Promoting Resilience in Stress Management" intervention is a skills-based, early palliative care intervention with demonstrated efficacy in adolescents and young adults with cancer. **AIM:** Utilizing data from a randomized clinical trial of Promoting Resilience in Stress Management versus Usual Care, we examined whether response to Promoting Resilience in Stress Management differed across key sociodemographic characteristics. **DESIGN:** Adolescents and young adults with cancer completed patient-reported outcome measures of resilience, hope, benefit-finding, quality of life, and distress at enrollment and 6 months. Participants were stratified by sex, age, race, and neighborhood socioeconomic disadvantage based on home address (Area Deprivation Index scores with 8-10 = most disadvantaged). Differences in the magnitude of effect sizes between stratification subgroups were noted using a conservative cutoff of  $d > 0.5$ . **SETTING/PARTICIPANTS:** Participants were 12 to 25 years old, English-speaking, and receiving cancer care at Seattle Children's Hospital. **RESULTS:** In total, 92 adolescents and young adults (48 Promoting Resilience in Stress Management, 44 Usual Care) completed baseline measures. They were 43% female, 73% 12 to 17 years old, 64% White, and 24% most disadvantaged. Effect sizes stratified by sex, age, and race were in an expected positive direction and of similar magnitude for the majority of outcomes with some exceptions in magnitude of

treatment effect. Those who lived in less disadvantaged neighborhoods benefited more from Promoting Resilience in Stress Management, and those living in most disadvantaged neighborhoods benefited less. CONCLUSION: The "Promoting Resilience in Stress Management" intervention demonstrated a positive effect for the majority of outcomes regardless of sex, age, and race. It may not be as helpful for adolescents and young adults living in disadvantaged neighborhoods. Future studies must confirm its generalizability and integrate opportunities for improvement by targeting individual needs.

<https://pubmed.ncbi.nlm.nih.gov/31680625/>

**Lindley, L. C., Cozad, M. J. and Fortney, C. A. (2020). "Pediatric Complex Chronic Conditions: Evaluating Two Versions of the Classification System." West J Nurs Res 42(6): 454-461.**

The original pediatric complex chronic conditions (CCC) classification system developed in 2000/2001 is the gold standard in classifying children with life-limiting illnesses. It was significantly modified in 2014; yet the two systems have not been evaluated. The objective of this study was to evaluate the agreement and validity of the original versus the modified CCC classification systems. Healthcare Cost and Utilization Project (HCUP) Kids' Inpatient Database (KID) data from 2012 was used with a sample of infant decedents less than 1 year. The agreement (i.e., Cohen's Kappa Statistic) and validity (i.e., sensitivity, specificity, and positive predictive value [PPV]) statistics were calculated. Among the 10,175 infants that were classified, the modified system performed well in identifying infants who had a CCC, and it captured infants that the original classification did not. The modified system represents an improvement over the original, but additional testing is warranted.

<https://pubmed.ncbi.nlm.nih.gov/31354080/>

**Liu, W., Kleine-Holthaus, S. M., Herranz-Martin, S., Aristorena, M., Mole, S. E., Smith, A. J., Ali, R. R. and Rahim, A. A. (2020). "Experimental gene therapies for the NCLs." Biochim Biophys Acta Mol Basis Dis 1866(9): 165772.**

The neuronal ceroid lipofuscinoses (NCLs), also known as Batten disease, are a group of rare monogenic neurodegenerative diseases predominantly affecting children. All NCLs are lethal and incurable and only one has an approved treatment available. To date, 13 NCL subtypes (CLN1-8, CLN10-14) have been identified, based on the particular disease-causing defective gene. The exact functions of NCL proteins and the pathological mechanisms underlying the diseases are still unclear. However, gene therapy has emerged as an attractive therapeutic strategy for this group of conditions. Here we provide a short review discussing updates on the current gene therapy studies for the NCLs.

<https://pubmed.ncbi.nlm.nih.gov/32220628/>

**Łoboda, A. and Dulak, J. (2020). "Muscle and cardiac therapeutic strategies for Duchenne muscular dystrophy: past, present, and future." Pharmacol Rep, 10.1007/s43440-020-00134-x.**

**BACKGROUND:** Duchenne muscular dystrophy (DMD) is a severe X-linked neuromuscular childhood disorder that causes progressive muscle weakness and degeneration and results in functional decline, loss of ambulation and early death of young men due to cardiac or respiratory failure. Although the major cause of the disease has been known for many years-namely mutation in the DMD gene encoding dystrophin, one of the largest human genes-DMD is still incurable, and its treatment is challenging. **METHODS:** A comprehensive and systematic review of literature on the gene, cell, and pharmacological experimental therapies aimed at restoring functional dystrophin or to counteract the associated processes contributing to disease progression like inflammation, fibrosis, calcium signaling or angiogenesis was carried out. **RESULTS:** Although some therapies lead to satisfying effects in skeletal muscle, they are highly ineffective in the heart; therefore, targeting defective cardiac and respiratory systems is vital in DMD patients. Unfortunately, most of the pharmacological compounds treat only the symptoms of the disease. Some drugs addressing the underlying cause, like eteplirsen, golodirsen, and ataluren, have recently been conditionally approved; however, they can correct only specific mutations in the DMD gene and are therefore suitable for small sub-populations of affected individuals. **CONCLUSION:** In this review, we summarize the possible therapeutic options and describe the current status of various, still imperfect, strategies used for attenuating the disease progression.

<https://pubmed.ncbi.nlm.nih.gov/32691346/>

Lu, Q., Xiang, S. T., Lin, K. Y., Deng, Y. and Li, X. (2020). "Estimation of Pediatric End-of-Life Palliative Care Needs in China: A Secondary Analysis of Mortality Data From the 2017 National Mortality Surveillance System." J Pain Symptom Manage 59(6): e5-e8.

<https://pubmed.ncbi.nlm.nih.gov/32119903/>

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://pubmed.ncbi.nlm.nih.gov/31013460/>

**Ou, L., Przybilla, M. J., Tăbăran, A. F., Overn, P., O'Sullivan, M. G., Jiang, X., Sidhu, R., Kell, P. J., Ory, D. S. and Whitley, C. B. (2020). "A novel gene editing system to treat both Tay-Sachs and Sandhoff diseases." *Gene Ther* 27(5): 226-236.**

The GM2-gangliosidoses are neurological diseases causing premature death, thus developing effective treatment protocols is urgent. GM2-gangliosidoses result from deficiency of a lysosomal enzyme  $\beta$ -hexosaminidase (Hex) and subsequent accumulation of GM2 gangliosides. Genetic changes in HEXA, encoding the Hex  $\alpha$  subunit, or HEXB, encoding the Hex  $\beta$  subunit, causes Tay-Sachs disease and Sandhoff disease, respectively. Previous studies have showed that a modified human Hex  $\mu$  subunit (HEXM) can treat both Tay-Sachs and Sandhoff diseases by forming a homodimer to degrade GM2 gangliosides. To this end, we applied this HEXM subunit in our PS813 gene editing system to treat neonatal Sandhoff mice. Through AAV delivery of the CRISPR system, a promoterless HEXM cDNA will be integrated into the albumin safe harbor locus, and lysosomal enzyme will be expressed and secreted from edited hepatocytes. 4 months after the i.v. of AAV vectors, plasma MUGS and MUG activities reached up to 144- and 17-fold of wild-type levels ( $n = 10$ ,  $p < 0.0001$ ), respectively. More importantly, MUGS and MUG activities in the brain also increased significantly compared with untreated Sandhoff mice ( $p < 0.001$ ). Further, HPLC-MS/MS analysis showed that GM2 gangliosides in multiple tissues, except the brain, of treated mice were reduced to normal levels. Rotarod analysis showed that coordination and motor memory of treated mice were improved ( $p < 0.05$ ). Histological analysis of H&E stained tissues showed reduced cellular vacuolation in the brain and liver of treated Sandhoff mice. These results demonstrate the potential of developing a treatment of in vivo genome editing for Tay-Sachs and Sandhoff patients.  
<https://pubmed.ncbi.nlm.nih.gov/31896760/>

**Passone, C. G. B., Grisi, S. J., Farhat, S. C., Manna, T. D., Pastorino, A. C., Alveno, R. A., Miranda, C. V. S., Waetge, A. R., Cordon, M. N., Odone-Filho, V., Tannuri, U., Carvalho, W. B., Carneiro-Sampaio, M. and Silva, C. A. (2020). "COMPLEXITY OF PEDIATRIC CHRONIC DISEASE: CROSS-SECTIONAL STUDY WITH 16,237 PATIENTS FOLLOWED BY MULTIPLE MEDICAL SPECIALTIES." *Rev Paul Pediatr* 38: e2018101.**

**OBJECTIVE:** To assess demographic data and characteristics of children and adolescents with pediatric chronic diseases (PCD), according to the number of specialties/patient. **METHODS:** We performed a cross-sectional study with 16,237 PCD patients at outpatient clinics in one year. Data were analyzed by an electronic data system, according to the number of physician appointments for PCD. This study assessed: demographic data, follow-up characteristics, types of medical specialty, diagnosis (International Statistical Classification of Diseases and Related Health Problems - ICD-10), number of day hospital clinic visits, and acute complications. **RESULTS:** Patients followed by  $\geq 3$  specialties simultaneously showed a significantly

higher duration of follow-up compared to those followed by  $\leq 2$  specialties [2.1 (0.4-16.4) vs. 1.4 (0.1-16.2) years;  $p < 0.001$ ] and a higher number of appointments in all specialties. The most prevalent medical areas in patients followed by  $\geq 3$  specialties were: Psychiatry (Odds Ratio - OR=8.0; confidence interval of 95% - 95%CI 6-10.7;  $p < 0.001$ ), Palliative/Pain Care (OR=7.4; 95%CI 5.7-9.7;  $p < 0.001$ ), Infectious Disease (OR=7.0; 95%CI 6.4-7.8;  $p < 0.001$ ) and Nutrology (OR=6.9; 95%CI 5.6-8.4;  $p < 0.001$ ). Logistic regressions demonstrated that PCD patients followed by  $\geq 3$  specialties were associated with high risk for: number of appointments/patient (OR=9.2; 95%CI 8.0-10.5;  $p < 0.001$ ), day hospital clinic visits (OR=4.8; 95%CI 3.8-5.9;  $p < 0.001$ ), emergency department visits (OR=3.2; 95%CI 2.9-3.5;  $p < 0.001$ ), hospitalizations (OR=3.0; 95%CI 2.7-3.3;  $p < 0.001$ ), intensive care admissions (OR=2.5; 95%CI 2.1-3.0;  $p < 0.001$ ), and deaths (OR=2.8; 95%CI 1.9-4.0;  $p < 0.001$ ). The diagnosis of asthma, obesity, chronic pain, and transplant was significantly higher in patients followed by  $\geq 3$  specialties.

CONCLUSIONS: The present study showed that PCD patients who required simultaneous care from multiple medical specialties had complex and severe diseases, with specific diagnoses.

Publisher: Abstract available from the publisher.

<https://pubmed.ncbi.nlm.nih.gov/31778404/>

Price, J., Lee, J., Willcox, M. and Harnden, A. (2019). "Place of death, care-seeking and care pathway progression in the final illnesses of children under five years of age in sub-Saharan Africa: a systematic review." *J Glob Health* 9(2): 020422.

BACKGROUND: Half of all under-5 deaths occur in sub-Saharan Africa. Reducing child mortality requires understanding of the modifiable factors that contribute to death. Social autopsies collect information about place of death, care-seeking and care-provision, but this has not been pooled to learn wider lessons. We therefore undertook a systematic review to collect, evaluate, map, and pool all the available evidence for sub-Saharan Africa. METHODS: We searched PubMed, Embase, Global Health, the Cochrane Library and grey literature for studies relating to under-5 deaths in sub-Saharan Africa with information on place of death and/or care-seeking during a child's final illness. We assessed study quality with a modified Axis tool. We pooled proportions using random effects meta-analysis for place of death and for each stage of the Pathways to Survival framework. Pre-specified subgroup analysis included age group, national income and user-fee policy. We explored heterogeneity with meta-regression. Our protocol was published prospectively (CRD42018111484). RESULTS: We included 34 studies from 17 countries. Approximately half of the children died at home, irrespective of age. More children died at home in settings with user-fees (69.1%, 95% confidence interval (CI) = 56.2-80.6,  $I(2) = 98.4\%$ ) compared to settings without user-fees (43.8%, 95% CI = 34.3-53.5,  $I(2) = 96.7\%$ ). Signs of illness were present in over 95% of children but care-seeking differed by age. 40.1% of neonates (95% CI = 20.7-61.3,  $I(2) = 98.0\%$ ) died without receiving any care, compared to 6.4% of older children (95% CI = 4.2%-9.0%,  $I(2) = 90.6\%$ ). Care-seeking outside the home was less common in neonatal deaths (50.5%, 95% CI = 35.6-65.3,  $I(2) = 98.3\%$ ) compared to infants and young children (82.4%, 95% CI = 79.4%-85.2%,  $I(2) = 87.5\%$ ). In both age groups, most children were taken for formal care. Healthcare facilities discharged 69.6% of infants and young children who arrived alive (95% CI = 59.6-78.7,  $I(2) = 95.5\%$ ), of whom only 34.9% were referred for further care (95% CI = 15.1-57.9,  $I(2) = 98.7\%$ ). CONCLUSIONS: Despite similar distributions in place of death for

neonates and infants and young children, care-seeking behaviour differed by age groups. Poor illness recognition is implicated in neonatal deaths, but death despite care-seeking implies inadequate quality care and referral for older children. Understanding such care-seeking patterns enables targeted interventions to reduce under-5 mortality across the region.

<https://pubmed.ncbi.nlm.nih.gov/31673338/>

**Raikwar, S. P., Kikkeri, N. S., Sakuru, R., Saeed, D., Zahoor, H., Premkumar, K., Mentor, S., Thangavel, R., Dubova, I., Ahmed, M. E., Selvakumar, G. P., Kempuraj, D., Zaheer, S., Iyer, S. S. and Zaheer, A. (2019). "Next Generation Precision Medicine: CRISPR-mediated Genome Editing for the Treatment of Neurodegenerative Disorders." *J Neuroimmune Pharmacol* 14(4): 608-641.**

Despite significant advancements in the field of molecular neurobiology especially neuroinflammation and neurodegeneration, the highly complex molecular mechanisms underlying neurodegenerative diseases remain elusive. As a result, the development of the next generation neurotherapeutics has experienced a considerable lag phase. Recent advancements in the field of genome editing offer a new template for dissecting the precise molecular pathways underlying the complex neurodegenerative disorders. We believe that the innovative genome and transcriptome editing strategies offer an excellent opportunity to decipher novel therapeutic targets, develop novel neurodegenerative disease models, develop neuroimaging modalities, develop next-generation diagnostics as well as develop patient-specific precision-targeted personalized therapies to effectively treat neurodegenerative disorders including Alzheimer's disease, Parkinson's disease, Huntington's disease, Amyotrophic lateral sclerosis, Frontotemporal dementia etc. Here, we review the latest developments in the field of CRISPR-mediated genome editing and provide unbiased futuristic insights regarding its translational potential to improve the treatment outcomes and minimize financial burden. However, despite significant advancements, we would caution the scientific community that since the CRISPR field is still evolving, currently we do not know the full spectrum of CRISPR-mediated side effects. In the wake of the recent news regarding CRISPR-edited human babies being born in China, we urge the scientific community to maintain high scientific and ethical standards and utilize CRISPR for developing in vitro disease in a dish model, in vivo testing in nonhuman primates and lower vertebrates and for the development of neurotherapeutics for the currently incurable neurodegenerative disorders. Graphical Abstract.

<https://pubmed.ncbi.nlm.nih.gov/31011884/>

**Renton, K., Mayer, A. T., Alison, L. and Yeomanson, D. (2020). "Factors associated with place of death for children in South Yorkshire: a retrospective cohort study." *BMJ Support Palliat Care* 10(1): e10.**

**OBJECTIVES:** Place of death (POD) is considered a key quality indicator for adult end-of-life care, but paediatric evidence is limited. Data from Child Death Overview Panel (CDOP) databases provides an opportunity to describe trends in POD as regional paediatric palliative medicine (PPM) options have increased. Aims were to identify and describe trends in POD for children in South Yorkshire. **METHODS:** Retrospective cohort study. Anonymised data extracted from five CDOP databases 2008-2015. Data included age, gender, ethnicity, postcode (outward code only), POD, classification and

category of death. Descriptive statistical analysis using  $\chi^2$  test was used to assess intergroup differences. RESULTS: 748 deaths were notified from 2008 to 2015. Neonatal deaths were excluded, 46% (n=345). Of non-neonatal deaths (n=403), 58% (n=232) were 'expected'. Of expected deaths (n=232), 19% (n=45) died in home, 19% (n=45) died in hospice and 61% (n=141) died in hospital. This was significantly different from comparable national data which showed considerably more hospital deaths. There was no significant change in POD over time. CONCLUSION: Hospital remains the POD for most children, whether deaths are 'expected' or not, suggesting specialised PPM should be expanded into the hospital setting. More research is needed regarding preference for POD. This study may help inform future service planning for PPM and hospice development.  
<https://pubmed.ncbi.nlm.nih.gov/30446488/>

**Silver, R. M., Siassakos, D. and Dudley, D. J. (2020). "The enemy of the good in assigning cause of fetal death." *Bjog* 127(5): 536.**

In this issue of *BJOG*, Goldenberg and McClure underscore some of the problems with assigning causes of death to stillbirths and neonatal deaths in low-resource settings (*BJOG* 2020;127:532–5). They also point the way forward. Classification or assigning causes of death is a key step towards prevention of stillbirth and neonatal death. However, ascertaining causes of death is extremely challenging in low-income countries owing to limited resources and lack of personnel, and continues to be a challenge even in well-resourced countries, where a complete evaluation for cause of stillbirth (including autopsy, placental pathology and genetic testing) can be stymied by cost concerns.

<https://pubmed.ncbi.nlm.nih.gov/31880045/>

**Thiels, C., Stahl, A., Saft, C., Juckel, G. and Lücke, T. (2020). "[Huntington's disease with childhood and adolescent onset: course of disease, clinical presentation and diagnostic challenges]." *Fortschr Neurol Psychiatr*, 10.1055/a-1082-6605.**

Huntington's disease (HD) is an autosomal-dominant neurodegenerative disorder caused by a gene mutation in chromosome 4 that leads to an expansion of CAG - triplet repeats. It occurs mainly between the age of 30 and 50. Only less than 10 % of HD patients are younger than 20 years. In contrast to adult patients young HD patients show more often psychiatric and cognitive symptoms at disease onset than chorea. One third of the children with HD develops an epilepsy. We present 6 children diagnosed with HD in different stages of childhood. We describe first symptoms as well as genetic characteristics and other distinctive features. Both the clinical presentation and the course of HD in childhood differ from HD in adults. In adolescents the clinical symptoms at onset are often psychiatric (like depression or attention deficit disorder). Choreatic movements typical for adult HD patients are missing. Due to the low prevalence of HD in childhood and the variability of clinical symptoms the process of diagnosing HD in children is difficult. Very often the diagnosis is made years after the first symptoms. Early diagnosis, however, is often important for managing social problems and problems in school.

<https://pubmed.ncbi.nlm.nih.gov/32369858/>

Vita, G. L. and Vita, G. (2020). "Is it the right time for an infant screening for Duchenne muscular dystrophy?" Neurol Sci 41(7): 1677-1683.

Newborn screening (NBS) is an essential, preventive public health programme for early identification of disorders whose early treatment can lead to significant reduction in morbidity and mortality. NBS for Duchenne muscular dystrophy (DMD) has been a controversial matter for many years, because of false positives, the lack of effective drugs and the need of more data about screening efficacy. The still high diagnostic delay of DMD and the current availability of drugs such as steroid, ataluren, eteplirsen, golodirsen and forthcoming new drugs, improving the clinical conditions if early started, make appropriate to begin a concrete discussion between stakeholders to identify best practice for DMD screening. A two-step system CK/DNA screening programme is presented to be performed in male infants aged between 6 months and 42 months involving more than 30,000 male infants. Five to eight DMD subjects are believed to be diagnosed. The pilot project would give the opportunity to test in a small population the feasibility of an infant screening programme, which in the near future could be applicable to an entire country.

<https://pubmed.ncbi.nlm.nih.gov/32112218/>

Wijngaarde, C. A., Veldhoen, E. S., van Eijk, R. P. A., Stam, M., Otto, L. A. M., Asselman, F. L., Wösten-van Asperen, R. M., Hulzebos, E. H. J., Verweij-van den Oudenrijn, L. P., Bartels, B., Cuppen, I., Wadman, R. I., van den Berg, L. H., van der Ent, C. K. and van der Pol, W. L. (2020). "Natural history of lung function in spinal muscular atrophy." Orphanet J Rare Dis 15(1): 88.

**BACKGROUND:** Respiratory muscle weakness is an important feature of spinal muscular atrophy (SMA). Progressive lung function decline is the most important cause of mortality and morbidity in patients. The natural history of lung function in SMA has, however, not been studied in much detail. **RESULTS:** We analysed 2098 measurements of lung function from 170 treatment-naïve patients with SMA types 1c-4, aged 4-74 years. All patients are participating in an ongoing population-based prevalence cohort study. We measured Forced Expiratory Volume in 1 s (FEV(1)), Forced Vital Capacity (FVC), and Vital Capacity (VC). Longitudinal patterns of lung function were analysed using linear mixed-effects and non-linear models. Additionally, we also assessed postural effects on results of FEV(1) and FVC tests. In early-onset SMA types (1c-3a), we observed a progressive decline of lung function at younger ages with relative stabilisation during adulthood. Estimated baseline values were significantly lower in more severely affected patients: %FEV(1) ranged from 42% in SMA type 1c to 100% in type 3b, %FVC 50 to 109%, and %VC 44 to 96%. Average annual decline rates also differed significantly between SMA types, ranging from - 0.1% to - 1.4% for FEV(1), - 0.2% to - 1.4% for FVC, and + 0.2% to - 1.7% for VC. In contrast to SMA types 1c-3a, we found normal values for all outcomes in later-onset SMA types 3b and 4 throughout life, although with some exceptions and based on limited available data. Finally, we found no important differences in FVC or FEV(1) values measured in either sitting or supine position. **CONCLUSIONS:** Our data illustrate the longitudinal course of lung function in patients with SMA, which is characterised by a progressive decline in childhood and stabilisation in early adulthood. The data do not support an additional benefit of measuring FEV(1) or FVC in both sitting and supine position. These data may serve as a reference to assess longer-term outcomes in clinical trials.

<https://pubmed.ncbi.nlm.nih.gov/32276635/>

Williams, V., Jaiswal, N., Chauhan, A., Pradhan, P., Jayashree, M. and Singh, M. (2020). "Time of Pediatric Intensive Care Unit Admission and Mortality: A Systematic Review and Meta-Analysis." J Pediatr Intensive Care 9(1): 1-11.

The aim of this study was to determine the association between the time of admission (day, night, and/or weekends) and mortality among critically ill children admitted to a pediatric intensive care unit (PICU). Electronic databases that were searched include PubMed, Embase, Web of Science, CINAHL (Cumulative Index of Nursing and Allied Health Literature), Ovid, and Cochrane Library since inception till June 15, 2018. The article included observational studies reporting inhospital mortality and the time of admission to PICU limited to patients aged younger than 18 years. Meta-analysis was performed by a frequentist approach with both fixed and random effect models. The GRADE (Grading of Recommendations Assessment, Development, and Evaluation) approach was used to evaluate the quality of evidence. Ten studies met our inclusion criteria. Five studies comparing weekday with weekend admissions showed better odds of survival on weekdays (odds ratio [OR]: 0.77; 95% confidence interval [CI]: 0.60-0.99). Pooled data of four studies showed that odds of mortality were similar between day and night admissions (OR: 0.93; 95% CI: 0.77-1.13). Similarly, three studies comparing admission during off-hours versus regular hours did not show better odds of survival during regular hours (OR: 0.77; 95% CI: 0.57-1.05). Heterogeneity was significant due to variable sample sizes and time period. Inconsistency in adjusting for confounders across the included studies precluded us from analyzing the adjusted risk of mortality. Weekday admissions to PICU were associated with lesser odds of mortality. No significant differences in the odds of mortality were found between admissions during day versus night or between admission during regular hours and that during off-hours. However, the evidence is of low quality and requires larger prospective studies.

<https://pubmed.ncbi.nlm.nih.gov/31984150/>

Wittlieb-Weber, C. A., Knecht, K. R., Villa, C. R., Cunningham, C., Conway, J., Bock, M. J., Gambetta, K. E., Lal, A. K., Schumacher, K. R., Law, S. P., Deshpande, S. R., West, S. C., Friedland-Little, J. M., Lytrivi, I. D., McCulloch, M. A., Butts, R. J., Weber, D. R. and Johnson, J. N. (2020). "Risk Factors for Cardiac and Non-cardiac Causes of Death in Males with Duchenne Muscular Dystrophy." Pediatr Cardiol 41(4): 764-771.

As survival and neuromuscular function in Duchenne muscular dystrophy (DMD) have improved with glucocorticoid (GC) therapy and ventilatory support, cardiac deaths are increasing. Little is known about risk factors for cardiac and non-cardiac causes of death in DMD. A multi-center retrospective cohort study of 408 males with DMD, followed from January 1, 2005 to December 31, 2015, was conducted to identify risk factors for death. Those dying of cardiac causes were compared to those dying of non-cardiac causes and to those alive at study end. There were 29 (7.1%) deaths at a median age of 19.5 (IQR: 16.9-24.6) years; 8 (27.6%) cardiac, and 21 non-cardiac. Those living were younger [14.9 (IQR: 11.0-19.1) years] than those dying of cardiac [18 (IQR 15.5-24) years,  $p = 0.03$ ] and non-cardiac [19 (IQR: 16.5-23) years,  $p = 0.002$ ]

causes. GC use was lower for those dying of cardiac causes compared to those living [2/8 (25%) vs. 304/378 (80.4%),  $p = 0.001$ ]. Last ejection fraction prior to death/study end was lower for those dying of cardiac causes compared to those living ( $37.5\% \pm 12.8$  vs.  $54.5\% \pm 10.8$ ,  $p = 0.01$ ) but not compared to those dying of non-cardiac causes ( $37.5\% \pm 12.8$  vs.  $41.2\% \pm 19.3$ ,  $p = 0.58$ ). In a large DMD cohort, approximately 30% of deaths were cardiac. Lack of GC use was associated with cardiac causes of death, while systolic dysfunction was associated with death from any cause. Further work is needed to ensure guideline adherence and to define optimal management of systolic dysfunction in males with DMD with hopes of extending survival.

<https://pubmed.ncbi.nlm.nih.gov/32016582/>

**Yeo, C. J. J. and Darras, B. T. (2020). "Overturning the Paradigm of Spinal Muscular Atrophy as Just a Motor Neuron Disease." *Pediatr Neurol* 109: 12-19.**

Spinal muscular atrophy is typically characterized as a motor neuron disease. Untreated patients with the most severe form, spinal muscular atrophy type 1, die early with infantile-onset progressive skeletal, bulbar, and respiratory muscle weakness. Such patients are now living longer due to new disease-modifying treatments such as gene replacement therapy (onasemnogene abeparvovec), recently approved by the US Food and Drug Administration, and nusinersen, a central nervous system-directed treatment which was approved by the US Food and Drug Administration three years ago. This has created an area of pressing clinical need: if spinal muscular atrophy is a multisystem disease, dysfunction of peripheral tissues and organs may become significant comorbidities as these patients survive into childhood and adulthood. In this review, we have compiled autopsy data, case reports, and cohort studies of peripheral tissue involvement in patients and animal models with spinal muscular atrophy. We have also evaluated preclinical studies addressing the question of whether peripheral expression of survival motor neuron is necessary and/or sufficient for motor neuron function and survival. Indeed, spinal muscular atrophy patient data suggest that spinal muscular atrophy is a multisystem disease with dysfunction in skeletal muscle, heart, kidney, liver, pancreas, spleen, bone, connective tissues, and immune systems. The peripheral requirement of SMN in each organ and how these contribute to motor neuron function and survival remains to be answered. A systemic (peripheral and central nervous system) approach to therapy during early development is most likely to effectively maximize positive clinical outcome.

<https://pubmed.ncbi.nlm.nih.gov/32409122/>

**Young, A. and Duke, T. (2020). "The process of implementing child mortality reviews in low- and middle-income countries: a narrative systematic review." *Trop Med Int Health* 25(7): 764-773.**

**OBJECTIVES:** This review aims to describe the processes that have been used to implement child mortality reviews in LMICs and to identify the facilitators and barriers to their implementation and impact. This will help to inform healthcare professionals and managers planning to implement a child mortality review in their setting. **METHODS:** MEDLINE and Embase databases were searched for papers published between January 1996 and April 2019. Studies reporting the implementation of a child mortality review process in LMICs were considered eligible. A narrative approach was used to

describe the stages in the audit process outlined in the WHO 'Operational guide for facility-based audit and review of paediatric mortality' which were completed, and to synthesise the barriers and facilitators to implementation and impact of the child mortality review process. RESULTS: From 776 potentially relevant articles, seven studies were included. In six studies, problems contributing to child deaths and possible solutions were identified, in four, these solutions were implemented, and in one, this implementation was monitored. Key factors influencing implementation and impact were attendance at meetings, use of a blame-free approach, allocating adequate human and financial resources to make changes, and level of engagement from leadership. CONCLUSIONS: Despite the common use of mortality reviews in paediatric departments, there are few studies published on this topic. The transition from identifying problems and solutions to implementing and monitoring action plans appears to be the most difficult aspect of the process, which requires commitment of adequate resources and strong leadership.

<https://pubmed.ncbi.nlm.nih.gov/32307796/>

Zhou, X., Niu, X., Sun, K., Li, J., Mao, Q. and Liu, Y. (2020). "Pediatric Glioma Outcomes: Predictors of Early Mortality." *World Neurosurg* 139: e700-e707.

OBJECTIVE: To assess the early mortality in pediatric glioma and identify predictors of early mortality, which may provide insight into the therapeutic strategies for children with a high risk of early mortality. METHODS: We used SEER\*Stat 8.3.5 software to extract data of pediatric glioma from the Surveillance, Epidemiology, and End Results database. Logistical regression to identify the independent factors in predicting early mortality. RESULTS: A total of 3035 male and 2741 female patients were enrolled in the present study. The death rates within 1 month and 3 months after diagnosis were 1.32% and 2.44%, respectively. Early mortality decreased significantly during the past 40 years. Our results showed that glioblastoma, anaplastic glioma, and oligodendroglioma were risk factors of early mortality for children diagnosed with glioma, whereas advanced age, gross total resection, radiation, and chemotherapy were associated with decreased early mortality. CONCLUSIONS: We found a decrease in early mortality during the past 40 years. The death rates within 1 month and 3 months after diagnosis were 1.32% and 2.44%, respectively. Age at diagnosis, histologic subtype, the extent of resection, chemotherapy, and radiation were associated with early mortality in pediatric glioma.

<https://pubmed.ncbi.nlm.nih.gov/32389863/>

## **Ethical & Clinical Decision Making**

(2020). "Management of Stillbirth: Obstetric Care Consensus No, 10 Summary." *Obstet Gynecol* 135(3): 747-751.

Stillbirth is one of the most common adverse pregnancy outcomes, occurring in 1 in 160 deliveries in the United States. In developed countries, the most prevalent risk factors associated with stillbirth are non-Hispanic black race, nulliparity, advanced maternal age, obesity, pre-existing diabetes, chronic hypertension, smoking, alcohol use, having a pregnancy using assisted reproductive technology, multiple gestation, male fetal sex, unmarried status, and past obstetric history. Although some of these

factors may be modifiable (such as smoking), many are not. The study of specific causes of stillbirth has been hampered by the lack of uniform protocols to evaluate and classify stillbirths and by decreasing autopsy rates. In any specific case, it may be difficult to assign a definite cause to a stillbirth. A significant proportion of stillbirths remains unexplained even after a thorough evaluation. Evaluation of a stillbirth should include fetal autopsy; gross and histologic examination of the placenta, umbilical cord, and membranes; and genetic evaluation. The method and timing of delivery after a stillbirth depend on the gestational age at which the death occurred, maternal obstetric history (eg, previous hysterectomy), and maternal preference. Health care providers should weigh the risks and benefits of each strategy in a given clinical scenario and consider available institutional expertise. Patient support should include emotional support and clear communication of test results. Referral to a bereavement counselor, peer support group, or mental health professional may be advisable for management of grief and depression.

<https://pubmed.ncbi.nlm.nih.gov/32080052/>

**Adams, S. Y., Tucker, R., Clark, M. A. and Lechner, B. E. (2020). "Quality of life": parent and neonatologist perspectives." *J Perinatol*, 10.1038/s41372-020-0654-9: 1-12.**

**OBJECTIVE:** To assess how physicians and families understand quality of life (QOL) for NICU patients, and to explore the feasibility of developing a standardized definition for QOL. **STUDY DESIGN:** Surveys were developed and administered to neonatologists and eligible families. Quantitative analysis was conducted using standard statistical methods. Qualitative analysis was conducted using NVivo software. Focus groups were conducted with the same groups, and audio recordings were obtained and analyzed for recurring themes. **RESULTS:** Both parents and physicians value QOL as a metric for guiding care in the NICU. Parents were more likely to accept higher levels of disability, while neonatologists were more likely to accept higher levels of dependence on medical equipment. In relation to infant QOL, predominant themes expressed in the parent focus groups were stress levels in the NICU, advocating as parents, and the way in which long-term outcomes were presented by the medical team; in the physician focus group, the ambiguity of predicting outcomes and thus QOL was the main theme. **CONCLUSIONS:** Both parents and physicians recognize the importance of QOL in the decision-making process for critically ill infants, but the two groups differ in their assessment of what QOL means in this context. These data suggest that QOL cannot be adequately defined for standardized use in a clinical context, and as such, should be used thoughtfully by neonatologists in discussions of end-of-life care.

<https://pubmed.ncbi.nlm.nih.gov/32214216/>

**Af Sandeberg, M., Bartholdson, C. and Pergert, P. (2020). "Important situations that capture moral distress in paediatric oncology." *BMC Med Ethics* 21(1): 6.**

**BACKGROUND:** The paediatric Moral Distress Scale-Revised (MDS-R) was previously translated and adapted to Swedish paediatric oncology. Cognitive interviews revealed five not captured situations among the 21 items, resulting in five added items: 22) Lack of time for conversations with patients/families, 23) Parents' unrealistic expectations, 24) Not to talk about death with a dying child, 25) To perform painful procedures, 26)

To decide on treatment/care when uncertain. The aim was to explore experiences of moral distress in the five added situations in the Swedish paediatric MDS-R, among healthcare professionals (HCPs) in paediatric oncology. METHODS: In this national cross-sectional survey, the Swedish paediatric MDS-R, including five added items, were used. Descriptive statistics, non-parametric analysis of differences between professions and a MDS-R score for each item were calculated. Internal consistency was tested using Cronbach's alpha and inter-item correlation test. HCPs (n = 278) at all six Swedish paediatric oncology centres participated (> 89%). The Regional Ethical Review Board had no objections. Consent was assumed when the survey was returned. RESULTS: Nursing assistants (NAs) reported higher intensity and lower frequency on all added items; registered nurses (RNs) reported a higher frequency on item 22-25; medical doctors (MDs) reported higher MDS-R score on item 26. On item 22, intensity was moderate for RNs and MDs and high for NAs, and frequency was high among all. Item 22, had the second highest MDS-R score of all 26 for all professional groups. On item 23, the level of disturbance was low but it occurred often. The 26-item version showed good internal consistency for the overall sample and for all professional groups. However, item 22 and 24 could be viewed as redundant to two of the original 21. CONCLUSION: In accordance with other studies, the intensity was higher than the frequency, however, the frequency of the added items was higher than of the original items. In line with previous research, item 22 and 23 are important elements of moral distress. RNs experience the situations more often while NAs find them more disturbing. The results indicate that the added items are important in capturing moral distress in paediatric oncology.

<https://pubmed.ncbi.nlm.nih.gov/31931787/>

**Albersheim, S. (2020). "The Extremely Preterm Infant: Ethical Considerations in Life-and-Death Decision-Making." *Front Pediatr* 8: 55.**

Care of the preterm infant has improved tremendously over the last 60 years, with attendant improvement in outcomes. For the extremely preterm infant, <28 weeks' gestation, concerns related to survival as well as neurodevelopmental impairment, have influenced decision-making to a much larger extent than seen in older children.

Possible reasons for conferring a different status on extremely preterm infants include: (1) the belief that the brain is a privileged organ, (2) the degree of medical uncertainty in terms of outcomes, (3) the fact that the family will deal with the psychological, emotional, physical, and financial consequences of treatment decisions, (4) that the extremely preterm looks more like a fetus than a term newborn, (5) the initial lack of relational identity, (6) the fact that extremely preterm infants are technology-dependent, and (7) the timing of decision-making around delivery. Treating extremely preterm infants differently does not hold up to scrutiny. They are owed the same respect as other pediatric patients, in terms of personhood, and we have the same duties to care for them. However, the degree of medical uncertainty and the fact that parents will deal with the consequences of decision-making, highlights the importance of providing a wide band of discretion in parental decision-making authority. Ethical principles considered in decision-making include best interest (historically the sine qua non of pediatric decision-making), a reasonable person standard, the "good enough" parent, and the harm principle, the latter two being more pragmatic. To operationalize these principles, potential models for decision-making are the Zone of Parental Discretion, the Not Unreasonable Standard, and a Shared Decision-Making model. In the final analysis

shared decision-making with a wide zone of parental discretion, which is based on the harm principle, would provide fair and equitable decision-making for the extremely preterm infant. However, in the rare circumstance where parents do not wish to embark upon intensive care, against medical recommendations, it would be most helpful to develop local guidelines both for support of health care practitioners and to provide consistency of care for extremely preterm infants.

<https://pubmed.ncbi.nlm.nih.gov/32175292/>

**Anderson, A. K., Burke, K., Bendle, L., Koh, M., McCulloch, R. and Breen, M. (2019). "Artificial nutrition and hydration for children and young people towards end of life: consensus guidelines across four specialist paediatric palliative care centres." *BMJ Support Palliat Care*, 10.1136/bmjspcare-2019-001909.**

There is a paucity of evidence on the role, use, benefit and challenges of artificial nutrition and hydration (ANH) in children at end of life. Parents express the difficulty they face with making the decision to withdraw ANH. Decision-making on the role of ANH in an individual child requires careful multidisciplinary team deliberation and clear goals of care with children and families. Four paediatric palliative care specialist centres reviewed the current literature and developed consensus guidelines on ANH at end of life. These guidelines seek to provide a practical approach to clinical decision-making on the role of ANH in a child or young person entering the end-of-life phase.

<https://pubmed.ncbi.nlm.nih.gov/31630111/>

**Anderson, M., Youngner, S., Smith, R. D., Nandyal, R. R., Orlowski, J. P., Jessie Hill, B. and Barsman, S. G. (2020). "Neonatal Organ and Tissue Donation for Research: Options Following Death by Natural Causes." *Cell Tissue Bank* 21(2): 289-302.**

The donation of organs and tissues from neonates (birth to 28 days) for transplantation has been a relatively infrequent occurrence. Less common has been the use of neonatal organs and tissues for research. Specific ethical and legal questions beg for rational and transparent guidelines with which to evaluate referrals of potential donors. Donation of organs and tissues from a neonate can play a key role in the care and support provided to families by health care professionals around the time of a neonate's death. We report on the recovery of neonatal organs and tissues for research. A working group made up of bioethicists, neonatologists, lawyers, obstetric practitioners as well as organ procurement and tissue banking professionals evaluated legal, ethical and medical issues. Neonatal donor family members were also consulted. Our primary goals were (a) to ensure that referrals were made in compliance with all applicable federal and state laws, regulations and institutional protocols, and (b) to follow acceptable ethical standards. Algorithms and policies designed to assist in the evaluation of potential neonatal donors were developed. Neonatal donation is proving increasingly valuable for research into areas including diabetes, pulmonary, gastrointestinal, genitourinary and neurological development, rheumatoid arthritis, autism, childhood psychiatric and neurologic disorders, treatment of MRSA infection and pediatric emergency resuscitation. The development of policies and procedures will assist medical professionals who wish to offer the option of donation to family members anticipating the death of a neonate.

<https://pubmed.ncbi.nlm.nih.gov/32166424/>

Brick, C., Kahane, G., Wilkinson, D., Caviola, L. and Savulescu, J. (2020). "Worth living or worth dying? The views of the general public about allowing disabled children to die." J Med Ethics 46(1): 7-15.

**BACKGROUND:** Decisions about withdrawal of life support for infants have given rise to legal battles between physicians and parents creating intense media attention. It is unclear how we should evaluate when life is no longer worth living for an infant. Public attitudes towards treatment withdrawal and the role of parents in situations of disagreement have not previously been assessed. **METHODS:** An online survey was conducted with a sample of the UK public to assess public views about the benefit of life in hypothetical cases similar to real cases heard by the UK courts (eg, Charlie Gard, Alfie Evans). We then evaluated these public views in comparison with existing ethical frameworks for decision-making. **RESULTS:** One hundred and thirty participants completed the survey. The majority (94%) agreed that an infant's life may have no benefit when well-being falls below a critical level. Decisions to withdraw treatment were positively associated with the importance of use of medical resources, the infant's ability to have emotional relationships, and mental abilities. Up to 50% of participants in each case believed it was permissible to either continue or withdraw treatment. **CONCLUSION:** Despite the controversy, our findings indicate that in the most severe cases, most people agree that life is not worth living for a profoundly disabled infant. Our survey found wide acceptance of at least the permissibility of withdrawal of treatment across a range of cases, though also a reluctance to overrule parents' decisions. These findings may be useful when constructing guidelines for clinical practice.

<https://pubmed.ncbi.nlm.nih.gov/31615879/>

Brouwer, M., Maeckelberghe, E., Brincke, H. T., Meulenbeek-Ten Brincke, M. and Verhagen, E. (2020). "Pediatric Brain Tumors: Narrating Suffering and End-of-Life Decision making." Camb Q Healthc Ethics 29(3): 338-345.

When talking about decision making for children with a life-threatening condition, the death of children with brain tumors deserves special attention. The last days of the lives of these children can be particularly harsh for by standers, and raise questions about the suffering of these children themselves. In the Netherlands, these children are part of the group for whom a wide range of end-of-life decisions are discussed, and questions raised. What does the end-of-life for these children look like, and what motivates physicians and parents to make decisions that may affect the life and death of these children? This article highlights the story of the parents of the sisters Roos and Noor. When both their daughters were diagnosed with a hereditary brain tumor, they had to make similar decisions twice. Their story sheds light on the suffering of children in the terminal phase, and how this suffering may motivate parents and physicians to make decisions that influence the end of life of these children's lives. We argue that complete knowledge about suffering in the terminal phase of children with brain tumors is impossible. However, by collecting experiences like those of Roos and Noor, we can move toward an experienced-based understanding and better guide parents and physicians through these hardest of decisions.

<https://pubmed.ncbi.nlm.nih.gov/32484136/>

Carroll, R. S., Hirst, E., Hudson, M., Shaw, M. and Deutsch, S. A. (2020). "End-of-life medical decision-making for children in custody: A collaborative, multi-stakeholder practical approach." Child Abuse Negl 103: 104441.

**BACKGROUND:** Parents have a constitutionally-protected, fundamental right to make decisions concerning the health and well-being of their children, afforded by the Due Process Clause of the Fourteenth Amendment. However, parental rights are not absolute, and may be curtailed after a finding of parental "unfitness" including perpetration of egregious child abuse/neglect. Court intervention may be necessary to assert "parens patriae" authority to protect a child's well-being. Disagreements over medical care for a child (particularly when parent maltreatment resulted in life-altering clinical conditions and parents are suspected of perpetrating abusive injuries) often pose conflicts of interest. End-of-life decision-making involving abuse perpetrators may be influenced by self-interest, due to potential for escalation of criminal charges. **OBJECTIVE:** Discuss medico-legal decision-making for children in child welfare custody using a detailed case example involving a child near-fatally, abusively injured by his parents; review of relevant case law/national legal precedents; and clinical policy statements guiding end-of-life decision-making for pediatric patients. **PARTICIPANTS/SETTING/METHODS:** Using an exploratory, quasi-qualitative approach, perceived experiences of purposefully-selected taskforce members identified key themes that informed a care de-escalation protocol, implemented across the state. **RESULTS:** Key themes included coordinated communication, expedited legal proceedings, and balancing child's best interest (the right not to suffer for a prolonged period of time or sustain complications) with parents' rights and due process concerns, and informed protocol development. **CONCLUSIONS:** Practicable guidance established in the protocol can be theoretically adapted at the local level to address the complexity inherent in end-of-life decision-making for children in custody.

<https://pubmed.ncbi.nlm.nih.gov/32143092/>

Cousino, M. K., Miller, V. A., Smith, C., Uzark, K., Lowery, R., Rottach, N., Blume, E. D. and Schumacher, K. R. (2020). "Medical and end-of-life decision making in adolescents' pre-heart transplant: A descriptive pilot study." Palliat Med 34(3): 272-280.

**BACKGROUND:** Adolescents and young adults undergoing heart transplantation experience risks of morbidity and mortality both pre- and post-transplant. To improve end-of-life care for this population, it is necessary to understand their medical and end-of-life decision-making preferences. **AIM:** (1) To examine adolescent/young adult decision-making involvement specific to heart transplant listing, and (2) to characterize their preferences specific to medical and end-of-life decision making. **DESIGN:** This cross-sectional research study utilized survey methods. Data were collected from October 2016 to March 2018. **SETTING/PARTICIPANTS:** Twelve adolescent and young adult patients listed for heart transplant (ages = 12-19 years) and one parent for each were enrolled at a single-center, US children's hospital. **RESULTS:** Consistent with their preferences, the majority of adolescent/young adult participants (82%) perceived a high level of involvement in the decision to be listed for transplant. Patient involvement in this decision was primarily by way of seeking advice or information from their parents and being asked to express their opinion from parents. Despite a

preference among patients to discuss their prognosis and be involved in end-of-life decision making if seriously ill, only 42% of patients had discussed their end-of-life wishes with anyone. Few parents recounted having such discussions. Preferences regarding the timing and nature of end-of-life decision-making discussions varied. CONCLUSIONS: Although young people are involved in the decision to pursue heart transplantation, little attention is paid to involving them in discussions regarding end-of-life decision making in a manner that is consistent with individual preferences.

<https://pubmed.ncbi.nlm.nih.gov/31647374/>

**Dagla, M., Petousi, V. and Poulios, A. (2020). "Bioethical Decisions in Neonatal Intensive Care: Neonatologists' Self-Reported Practices in Greek NICUs." Int J Environ Res Public Health 17(10).**

This study presents, for the first time, empirical data on practices regarding bioethical decision-making in treatment of preterm and ill newborns in Greece. The aim of the study was to: a) record self-reported practices and involvement of Greek physicians in decisions of withholding and withdrawing neonatal intensive care, and b) explore the implication of cultural, ethical, and professional parameters in decision-making. Methods: 71 physicians, employed fulltime in all public Neonatal Intensive Care Units (NICUs) (n = 17) in Greece, completed an anonymous questionnaire between May 2009 and May 2011. Results: One-third of the physicians in our sample admitted that they have, at least once in the past, decided the limitation of intensive care of a newborn close to death (37.7%) and/or a newborn with unfavorable neurological prognosis (30.8%). The higher the physicians' support towards the value of quality of human life, the more probable it was that they had taken a decision to withhold or withdraw neonatal intensive care ( $p < 0.05$ ). Conclusions: Our research shows that Greek NICU physicians report considerably lower levels of ethical decision-making regarding preterm and ill newborns compared to their counterparts in other European countries. Clinical practices and attitudes towards ethical decision-making appear to be influenced mainly by the Greek physicians' values.

<https://pubmed.ncbi.nlm.nih.gov/32429230/>

**DeMichelis, C., Zlotnik Shaul, R. and Rapoport, A. (2020). "Continuing the conversation about medical assistance in dying." J Med Ethics 46(1): 53-54.**

In their summary and critique, Gamble, Gamble, and Pruski mischaracterise both the central arguments and the primary objectives of our original paper. Our paper does not provide an ethical justification for paediatric Medical Assistance in Dying (MAID) by comparing it with other end of life care options. In fact, it does not offer arguments about the permissibility of MAID for capable young people at all. Instead, our paper focuses on the ethical questions that emerged as we worked to develop a policy for responding to MAID requests at our tertiary paediatric institution. Following the Supreme Court of Canada's recent decriminalisation of MAID, our hospital needed to answer immediate on-the-ground questions such as: 'What are we going to do if an 18-year-old patient in our care requested MAID today, as is now their legal right? How should we protect their privacy? What is the best way to ensure patients are informed when making these decisions?' On these important questions, Gamble, Gamble, and Pruski are silent.

<https://pubmed.ncbi.nlm.nih.gov/31395692/>

Dewan, M., Muthu, N., Shelov, E., Bonafide, C. P., Brady, P., Davis, D., Kirkendall, E. S., Niles, D., Sutton, R. M., Traynor, D., Tegtmeier, K., Nadkarni, V. and Wolfe, H. (2020). "Performance of a Clinical Decision Support Tool to Identify PICU Patients at High Risk for Clinical Deterioration." *Pediatr Crit Care Med* 21(2): 129-135.

**OBJECTIVES:** To evaluate the translation of a paper high-risk checklist for PICU patients at risk of clinical deterioration to an automated clinical decision support tool. **DESIGN:** Retrospective, observational cohort study of an automated clinical decision support tool, the PICU Warning Tool, adapted from a paper checklist to predict clinical deterioration events in PICU patients within 24 hours. **SETTING:** Two quaternary care medical-surgical PICUs-The Children's Hospital of Philadelphia and Cincinnati Children's Hospital Medical Center. **PATIENTS:** The study included all patients admitted from July 1, 2014, to June 30, 2015, the year prior to the initiation of any focused situational awareness work at either institution. **INTERVENTIONS:** We replicated the predictions of the real-time PICU Warning Tool by retrospectively querying the institutional data warehouse to identify all patients that would have flagged as high-risk by the PICU Warning Tool for their index deterioration. **MEASUREMENTS AND MAIN RESULTS:** The primary exposure of interest was determination of high-risk status during PICU admission via the PICU Warning Tool. The primary outcome of interest was clinical deterioration event within 24 hours of a positive screen. The date and time of the deterioration event was used as the index time point. We evaluated the sensitivity, specificity, positive predictive value, and negative predictive value of the performance of the PICU Warning Tool. There were 6,233 patients evaluated with 233 clinical deterioration events experienced by 154 individual patients. The positive predictive value of the PICU Warning Tool was 7.1% with a number needed to screen of 14 patients for each index clinical deterioration event. The most predictive of the individual criteria were elevated lactic acidosis, high mean airway pressure, and profound acidosis. **CONCLUSIONS:** Performance of a clinical decision support translation of a paper-based tool showed inferior test characteristics. Improved feasibility of identification of high-risk patients using automated tools must be balanced with performance.

<https://pubmed.ncbi.nlm.nih.gov/31577691/>

Dierickx, S., Onwuteaka-Philipsen, B., Penders, Y., Cohen, J., van der Heide, A., Puhan, M. A., Ziegler, S., Bosshard, G., Deliens, L. and Chambaere, K. (2020). "Commonalities and differences in legal euthanasia and physician-assisted suicide in three countries: a population-level comparison." *Int J Public Health* 65(1): 65-73.

**OBJECTIVES:** To describe and compare euthanasia and physician-assisted suicide (EAS) practice in Flanders, Belgium (BE), the Netherlands (NL) and Switzerland (CH). **METHODS:** Mortality follow-back surveys among attending physicians of a random sample of death certificates. **RESULTS:** We studied 349 EAS deaths in BE (4.6% of all deaths), 851 in NL (4.6% of all deaths) and 65 in CH (1.4% of all deaths). People who died by EAS were mostly aged 65 or older (BE: 81%, NL: 77% and CH: 71%) and were mostly diagnosed with cancer (BE: 57% and NL: 66%). Home was the most common place of death in NL (79%), while in BE and CH, more variation was found regarding to place of death. The decision to perform EAS was more frequently discussed with a

colleague physician in BE (93%) and NL (90%) than in CH (60%). CONCLUSIONS: EAS practice characteristics vary considerably in the studied countries with legal EAS. In addition to the legal context, cultural factors as well as the manner in which legislation is implemented play a role in how EAS legislation translates into practice.

<https://pubmed.ncbi.nlm.nih.gov/31297558/>

**Dombrecht, L., Cohen, J., Cools, F., Deliens, L., Goossens, L., Naulaers, G., Beernaert, K. and Chambaere, K. (2020). "Psychological support in end-of-life decision-making in neonatal intensive care units: Full population survey among neonatologists and neonatal nurses." *Palliat Med* 34(3): 430-434.**

**BACKGROUND:** Moral distress and burnout related to end-of-life decisions in neonates is common in neonatologists and nurses working in neonatal intensive care units. Attention to their emotional burden and psychological support in research is lacking.

**AIM:** To evaluate perceived psychological support in relation to end-of-life decisions of neonatologists and nurses working in Flemish neonatal intensive care units and to analyse whether or not this support is sufficient. **DESIGN/PARTICIPANTS:** A self-administered questionnaire was sent to all neonatologists and neonatal nurses of all eight Flemish neonatal intensive care units (Belgium) in May 2017. The response rate was 63% (52/83) for neonatologists and 46% (250/527) for nurses. Respondents indicated their level of agreement (5-point Likert-type scale) with seven statements regarding psychological support. **RESULTS:** About 70% of neonatologists and nurses reported experiencing more stress than normal when confronted with an end-of-life decision; 86% of neonatologists feel supported by their colleagues when they make end-of-life decisions, 45% of nurses feel that the treating physician listens to their opinion when end-of-life decisions are made. About 60% of both neonatologists and nurses would like more psychological support offered by their department when confronted with end-of-life decisions, and 41% of neonatologists and 50% of nurses stated they did not have enough psychological support from their department when a patient died. Demographic groups did not differ in terms of perceived lack of sufficient support. **CONCLUSION:** Even though neonatal intensive care unit colleagues generally support each other in difficult end-of-life decisions, the psychological support provided by their department is currently not sufficient. Professional ad hoc counselling or standard debriefings could substantially improve this perceived lack of support.

<https://pubmed.ncbi.nlm.nih.gov/31739740/>

**Dreesens, D., Veul, L., Westermann, J., Wijnands, N., Kremer, L., van der Weijden, T. and Verhagen, E. (2019). "The clinical practice guideline palliative care for children and other strategies to enhance shared decision-making in pediatric palliative care; pediatricians' critical reflections." *BMC Pediatr* 19(1): 467.**

**BACKGROUND:** Because of practice variation and new developments in palliative pediatric care, the Dutch Association of Pediatrics decided to develop the clinical practice guideline (CPG) palliative care for children. With this guideline, the association also wanted to precipitate an attitude shift towards shared decision-making (SDM) and therefore integrated SDM in the CPG Palliative care for children. The aim was to gain insight if integrating SDM in CPGs can potentially encourage pediatricians to practice SDM. Its objectives were to explore pediatricians' attitudes and thoughts regarding (1) recommendations on SDM in CPGs in general and the guideline Palliative care for

children specifically; (2) other SDM enhancing strategies or tools linked to CPGs. METHODS: Semi-structured face-to-face interviews. Pediatricians (15) were recruited through purposive sampling in three university-based pediatric centers in the Netherlands. The interviews were audio-recorded and transcribed verbatim, coded by at least two authors and analyzed with NVivo. RESULTS: Some pediatricians considered SDM a skill or attitude that cannot be addressed by clinical practice guidelines. According to others, however, clinical practice guidelines could enhance SDM. In case of the guideline Palliative care for children, the recommendations needed to focus more on how to practice SDM, and offer more detailed recommendations, preferring a recommendation stating multiple options. Most interviewed pediatricians felt that patient decision aids were beneficial to patients, and could ensure that all topics relevant to the patient are covered, even topics the pediatrician might not consider him or herself, or deems less important. Regardless of the perceived benefit, some pediatricians preferred providing the information themselves instead of using a patient decision aid. CONCLUSIONS: For clinical practice guidelines to potentially enhance SDM, guideline developers should avoid blanket recommendations in the case of preference sensitive choices, and SDM should not be limited to recommendations on non-treatment decisions. Furthermore, preference sensitive recommendations are preferably linked with patient decision aids.

<https://pubmed.ncbi.nlm.nih.gov/31783822/>

**Durbach, N. (2020). "Dead or Alive? Stillbirth Registration, Premature Babies, and the Definition of Life in England and Wales, 1836-1960." *Bull Hist Med* 94(1): 64-90.**

When stillbirth registration became mandatory in England and Wales in 1926, it was not to amass statistics in the service of public health. Instead, it was part of broader anxieties that victims of infanticide were being disposed of under the guise of having been stillborn. But because it necessitated distinguishing between the living and the dead, the legislation that introduced stillbirth registration generated debate about the definition of life itself. This focused both on what counted as a sign of life and on questions about the viability of preterm infants. These contentious disputes had serious repercussions for the treatment of premature births well into the twentieth century. Significantly, they also underscore that what classifies a person as dead or alive is never self-evident. Instead, the state's authorized definition of life is under permanent negotiation as it is always mobilized in the service of particular regimes of power.

<https://pubmed.ncbi.nlm.nih.gov/32362594/>

**Feder, K. J. and Finn, J. I. (2019). "How Should Clinical Ethics Consultants Support Parents' Decision Making?" *AMA J Ethics* 21(10): E831-837.**

Clinical ethics consultants (CECs) frequently provide guidance to parents feeling grief and uncertainty. In response to a case in which a CEC works with parents making end-of-life decisions for their child, we argue that CECs should use insights from decision science to consider how emotional distress, information-processing heuristics, and person-environment relationships can influence decision making. Rather than rely on decision aids, CECs should take a personalized, values-based approach to facilitating decision making that acknowledges context and a plurality of possible "right" answers. By using this approach and insights from decision science to support parental decision

making, the consultation itself becomes a decision aid, as consultants and parents engage in shared decision making through facilitated discussion and reflection.  
<https://pubmed.ncbi.nlm.nih.gov/31651381/>

Feltman, D. M., Fritz, K. A., Datta, A., Carlos, C., Hayslett, D., Tonismae, T., Lawrence, C., Batton, E., Coleman, T., Jain, M., Andrews, B., Famuyide, M., Tucker Edmonds, B., Laventhal, N. and Leuthner, S. (2020). "Antenatal Periviability Counseling and Decision Making: A Retrospective Examination by the Investigating Neonatal Decisions for Extremely Early Deliveries Study Group." *Am J Perinatol* 37(2): 184-195.

OBJECTIVE: To describe periviability counseling practices and decision making.  
STUDY DESIGN: This is a retrospective review of mothers and newborns delivering between 22 and 24 completed weeks from 2011 to 2015 at six U.S. centers. Maternal and fetal/neonatal clinical and maternal sociodemographic data from medical records and geocoded sociodemographic information were collected. Separate analyses examined characteristics surrounding receiving neonatology consultation; planning neonatal resuscitation; and centers' planned resuscitation rates. RESULTS: Neonatology consultations were documented for 40, 63, and 72% of 498 mothers delivering at 22, 23, and 24 weeks, respectively. Consult versus no-consult mothers had longer median admission-to-delivery intervals (58.7 vs. 8.7 h,  $p < 0.001$ ). Consultations were seen more frequently when parental decision making was evident. In total, 76% of mothers had neonatal resuscitation planned. Resuscitation versus no-resuscitation newborns had higher mean gestational ages (24.0 vs. 22.9 weeks,  $p < 0.001$ ) and birthweights (618 vs. 469 g,  $p < 0.001$ ). Planned resuscitation rates differed at higher (HR) versus lower (LR) rate centers at 22 (43 vs. 7%,  $p < 0.001$ ) and 23 (85 vs. 58%,  $p < 0.001$ ) weeks. HR versus LR centers' populations had more socioeconomic hardship markers but fewer social work consultations (odds ratio: 0.31; confidence interval: 0.15-0.59,  $p < 0.001$ ). CONCLUSION: Areas requiring improvement included delivery/content of neonatology consultations, social work support, consideration of centers' patient populations, and opportunities for shared decisions.  
<https://pubmed.ncbi.nlm.nih.gov/31437859/>

Forman, E. N. and Ladd, R. E. (2019). "Caring for Dying Children." *Am J Bioeth* 19(12): 73-74.  
<https://pubmed.ncbi.nlm.nih.gov/31746707/>

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://pubmed.ncbi.nlm.nih.gov/31320406/>

**Herbst, L. A. and deSante-Bertkau, J. (2020). "Ethical Dilemmas at the Beginning and End of Life: A Needs-Based, Experience-Informed, Small-Group, Case-Based Curriculum for Pediatric Residents." *MedEdPORTAL* 16: 10895.**

**INTRODUCTION:** Pediatric residents are faced with ethical dilemmas in beginning- and end-of-life situations throughout their training. These situations are innately challenging, yet despite recommendations that residents receive training in ethics and end-of-life domains, they continue to report the need for additional training. To address these concerns, we developed an interactive and reflective palliative care and medical ethics curriculum including sessions focusing on ethical dilemmas at the beginning and end of life. **METHODS:** This module includes a trio of case-based, small-group discussions on artificial nutrition and hydration, futility, and ethical considerations in neonatology. Content was developed based on a needs assessment, input from local experts, and previously published material. Trainees completed assessments of comfort and understanding before and after each session. **RESULTS:** The module was attended and assessed by an average of 27 trainees per session, including residents and medical students. Knowledge of ethical considerations improved after individual sessions, with 86% of trainees reporting understanding ethical considerations involved in the decision to withdraw or withhold medically provided nutrition and hydration and 67% of trainees reporting understanding the use of the term futility. Trainee comfort in providing counseling or recommendations regarding specific ethical issues demonstrated a trend toward improvement but did not reach statistical significance. **DISCUSSION:** We successfully implemented this innovative module, which increased trainees' comfort with end-of-life care and ethical conflicts. Future studies should focus on the trainees' ability to implement these skills in clinical practice.

<https://pubmed.ncbi.nlm.nih.gov/32352032/>

**Lemos, A., Soares, H. and Guimarães, H. (2020). "Decision-making at the limit of viability: an overview." *Minerva Pediatr*, 10.23736/s0026-4946.20.05825-9.**

Babies born at the limit of viability have a high risk of morbidity and mortality. Despite great advances in science, the approach to these newborns remains challenging. Thus, this study reviewed the literature regarding the treatment of newborns at the limit of viability. There are several interventions that can be applied before and after birth to increase the baby's survival with the least sequelae possible, but different countries make different recommendations on the gestational age that each treatment should be given. There is more consensus on the extremities of viability, being that, at the lower extremity, comfort care is preferred and active care in newborns with higher gestational age. The higher the gestational age at birth, the higher the survival and survival without

morbidity rates. At all gestational ages, it is important to take into account the suffering of these babies and to provide them the best quality of life possible. Sometimes palliative care is the best therapeutic approach. The parents of these babies should be included in the decision-making process, if they wish, always respecting their needs and wishes. Nevertheless, the process of having such an immature child can be very painful for parents, so it is also important to take into account their suffering and provide them with all the necessary support. This support should be maintained even after the death of the newborn.

<https://pubmed.ncbi.nlm.nih.gov/32418408/>

Levy, C., Weeks, K. S., Benson, R. J., Miller, J. M., Higgins, J., Deutsch, S. A. and Lantos, J. D. (2019). "Failure to Provide Adequate Palliative Care May Be Medical Neglect." *Pediatrics* 144(4).

Doctors are required to notify Child Protective Services (CPS) if parents do not provide appropriate medical care for their children. But criteria for reporting medical neglect are vague. Which treatments properly fall within the realm of shared decision-making in which parents can decide whether to accept doctors' recommendations? Which treatments are so clearly in the child's interest that it would be neglectful to refuse them? When to report medical neglect concerns to CPS may be controversial. It would seem inhumane to allow a child to suffer because of parental refusal to administer proper analgesia. In this ethics rounds, we present a case of an adolescent with chronic pain who is terminally ill. Her parents were not adherent to recommended analgesia regimens. Her palliative care team had to decide whether to report the case to CPS.

<https://pubmed.ncbi.nlm.nih.gov/31484675/>

Lewis, C., Riddington, M., Hill, M., Bevan, C., Fisher, J., Lyas, L., Chalmers, A., Arthurs, O. J., Hutchinson, J. C., Chitty, L. S. and Sebire, N. (2019). "'The communication and support from the health professional is incredibly important': A qualitative study exploring the processes and practices that support parental decision-making about postmortem examination." *Prenat Diagn* 39(13): 1242-1253.

**BACKGROUND:** Consent rates for postmortem (PM) examination in the perinatal and paediatric setting have dropped significantly in the United Kingdom, the United States, and the Western Europe. We explored the factors that act as facilitators or barriers to consent and identified processes and practices that support parental decision-making. **METHODS:** A qualitative study conducted with bereaved parents, parent advocates, and health care professionals in the United Kingdom. Analysis was conducted on 439 free-text comments within a cross-sectional survey, interviews with a subset of 20 survey respondents and 25 health professionals, and a focus group with five parent advocates. **RESULTS:** Three broad parental decision-making groups were identified: 1, "Not open to postmortem examination"; 2, "Consent regardless of concerns"; and 3, "Initially undecided." Decisional drivers that were particularly important for this "undecided" group were "the initial approach," "adjustment and deliberation," "detailed discussion about the procedure," and "formal consent." The way in which these were managed by health care staff significantly impacted whether those parents' consented to PM, particularly for those who are ambivalent about the procedure. **CONCLUSIONS:**

We propose a set of recommendations to improve the way PM counselling and consent is managed. Adopting such measures is likely to lead to improved family experience and more consistent and high-quality discussion regarding PM.

<https://pubmed.ncbi.nlm.nih.gov/31682025/>

Lövgren, M., Melin-Johansson, C., Udo, C. and Sveen, J. (2019). "Telling the truth to dying children-End-of-life communication with families." *Acta Paediatr* 108(11): 2111-2112.

<https://pubmed.ncbi.nlm.nih.gov/31299110/>

Marland, E. and Davies, B. (2019). "In the child's best interests: should life be sustained when further treatment is futile?" *Nurs Child Young People* 31(6): 23-27.

The aim of this article is to explore the concept of medical futility and the withdrawal of care for children in intensive care units. There have been several recent cases where medical staff have considered that there was no possibility of recovery for a child, yet their clinical judgments were challenged by the parents. The private anguish of these families became public, social media heightened emotions and this was followed by political and religious intrusion. Innovations in medical treatment and technological advances raise issues for all those involved in the care of children and young people especially when decisions need to be made about end of life care. Healthcare professionals have a moral and legal obligation to determine when treatment should cease in cases where it is determined to be futile. The aim should be to work collaboratively with parents but all decisions must be made in the best interests of the child. However, medical staff and parents may have differing opinions about care decisions. In part, this may be as a result of their unique relationships with the child and different understanding of the extent to which the child is in discomfort or can endure pain.

<https://pubmed.ncbi.nlm.nih.gov/31299110/>

Medeiros, C., Buckley, L., Metcalfe, K., Narayanan, U. G. and Widger, K. (2020). "Decision aids available for parents making end-of-life or palliative care decisions for children: A scoping review." *J Paediatr Child Health* 56(5): 692-703.

AIM: To identify and assess the quality of decision aids that align the decision, values and information provided for parents making end-of-life or palliative care decisions for children with life-threatening conditions. METHODS: Six databases and the grey literature were searched in December 2018. Two reviewers independently reviewed database citations, and one reviewed grey literature citations. Citation chaining via Scopus was conducted. Quality was assessed using IPDAS Collaboration Criteria. RESULTS: After reviewing 18 671 database citations and 10 988 grey literature citations, 18 citations describing 11 decision aids remained. Decision aids targeted premature infants, children requiring airway management, children with cancer and children with scoliosis. Three aids underwent testing beyond initial development. Quality scores averaged 27 of 50 points. CONCLUSIONS: There are few high-quality decision aids available for use and a lack evidence of widespread clinical use. Additional research is needed to support systematic development and the use of decision aids with families.

<https://pubmed.ncbi.nlm.nih.gov/32281164/>

Mekelenkamp, H., Lankester, A. C., Bierings, M. B., Smiers, F. J. W., de Vries, M. C. and Kars, M. C. (2020). "Parental experiences in end-of-life decision-making in allogeneic pediatric stem cell transplantation: "Have I been a good parent?"." *Pediatr Blood Cancer* 67(5): e28229.

**BACKGROUND:** In pediatric hematopoietic stem cell transplantation (HSCT), the end-of-life (EOL) phase and the loss of the child is often characterized by a sudden deterioration of the child following a period of intensive curative treatment. This demands a fast transition for parents. Therefore, an understanding of the parents' perspective on decision-making in such a complex situation is needed. This study aims to gain insight in parental experiences in EOL decision-making in allogeneic pediatric HSCT. **METHODS:** A qualitative descriptive study was performed among parents of eight families. Data were thematically analyzed. **RESULTS:** All parents were aware of their child's deterioration. Six families were confronted with a rapid deterioration, while two families experienced a gradual realization that their child would not survive. Parental EOL decision-making in pediatric HSCT shows a reflective perspective on the meaning of parenthood in EOL decision-making. Two central themes were identified: "survival-oriented decision-making" and "struggling with doubts in hindsight." Six subthemes within the first theme described the parents' goal of doing everything to achieve survival. **DISCUSSION:** Parents experienced EOL decision-making mainly as a process guided by health care professionals (HCPs) based on the child's condition and treatment possibilities. The decision-making is characterized by following opportunities and focusing on hope for cure. In hindsight parents experienced doubts about treatment steps and their child's suffering. HCPs can strengthen the parental role by an early integration of palliative care, providing timely support to parents in the process of imminent loss. Advance care planning can be used to support communication processes, defining preferences for future care.

<https://pubmed.ncbi.nlm.nih.gov/32134215/>

Messika, J., Boussard, N., Guérin, C., Michel, F., Nseir, S., Yonis, H., Barbier, C. M., Rouzé, A., Fouilloux, V., Gaudry, S., Ricard, J. D., Silverman, H. and Dreyfuss, D. (2020). "Strengths of the French end-of-life Law as Well as its Shortcomings in Handling Intractable Disputes Between Physicians and Families." *New Bioeth* 26(1): 53-74.

French end-of-life law aims at protecting patients from unreasonable treatments, but has been used to force caregivers to prolong treatments deemed unreasonable. We describe six cases (five intensive care unit patients including two children) where families disagreed with a decision to withdraw treatments and sued medical teams. An emergent inquiry was instigated by the families. In two cases, the court rejected the families' inquiries. In two cases, the families appealed the decision, and in both the first jurisdiction decision was confirmed, compelling caregivers to pursue treatments, even though they deemed them unreasonable. We discuss how this law may be perverted. Legal procedures may result in the units' disorganisation and give rise to caregivers' stress. Families' requests may be subtended by religious beliefs. French end-of-life law has benefits in theoretically constraining physicians to withhold or withdraw disproportionate therapies. These cases underline some caveats and the perverse effects of its literal reading.

<https://pubmed.ncbi.nlm.nih.gov/32065064/>

Mitchell, S. J., Slowther, A. M., Coad, J., Akhtar, S., Hyde, E., Khan, D. and Dale, J. (2019). "Ethics and patient and public involvement with children and young people." Arch Dis Child Educ Pract Ed 104(4): 195-200.

Patient and public involvement (PPI) is important both in research and in quality improvement activities related to healthcare services. While PPI activities do not require formal ethical approval, they can raise a number of ethical concerns, through the introduction of complex technical medical concepts, challenging language or sensitive subject areas. There is very little published literature to guide ethical practice in this area. We have been conducting PPI with children and young people throughout a research study in paediatric palliative care. PPI started during the application process and continued to guide and shape the research as it progressed. Ethical issues can arise at any time in PPI work. Although many can be predicted and planned for, the nature of PPI means that researchers can be presented with ideas and concepts they had not previously considered, requiring reflexivity and a reactive approach. This paper describes how we considered and addressed the potential ethical issues of PPI within our research. The approach that emerged provides a framework that can be adapted to a range of contexts and will be of immediate relevance to researchers and clinicians who are conducting PPI to inform their work.

<https://pubmed.ncbi.nlm.nih.gov/29440127/>

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://pubmed.ncbi.nlm.nih.gov/29656703/>

Moreton, K. L. (2020). "Reflecting on 'Hannah's Choice': Using the Ethics of Care to Justify Child Participation in End of Life Decision-Making." *Med Law Rev* 28(1): 124-154.

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://pubmed.ncbi.nlm.nih.gov/31257451/>

Needle, J. S., Peden-McAlpine, C., Liaschenko, J., Koschmann, K., Sanders, N., Smith, A., Schellinger, S. E. and Lyon, M. E. (2020). "'Can you tell me why you made that choice?': A qualitative study of the influences on treatment decisions in advance care planning among adolescents and young adults undergoing bone marrow transplant." *Palliat Med* 34(3): 281-290.

**BACKGROUND:** Adolescent and young adult advance care planning is beneficial in improving communication between patients, surrogates, and clinicians. The influences on treatment decisions among adolescents and young adults are underexplored in the literature. **AIM:** The aim of this study was to explore and better understand the influences on decision-making for adolescent and young adult bone marrow transplant patients about future medical care. **DESIGN:** Clinical case studies and qualitative inductive content analysis of treatment decisions made during the Respecting Choices(®) Next Steps Pediatric Advance Care Planning conversation as a component of the Family-Centered Advance Care Planning Intervention.

**SETTINGS/PARTICIPANTS:** A total of 10 adolescent and young adult patients (aged 14-27 years) undergoing bone marrow transplant at an academic Midwest children's hospital were involved in the study. **RESULTS:** Influences on participants' decisions were consideration for family, quality of life, and awareness of self. Desire to avoid suffering and maintain an acceptable quality of life was often in competition with participant's concern over the perceived negative impact of discontinuing treatment on their families. **CONCLUSION:** This study highlights that adolescent and young adult bone marrow transplant patients are capable of meaningful deliberation about future treatment decisions. Influences on decision-making should be incorporated into advance care planning conversations to facilitate communication between patients and

their surrogates. Longitudinal research is needed to explore these influences throughout the trajectory of illness.

<https://pubmed.ncbi.nlm.nih.gov/31659933/>

**Nelson, R. H. (2020). "Public views about quality of life and treatment withdrawal in infants: limitations and directions for future research." *J Med Ethics* 46(1): 20-21.**

<https://pubmed.ncbi.nlm.nih.gov/31659933/>

**Neubauer, K. and Boss, R. D. (2020). "Ethical considerations for cardiac surgical interventions in children with trisomy 13 and trisomy 18." *Am J Med Genet C Semin Med Genet* 184(1): 187-191.**

Medical and surgical approaches to children with trisomy 13 and 18 are evolving, and an increasing number of patients are being considered for simple and complex cardiac procedures. This review describes how the shifts in medical and social considerations for children with trisomy 13 and 18 mirror the shifts that occurred 50 years ago for children with trisomy 21. Yet the variability in cardiac lesions, and variability in non-cardiac comorbidities, is much greater for patients with trisomy 13 and 18 than for those with trisomy 21. That variability, combined with the severe neurologic impairment in survivors, complicates the current risk: benefit balance of surgical intervention.

Consistent approaches to care for these patients should be built on an evidence base, and should include contributions from specialists in medical ethics and palliative care.

<https://pubmed.ncbi.nlm.nih.gov/31975573/>

**Owen, K. (2020). "Taking courage: Neonatal euthanasia and ethical leadership." *Nurs Ethics* 27(1): 321-325.**

<https://pubmed.ncbi.nlm.nih.gov/30514168/>

**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://pubmed.ncbi.nlm.nih.gov/31408889/>

**Pinto Taylor, E. and Doolittle, B. (2020). "Caregiver Decision-Making for Terminally Ill Children: A Qualitative Study." *J Palliat Care* 35(3): 161-166.**

**INTRODUCTION:** Many children are born with life-limiting illnesses. Medical decision-making for these children by caregivers is complex and causes significant psychosocial distress, which can be partially alleviated by effective communication with medical providers. In order for providers to support caregivers, this study explores how caregivers make decisions regarding the medical care of their terminally ill children.

**METHODS:** Semistructured interviews were conducted among caregivers of terminally ill children. Participation was voluntary and confidential. The institutional review board approved the protocol. Transcripts were read and coded by 2 authors using inductive, concurrent analysis to reach thematic saturation and generate common themes.

**RESULTS:** Nine interviews were completed, discussing the care of 10 children. Caregivers described decision-making as impacted by their relationships with medical providers of 2 distinct types-trusting and nontrusting. Trusting relationships were notable for a longitudinal relationship with medical staff who empowered caregivers and treated the patient primarily as a child. Nontrusting relationships were noted when the medical team objectified their child as a "patient" and appeared to withhold information. Also, nontrusting relationships occurred when caregivers felt frustration with needing to educate health-care providers about their child's illness. **CONCLUSION:** Decision-making by caregivers of terminally ill children is complex, and supporting families in this process is a critical role of all medical providers. A trusting relationship with medical team members was identified as an effective tool for well-supported decision-making, which can potentially alleviate the suffering of the child and distress of the caregivers during this emotionally charged time.

<https://pubmed.ncbi.nlm.nih.gov/31722609/>

**Rady, M. Y. (2020). "RETRACTED: Routine parental request of organ donation in end-of-life care of children in the United Kingdom: Unresolved medical, legal, cultural and religious challenges." *Med Leg J* 88(2): Np1-np4.**

The Journal Editors have determined the research reported in a publication (Darlington et al. Parents' experiences of requests for organ and tissue donation: the value of asking. *Arch Dis Child* 2019; 104: 837-843) discussed in the above paper was misunderstood and mischaracterised. As a result, this paper has been retracted from publication.

<https://pubmed.ncbi.nlm.nih.gov/32410498/>

**Salter, E. K. (2020). "The new futility? The rhetoric and role of "suffering" in pediatric decision-making." *Nurs Ethics* 27(1): 16-27.**

This article argues that while the presence and influence of "futility" as a concept in medical decision-making has declined over the past decade, medicine is seeing the rise of a new concept with similar features: suffering. Like futility, suffering may appear to have a consistent meaning, but in actuality, the concept is colloquially invoked to refer to very different experiences. Like "futility," claims of patient "suffering" have been

used (perhaps sometimes consciously, but most often unconsciously) to smuggle value judgments about quality of life into decision-making. And like "futility," it would behoove us to recognize the need for new, clearer terminology. This article will focus specifically on second hand claims of patient suffering in pediatrics, but the conclusions could be similarly applied to medical decisions for adults being made by surrogate decision-makers. While I will argue that suffering, like futility, is not sufficient wholesale justification for making unilateral treatment decisions, I will also argue that claims of patient suffering cannot be ignored, and that they almost always deserve some kind of response. In the final section, I offer practical suggestions for how to respond to claims of patient suffering.

<https://pubmed.ncbi.nlm.nih.gov/31032704/>

**Shaw, C., Connabeer, K., Drew, P., Gallagher, K., Aladangady, N. and Marlow, N. (2020). "Initiating end-of-life decisions with parents of infants receiving neonatal intensive care." *Patient Educ Couns* 103(7): 1351-1357.**

**OBJECTIVE:** To investigate whether parent-initiated or doctor-initiated decisions about limiting life-sustaining treatment (LST) in neonatal care has consequences for how possible courses of action are presented. **METHOD:** Formal conversations (n = 27) between doctors and parents of critically ill babies from two level 3 neonatal intensive care units were audio or video recorded. Sequences of talk where decisions about limiting LST were presented were analysed using Conversation Analysis and coded using a Conversation Analytic informed coding framework. Relationships between codes were analysed using Fisher's exact test. **RESULTS:** When parents initiated the decision point, doctors subsequently tended to refer to or list available options. When doctors initiated, they tended to use 'recommendations' or 'single-option' choice (conditional) formats (p=0.017) that did not include multiple treatment options. Parent initiations overwhelmingly concerned withdrawal, as opposed to withholding of LST (p=0.030). **CONCLUSION:** Aligning parents to the trajectory of the news about their baby's poor condition may influence how the doctor subsequently presents the decision to limit LST, and thereby the extent to which parents are invited to participate in shared decision-making. **PRACTICE IMPLICATIONS:** Explicitly proposing treatment options may provide parents with opportunities to be involved in decisions for their critically ill babies, thereby fostering shared decision-making.

<https://pubmed.ncbi.nlm.nih.gov/32111382/>

**Silberberg, A., Robetto, J., Grimaux, G., Nucifora, L. and Moreno Villares, J. M. (2020). "Ethical issues about the paradigm shift in the treatment of children with trisomy 18." *Eur J Pediatr* 179(3): 493-497.**

Until recently, trisomy 18 was considered a disease incompatible with life, with a high percentage of electively terminated pregnancies. The usual behavior was denial of treatment. But some medical interventions have changed the survival of children. A search for articles published in the PubMed database on the latest medical decisions in newborns with trisomy 18 was done. Two main subjects were examined: (1) the chances of survival and (2) the perception of quality of life. Trisomy 18 is no longer considered a disease incompatible with life, and the discussion has shifted towards the type of treatment that is appropriate to initiate at birth. There are two medical attitudes

towards these children: either palliative care or life-prolonging interventions. With medical intervention, the survival is as high as 23% at 5 years of age. Regarding the quality of life, all decision-makers emphasize the possibility of taking the child home. The physicians' perception is more pessimistic than that of the parents. Only a few children benefit from medical interventions. Conclusion: There is a rethinking of treatment behavior in children with trisomy 18. The possible quality of life achieved should be further investigated. It seems inappropriate to simply dismiss medical interventions.

What is Known

- Until recently, trisomy 18 was considered a disease incompatible with life. The most common behavior was abortion and denial of treatment.

What is New

- It is no longer considered a lethal disease. The type of medical intervention that is appropriate to perform is now being discussed. Selected children benefit from an interventionist approach.

<https://pubmed.ncbi.nlm.nih.gov/31814050/>

**Singh, H. K., Macdonald, M. E. and Carnevale, F. A. (2020). "Considering medical assistance in dying for minors: the complexities of children's voices." J Med Ethics 46(6): 399-404.**

Medical assistance in dying (MAID) legislation in Canada followed much deliberation after the Supreme Court of Canada's ruling in *Carter v. Canada*. Included in this deliberation was the Special Joint Committee on Physician Assisted Dying's recommendation to extend MAID legislation beyond the inclusion of adults to mature minors. Children's agency is a construct advanced within childhood studies literature which entails eliciting children's voices in order to recognise children as active participants in constructing their own childhoods. Using this framework, we consider the possible extension of MAID legislation to most minors. We highlight important questions regarding how insights from children's voices could be mobilised in the life or death context of MAID. We conclude that children's voices have the potential to help determine their eligibility for MAID; however, incorporating children's voices in the context of MAID requires careful consideration due to the complexity of voice.

<https://pubmed.ncbi.nlm.nih.gov/32332149/>

**Smok, D. and Prager, K. M. (2020). "The ethics of neurologically complicated pregnancies." Handb Clin Neurol 171: 227-242.**

Bioethical conflicts in pregnancy are distinguished from those in other areas of medicine due to competing interests between mother and fetus because of their shared biology. Historically, prior to the advent of fetal therapy and advances in medical technology, the maternal-fetal complex was considered to be a single entity. With advances in medicine, treatment options can now be directed at both the mother and the fetus, and a duality has evolved in the maternal-fetal unit. Thus at some point during pregnancy, two individuals rather than just one are the responsibility of the physician. In determining how to properly care for the pregnant woman with a neurologic condition, therapeutic choices must take into consideration the impact a treatment will have on both the mother and the fetus. Since what benefits one may harm the other, tension

results from the need to choose. This chapter will highlight ethical conflicts arising at the interface of obstetrics and neurology. We will delve into situations where difficult reproductive and therapeutic decisions must be made in pregnant women with intellectual disabilities, stroke, brain tumors, and epilepsy. The complexity of brain death in pregnancy will be analyzed, acknowledging the influence of politics, law, and religion that bears on ethical decision-making. In approaching ethical dilemmas encountered in pregnancies complicated by neurologic conditions, frameworks based on principles, virtues, care, and feminist ethics, and case precedents will be applied to facilitate ethically appropriate shared decision-making. We hope that this chapter will provide valuable guidance for providers caring for this complex obstetric population.

<https://pubmed.ncbi.nlm.nih.gov/32736753/>

**Strupp, J., Köneke, V., Rietz, C. and Voltz, R. (2019). "Perceptions of and Attitudes Toward Death, Dying, Grief, and the Finitude of Life-A Representative Survey Among the General Public in Germany." Omega (Westport), 10.1177/0030222819882220: 30222819882220.**

Some end-of-life aspects have become a significant political and social issue such as elderly care and euthanasia. But hardly anything is known about how the general public in Germany thinks about death and dying more generally. Therefore, we conducted a representative online survey (N = 997) regarding 21 end-of-life aspects. Differences between subgroups were analyzed by conducting analyses of variance and Tukey honestly significance difference post hoc tests and by performing t tests. The findings revealed that the general public is open to engaging with topics of death, dying, and grief and that death education might even be promoted for children. Most participants appraised dealing with the finitude of life as part of a good life, but few have contemplated death and dying themselves so far. Attitudes and perceptions were related to age, subjective health, religious denomination, and gender. The survey provides useful implications for community palliative care, death education, and communication with dying people.

<https://pubmed.ncbi.nlm.nih.gov/31615342/>

**Truog, R. D. (2020). "Is 'best interests' the right standard in cases like that of Charlie Gard?" J Med Ethics 46(1): 16-17.**

Savulescu and colleagues have provided interesting insights into how the UK public view the 'best interests' of children like Charlie Gard. But is best interests the right standard for evaluating these types of cases? In the USA, both clinical decisions and legal judgments tend to follow the 'harm principle', which holds that parental choices for their children should prevail unless their decisions subject the child to avoidable harm. The case of Charlie Gard, and others like it, show how the USA and the UK have strikingly different approaches for making decisions about the treatment of severely disabled children.

<https://pubmed.ncbi.nlm.nih.gov/31662479/>

**Ursin, L. and Syltern, J. (2020). "Protect us from ourselves: Balancing the parental instinct of saving." Nurs Ethics 27(5): 1282-1296.**

**BACKGROUND:** Neonatologists, legal experts and ethicists extensively discuss the ethical challenges of decision-making when a child is born at the limit of viability. The voices of parents are less heard in this discussion. In Norway, parents are actively shielded from the burden of decision-making responsibility. In an era of increasing patient autonomy, is this position still defensible? **RESEARCH QUESTION:** In this article, we discuss the role of parents in neonatal decision-making, based on the following research question: Should parents decide whether to provide lifesaving treatment when their child is born at the limit of viability? **RESEARCH DESIGN:** We conducted eight interviews with 12 parents, 4 individuals and 4 couples, all having experienced prenatal counselling at the limit of viability. The interviews took place at different university locations in Norway in the years 2014-2018. **ETHICAL CONSIDERATIONS:** All study participants gave their written informed consent. The Regional Committee for Medical Research Ethics approved the study. **FINDINGS:** We identified six main themes in parents' responses to the research question. Parents (1) experienced an emotional turmoil confronted with birth at the border of viability, (2) emphasized the importance of being involved in decision-making, (3) described and reflected on the need to balance the parental instinct of saving, (4) were concerned about the dilemmas involved in protecting the family, (5) were worried about the burden of overwhelming responsibility and (6) called for guideline relief. **CONCLUSION:** The perceived parental instinct of saving the life of their child makes it hard for parents to step away from a call for 'everything to be done'. Involvement of an interprofessional periviability team drawing on the experiences and viewpoints of nurses and neonatologists in decision-making is needed to protect both infants and parents against undue parental push for treatment and enable parents to make good decisions regarding their child.

<https://pubmed.ncbi.nlm.nih.gov/31505995/>

**Wilkinson, D. and Moore, G. (2020). "The genetic crystal ball: new answers and new questions for infants with neuromuscular disorders and respiratory failure." *Arch Dis Child* 105(4): 313-314.**

In paediatric and neonatal intensive care, ethical questions about the benefits and burdens of treatment for children and infants with severe neurological disorders are fraught, but relatively familiar.<sup>1</sup> However, for rare disorders, like XLMTM, answering parents' questions adequately and honestly has often been extremely difficult. Sometimes that difficulty has arisen because it has taken a long time to reach a definitive diagnosis (the average age at diagnosis for XLMTM is 4 months<sup>2</sup>). However, even with a diagnosis, available information on outcomes may be difficult to interpret.

<https://pubmed.ncbi.nlm.nih.gov/32041733/>

**Yamaji, N., Suto, M., Takemoto, Y., Suzuki, D., Lopes, K. D. S. and Ota, E. (2020). "Supporting the Decision Making of Children With Cancer: A Meta-synthesis." *J Pediatr Oncol Nurs*, 10.1177/1043454220919711: 1043454220919711.**

**Background:** Recently, awareness of children's decision making has increased in an effort to enhance palliative care. However, the conceptual framework for decision making among children with cancer remains unclear. **Aims:** We clarified the decision-making process of children with cancer regarding their care, treatment, and support

from family and health care professionals, and identified their needs and preferences. Design: We used metaethnography to conduct a metasynthesis of relevant studies. Data sources: We searched PubMed, EMBASE, PsycINFO, MEDLINE, and CINAHL. This report was prepared in accordance with the PRISMA statement. Results: Of the 7,237 retrieved studies, 27 met our inclusion criteria. Four themes emerged that reflected the decision-making process of children with cancer: (a) facing changes brought about by a health threat, (b) preparing for action, (c) asserting one's choice, and (d) internal and external influences. Conclusion: Children with cancer initially undergo a decision-making process. Respecting children's preferences, values, and emotions may help build trusting relationships and promote their decision-making capability. Future research should focus on children's emotions, cognition, development, and interactions with parents and health care professionals.

<https://pubmed.ncbi.nlm.nih.gov/32456542/>

**Yotani, N., Nabetani, M., Feudtner, C., Honda, J., Kizawa, Y. and Iijima, K. (2020). "Withholding and withdrawal of life-sustaining treatments for neonate in Japan: Are hospital practices associated with physicians' beliefs, practices, or perceived barriers?" *Early Hum Dev* 141: 104931.**

OBJECTIVE: To describe the current status of withholding or withdrawal of life-sustaining interventions (LSI) for neonates in Japan and to identify physician- and institutional-related factors that may affect advance care planning (ACP) practices with parents. STUDY DESIGN: A self-reported questionnaire was administered to assess frequency of withholding and withdrawing intensive care at the respondent's facility, the physician's degree of affirming various beliefs about end-of-life care that was compared to 7 European countries, their self-reported ACP practices and perceived barriers to ACP. Three neonatologists at all 298 facilities accredited by the Japan Society for Neonatal Health and Development were surveyed, with 572 neonatologists at 217 facilities responding. RESULTS: At 76% of facilities, withdrawing intensive care treatments was "never" done, while withholding intensive care had been done "sometimes" or more frequently at 82% of facilities. Japanese neonatologists differed from European neonatologists regarding their degree of affirmation of 3 out of 7 queried beliefs about end-of-life care. In hospitals that were more likely to "sometimes" (or more often) withdraw treatments, respondents were less likely to affirm beliefs about doing "everything possible" or providing the "maximum of intensive care". Self-reported ACP practices did not vary between neonatologists based on their hospital's overall pattern of withholding or withdrawing treatments. CONCLUSION: Among NICU facilities in Japan, 21% had been sometimes withdrawing LSI and 82% had been "sometimes" withholding LSI. Institutional treatment practices may have a strong association with physicians' beliefs that then affect end-of-life discussions, but not with self-reported ACP practices.

<https://pubmed.ncbi.nlm.nih.gov/31810052/>

## Outcomes & Instruments

Abdelmabood, S., Fouda, A. E., Boujettif, F. and Mansour, A. (2020). "Treatment outcomes of children with acute lymphoblastic leukemia in a middle-income developing country: high mortalities, early relapses, and poor survival." *J Pediatr (Rio J)* 96(1): 108-116.

**OBJECTIVE:** Acute lymphoblastic leukemia is the most common childhood cancer, yet surprisingly, very few studies have reported the treatment outcomes and the relapse rate of patients from low/middle-income countries. **METHOD:** This study was a 5-year retrospective cohort study. It was conducted at Oncology Center of Mansoura University in Egypt and aimed to estimate the treatment outcomes and the relapse rates of newly diagnosed acute lymphoblastic leukemia in children. **RESULTS:** Two hundred children suffering from acute lymphoblastic leukemia were studied; forty-six patients (23%) died during induction and most of those deaths were related to infection. Forty-one patients (27%) relapsed out of the 152 patients who achieved complete remission. The most common site of relapse was the bone marrow, followed by the isolated central nervous system, 53.7% and 31.7%, respectively. Seventy-eight percent of relapses occurred very early/early rather than later. The majority of relapse patients' deaths were related to infection and disease progression. The 5-year overall survival rate for patients was 63.1% (82.1% for non-relapsed compared to 36.6% for relapsed patients). **CONCLUSION:** There was a high incidence of induction deaths related to infection and high percentages of very early/early relapses, with high mortalities and low 5-year overall survival rates. These findings suggest the urgent need for modification of chemotherapy regimens to be suitable for the local conditions, including implementation of supportive care and infection control policies. There is also a requirement for antimicrobial prophylaxis during induction period combined with the necessary increase in government healthcare spending to improve the survival of acute lymphoblastic leukemia in Egyptian children.

<https://pubmed.ncbi.nlm.nih.gov/30240631/>

Affonseca, C. A., Carvalho, L. F. A., Quinet, R. P. B., Guimarães, M., Cury, V. F. and Rotta, A. T. (2019). "Palliative extubation: five-year experience in a pediatric hospital." *J Pediatr (Rio J)*, 10.1016/j.jpmed.2019.07.005.

**OBJECTIVE:** To present the characteristics of pediatric patients with chronic and irreversible diseases who underwent palliative extubation. **METHOD:** This is a descriptive analysis of a case series of patients admitted to a public pediatric hospital, with chronic and irreversible diseases, permanently dependent on ventilatory support, who underwent palliative extubation between April 2014 and May 2019. The following information was collected from the medical records: demographic data, diagnosis, duration and type of mechanical ventilation; date, time, and place of palliative extubation; medications used; symptoms observed; and hospital outcome. **RESULTS:** A total of 19 patients with a mean age of 2.2 years underwent palliative extubation. 68.4% of extubations were performed in the ICU; 11 patients (57.9%) died in the hospital. The time between mechanical ventilation withdrawal and in-hospital death ranged from 15min to five days. Thirteen patients had an orotracheal tube and the others a tracheostomy. The main symptoms were dyspnea and pain, and the main

drugs used to control symptoms were opioids and benzodiazepines. CONCLUSIONS: It was not possible to identify predictors of in-hospital death after ventilatory support withdrawal. Palliative extubation requires specialized care, with the presence and availability of a multidisciplinary team with adequate training in symptom control and palliative care.

<https://pubmed.ncbi.nlm.nih.gov/31493370/>

Albaba, H., Barnes, T. A., Veitch, Z., Brown, M. C., Shakik, S., Su, S., Naik, H., Wang, T., Liang, M., Perez-Cosio, A., Eng, L., Mittmann, N., Xu, W., Howell, D. and Liu, G. (2019). "Acceptability of Routine Evaluations Using Patient-Reported Outcomes of Common Terminology Criteria for Adverse Events and Other Patient-Reported Symptom Outcome Tools in Cancer Outpatients: Princess Margaret Cancer Centre Experience." *Oncologist* 24(11): e1219-e1227.

BACKGROUND: Recent studies have demonstrated improved outcomes with real-time patient-reported outcome questionnaires (PRO questionnaires) using questions adapted for patient use from the National Cancer Institute's Common Terminology Criteria for Adverse Events (CTCAE). Outside of the clinical trial setting, limited information exists on factors affecting the completion of PRO questionnaires in routine practice. The primary aim of this prospective cross-sectional study was to evaluate patient willingness to complete PRO questionnaires on a regular basis and to better understand responder biases to improve patient feedback. MATERIALS AND METHODS: Patients performing PRO-CTCAE toxicity and symptom PRO questionnaires in oncology clinics at Princess Margaret Cancer Centre from 2013 to 2016 were assessed for their willingness to complete PRO questionnaires using a nine-item, tablet-based acceptability survey. Patient-reported characteristics (i.e., age, sex, language, marital status, education, occupation, etc.), cancer type, treatment modalities, and health metrics (i.e., Eastern Cooperative Oncology Group) were also collected. Characteristics were evaluated by logistic regression (odds ratios [OR]) using the primary outcome with prespecified levels of significance for univariate ( $p \leq .10$ ), and additional multivariate ( $p \leq .05$ ) testing. RESULTS: A total of 1,792 patients (median age 60 years; range 18-97) with various cancer diagnoses were assessed. A greater proportion of female (56%) and white (74%) respondents with an annual household income of <\$100,000 (69%) participated. More than half (58%) of respondents were willing to complete PRO questionnaires at every clinic visit, and a high proportion (77%) found utility in reporting physical and emotional feelings to clinicians using PRO questionnaires. In general, patients did not find that PRO questionnaires made clinic visits more difficult (93%). In uni- and multivariable testing, patients were more willing to complete sleep- and fatigue-related PRO questionnaires relative to chemotoxicity-based PRO questionnaires (OR 1.52;  $p = .012$ ). Patients aged 40-65 versus 18-40 years were also more likely to report high PRO questionnaire acceptability (OR 1.49;  $p = .025$ ). Additional patient characteristics such as white ethnicity (OR 1.76), Canada as country of birth (OR 1.66), and English language (OR 2.15) relative to other had higher acceptability on uni- ( $p < .001$ ) and multivariable ( $p < .001$ ) analyses. Patients reporting treatment intent as palliative (OR 0.69;  $p = .0013$ ) or hematological (OR 0.73;  $p = .027$ ) were less likely to report high PRO questionnaire acceptability on univariable analysis; however, only palliative patients (OR 0.72) maintained this effect on multivariable testing ( $p = .012$ ). Patients reporting higher health utility scores (per change in .05) also had significantly increased PRO questionnaire acceptability in uni- (OR 1.06;  $p < .001$ ) and

multivariable (OR 1.05;  $p = .008$ ) analyses. No significant differences in PRO questionnaire acceptability were seen between cancer types, education level, household income, employment status, or treatment modality. **CONCLUSION:** Routine assessment using PRO questionnaires is associated with moderate acceptability by patients with cancer. Specific patient characteristics are associated with higher completion willingness. Additional research is necessary to identify factors associated with low acceptability of PRO questionnaires and to develop site-, ethnicity-, and treatment-specific instruments to assess the value of PRO questionnaires for symptom monitoring in clinical practice. **IMPLICATIONS FOR PRACTICE:** This study will help to identify the clinical, demographic, and survey characteristics associated with willingness to complete patient-reported outcome questionnaires regularly in the cancer outpatient setting.

<https://pubmed.ncbi.nlm.nih.gov/31409744/>

**Amiri, A., Vehviläinen-Julkunen, K., Solankallio-Vahteri, T. and Tuomi, S. (2020). "Impact of nurse staffing on reducing infant, neonatal and perinatal mortality rates: Evidence from panel data analysis in 35 OECD countries." *Int J Nurs Sci* 7(2): 161-169.**

**OBJECTIVES:** To investigate the magnitude of effect nurse staffing had on decreasing the newborn mortality rates in member countries of Organisation for Economic Co-operation and Development (OECD). **METHODS:** The statistical technique of panel data analysis was applied to explore the possibility of association between the number of nurses' density per 1,000 population and infant, neonatal and perinatal mortality rates (IMR, NMR and PMR) per 1000 births. The observations of 35 OECD countries were collected over the period of 2000 through 2016. **RESULTS:** There were significant associations between nurse staffing and IMR, NMR and PMR i.e. a 1% increase in nurse-staffing level reduced IMR, NMR and PMR by 0.98%, 0.97% and 0.96%, respectively. Furthermore, the role of nursing-related services in declining the average of newborn mortality rates were investigated at the highest level in Slovenia (-5.50), Sweden (-3.34), Iceland (-2.51), Czech Republic (-1.86), Japan (-1.64) and Finland (-1.64). Moreover, if the current relationship between nurse-staffing level and newborn mortality rates are disturbed with nursing shortage (e.g. in Slovak Republic and Israel), then it takes about 17 years for the mortality rates to reduce and restore back to the previous equilibrium. **CONCLUSIONS:** A higher proportion of nurses' density per 1,000 population is associated with lower newborn mortality rates. In addition, the nursing-related services of Slovenia, Sweden, Iceland, Czech Republic, Japan and Finland with the highest impact on improving the health level of newborns would be good patterns for other developed countries in maternity and child health care .

<https://pubmed.ncbi.nlm.nih.gov/32685612/>

**Ashburn, N. P., Ryder, C. W., Angi, R. M., Snavey, A. C., Nelson, R. D., Bozeman, W. P., McGinnis, H. D., Winslow, J. T. and Stopyra, J. P. (2020). "One-Year Mortality and Associated Factors in Patients Receiving Out-of-Hospital Naloxone for Presumed Opioid Overdose." *Ann Emerg Med* 75(5): 559-567.**

**STUDY OBJECTIVE:** Out-of-hospital naloxone has been championed as a lifesaving solution during the opioid epidemic. However, the long-term outcomes of out-of-hospital naloxone recipients are unknown. The objectives of this study are to describe

the 1-year mortality of presumed opioid overdose victims identified by receiving out-of-hospital naloxone and to determine which patient factors are associated with subsequent mortality. METHODS: This was a regional retrospective cohort study of out-of-hospital records from 7 North Carolina counties from January 1, 2015 to February 28, 2017. Patients who received out-of-hospital naloxone were included. Out-of-hospital providers subjectively assessed patients for improvement after administering naloxone. Naloxone recipients were cross-referenced with the North Carolina death index to examine mortality at days 0, 1, 30, and 365. Naloxone recipient mortality was compared with the age-adjusted, at-large population's mortality rate in 2017. Generalized estimating equations and Cox proportional hazards models were used to assess for mortality-associated factors. RESULTS: Of 3,085 out-of-hospital naloxone encounters, 72.7% of patients (n=2,244) improved, whereas 27.3% (n=841) had no improvement with naloxone. At day 365, 12.0% (n=269) of the improved subgroup, 22.6% (n=190) of the no improvement subgroup, and 14.9% (n=459) of the whole population were dead. Naloxone recipients who improved were 13.2 times (95% confidence interval 13.0 to 13.3) more likely to be dead at 1 year than a member of the general populace after age adjusting of the at-large population to match this study population. Older age and being black were associated with 1-year mortality, whereas sex and multiple overdoses were not. CONCLUSION: Opioid overdose identified by receiving out-of-hospital naloxone with clinical improvement carries a 13-fold increase in mortality compared to the general population. This suggests that this is a high-risk population that deserves attention from public health officials, policymakers, and health care providers in regard to the development of long-term solutions.

<https://pubmed.ncbi.nlm.nih.gov/31983499/>

**Balasubramanian, S., Rao, N. M., Goenka, A., Roderick, M. and Ramanan, A. V. (2020). "Coronavirus Disease 2019 (COVID-19) in Children - What We Know So Far and What We Do Not." *Indian Pediatr* 57(5): 435-442.**

Pediatric coronavirus disease-19 (COVID-19) infection is relatively mild when compared to adults, and children are reported to have a better prognosis. Mortality in children appears rare. Clinical features of COVID-19 in children include fever and cough, but a large proportion of infected children appears to be asymptomatic and may contribute to transmission. It remains unclear why children and young adults are less severely affected than older individuals, but this might involve differences in immune system function in the elderly and/or differences in the expression/function of the cellular receptor for Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2)-Angiotensin converting enzyme 2 (ACE2). Laboratory findings and chest imaging may not be specific in children with COVID-19. Diagnosis is by Reverse transcriptase-Polymerase chain reaction (RT-PCR) testing of upper or lower respiratory tract secretions. This review additionally considers COVID-19 in immunosuppressed children, and also suggests a management algorithm for the few children who appear to present with life threatening infection, including the potential use of antiviral and immunomodulatory treatment. The most significant threat to global child health from SARS-CoV-2 is unlikely to be related to COVID 19 in children, but rather the socio-economic consequences of a prolonged pandemic.

<https://pubmed.ncbi.nlm.nih.gov/32273490/>

Barker, M. M., Bland, M. and Fraser, L. K. (2020). "Anxiety and Depression Prevalence in Children, Adolescents, and Young Adults With Life-Limiting Conditions-Reply." *JAMA Pediatr* 174(2): 208-209.  
<https://pubmed.ncbi.nlm.nih.gov/31841601/>

Battaglia, S., Orizio, P., Boroni, G., Cheli, M., Colusso, M. M., Parolini, F., Bianchi, A. and Alberti, D. (2020). "Total Oesophagogastric Dissociation in Neurologically Impaired Children: 18 Years' Experience and Long-term Follow-up." *J Pediatr Gastroenterol Nutr* 70(4): 457-461.

OBJECTIVES: Total oesophagogastric dissociation (TOGD) is an alternative anti-reflux surgery for neurologically impaired children because of a 16% to 38% fundoplication failure rate. This study evaluates TOGD's feasibility and its long-term efficacy both as a Primary and as a "Rescue" procedure after failed fundoplication. METHODS: Thirty patients (18 boys) who underwent TOGD between 2000 and 2018 in 2 Italian Centres were retrospectively reviewed. Twenty-three were Primary procedures and 7 were "Rescue" ones. Inclusion criteria were severe neurodisability, intractable gastroesophageal reflux, and dysphagia. RESULTS: Preoperatively, all children had regurgitation, vomiting or retching, and 93% had unsafe swallowing and aspiration, with recurrent chest infections/aspiration pneumonia. Median relative weight was 77% (48%--118%). All patients were taking antireflux medication before surgery. Median age at TOGD was 6.48 years (0.69--22.18). Median follow-up was 3.5 years (0.6-17.7). No recurrence of gastroesophageal reflux (GER) and vomiting was recorded. The number of chest infections and length of hospital stay showed a significant decrease (P value <0.0001 for both), whereas median relative weight reached 101% (P value 0.002). Parents'/caregivers' perception of outcome showed a significant improvement. Six patients (20%) experienced early complications and 3 required surgical intervention. Three late complications (10%) also required surgery. There was no surgery-related mortality. CONCLUSION: TOGD is an effective procedure with an acceptably low complication rate for children with severe neurological impairment and is followed by a major improvement in general health and quality of life for children and families. There was no substantial difference in outcome between Primary and "Rescue" procedures.  
<https://pubmed.ncbi.nlm.nih.gov/31913925/>

Battisti, K. A., Cohen, D. M., Bourgeois, T., Kline, D., Zhao, S. and Iyer, M. S. (2020). "A Paucity of Code Status Documentation Despite Increasing Complex Chronic Disease in Pediatrics." *J Palliat Med*, 10.1089/jpm.2019.0630.

Objectives: An increasing number of children are living with complex chronic diseases (CCDs) due to medical advances. Despite a need for code status discussions (CSDs), there is great variability in the frequency and documentation of such conversations. The objective was to identify gaps in the documentation of CSDs within the electronic health record (EHR), focusing on patients with CCDs. Methods: This was a retrospective review of all patients admitted from the emergency department of a tertiary care children's hospital in 2016. An EHR query using the Apache Hadoop cluster and manual review identified documentation of CSDs, including (1) code status orders, (2) advance directives, and (3) CSDs in provider notes. Patient complexity was stratified using the Pediatric Medical Complexity Algorithm 3.0. Comparative analysis was performed using chi-square, Kruskal-Wallis tests and multivariable logistic regression.

Results: There were 12,648 unique patients of whom 4157 (32.9%) had CCD. Only 209 (1.7%) patients had a code status documented, of whom 200 (95.7%) had CCD. Of 528 (4.2%) patients  $\geq 18$  years of age, 428 (81.1%) had CCD and only 65 (12.3%) had CSDs. Palliative care consultation increased odds of CSDs (OR: 21.4, 95% CI: 13.8-33.2,  $p < 0.0001$ ), whereas African American race decreased odds of CSDs (OR: 0.42, 95% CI: 0.27-0.64,  $p < 0.0001$ ). Conclusions: Among admitted pediatric patients, most do not have documentation of CSDs, including those with CCD and patients  $\geq 18$  years of age. Improvements in both frequency and consistency of CSD documentation are needed to inform the family-centered care of patients living with CCDs.

<https://pubmed.ncbi.nlm.nih.gov/32213109/>

**Berrios, C., Koertje, C., Noel-MacDonnell, J., Soden, S. and Lantos, J. (2020). "Parents of newborns in the NICU enrolled in genome sequencing research: hopeful, but not naïve." *Genet Med* 22(2): 416-422.**

**PURPOSE:** In 2014, our institution launched a randomized controlled trial (RCT) comparing rapid genome sequencing (GS) to standard clinical evaluations of infants with suspected genetic disorders. This study aimed to understand parental response to the use of GS for their newborn babies. **METHODS:** Twenty-three of 128 parents whose infant had enrolled in the RCT completed a retrospective survey and interview addressing attitudes about GS and responses to receiving diagnostic information. We also collected information about participants' genetic literacy, genetic knowledge, numeracy, and symptoms of anxiety and depression. **RESULTS:** The majority reported positive (13; 56.5%) or neutral 4 (4; 17.4%) feelings when approached about GS for their infant and 100% felt that GS was generally beneficial. The 12 participants who had received a unifying diagnosis for their child's symptoms described personal utility of the information. Some reported the diagnosis led to changes in medical care. Participants showed understanding of some of the psychological risks of GS. For example, 21 (91.3%) agreed or strongly agreed that genetic testing could reveal disturbing results. **CONCLUSIONS:** Parents who enrolled their newborn in a RCT of GS demonstrated awareness of a psychological risk, but generally held positive beliefs about GS and perceived the benefits outweighed the risk.

<https://pubmed.ncbi.nlm.nih.gov/31467447/>

**Bobillo-Perez, S., Segura, S., Girona-Alarcon, M., Felipe, A., Balaguer, M., Hernandez-Platero, L., Sole-Ribalta, A., Guitart, C., Jordan, I. and Cambra, F. J. (2020). "End-of-life care in a pediatric intensive care unit: the impact of the development of a palliative care unit." *BMC Palliat Care* 19(1): 74.**

**BACKGROUND:** The purpose of this paper is to describe how end-of-life care is managed when life-support limitation is decided in a Pediatric Intensive Care Unit and to analyze the influence of the further development of the Palliative Care Unit. **METHODS:** A 15-year retrospective study of children who died after life-support limitation was initiated in a pediatric intensive care unit. Patients were divided into two groups, pre- and post-palliative care unit development. Epidemiological and clinical data, the decision-making process, and the approach were analyzed. Data was obtained from patient medical records. **RESULTS:** One hundred seventy-five patients were included. The main reason for admission was respiratory failure (86/175). A

previous pathology was present in 152 patients (61/152 were neurological issues). The medical team and family participated together in the decision-making in 145 cases (82.8%). The family made the request in 10 cases (9 vs. 1,  $p = 0.019$ ). Withdrawal was the main life-support limitation (113/175), followed by withholding life-sustaining treatments (37/175). Withdrawal was more frequent in the post-palliative group (57.4% vs. 74.3%,  $p = 0.031$ ). In absolute numbers, respiratory support was the main type of support withdrawn. CONCLUSIONS: The main cause of life-support limitation was the unfavourable evolution of the underlying pathology. Families were involved in the decision-making process in a high percentage of the cases. The development of the Palliative Care Unit changed life-support limitation in our unit, with differences detected in the type of patient and in the strategy used. Increased confidence among intensivists when providing end-of-life care, and the availability of a Palliative Care Unit may contribute to improvements in the quality of end-of-life care.

<https://pubmed.ncbi.nlm.nih.gov/32466785/>

**Brown, M. A., Rajamarthandan, S., Francis, B., O'Leary-Kelly, M. K. and Sinha, P. (2020). "Update on stem cell technologies in congenital heart disease." *J Card Surg* 35(1): 174-179.**

BACKGROUND: Congenital heart disease (CHD) continues to be among the most common birth defects, affecting an estimated 40 000 births annually in the United States. The most common complication of CHD is heart failure. With improved medical management and surgical outcomes, survival for complex congenital heart defects has dramatically improved, but consequentially there are more adults with CHD than children with CHD. Due to longer-term sequelae of CHD, surgical and medical treatment previously thought to be curative is now realized at best to be palliative, and there is a considerable burden of CHD-related heart failure. Stem cell therapy as an adjunct to current surgical and medical strategies is being explored in an effort to ameliorate CHD-related heart failure. This review aims to explore the current literature with regard to stem cell therapy for CHD as well as ongoing trials. METHODS: A MEDLINE (Ovid), MEDLINE (Pubmed), and clinicaltrials.gov search were performed using the medical subject headings congenital heart defects combined with hematopoietic stem cells, stem cell transplantation, mesenchymal stem cells (MSC), cell- or tissue-based therapy, or MSC transplantation. Articles must have been published after 2010. RESULTS: Twenty three articles and 9 ongoing trials met all inclusion criteria. CONCLUSIONS: Areas of interest include myocardiocyte regeneration, tissue graft development to minimize reoperations, and methods of stem cell delivery. While several small trials are showing promise, it is too soon to make definitive statements about the future of stem cell therapies in this field.

<https://pubmed.ncbi.nlm.nih.gov/31705822/>

**Burke, K., Coombes, L. H., Petruckevitch, A. and Anderson, A. K. (2020). "Inter-Rater Reliability of the Phase of Illness Tool in Pediatric Palliative Care." *Am J Hosp Palliat Care* 37(10): 837-843.**

BACKGROUND: Phase of Illness is used to describe the stages of a patient's illness in the palliative care setting. Categorization is based on individual needs, family

circumstances, and the adequacy of a care plan. Substantial ( $\kappa = .67$ ) and moderate ( $\kappa = .52$ ) inter-rater reliability is demonstrated when categorizing adults; however, there is a lack of similar studies in pediatrics. OBJECTIVE: To test the inter-rater reliability of health-care professionals when assigning pediatric palliative care patients to a Phase of Illness. Furthermore, to obtain user views on phase definitions, ease of assignment, feasibility and acceptability of use. METHOD: A prospective cohort study in which up to 9 health-care professionals' independently allocated 80 pediatric patients to a Phase of Illness and reported on their experiences. This study took place between June and November 2017. RESULTS: Professionals achieved a moderate level of agreement ( $\kappa = 0.50$ ). Kappa values per phase were as follows: stable = 0.63 (substantial), unstable = 0.26 (fair), deteriorating = 0.45 (moderate), and dying = 0.43 (moderate). For the majority of allocations, professionals report that the phase definitions described patients very well (76.1%), and they found it easy to assign patients (73.5%). However, the unstable phase caused the most uncertainty. CONCLUSION: The results of this study suggest Phase of Illness is a moderately reliable, acceptable, and feasible tool for use in pediatric palliative care. Current results are similar to those found in some adult studies. However, in a quarter of cases, users report some uncertainty in the application of the tool, and further study is warranted to explore whether suggested refinements improve its psychometric properties.

<https://pubmed.ncbi.nlm.nih.gov/32189508/>

**Burkhart, H. M., Qureshi, M. Y., Rossano, J. W., Cantero Peral, S., O'Leary, P. W., Hathcock, M., Kremers, W. and Nelson, T. J. (2019). "Autologous stem cell therapy for hypoplastic left heart syndrome: Safety and feasibility of intraoperative intramyocardial injections." *J Thorac Cardiovasc Surg* 158(6): 1614-1623.**

OBJECTIVES: Staged surgical palliation for hypoplastic left heart syndrome results in an increased workload on the right ventricle serving as the systemic ventricle. Concerns for cardiac dysfunction and long-term heart failure have generated interest in first-in-infant, cell-based therapies as an additional surgical treatment modality. METHODS: A phase 1 clinical trial was conducted to evaluate the safety and feasibility of direct intramyocardial injection of autologous umbilical cord blood-derived mononuclear cells in 10 infants with hypoplastic left heart syndrome at the time of stage II palliation. RESULTS: All 10 patients underwent successful stage II palliation and intramyocardial injection of umbilical cord blood-derived mononuclear cells. Operative mortality was 0%. There was a single adverse event related to cell delivery: An injection site epicardial bleed that required simple oversew. The cohort did not demonstrate any significant safety concerns over 6 months. Additionally, the treatment group did not demonstrate any reduction in cardiac function in the context of the study related intramyocardial injections of autologous cells. CONCLUSIONS: This phase 1 clinical trial showed that delivering autologous umbilical cord blood-derived mononuclear cells directly into the right ventricular myocardium during planned stage II surgical palliation for hypoplastic left heart syndrome was safe and feasible. Secondary findings of preservation of baseline right ventricular function throughout follow-up and normalized growth rates support the design of a phase 2b follow-up trial.

<https://pubmed.ncbi.nlm.nih.gov/31345560/>

Campbell, C. T., Grey, E., Munoz-Pareja, J. and Manasco, K. B. (2020). "An Evaluation of Risperidone Dosing for Pediatric Delirium in Children Less Than or Equal to 2 Years of Age." *Ann Pharmacother* 54(5): 464-469.

Background: Risperidone dosing and safety data are limited in patients  $\leq 2$  years of age. Objective: To describe the dosing strategies, safety, and tolerability of risperidone in infants  $\leq 2$  years of age. Methods: An institutional review board-approved retrospective study was conducted in a 24-bed pediatric intensive care unit at an academic medical center in patients  $\leq 2$  years of age receiving risperidone for the management of ICU delirium. The primary outcome was mean initial daily dose of risperidone. Secondary outcomes included mean daily dose, dosing frequency, treatment duration, and adverse effects. Results: Seventeen patients who received at least 1 dose of risperidone were included in the study. The initial daily dose ranged from 0.1 to 0.25 mg (0.01-0.04 mg/kg), with a mean of 0.17 mg (0.02 mg/kg). Most patients were initiated on once-daily dosing (76.5%) versus twice-daily dosing (17.6%). More than 80% of patients required a dose increase during therapy. Median daily doses of fentanyl, morphine, ketamine, and midazolam were decreased following initiation of risperidone. No adverse events that led to discontinuation of risperidone were reported. Conclusion and Relevance: Risperidone was found to be safe and well tolerated at daily doses of risperidone of 0.1 to 0.25 mg in 1 or 2 doses per day in patients  $\leq 2$  years old for the management of ICU delirium. To our knowledge, these results provide the largest cohort describing dosing recommendations specific for risperidone in this age group. Further investigation on the effect of antipsychotic administration on other sedation and analgesic regimens is necessary.

<https://pubmed.ncbi.nlm.nih.gov/31771334/>

Chambers, G. M., Settumba, S. N., Carey, K. A., Cairns, A., Menezes, M. P., Ryan, M. and Farrar, M. A. (2020). "Prenusinersen economic and health-related quality of life burden of spinal muscular atrophy." *Neurology* 95(1): e1-e10.

OBJECTIVE: To quantify the economic and health-related quality of life (HRQoL) burden incurred by households with a child affected by spinal muscular atrophy (SMA).

METHODS: Hospital records, insurance claims, and detailed resource use questionnaires completed by caregivers were used to capture the direct and indirect costs to households of 40 children affected by SMA I, II, and III in Australia between 2016 and 2017. Prevalence costing methods were used and reported in 2017 US dollar (USD) purchasing power parity (PPP). The HRQoL for patients and primary caregivers was quantified with the youth version of the EQ-5D and CareQoL multiattribute utility instruments and Australian utility weights. RESULTS: The average total annual cost of SMA per household was \$143,705 USD PPP for all SMA types (SMA I \$229,346, SMA II \$150,909, SMA III \$94,948). Direct costs accounted for 56% of total costs. The average total indirect health care costs for all SMA types were \$63,145 per annum and were highest in families affected by SMA II. Loss of income and unpaid informal care made up 24.2% and 19.8% respectively, of annual SMA costs. Three of 4 (78%) caregivers stated that they experienced financial problems because of care tasks. The loss in HRQoL of children affected by SMA and caregivers was substantial, with average caregiver and patient scores of 0.708 and 0.115, respectively (reference range 0 = death and 1 = full health). CONCLUSION: Our results

demonstrate the substantial and far-ranging economic and quality of life burden on households and society of SMA and are essential to fully understanding the health benefits and cost-effectiveness associated with emerging disease-modifying therapies for SMA.

<https://pubmed.ncbi.nlm.nih.gov/32513788/>

**Chen, T. H. (2020). "New and Developing Therapies in Spinal Muscular Atrophy: From Genotype to Phenotype to Treatment and Where Do We Stand?" *Int J Mol Sci* 21(9).**

Spinal muscular atrophy (SMA) is a congenital neuromuscular disorder characterized by motor neuron loss, resulting in progressive weakness. SMA is notable in the health care community because it accounts for the most common cause of infant death resulting from a genetic defect. SMA is caused by low levels of the survival motor neuron protein (SMN) resulting from SMN1 gene mutations or deletions. However, patients always harbor various copies of SMN2, an almost identical but functionally deficient copy of the gene. A genotype-phenotype correlation suggests that SMN2 is a potent disease modifier for SMA, which also represents the primary target for potential therapies. Increasing comprehension of SMA pathophysiology, including the characterization of SMN1 and SMN2 genes and SMN protein functions, has led to the development of multiple therapeutic approaches. Until the end of 2016, no cure was available for SMA, and management consisted of supportive measures. Two breakthrough SMN-targeted treatments, either using antisense oligonucleotides (ASOs) or virus-mediated gene therapy, have recently been approved. These two novel therapeutics have a common objective: to increase the production of SMN protein in MNs and thereby improve motor function and survival. However, neither therapy currently provides a complete cure. Treating patients with SMA brings new responsibilities and unique dilemmas. As SMA is such a devastating disease, it is reasonable to assume that a unique therapeutic solution may not be sufficient. Current approaches under clinical investigation differ in administration routes, frequency of dosing, intrathecal versus systemic delivery, and mechanisms of action. Besides, emerging clinical trials evaluating the efficacy of either SMN-dependent or SMN-independent approaches are ongoing. This review aims to address the different knowledge gaps between genotype, phenotypes, and potential therapeutics.

<https://pubmed.ncbi.nlm.nih.gov/32392694/>

**Chen, X., Sanchis-Juan, A., French, C. E., Connell, A. J., Delon, I., Kingsbury, Z., Chawla, A., Halpern, A. L., Taft, R. J., Bentley, D. R., Butchbach, M. E. R., Raymond, F. L. and Eberle, M. A. (2020). "Spinal muscular atrophy diagnosis and carrier screening from genome sequencing data." *Genet Med* 22(5): 945-953.**

**PURPOSE:** Spinal muscular atrophy (SMA), caused by loss of the SMN1 gene, is a leading cause of early childhood death. Due to the near identical sequences of SMN1 and SMN2, analysis of this region is challenging. Population-wide SMA screening to quantify the SMN1 copy number (CN) is recommended by the American College of Medical Genetics and Genomics. **METHODS:** We developed a method that accurately identifies the CN of SMN1 and SMN2 using genome sequencing (GS) data by analyzing read depth and eight informative reference genome differences between SMN1/2. **RESULTS:** We characterized SMN1/2 in 12,747 genomes, identified 1568 samples

with SMN1 gains or losses and 6615 samples with SMN2 gains or losses, and calculated a pan-ethnic carrier frequency of 2%, consistent with previous studies. Additionally, 99.8% of our SMN1 and 99.7% of SMN2 CN calls agreed with orthogonal methods, with a recall of 100% for SMA and 97.8% for carriers, and a precision of 100% for both SMA and carriers. CONCLUSION: This SMN copy-number caller can be used to identify both carrier and affected status of SMA, enabling SMA testing to be offered as a comprehensive test in neonatal care and an accurate carrier screening tool in GS sequencing projects.

<https://pubmed.ncbi.nlm.nih.gov/32066871/>

**Cheng, B. T. and Wangmo, T. (2020). "Palliative care utilization in hospitalized children with cancer." *Pediatr Blood Cancer* 67(1): e28013.**

BACKGROUND: There is growing evidence that palliative care (PC) is associated with increased quality of life in children with cancer. Despite increasing recommendations in support of PC to improve pediatric oncology care, little is known about its patterns of use. METHODS: We analyzed the 2005-2011 National Inpatient Sample, a representative, cross-sectional sample of US hospital admissions. Our study cohort comprised 10 960 hospitalizations of children with cancer and high in-hospital mortality risk. Survey-weighted regression models were constructed to determine associations of person- and hospital-level characteristics with PC involvement and healthcare costs. RESULTS: Overall, 4.4% of hospitalizations included PC involvement. In regression models invoking stepwise variable selection, a shorter length of stay (PC vs no PC; mean: 23.9 vs 32.6 days), solid cancer (solid vs hematologic vs brain cancer; PC use: 7.4% vs 2.8% vs 5.5%), and older age (PC vs no PC; mean: 10.2 vs 8.9 years) were associated with PC use. PC utilization was also associated with lower overall and daily hospital costs. CONCLUSIONS: One in 20 pediatric inpatients with cancer and high mortality risk receives PC, with differential utilization by socio-economic groups. These results have significant implications for public health resource allocation and the delivery of pediatric PC as high-value care. Future research should focus on the development of new tools to help physicians assess when PC is appropriate for their patients.

<https://pubmed.ncbi.nlm.nih.gov/31612605/>

**Chong, P. H., Soo, J., Yeo, Z. Z., Ang, R. Q. and Ting, C. (2020). "Who needs and continues to need paediatric palliative care? An evaluation of utility and feasibility of the Paediatric Palliative Screening scale (PaPaS)." *BMC Palliat Care* 19(1): 18.**

BACKGROUND: While the populations of children who can benefit from paediatric palliative care (PPC) have been broadly defined, identifying individual patients to receive PPC has been problematic in practice. The Paediatric Palliative Screening scale (PaPaS) is a multi-dimensional tool that assesses palliative care needs in children and families to facilitate timely referrals. This study evaluates its use to manage new referrals and ongoing review of patients receiving home-based PPC in Singapore. METHODS: Using a retrospective cohort study design, 199 patients admitted to receive PPC via clinician screening were scored using PaPaS. Eighty-four patients in two groups were scored again at one of two following milestones: one-year service continuation mark or point of discharge before a year. Accuracy measures were compared against clinical assessment. RESULTS: 96.98% of patients scored 15 and above on admission (indicating need for PPC). Patients assessed at following milestones were effectively

stratified; those who continued to receive service after 1 year scored significantly higher (M = 19.23) compared to those who were discharged within a year (M = 7.86). Sensitivity and specificity for PaPaS were calculated at 82.54 and 100% respectively. Overall congruence with clinician-based decisions supports the utility of PaPaS as a screening tool in PPC. Recommendations to improve the scale further are proposed. CONCLUSION: The PaPaS is a practical screening tool that signposts PPC needs within the clinical setting. This facilitates early referrals to PPC, without having to specify individual prognoses that are often uncertain. Other benefits include optimised continuity of care and implications for resource allocation.  
<https://pubmed.ncbi.nlm.nih.gov/32041616/>

**Christiansen, S. G., Reneflot, A., Stene-Larsen, K. and Hauge, L. J. (2020). "Alcohol-related mortality following the loss of a child: a register-based follow-up study from Norway." *BMJ Open* 10(6): e038826.**

OBJECTIVES: The death of one's child is one of the most stressful events a person can experience. Research has shown that bereaved parents have a higher mortality than non-bereaved parents. This increased mortality might partly be caused directly by long-term stress. However, changes in health behaviour such as an increase in alcohol consumption might also play a role. This study examines the association between losing a child and alcohol-related mortality. In addition to Cox regression models using data covering the entire Norwegian adult population, we employ sibling fixed-effect models in order to partly control for genes and childhood experiences that might be associated with both losing a child and alcohol-related mortality. DESIGN: A follow-up study between 1986 and 2014 based on Norwegian register data. SETTING: Norway. PARTICIPANTS: The entire Norwegian adult population. PRIMARY OUTCOME MEASURE: Alcohol-related mortality. RESULTS: An increased alcohol-related mortality was found among parents who had experienced the death of a child. The HR of alcohol-related mortality among those bereaved of a child was 1.59 (95% CI 1.48 to 1.71) compared with non-bereaved parents, for women 2.03 (95% CI 1.78 to 2.32) and for men 1.46 (95% CI 1.34 to 1.59). After including sibling fixed effects, the HR of alcohol-related mortality among parents who had lost a child was 1.30 (95% CI 1.03 to 1.64). CONCLUSIONS: This study provides evidence of an elevated alcohol-related mortality among parents who have lost a child compared with non-bereaved parents. Although strongly attenuated, there is still an association when adjusting for genetic predisposition for alcohol problems as well as childhood environment using sibling fixed-effect models.  
<https://pubmed.ncbi.nlm.nih.gov/32041616/>

**Cohn, L. N., Pechlivanoglou, P., Lee, Y., Mahant, S., Orkin, J., Marson, A. and Cohen, E. (2020). "Health Outcomes of Parents of Children with Chronic Illness: A Systematic Review and Meta-Analysis." *J Pediatr* 218: 166-177.e162.**

OBJECTIVE: To assess health outcomes of parents caring for children with chronic illnesses compared with parents of healthy children. STUDY DESIGN: We searched OvidSP MEDLINE, EBM Reviews-Cochrane Central Register of Controlled Trials, EMBASE, and EBSCOHost CINAHL through September 2019. Included were English-language studies reporting health conditions or mortality of parents of affected children

compared with healthy controls. RESULTS: Of 12 181 screened publications, 26 met inclusion criteria. Eight studies reported on anxiety, 23 on depression, 1 on mortality, and 1 on cardiovascular disease. Parents of chronically ill children had greater anxiety (standardized mean difference 0.42; 95% CI 0.24-0.60;  $P < .001$ ) and depression scores (standardized mean difference 0.35; 95% CI 0.26-0.45;  $P < .001$ ) than parents of healthy children. Thirty-five percent of parents of affected children met cut-offs for clinical depression, compared with 19% in the control (relative risk 1.75; 95% CI 1.55-1.97). Fifty-seven percent of such parents met cut-offs for anxiety, compared with 38% in the control (relative risk 1.40; 95% CI 1.18-1.67). One study of mothers of children with congenital anomalies reported a greater mortality risk than a comparison (adjusted hazard ratio 1.22; 95% CI 1.15-1.29), and another reported that these mothers experience an increased risk of cardiovascular disease (adjusted hazard ratio 1.15; 95% CI 1.07-1.23). CONCLUSIONS: Parents of chronically ill children experience poorer mental health (more anxiety and depression), and mothers of those with congenital anomalies may have greater risk of cardiovascular disease and mortality than parents of unaffected children. Our findings suggest a need for targeted interventions to attenuate adverse parental caregiver health outcomes. PRIOR REGISTRATION: PROSPERO CRD42018094657 ([https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=94657](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=94657)). <https://pubmed.ncbi.nlm.nih.gov/31916997/>

Côté-Arsenault, D., Denney-Koelsch, E. M., McCoy, T. P. and Kavanaugh, K. (2019). "African American and Latino bereaved parent health outcomes after receiving perinatal palliative care: A comparative mixed methods case study." *Appl Nurs Res* 50: 151200.

BACKGROUND: Death of one's infant is devastating to parents, negatively impacting couple relationships and their own health. The impact of a prenatally diagnosed life-limiting fetal condition (LLFC) on parents of minority status is unclear. AIM: This comparative mixed methods case study examined the person characteristics, quality of perinatal palliative care (PPC) received and parent health outcomes. METHODS: Bereaved couples, 11 mothers and 3 fathers of minority or mixed races (11 African American and Latino, 1 White Latino and 2 White parents) completed the survey; 7 were interviewed. RESULTS: Parents rated their general health close to good, physical health close to normal but mental health lower than the population norm. Clinical caseness (abnormal levels) of anxiety were reported in 50% of parents whereas depression scores were normal. The experience of fetal diagnosis and infant death had a negative impact on the health of 40% of participants however, parents could not identify what specifically caused their health problems. Most were satisfied with their PPC but some shared that original providers were not supportive of pregnancy continuation. After the baby's death, 71% reported closer/stronger couple relationships. Two contrasting cases are presented. Once parents found PPC, their baby was treated as a person, they spent time with their baby after birth, and found ways to make meaning through continuing bonds. CONCLUSION: Despite high overall satisfaction with PPC, bereaved parents were deeply impacted by their infant's death. Mixed methods case study design illuminated the complicated journeys of parents continuing their pregnancy with a LLFC. <https://pubmed.ncbi.nlm.nih.gov/31735485/>

Dallas, J., Englot, D. J. and Naftel, R. P. (2020). "Neurosurgical approaches to pediatric epilepsy: Indications, techniques, and outcomes of common surgical procedures." *Seizure* 77: 76-85.

Epilepsy is a common pediatric neurological condition, and approximately one-third of children with epilepsy are refractory to medical management. For these children neurosurgery may be indicated, but operative success is dependent on complete delineation of the epileptogenic zone. In this review, surgical techniques for pediatric epilepsy are considered. First, potentially-curative operations are discussed and broadly divided into resections and disconnections. Then, two palliative approaches to seizure control are reviewed. Finally, future neurosurgical approaches to epilepsy are considered.

<https://pubmed.ncbi.nlm.nih.gov/30473268/>

de Noriega, Í., Barceló, M., Pérez, M., Puertas, V., García-Salido, A. and Martino, R. (2020). "[Hospital admissions into paediatric palliative care: A retrospective study]." *An Pediatr (Barc)* 92(2): 94-101.

INTRODUCTION: Patients may be admitted to hospital by paediatric palliative care units (PPCU) for different reasons, due to their different needs and clinical problems. The objective of this study is to present the data of patients admitted to the PPCU of the Autonomous Community of Madrid. METHODS: Descriptive retrospective study was conducted by reviewing the clinical records of the PPCU between January 2011 and December 2016. RESULTS: Of 499 patients attended in this period, 166 (33%) were admitted to hospital at some point, generating a total of 314 episodes. Respiratory problems (34%) were the main cause of admission. Gastrostomy intervention (23 patients) was the commonest reason for a surgical admission. In this period, 46 patients died during hospitalisation. The highest frequencies of death, according to the admission cause, were respiratory problems (18 out of 46) and end-of-life care (11 out of 46). More than half (59%) of admissions lasted less than 7 days and 88% were 15 days or less. CONCLUSIONS: The causes and characteristics of the hospital admissions at a PPCU are heterogeneous, with respiratory problems being the most common cause of admission. The duration of the hospitalisation appears to be similar to that described for acute palliative care units. The creation of a specific PPCU that can refer their patients for hospital admission might help to improve continuity of care.

<https://pubmed.ncbi.nlm.nih.gov/30890313/>

De Vivo, D. C., Bertini, E., Swoboda, K. J., Hwu, W. L., Crawford, T. O., Finkel, R. S., Kirschner, J., Kuntz, N. L., Parsons, J. A., Ryan, M. M., Butterfield, R. J., Topaloglu, H., Ben-Omran, T., Sansone, V. A., Jong, Y. J., Shu, F., Staropoli, J. F., Kerr, D., Sandroock, A. W., Stebbins, C., Petrillo, M., Braley, G., Johnson, K., Foster, R., Gheuens, S., Bhan, I., Reyna, S. P., Fradette, S. and Farwell, W. (2019). "Nusinersen initiated in infants during the presymptomatic stage of spinal muscular atrophy: Interim efficacy and safety results from the Phase 2 NURTURE study." *Neuromuscul Disord* 29(11): 842-856.

Spinal muscular atrophy (SMA) is a neurodegenerative disease associated with severe muscle atrophy and weakness in the limbs and trunk. We report interim efficacy and

safety outcomes as of March 29, 2019 in 25 children with genetically diagnosed SMA who first received nusinersen in infancy while presymptomatic in the ongoing Phase 2, multisite, open-label, single-arm NURTURE trial. Fifteen children have two SMN2 copies and 10 have three SMN2 copies. At last visit, children were median (range) 34.8 [25.7-45.4] months of age and past the expected age of symptom onset for SMA Types I or II; all were alive and none required tracheostomy or permanent ventilation. Four (16%) participants with two SMN2 copies utilized respiratory support for  $\geq 6$  h/day for  $\geq 7$  consecutive days that was initiated during acute, reversible illnesses. All 25 participants achieved the ability to sit without support, 23/25 (92%) achieved walking with assistance, and 22/25 (88%) achieved walking independently. Eight infants had adverse events considered possibly related to nusinersen by the study investigators. These results, representing a median 2.9 years of follow up, emphasize the importance of proactive treatment with nusinersen immediately after establishing the genetic diagnosis of SMA in presymptomatic infants and emerging newborn screening efforts. <https://pubmed.ncbi.nlm.nih.gov/31704158/>

**Delgado-Corcoran, C., Wawrzynski, S. E., Bennett, E. E., Green, D., Bodily, S., Moore, D., Cook, L. J. and Olson, L. M. (2020). "Palliative Care in Children With Heart Disease Treated in an ICU." *Pediatr Crit Care Med* 21(5): 423-429.**

**OBJECTIVES:** Describe pediatric palliative care consult in children with heart disease; retrospectively apply Center to Advance Palliative Care criteria for pediatric palliative care consults; determine the impact of pediatric palliative care on end of life. **DESIGN:** A retrospective single-center study. **SETTING:** A 16-bed cardiac ICU in a university-affiliated tertiary care children's hospital. **PATIENTS:** Children (0-21 yr old) with heart disease admitted to the cardiac ICU from January 2014 to June 2017. **MEASUREMENTS AND MAIN RESULTS:** Over 1,000 patients (n = 1, 389) were admitted to the cardiac ICU with 112 (8%) receiving a pediatric palliative care consultation. Patients who received a consult were different from those who did not. Patients who received pediatric palliative care were younger at first hospital admission (median 63 vs 239 d; p = 0.003), had a higher median number of complex chronic conditions at the end of first hospitalization (3 vs 1; p < 0.001), longer cumulative length of stay in the cardiac ICU (11 vs 2 d; p < 0.001) and hospital (60 vs 7 d; p < 0.001), and higher mortality rates (38% vs 3%; p < 0.001). When comparing location and modes of death, patients who received pediatric palliative care were more likely to die at home (24% vs 2%; p = 0.02) and had more comfort care at the end of life (36% vs 2%; p = 0.002) compared to those who did not. The Center to Advance Palliative Care guidelines identified 158 patients who were eligible for pediatric palliative care consultation; however, only 30 patients (19%) in our sample received a consult. **CONCLUSIONS:** Pediatric palliative care consult rarely occurred in the cardiac ICU. Patients who received a consult were medically complex and experienced high mortality. Comfort care at the end of life and death at home was more common when pediatric palliative care was consulted. Missed referrals were apparent when Center to Advance Palliative Care criteria were retrospectively applied. <https://pubmed.ncbi.nlm.nih.gov/32142011/>

**Dursun, A., Özsoylu, S. and Akyıldız, B. N. (2020). "Outcomes and prognostic factors for pediatric cancer patients admitted to an intensive care unit in a university hospital." *Turk J Pediatr* 62(2): 252-258.**

**BACKGROUND AND OBJECTIVES:** The aim of this study was to investigate the factors predicting Pediatric Intensive Care Unit (PICU) mortality and the outcomes in cancer patients admitted to PICU. **METHODS:** We conducted a retrospective study in 48 consecutive cancer patients admitted to the PICU between January 1, 2015 and January 1, 2018. A total of 48 patients (21 males and 27 females) were enrolled in this study. **RESULTS:** The median age was 77 (33,5-149) months. The median duration of PICU stay was 5 (2-9) days. Patients were classified according to their stage of disease. Ten (20.8%) patients were in the remission group, 9 (18.8%) patients were in the induction period and 29 (60.5%) patients were in the progressive disease groups. Thirty-nine patients (81.2%) had hematological malignancies, 6 (12.5%) had extracranial solid tumors and 3 (6.3%) had intracranial solid tumors. Thirty-seven patients died and the mortality rate was found to be 77.1%. mortality rates were 11%, 88% and 93% for patients in remission, during induction period and in the progressive disease group, respectively ( $p < 0.01$ ). The most frequent reasons of PICU admission were respiratory failure in 29 (60.4%), sepsis in 12 (25%), circulatory collapse in 2 (4.2%), and other reasons in 5 patients (10.4%). The median PRISM III among survivors was significantly lower than non-survivors ( $13.1 \pm 6.4$ ; vs.  $20.7 \pm 5.2$ ;  $p < 0.001$ ). At a cut-off value of 13, the sensitivity of the PRISM III was 94.4% and the specificity was 58.3% (AUC: 0.821). OSD was present in 41 (85%) patients, 82% of them died (34/41). The presence of MOF, the use of mechanical ventilation and inotrop support were significantly related with mortality. Univariate logistic regression analysis showed that male gender [odds ratio (OR)=5.588,  $P= 0.041$ , 95% confidence interval (95%CI) 1.070-29.191], presence of organ system dysfunction [OR=12.143,  $P= 0.008$ , 95%CI 1.947- 75.736], need for mechanical ventilation [OR=34.000,  $P= 0.001$ , 95%CI 5.272-219.262], IS [OR=8.5,  $P= 0.001$ , 95%CI 1.318-54.817] were the predictors of high mortality in pediatric cancer patients. PRISM III score  $\geq 13$  was a predictive criteria of PICU mortality. **CONCLUSION:** We conclude that the key to improving survival rates is to pick up on this group of patients as soon as possible. We believe that cancer patients could be saved by earlier evaluation and intervention by the PICU team when they have a less severe disease.

<https://pubmed.ncbi.nlm.nih.gov/32419417/>

**Ennamuri, S., Abramson, E., Mauer, E., Gerber, L. M. and Nellis, M. E. (2020). "Changes in Clinical Course Before and After Do-Not-Resuscitate Order Placement in a Pediatric Intensive Care Unit Setting." *J Palliat Med*, 10.1089/jpm.2019.0572.**

**Background:** The relationship between clinical course and do-not-resuscitate (DNR) status has not been well studied in the pediatric intensive care unit (PICU) setting. **Objective:** To describe the relationship between DNR order placement and clinical course. **Design:** Single center retrospective cohort study. **Setting/Subjects:** Patients, ages 0-18 years, who have died in the PICU from 2008 to 2016. **Measurements:** Retrospective chart review of DNR status, patient characteristics, and clinical course. We compared length of stay and number of consults/procedures/imaging studies done on patients with early DNR (>48 hours before death), late DNR (within 48 hours of death), and no DNR order placement. **Results:** One-hundred and sixty-one children were included. Nearly half (48%) were male with median (interquartile range) age of 3 years (0-12). One-third (58) had an underlying oncologic diagnosis. Eighteen percent (29/161) were classified as early DNR, 33% (53/161) as late DNR, and 49% (79/161) as

no DNR. We found no differences in patient characteristics or risk of mortality at admission among the groups. The early DNR group showed decreased number of invasive procedures (0.68), imaging studies (1), and consults (0.21) per day when compared with the late (2, 1.53, 0.50) and no DNR groups (2.09, 1.73, 0.43). Conclusion: Our results suggest that early DNR placement in the PICU is associated with a change in clinical course centered around less invasive care. Earlier DNR placement can potentially trigger a shift in care goals that could improve the quality of life for patients and mitigate emotional and physical toll on patients and their families during the highly stressful end-of-life time period.  
<https://pubmed.ncbi.nlm.nih.gov/32250188/>

**Fahner, J., Rietjens, J., van der Heide, A., Milota, M., van Delden, J. and Kars, M. (2020). "Evaluation showed that stakeholders valued the support provided by the Implementing Pediatric Advance Care Planning Toolkit." *Acta Paediatr*, 10.1111/apa.15370.**

AIM: This study described the development, and pilot evaluation, of the Implementing Pediatric Advance Care Planning Toolkit (IMPACT). METHODS: Key elements of paediatric advance care planning (ACP) were defined using a systematic review, a survey of 168 paediatricians and qualitative studies of 13 children with life-limiting conditions, 20 parents and 18 paediatricians. Participants were purposively recruited from six Dutch university hospitals during September 2016 and November 2018. Key elements were translated into intervention components guided by theory. The acceptability of the content was evaluated by a qualitative pilot study during February and September 2019. This focused on 27 children with life-limiting conditions from hospitals, a hospice and home care, together with 41 parents, 11 physicians and seven nurses who cared for them. RESULTS: IMPACT provided a holistic, caring approach to ACP, gave children a voice and cared for their parents. It provided information on ACP for families and clinicians, manuals to structure ACP conversations and training for clinicians in communication skills and supportive attitudes. The 53 pilot study participants felt that IMPACT was appropriate for paediatric ACP. CONCLUSION: IMPACT was an appropriate intervention that supported a holistic approach towards paediatric ACP, focused on the child's perspective and provided care for their parents.  
<https://pubmed.ncbi.nlm.nih.gov/32434275/>

**Fortney, C. and Campbell, M. L. (2020). "Development and Content Validity of a Respiratory Distress Observation Scale-Infant." *J Palliat Med* 23(6): 838-841.**

Background: Respiratory distress is one of the most commonly reported symptoms in infants in the neonatal intensive care unit and can lead to substantial morbidity and mortality if not assessed and managed appropriately. Yet, a validated scale for assessing respiratory distress across clinicians in infants is not available. Furthermore, a valid and reliable scale is needed as a dependent measure in studies about infant respiratory distress. Objective: The purpose of this study was to establish a content validity index (CVI) of a modification of the Respiratory Distress Observation Scale(©) (RDOS) for use with infants who are at least 37 weeks gestational age. Design: The RDOS(©) was revised using the respiratory characteristics of infants and offered to clinical experts for review. Setting/Subjects: A pool of nine experts in neonatal care, including two neonatologists, two nurse practitioners, one respiratory therapist, two

staff nurses, and two nurse scientists, evaluated the revised scale for content validity. Results: The scale CVI was calculated by averaging the item CVIs that were  $\geq 0.80$  yielding a scale CVI = 0.96. Our content experts further recommended adding the variable capillary perfusion. Conclusions: Content validity was established. This RDOS-Infant has clinical and research utility if subsequent psychometric testing yields additional acceptable reliability and validity statistics.

<https://pubmed.ncbi.nlm.nih.gov/31644359/>

**Friedel, M., Brichard, B., Boonen, S., Tonon, C., De Terwangne, B., Bellis, D., Mevisse, M., Fonteyne, C., Jaspard, M., Schruse, M., Harding, R., Downing, J., Namisango, E., Degryse, J. M. and Aujoulat, I. (2020). "Face and Content Validity, Acceptability, and Feasibility of the Adapted Version of the Children's Palliative Outcome Scale: A Qualitative Pilot Study." *J Palliat Med*, 10.1089/jpm.2019.0646.**

Objective: To assess the face and content validity, acceptability and feasibility of a French version of the Children's Palliative Outcome Scale (CPOS). Background: Instruments in French used to measure outcomes in pediatric palliative care are lacking. Methods: After forward-backward translation of the 12-item English CPOS to French, we conducted a qualitative pilot study. During semi structured interviews among children and parents, we used the CPOS, the Schedule for the Evaluation of Individual Quality of Life interview guide (SEIQoL) and the Quality of Life in Life-threatening Illness-Family Carer questionnaire (QOLLTI-F), in addition to three expert meetings with PLTs. Results: Fourteen children and adolescents (8-18 years) with life-limiting or life-threatening conditions cared for at home, in hospital or in respite care services, 19 parents, and 9 members of 4 pediatric liaison teams (PLTs) providing palliative care in a Belgian francophone region were included in the study. No families refused to participate. All children with verbal capacities chose to be interviewed in the presence of their parents and a PLT member. The children valued being given the opportunity to share their experiences. New QOL dimensions pertaining to social, emotional, and administrative health-care related issues were added to the original version of the 12-item CPOS, leading to a 22-item CPOS-2. Discussion: The CPOS-2 was perceived as relevant and easy to use by the principal stakeholders. Our study paves the way for a large-scale field study assessing its psychometric characteristics and its implementation in routine clinical care.

<https://pubmed.ncbi.nlm.nih.gov/32679002/>

**Fundora, M. P., Rodriguez, Z. and Mahle, W. T. (2020). "Futility in the paediatric cardiac ICU." *Cardiol Young*, 10.1017/s1047951120002061: 1-8.**

INTRODUCTION: Studies have suggested 5-20% of paediatric ICU patients may receive care felt to be futile. No data exists on the prevalence and impact of futile care in the Paediatric Cardiac ICU. The aim is to determine the prevalence and economic impact of futile care. MATERIALS AND METHOD: Retrospective cohort of patients with congenital cardiac disease 0-21 years old, with length of stay >30 days and died (2015-2018). Documentation of futility by the medical team was retrospectively and independently reviewed. RESULTS: Of the 127 deaths during the study period, 51 (40%) had hospitalisation >30 days, 13 (25%) had received futile care and 26 (51%) withdrew life-sustaining treatment. Futile care comprised 0.69% of total patient days

with no difference in charges from patients not receiving futile care. There was no difference in insurance, single motherhood, education, income, poverty, or unemployment in families continuing futile care or electing withdrawal of life-sustaining treatment. Black families were less likely than White families to elect for withdrawal ( $p = 0.01$ ), and Hispanic families were more likely to continue futile care than non-Hispanics ( $p = 0.044$ ). **CONCLUSIONS:** This is the first study to examine the impact of futile care and characteristics in the paediatric cardiac ICU. Black families were less likely to elect for withdrawal, while Hispanic families more likely to continue futile care. Futile care comprised 0.69% of bed days and little burden on resources. Cultural factors should be investigated to better support families through end-of-life decisions.

<https://pubmed.ncbi.nlm.nih.gov/32703329/>

**Gao, W., Song, Z., Ma, N., Dong, C., Meng, X., Sun, C., Qin, H., Han, C., Yang, Y., Zhang, F., Zheng, W. and Shen, Z. (2020). "Application of pediatric donors in split liver transplantation: Is there an age limit?" *Am J Transplant* 20(3): 817-824.**

The experience of using pediatric donors in split liver transplant is exceedingly rare. We aim to investigate the outcomes of recipients receiving split pediatric grafts. Sixteen pediatric recipients receiving split liver grafts from 8 pediatric donors < 7 years were enrolled. The donor and recipient characteristics, perioperative course, postoperative complications, and graft and recipient survival rates were evaluated. The mean follow-up time was  $8.0 \pm 2.3$  months. The graft and recipient survival rates were 100%. The liver function remained in the normal range at the end of the follow-up time in all recipients. No life-threatening complications were seen in these recipients, and the only surgery-related complication was portal vein stenosis in 1 recipient. Cytomegalovirus infection was the most common complication (62.5%). The transaminase level was significantly higher in extended right lobe recipients in the early postoperative days, but the difference vanished at the end of first week; postoperative complications and graft and recipient survival rates did not differ between left and right graft recipients. Notably, the youngest split donor graft (2.7 years old) was associated with ideal recipient outcomes. Split liver transplant using well-selected pediatric donors is a promising strategy to expand pediatric donor source in well-matched recipients.

<https://pubmed.ncbi.nlm.nih.gov/31597001/>

**Grande, R. A. A., Fernandes, G. A., Andrade, D. P., Matsunaga, N. Y., Oliveira, T., Almeida, C. C. B. and Cohen, M. A. (2020). "Noninvasive ventilation in a pediatric ICU: factors associated with failure." *J Bras Pneumol* 46(6): e20180053.**

**Objective** Evaluate the efficacy of Noninvasive Mechanical Ventilation (NIV) in preventing Endotracheal Intubation (ETI) in a heterogeneous pediatric population and identify predictive factors associated with NIV failure in Pediatric Intensive Care Unit (PICU). **Methods** Prospective non-randomized clinical trial conducted with patients aged 0-10 years, hospitalized in a PICU with NIV indication, who presented acute or chronic respiratory failure. Demographic data and clinical and cardiorespiratory parameters were evaluated, and patients who did not progress to ETI in 48 h after withdrawal of NIV were classified as "success group", whereas those who progressed to ETI were included in the "failure group". Multivariate logistic regression was performed to identify the predictive factors of failure to prevent ETI. **Results** Fifty-two patients, 27 (51.9%)

males, with median age of 6 (1-120) months were included in the study. When evaluating the effectiveness of NIV, 36 (69.2%) patients were successful, with no need for ETI. After analyzing the predictive factors associated with failure, patients with tachypnea after 2 h of NIV were 4.8 times more likely to require ETI in 48 h. Regardless of outcome, heart ( $p<0.001$ ) and respiratory ( $p<0.001$ ) rates decreased and oxygen saturation ( $p<0.001$ ) increased after 2 h of NIV. Conclusion We concluded that use of NIV was effective in the studied population, with significant improvement in cardiorespiratory parameters after 2 h of NIV, and that tachypnea was a predictive factor of failure to prevent ETI.

<https://pubmed.ncbi.nlm.nih.gov/32844891/>

**Grass, B., Scheidegger, S., Latal, B., Hagmann, C., Held, U. and Brotschi, B. (2020). "Short-term neurological improvement in neonates with hypoxic-ischemic encephalopathy predicts neurodevelopmental outcome at 18-24 months." *J Perinat Med* 48(3): 296-303.**

**Objectives** To evaluate the association of short-term neurological improvement until day of life 4 in neonates with hypoxic-ischemic encephalopathy (HIE) receiving therapeutic hypothermia (TH) with neurodevelopmental outcome at 18-24 months. **Methods** This is a retrospective analysis of prospectively collected data of 174 neonates with HIE registered in the Swiss National Asphyxia and Cooling Register between 2011 and 2013. TH was initiated according to national guidelines, and Sarnat staging was performed daily. Short-term neurological improvement was defined if Sarnat stage improved from admission until day 4 of life. Standardized neurodevelopmental assessments were performed at 18-24 months. Unfavorable outcome was defined as death before 2 years of age or severe or moderate disability at follow-up. **Results** One hundred and sixty-four of 174 neonates (94%) received TH, of those 30 (18%) died in the neonatal period (no late mortality). Eighty-one percent of the survivors (109/134) were seen at 18-24 months. Of the 164 cooled neonates, 62% had a short-term neurological improvement, and the Sarnat score remained unchanged in 33%. Short-term neurological improvement was associated with an odds ratio (OR) of 0.118 [95% confidence interval (CI) 0.051-0.271] for an unfavorable outcome at 18-24 months. **Conclusion** Short-term neurological improvement predicts neurodevelopmental outcome at 18-24 months in the era of TH. Clinical examination must be part of a comprehensive evaluation for prognostication in HIE.

<https://pubmed.ncbi.nlm.nih.gov/32069247/>

**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://pubmed.ncbi.nlm.nih.gov/31233350/>

**Haxel, C., Glickstein, J. and Parravicini, E. (2019). "Neonatal Palliative Care for Complicated Cardiac Anomalies: A 10-Year Experience of an Interdisciplinary Program at a Large Tertiary Cardiac Center." *J Pediatr* 214: 79-88.**

**OBJECTIVES:** To report the outcomes of a Neonatal Palliative Care (NPC) Program at a large tertiary cardiac center caring for a subset of fetuses and neonates with life-limiting cardiac diagnoses or cardiac diagnoses with medical comorbidities leading to adverse prognoses. **STUDY DESIGN:** The Neonatal Comfort Care Program at New York-Presbyterian Morgan Stanley Children's Hospital/Columbia University Medical Center is an interdisciplinary team that offers the option of NPC to neonates prenatally diagnosed with life-limiting conditions, including single ventricle (SV) congenital heart disease (CHD) or less severe forms of CHD complicated by multiorgan dysfunction or genetic syndromes. **RESULTS:** From 2008 to 2017, the Neonatal Comfort Care Program cared for 75 fetuses or neonates including 29 with isolated SV CHD, 36 with CHD and multiorgan dysfunction and/or severe genetic abnormalities, and 10 neonates with a prenatal diagnosis of isolated CHD and postnatal diagnoses of severe conditions who were initially in intensive care before transitioning to NPC because of a poor prognosis. **CONCLUSIONS:** At New York-Presbyterian Morgan Stanley Children's Hospital/Columbia University Medical Center, a large tertiary cardiac center, 13.5% of parents of fetuses or neonates with isolated SV CHD opted for NPC. Twenty-six of 29 newborns with SV CHD treated with NPC died. Of the remaining, 2 neonates with mixing lesions are alive at 3 and 5 years of age, and 1 neonate was initially treated with NPC and then pursued surgical palliation. These results suggest that NPC is a reasonable choice for neonates with SV CHD.  
<https://pubmed.ncbi.nlm.nih.gov/31655705/>

**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://pubmed.ncbi.nlm.nih.gov/31077783/>

Hui, D., Anderson, L., Tang, M., Park, M., Liu, D. and Bruera, E. (2020). "Examination of referral criteria for outpatient palliative care among patients with advanced cancer." *Support Care Cancer* 28(1): 295-301.

BACKGROUND: An international panel achieved consensus on 9 need-based and 2 time-based major referral criteria to identify patients appropriate for outpatient palliative care referral. To better understand the operational characteristics of these criteria, we examined the proportion and timing of patients who met these referral criteria at our Supportive Care Clinic. METHODS: We retrieved data on consecutive patients with advanced cancer who were referred to our Supportive Care Clinic between January 1, 2016, and February 18, 2016. We examined the proportion of patients who met each major criteria and its timing. RESULTS: Among 200 patients (mean age 60, 53% female), the median overall survival from outpatient palliative care referral was 14 (95% confidence interval 9.2, 17.5) months. A majority (n = 170, 85%) of patients met at least 1 major criteria; specifically, 28%, 30%, 20%, and 8% met 1, 2, 3, and  $\geq 4$  criteria, respectively. The most commonly met need-based criteria were severe physical symptoms (n = 140, 70%), emotional symptoms (n = 36, 18%), decision-making needs (n = 26, 13%), and brain/leptomeningeal metastases (n = 25, 13%). For time-based criteria, 54 (27%) were referred within 3 months of diagnosis of advanced cancer and 63 (32%) after progression from  $\geq 2$  lines of palliative systemic therapy. The median duration from patient first meeting any criterion to palliative care referral was 2.4 (interquartile range 0.1, 8.6) months. CONCLUSIONS: Patients were referred early to our palliative care clinic and a vast majority (85%) of them met at least one major criteria. Standardized referral based on these criteria may facilitate even earlier referral.

<https://pubmed.ncbi.nlm.nih.gov/31044305/>

Hully, M., Barnerias, C., Chabaliere, D., Le Guen, S., Germa, V., Deladriere, E., Vanhulle, C., Cuisset, J. M., Chabrol, B., Cancès, C., Vuillerot, C., Espil, C., Mayer, M., Nougues, M. C., Sabouraud, P., Lefranc, J., Laugel, V., Rivier, F., Louvier, U. W., Durigneux, J., Napuri, S., Sarret, C., Renouil, M., Masurel, A., Viallard, M. L. and Desguerre, I. (2020). "Palliative Care in SMA Type 1: A Prospective Multicenter French Study Based on Parents' Reports." *Front Pediatr* 8: 4.

Spinal muscular atrophy type 1 (SMA-1) is a severe neurodegenerative disorder, which in the absence of curative treatment, leads to death before 1 year of age in most cases. Caring for these short-lived and severely impaired infants requires palliative management. New drugs (nusinersen) have recently been developed that may modify SMA-1 natural history and thus raise ethical concerns about the appropriate level of care for patients. The national Hospital Clinical Research Program (PHRC) called "Assessment of clinical practices of palliative care in children with Spinal Muscular Atrophy Type 1 (SMA-1)" was a multicenter prospective study conducted in France between 2012 and 2016 to report palliative practices in SMA-1 in real life through prospective caregivers' reports about their infants' management. Thirty-nine patients were included in the prospective PHRC (17 centers). We also studied retrospective data regarding management of 43 other SMA-1 patients (18 centers) over the same period, including seven treated with nusinersen, in comparison with historical data from 222 patients previously published over two periods of 10 years (1989-2009). In the latest period studied, median age at diagnosis was 3 months [0.6-10.4]. Seventy-seven patients died at a median 6 months of age[1-27]: 32% at home and 8% in an intensive care unit. Eighty-five percent of patients received enteral nutrition, some through a gastrostomy (6%). Sixteen percent had a non-invasive ventilation (NIV). Seventy-seven percent received sedative treatment at the time of death. Over time, palliative management occurred more frequently at home with increased levels of technical supportive care (enteral nutrition, oxygenotherapy, and analgesic and sedative treatments). No statistical difference was found between the prospective and retrospective patients for the last period. However, significant differences were found between patients treated with nusinersen vs. those untreated. Our data confirm that palliative care is essential in management of SMA-1 patients and that parents are extensively involved in everyday patient care. Our data suggest that nusinersen treatment was accompanied by significantly more invasive supportive care, indicating that a re-examination of standard clinical practices should explicitly consider what treatment pathways are in infants' and caregivers' best interest. This study was registered on clinicaltrials.gov under the reference NCT01862042 (<https://clinicaltrials.gov/ct2/show/study/NCT01862042?cond=SMA1&rank=8>). <https://pubmed.ncbi.nlm.nih.gov/32133329/>

Jasem, Z. A., Darlington, A. S., Lambrick, D., Grisbrooke, J. and Randall, D. C. (2020). "Play in Children With Life-Threatening and Life-Limiting Conditions: A Scoping Review." *Am J Occup Ther* 74(1): 7401205040p7401205041-7401205040p7401205014.

IMPORTANCE: Play is essential to children and provides opportunities to promote their health and well-being. Children living with life-threatening and life-limiting conditions experience deprivation in play. OBJECTIVE: To conduct a scoping review of studies

that examined play of children with a life-threatening or life-limiting condition to explore their play characteristics and possible factors influencing their participation in play. DATA SOURCES: A search of literature published between 1990 and 2017 was conducted in the health, social care, and built-environment fields. The scoping review included multiple searches in electronic databases, a gray literature search, and manual searches of relevant journals and reference lists of included articles. STUDY SELECTION AND DATA COLLECTION: Defined criteria were used to select articles describing studies that examined the daily play of children ages 5-11 yr with life-threatening and life-limiting conditions; articles that focused on play as therapy or that used parents' accounts of a service were excluded. The identified articles were critically appraised with the Critical Appraisal Skills Programme and the Joanna Briggs Institute Critical Appraisal Tools. FINDINGS: Thirteen articles were reviewed. The findings indicate that children's play is influenced by their health conditions and play opportunities and by the limited availability of appropriate play equipment and spaces allowing play and social interaction. CONCLUSIONS AND RELEVANCE: Available appropriate play opportunities need to be maximized for children living with life-threatening and life-limiting conditions. This goal can be achieved by understanding and considering the needs of these children and by facilitating environmental enablers and limiting barriers. WHAT THIS ARTICLE ADDS: Promoting the participation in play of children who live with life-threatening and life-limiting conditions is important to their health and well-being and can be achieved by targeting the cultural, social, and physical environmental factors that shape the children's play.

<https://pubmed.ncbi.nlm.nih.gov/32078515/>

**John, M. M., Razzouk, A. J., Chinnock, R. E., Bock, M. J., Kuhn, M. A., Martens, T. P. and Bailey, L. L. (2019). "Primary Transplantation for Congenital Heart Disease in the Neonatal Period: Long-term Outcomes." *Ann Thorac Surg* 108(6): 1857-1864.**

BACKGROUND: Primary transplantation was developed in the 1980s as an alternative therapy to palliative reconstruction of uncorrectable congenital heart disease. Although transplantation achieved more favorable results, its utilization has been limited by the availability of donor organs. This review examines the long-term outcomes of heart transplantation in neonates at our institution. METHODS: The institutional pediatric heart transplant database was queried for all neonatal heart transplants performed between 1985 and 2017. Follow-up was obtained from medical records and an annually administered questionnaire. Overall survival and time to development of complications were estimated using the Kaplan Meier method. Univariate and multivariate analyses were performed to identify independent predictors of survival. RESULTS: Heart transplantation was performed in 104 neonates. Median age was 17 days. Hypoplastic left heart syndrome (classic or variant) was the primary diagnosis in 77.8% of patients. Survival at 10 years and 25 years was 73.9% and 55.8%, respectively. At 20 years, freedom from allograft vasculopathy and lymphoproliferative disease was 72.0% and 81.9%, respectively. Freedom from re-transplantation was 81.4% at 20 years. Eight patients (7.6%) developed end-stage renal disease. By multivariate analysis, lower glomerular filtration rate and allograft vasculopathy were the only significant predictors of death. CONCLUSIONS: Neonatal heart transplantation remains a durable therapy with very acceptable long-term survival. Children transplanted in the newborn period have the potential to reach adulthood with minimal need for reintervention.

<https://pubmed.ncbi.nlm.nih.gov/31362016/>

**Kinami, H., Morita, K., Ko, Y., Shinohara, G. and Hashimoto, K. (2019). "A Devised Option of Neonatal Palliation for Compromised Tetralogy of Fallot with Absent Pulmonary Valve Syndrome." *Ann Thorac Cardiovasc Surg* 25(5): 274-277.**

Neonatal primary repair of tetralogy of Fallot (TOF) with absent pulmonary valve (APV) syndrome is associated with high mortality rates. Our plan involves a staged repair that avoids one-stage intracardiac repair (ICR), with a first palliation that closes the main pulmonary orifice using an expanded polytetrafluoroethylene (ePTFE) patch, pulmonary arterioplasty, and an adjustable Blalock-Taussig (BT) shunt. This strategy was used for a neonatal case with TOF/APV syndrome with hypoplastic left ventricle (LV). There was evidence of subsequent progressive increase in the LV size, and bronchial compression was relieved and an ICR was performed successfully at 9 months of age. <https://pubmed.ncbi.nlm.nih.gov/29515081/>

**Knoll, C., Kaufman, B., Chen, S., Murray, J., Cohen, H., Sourkes, B. M., Rosenthal, D. N. and Hollander, S. A. (2019). "Palliative Care Engagement for Pediatric Ventricular Assist Device Patients: A Single-Center Experience." *Asaio j*, 10.1097/mat.0000000000001092.**

Outcomes in pediatric patients with ventricular assist devices (VADs) for advanced heart failure (HF) are improving, but the risk of associated morbidity and mortality remains substantial. Few data exist on the involvement of pediatric palliative care (PPC) in this high-risk patient population. We aimed to characterize the extent of palliative care involvement in the care of patients requiring VAD placement at our institution. Single-center retrospective chart review analyzing all VAD patients at a large pediatric center over a 4 year period. Timing and extent of palliative care subspecialty involvement were analyzed. Between January 2014 and December 2017, 55 HF patients underwent VAD implantation at our institution. Pediatric palliative care utilization steadily increased over consecutive years (2014: <10% of patients, 2015: 20% of patients, 2016: 50% of patients, and 2017: 65% of patients) and occurred in 42% (n = 23) of all patients. Of these, 57% (n = 13) occurred before VAD placement while 43% (n = 10) occurred after implantation. Patients who died during their VAD implant hospitalization (24%, n = 13) were nearly twice as likely to have PPC involvement (62%) as those who reached transplant (38%). Of those who died, patients who had PPC involved in their care were more likely to limit resuscitation efforts before their death. Four patients had advanced directives in place before VAD implant, of which three had PPC consultation before device placement. Three families (5%) refused PPC involvement when offered. Pediatric palliative care utilization is increasing in VAD patients at our institution. Early PPC involvement occurred in the majority of patients and appears to lead to more frequent discussion of goals-of-care and advanced directives.

<https://pubmed.ncbi.nlm.nih.gov/32740354/>

**Krikheli, L., Erickson, S., Carey, L. B., Carey-Sargeant, C. L. and Mathisen, B. A. (2020). "Perspectives of speech and language therapists in paediatric palliative care: an international exploratory study." *Int J Lang Commun Disord*, 10.1111/1460-6984.12539.**

**BACKGROUND:** The involvement of speech and language therapists (SLTs) within paediatric palliative care (PPC) settings has been recognized within the extant literature. However, there is little understanding of SLT's specific roles and practices when working with this vulnerable cohort of children and their families. As part of a larger body of work to develop consensus-based recommendations for SLTs working in PPC, it is important to investigate demographic and caseload characteristics. **AIMS:** This exploratory study aimed to gather previously undocumented international demographic data pertaining to SLT service provision, caseload and training in PPC. Additionally, it sought to ascertain the current treatment and assessment approaches of SLTs, and if variations exist in beliefs and practices. **METHODS & PROCEDURES:** An anonymous cross-sectional survey was designed and reported according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). The online survey consisted of 40 items spanning four domains: (1) demographic information, (2) caseload information, (3) service provision and (4) training and education. SLTs from Australia, Canada, New Zealand, the UK, Ireland and the United States were recruited using a purposive snowball sampling approach. Descriptive analysis of closed-ended survey responses and content analysis of open-ended responses are presented. **OUTCOMES & RESULTS:** A total of 52 respondents completed the survey. SLTs worked in a variety of PPC settings, with patients of varying age and disease groups. Over 50% of participants reported working in PPC for  $\leq 4$  years. Genetic disorders (34%), oncology (27%) and neurological conditions (21%) made up a significant portion of respondents' caseloads. Reported treatments and assessment approaches used by SLTs are not unique to a PPC population. Barriers and enablers for practice were identified. A portion of participants did not feel trained and prepared to assess (19.2%) or treat (15.4%) PPC clients. **CONCLUSIONS & IMPLICATIONS:** This study confirms that SLTs internationally have a role in the management of communication and swallowing impairments in a PPC context. However, whether current training and resources adequately support SLTs in this role remains questionable. This paper helps to provide SLTs, administrators, professional associations and tertiary institutions with foundational data to help inform workforce planning, advocacy efforts and training priorities. What this paper adds What is already known on the subject The published multidisciplinary literature has identified that SLTs have a role in PPC. However, there has been no targeted research investigating the professional characteristics of clinicians in this context, nor any detailed information regarding associated clinician beliefs or management approaches. What this paper adds to existing knowledge This study is a snapshot of attributes, practice patterns and beliefs of SLTs who work with a PPC population. It highlights SLT perspectives of education and training, as well as meta-perceptions of themselves within the multidisciplinary team. What are the potential or actual clinical implications of this work? Data presented in this paper will help to enable SLTs, organizations and associations to augment service provision and determine future professional development priorities within the field of PPC.

<https://pubmed.ncbi.nlm.nih.gov/32449577/>

Lazzarin, P., Giacomelli, L., Terrenato, I. and Benini, F. (2020). "A Tool for the Evaluation of Clinical Needs and Eligibility to Pediatric Palliative Care: The Validation of the ACCAPED Scale." *J Palliat Med*, 10.1089/jpm.2020.0148.

Background: Despite their importance, pediatric palliative care (PPC) services are still scantily diffused. In addition, eligibility criteria for PPC are quite complex. Consequently, clinicians require a tool that suggests how to refer patients with life-limiting diseases to the most appropriate service and how to properly allocate health care resources. Objective: Recently, the Accertamento dei bisogni Clinico-Assistenziali Complessi in PEDIatria (ACCAPED) scale has been developed by a group of experts in PPC to evaluate the specific clinical needs of pediatric patients with a life-limiting disease. This study presents the validation of the ACCAPED scale. Design: Validation of ACCAPED scale was pursued by means of description and analysis of clinical vignettes representing patients with challenging-to-evaluate needs who have to be referred to the most appropriate service (community care, general PPC, and specialized PPC). The evaluation of vignettes according to the clinical experience of the experts represented the gold standard against which the validity of the ACCAPED scale was tested by groups with different levels of experience (experts, pediatricians, and health care providers (HCPs) not involved in PPC). Results: Results show a very high concordance between the evaluation of the vignettes through the ACCAPED scale and the evaluation by the clinical experience for experts in PPC and pediatricians. A less favorable grade of concordance has been recorded for HCPs not involved in PPC, suggesting that educational efforts to improve basic knowledge of PPC within the medical community are needed. Conclusions: Overall, this study suggests that the ACCAPED scale is a useful tool to improve rationalization of resources and eligibility criteria for PPC. <https://pubmed.ncbi.nlm.nih.gov/32640899/>

Lee, B. K., Boyle, P. J., Zaslowe-Dude, C., Wolfe, J. and Marcus, K. J. (2020). "Palliative radiotherapy for pediatric patients: Parental perceptions of indication, intent, and outcomes." *Pediatr Blood Cancer* 67(1): e28003.

OBJECTIVES: Palliative radiation therapy (pRT) is often used to improve quality of life for pediatric patients. Though palliative doses are generally lower than those for cure, pRT may still introduce undesirable effects. The decision to pursue additional therapy for a child may be challenging and depends on parents' knowledge and expectations. The goal of this study was to explore parental perceptions of pRT. METHODS: Twenty-eight children referred for pRT were enrolled in our prospective study. Parents were counseled regarding the indication and expected outcomes. They then completed a series of questionnaires to assess their understanding of pRT, side effects that their child experienced, and how the outcomes compared to their expectations. RESULTS: The majority of parents listed pain relief and addressing new disease as the main indication for pRT. When asked about expectations, the majority chose improvement in quality of life and prolongation of their child's life. Interestingly, 32% of parents expected pRT to cure their child's disease. Most patients undergoing pRT did not experience any adverse symptoms. The outcomes of pRT in the majority of cases exceeded parental expectations. CONCLUSION: Improved quality of life with pRT sometimes blurs the distinction between palliation and cure. We found that most parents understand the aim to improve quality of life, although a proportion of parents perceived pRT as a cure to their child's disease. Despite this, the majority of parents reported that the outcome of the pRT course exceeded their expectations. We postulate that parents derive comfort from pursuing active treatment. <https://pubmed.ncbi.nlm.nih.gov/31584240/>

Lee, J., Kim, G. B., Song, M. K., Lee, S. Y., Kim, M. S. and Bae, E. J. (2020). "End-of-Life Care of Hospitalized Children with Advanced Heart Disease." J Korean Med Sci 35(16): e107.

**BACKGROUND:** Despite improvements in palliative care for critically ill children, the characteristics of end-of-life care for pediatric patients with advanced heart disease are not well-known. We investigated these characteristics among hospitalized children with advanced heart disease in a tertiary referral center in Korea. **METHODS:** We retrospectively reviewed the records of 136 patients with advanced heart disease who died in our pediatric department from January 2006 through December 2013.

**RESULTS:** The median age of patients at death was 10.0 months (range 1 day-28.3 years). The median duration of the final hospitalization was 16.5 days (range 1-690 days). Most patients (94.1%) died in the intensive care unit and had received mechanical ventilation (89.7%) and inotropic agents (91.2%) within 24 hours of death. The parents of 74 patients (54.4%) had an end-of-life care discussion with their physician, and the length of stay of these patients in the intensive care unit and in hospital was longer. Of the 90 patients who had been hospitalized for 7 days or more, the parents of 54 patients (60%) had a documented end-of-life care discussion. The time interval from the end-of-life care discussion to death was 3 days or less for 25 patients. **CONCLUSION:** Children dying of advanced heart disease receive intensive treatment at the end of life. Discussions regarding end-of-life issues are often postponed until immediately prior to death. A pediatric palliative care program must be implemented to improve the quality of death in pediatric patients with heart disease.

<https://pubmed.ncbi.nlm.nih.gov/32329256/>

Lewis-Newby, M., Sellers, D. E., Meyer, E. C., Solomon, M. Z., Zurakowski, D. and Truog, R. D. (2020). "Location of Clinician-Family Communication at the End of Life in the Pediatric Intensive Care Unit and Clinician Perception of Communication Quality." J Palliat Med 23(8): 1052-1059.

**Background:** Communication between clinicians and families of dying children in the pediatric intensive care unit (PICU) is critically important for optimal care of the child and the family. **Objective:** We examined the current state of clinician perspective on communication with families of dying children in the PICU. **Design:** Prospective case series over a 15-month study period. **Setting/Subjects:** We surveyed nurses, psychosocial staff, and physicians who cared for dying children in PICUs at five U.S. academic hospitals. **Measurements:** Clinicians reported on the location of communication, perceived barriers to end-of-life care, and rated the quality of communication (QOC). **Results:** We collected 565 surveys from 287 clinicians who cared for 169 dying children. Clinicians reported that the majority of communication occurred at the bedside, and less commonly family conferences and rounds. Ten barriers to care were examined and were reported with frequencies of 2%-32%. QOC was rated higher when the majority of conversations occurred during family conferences ( $p = 0.01$ ) and lower for patients of non-white race ( $p = 0.03$ ). QOC decreased when 8 of the 10 barriers to care were reported. **Conclusions:** When a child is dying, clinicians report that communication with the family occurs most frequently at the child's bedside. This has important implications for future ICU communication research as the majority of previous research and education has focused on family care

conferences. In addition, findings that QOC is perceived as lower for non-white patients and when clinicians perceive that barriers hindering care are present can help direct future efforts to improve communication in the PICU.

<https://pubmed.ncbi.nlm.nih.gov/32182154/>

**Lizotte, M. H., Barrington, K. J., Sultan, S., Pennaforte, T., Moussa, A., Lachance, C., Sureau, M., Zao, Y. and Janvier, A. (2020). "Techniques to Communicate Better With Parents During End-of-Life Scenarios in Neonatology." *Pediatrics* 145(2).**

**BACKGROUND AND OBJECTIVES:** Clinicians are urged to optimize communication with families, generally without empirical practical recommendations. The objective of this study was to identify core behaviors associated with good communication during and after an unsuccessful resuscitation, including parental perspectives. **METHODS:** Clinicians from different backgrounds participated in a standardized, videotaped, simulated neonatal resuscitation in the presence of parent actors. The infant remained pulseless; participants communicated with the parent actors before, during, and after discontinuing resuscitation. Twenty-one evaluators with varying expertise (including 6 bereaved parents) viewed the videos. They were asked to score clinician-parent communication and identify the top communicators. In open-ended questions, they were asked to describe 3 aspects that were well done and 3 that were not. Answers to open-ended questions were coded for easily reproducible behaviors. All the videos were then independently reviewed to evaluate whether these behaviors were present. **RESULTS:** Thirty-one participants' videos were examined by 21 evaluators (651 evaluations). Parents and actors agreed with clinicians 81% of the time about what constituted optimal communication. Good communicators were more likely to introduce themselves, use the infant's name, acknowledge parental presence, prepare the parents (for the resuscitation, then death), stop resuscitation without asking parents, clearly mention death, provide or enable proximity (clinician-parent, infant-parent, clinician-infant, mother-father), sit down, decrease guilt, permit silence, and have knowledge about procedures after death. Consistently, clinicians who displayed such behaviors had evaluations >9 out of 10 and were all ranked top 10 communicators. **CONCLUSIONS:** During a neonatal end-of-life scenario, many simple behaviors, identified by parents and providers, can optimize clinician-parent communication.

<https://pubmed.ncbi.nlm.nih.gov/31988171/>

**Lockwood, B. J., Ntukidem, O. L., Ehrman, S. E., Schnell, P. M., Klemanski, D. L., Bhatnagar, B. and Lustberg, M. (2020). "Palliative Care Referral Patterns for Adolescent and Young Adult Patients at a Comprehensive Cancer Center." *J Adolesc Young Adult Oncol*, 10.1089/jayao.2020.0081.**

Palliative care (PC) serves a valuable role throughout the disease trajectory for adolescents and young adults (AYAs) living with cancer. A 3-year retrospective chart review was performed to characterize AYA PC referral patterns in patients aged 18-39 years to identify strategies for improving PC access. Despite known benefits, AYA referrals to PC during oncologic treatment occurred only for a small percentage of eligible patients (8.4%), largely occurred in the inpatient setting (73%), and were more likely in specific cancer types with high symptom burden and/or poor survival, with the greatest penetrance noted in lung cancer (51%).

<https://pubmed.ncbi.nlm.nih.gov/32706607/>

Luz, J. K., Martini, J., Clever, K., Herschbach, P., Christiansen, H. and Schepper, F. (2020). "Psychometric Properties of the Fear of Progression Questionnaire for Children (FoP-Q-SF/C)." *Klin Padiatr* 232(3): 136-142.

**BACKGROUND:** Recent research shows that parents of children suffer from fear of progression (FoP), the fear of further disease progression. It is most possible that children also develop FoP, which could impair treatment and psychological health. The aim of this study is to adapt the adult's version of the Fear of Progression Questionnaire - Short Form (FoP-Q-SF) for children and to examine the psychometric properties in pediatric cancer patients. **PATIENTS:** 32 pediatric cancer patients between 10 and 18 years with different diagnoses and in different treatment states participated in this study. **METHOD:** In the cross-sectional study participants completed the adapted Fear of Progression Questionnaire - Short Form for Children (FoP-Q-SF/C) and self-report measures assessing quality of life, depression, fear and coping satisfaction. **RESULTS:** The questionnaire (FoP-Q-SF/C) showed adequate psychometric properties (Cronbachs  $\alpha=0.86$ ) and good results for construct validity. Significant medium to large correlations of children's FoP was observed with quality of life ( $r=-0.37$ ), depression ( $r=0.52$ ), fear ( $r=0.33 - 0.76$ ), and satisfaction with coping ( $r=-0.44$ ). One-fifth of the sample was classified as having high FoP with values over 37. **CONCLUSIONS:** The FoP-Q-SF/C is a short, economic questionnaire that is applicable in children with cancer. Clinicians can use the questionnaire to explore specific fear and the need for psychosocial support. Further research for specific treatment approaches for FoP in pediatric cancer patients are warranted.

<https://pubmed.ncbi.nlm.nih.gov/32193886/>

Lynch, F., Endacott, R. and Latour, J. M. (2020). "Patient diaries: Survey of paediatric intensive care units in the United Kingdom and Ireland." *Nurs Crit Care* 25(1): 31-36.

**AIM:** The aim of the study was to explore the incidence, use, and scope of patient diaries in paediatric intensive care units (PICUs) in the United Kingdom and Ireland. **DESIGN:** This was an electronic survey sent to 30 PICUs in the United Kingdom and Ireland. **RESULTS:** All PICUs ( $n = 30$ ) responded, and 43% ( $n = 13$ ) offered diaries. For those units that did not supply diaries, the reasons given were concerns around the legal and professional implication of using diaries. Parental/carer consent to use a diary was obtained informally (79%,  $n = 11$ ), and once there was agreement to provide a diary to parents, diaries were usually started immediately (72%,  $n = 12$ ). Parents were the main contributors to the diaries (94%,  $n = 17$ ), and the diaries were populated with photographs (94%,  $n = 15$ ), drawings (100%,  $n = 16$ ), and stickers (94%,  $n = 15$ ). The reasons for offering diaries were to fill gaps in memories, to engage with families, and to explain what has happened in lay language. The owner of the diary was reported to be the family (82%,  $n = 14$ ) and the child (12%,  $n = 2$ ). **CONCLUSIONS:** The use of patient diaries is an evolving intervention in paediatric intensive care settings in the United Kingdom and Ireland. This national survey has provided a clearer picture of how this intervention is used in the United Kingdom and Ireland. PICU patient diaries are used in a significant number of units, and how these are used is relatively standardized, although in some different ways from general ICUs. **RELEVANCE TO CLINICAL**

PRACTICE: This survey provides a baseline for future exploration, understanding, and promotion of patient diaries, as a well evaluated tool for the critically ill child and his or her family.

<https://pubmed.ncbi.nlm.nih.gov/31583802/>

Lyons-Warren, A. M., Stowe, R. C., Emrick, L. and Jarrell, J. A. (2019). "Early Identification of Pediatric Neurology Patients With Palliative Care Needs: A Pilot Study." *Am J Hosp Palliat Care* 36(11): 959-966.

Palliative care services are beneficial for pediatric neurology patients with chronic, life-limiting illnesses. However, timely referral to palliative care may be impeded due to an inability to identify appropriate patients. The aim of this pilot case-control study was to test a quantitative measure for identifying patients with unmet palliative care needs to facilitate appropriate referrals. First, a random subset of pediatric neurology patients were screened for number of hospital admissions, emergency center visits, and problems on the problem list. Screening results led to the hypothesis that having six or more hospital admissions in one year indicated unmet palliative care needs. Next, hospital admissions in the past year were counted for all patients admitted to the neurology service during a six-month period. Patients with six or more admissions as well as age- and gender-matched controls were assessed for unmet palliative care needs. In hospitalized pediatric neurology patients, having six or more admissions in the preceding year did not predict unmet palliative care needs. While this pilot study did not find a quantitative measure that identifies patients needing a palliative care consultation, the negative finding highlights an important distinction between unmet social needs that interfere with care and unmet palliative care needs. Further, the method of screening patients used in this study was simple to implement and provides a framework for future studies.

<https://pubmed.ncbi.nlm.nih.gov/31014075/>

Mack, J. W., Cronin, A. M., Uno, H., Shusterman, S., Twist, C. J., Bagatell, R., Rosenberg, A., Marachelian, A., Granger, M. M., Glade Bender, J., Baker, J. N., Park, J., Cohn, S. L., Levine, A., Taddei, S. and Diller, L. R. (2020). "Unrealistic parental expectations for cure in poor-prognosis childhood cancer." *Cancer* 126(2): 416-424.

BACKGROUND: Many parents of children with advanced cancer pursue curative goals when cure is no longer possible. To the authors' knowledge, no pediatric studies to date have prospectively evaluated prognosis communication or influences on decision making in poor-prognosis childhood cancer. METHODS: The authors conducted a prospective cohort study at 9 pediatric cancer centers that enrolled 95 parents of children with recurrent or refractory, high-risk neuroblastoma (63% of those who were approached), a condition for which cure rarely is achieved. Parents were surveyed regarding the child's likelihood of cure; their primary goal of care; the child's symptoms, suffering, and quality of life; and regret concerning the last treatment decision. Medical records identified care and treatment decisions. RESULTS: Only 26% of parents recognized that the chance of cure was <25%. When asked to choose a single most important goal of care, approximately 72% chose cure, 10% chose longer life, and 18% chose quality of life. Parents were more likely to prioritize quality of life when they recognized the child's poor prognosis (P = .002). Approximately 41% of parents

expressed regret about the most recent treatment decision. Parents were more likely to experience regret if the child had received higher intensity medical care (odds ratio [OR], 3.14; 95% CI, 1.31-7.51), experienced suffering with limited benefit from the most recent treatment (OR, 4.78; 95% CI, 1.16-19.72), or experienced suffering from symptoms (OR, 2.91; 95% CI, 1.18-7.16). CONCLUSIONS: Parents of children with poor-prognosis cancer frequently make decisions based on unrealistic expectations. New strategies for effective prognosis communication are needed.

<https://pubmed.ncbi.nlm.nih.gov/31584705/>

**Marcus, K. L., Santos, G., Ciapponi, A., Comandé, D., Bilodeau, M., Wolfe, J. and Dussel, V. (2020). "Impact of Specialized Pediatric Palliative Care: A Systematic Review." *J Pain Symptom Manage* 59(2): 339-364.e310.**

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://pubmed.ncbi.nlm.nih.gov/31404638/>

**Moody, K. M., Hendricks-Ferguson, V. L., Baker, R., Perkins, S. and Haase, J. E. (2020). "A Pilot Study of the Effects of COMPLETE: A Communication Plan Early Through End of Life, on End-of-Life Outcomes in Children With Cancer." *J Pain Symptom Manage* 60(2): 417-421.**

CONTEXT: Most children with cancer die in hospital settings, without hospice, and many suffer from high-intensity medical interventions and pain at end of life (EOL). OBJECTIVES: To examine the effects of COMPLETE: a communication plan early through EOL to increase hospice enrollment in children with cancer at EOL. METHODS: This is a two-phase, single-arm, two-center, and prospective pilot study of hospice enrollment in children with cancer whose parents received COMPLETE. COMPLETE is

a series of medical doctor (MD)/registered nurse (RN)-guided discussions of goals of care using visual aids that begin at diagnosis. COMPLETE training for MD/RNs in Phase II was revised to increase their use of empathy. Preintervention/postintervention measurements for child include: time of hospice enrollment, pain, high-intensity medical interventions at EOL, and location of death; and for parent the following: uncertainty and hope. RESULTS: Twenty-one parents of 18 children enrolled in the study, and 13 children were followed through EOL. At EOL, 11 (84.6%) died on home hospice or inpatient hospice, and only two (15%) received high-intensity medical interventions. Similar to published findings in the initial 13 parents enrolled in Phase I, parents in Phase II (n = 7) had improvement in hope and uncertainty, and child pain was decreased. Revised training resulted in significant improvement in MD/RN (N = 6) use of empathy (11% in Phase I vs. 100% in Phase II; P = 0.001). CONCLUSION: COMPLETE resulted in increased hospice enrollment in children with cancer at EOL compared with historical controls. In preanalysis/postanalysis, COMPLETE decreased child pain while supporting hope and reducing uncertainty in their parents. <https://pubmed.ncbi.nlm.nih.gov/32315752/>

**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://pubmed.ncbi.nlm.nih.gov/31366685/>

Mpody, C., Humphrey, L., Kim, S., Tobias, J. D. and Nafiu, O. O. (2020). "Racial Differences in Do-Not-Resuscitate Orders among Pediatric Surgical Patients in the United States." J Palliat Med, 10.1089/jpm.2020.0053.

Background: Very few studies have investigated the racial differences in do-not-resuscitate (DNR) orders in children, and these studies are limited to oncological cases. We aim to characterize the racial difference in DNR orders among U.S. pediatric surgical patients. Methods: We retrospectively evaluated the mortality of all children who underwent an inpatient surgery between 2012 and 2017 from the National Surgical Quality Improvement Program. We used log-binomial models to estimate the relative risk (RR) and 95% confidence interval (CI) of DNR use comparing white with African American (AA) children. To estimate the risk-adjusted difference in DNR orders, we controlled the analyses for age, prematurity status, emergent case status, American Society of Anesthesiologists class, year of operation, surgical specialty, and surgical complexity. Results: Between 2012 and 2017, a total of 276,917 children underwent inpatient surgery, of whom 0.8% (n = 1601) died within 30 days of operation. Of the 1601 mortality cases, we retained 1212 children who were of either AA (26.0%, n = 350) or white (63.9%, n = 862) race. Most children were neonates, had an American Society of Anesthesiologists class  $\geq 4$  (70.0%, n = 811), and developed one or more postoperative complications (68.7%, n = 833). Overall, AA children were more likely to be neonates at the time of surgery (42.0% vs. 40.3%,  $p < 0.001$ ), to be premature (66.3% vs. 49.0%,  $p < 0.001$ ), and develop one or more postoperative complications (73.7% vs. 66.7%,  $p = 0.017$ ). White children were three times more likely to have a DNR order than their AA peers (adjusted RR: 3.01, 95% CI: 1.09-8.56,  $p = 0.044$ ). Conclusion: Among pediatric surgical patients in the United States, children of white race were three times more likely to have a DNR order in place than their AA peers despite the latter being "sicker" and more likely to develop postoperative complications. The mechanisms underlying this racial difference deserve further elucidation to improve shared decision making and goal-concordant care.

<https://pubmed.ncbi.nlm.nih.gov/32543271/>

Nagoya, Y., Miyashita, M., Irie, W., Yotani, N. and Shiwaku, H. (2020). "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 23(1): 82-89.

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://pubmed.ncbi.nlm.nih.gov/31355699/>

**Namisango, E., Bristowe, K., Murtagh, F. E., Downing, J., Powell, R. A., Abas, M., Lohfeld, L., Ali, Z., Atieno, M., Haufiku, D., Guma, S., Luyirika, E. B., Mwangi-Powell, F. N., Higginson, I. J. and Harding, R. (2020). "Towards person-centred quality care for children with life-limiting and life-threatening illness: Self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study." *Palliat Med* 34(3): 319-335.**

**BACKGROUND:** Paediatric life-limiting and life-threatening conditions (life-limiting conditions) place significant strain on children, families and health systems. Given high service use among this population, it is essential that care addresses their main symptoms and concerns. **AIM:** This study aimed to identify the symptoms, concerns and other outcomes that matter to children with life-limiting conditions and their families in sub-Saharan Africa. **SETTING AND PARTICIPANTS:** Cross-sectional qualitative study in Kenya, Namibia, South Africa and Uganda. Children/caregivers of children aged 0-17 years with life-limiting conditions were purposively sampled by age, sex and diagnosis. Children aged 7 and above self-reported; caregiver proxies reported for children below 7 and those aged 7 and above unable to self-report. **RESULTS:** A total of 120 interviews were conducted with children with life-limiting conditions (n = 61; age range: 7-17 years), and where self-report was not possible, caregivers (n = 59) of children (age range: 0-17) were included. Conditions included advanced HIV (22%), cancer (19%), heart disease (16%) endocrine, blood and immune disorders (13%), neurological conditions (12%), sickle cell anaemia (10%) and renal disease (8%). Outcomes identified included physical concerns - pain and symptom distress; psychosocial concerns - family and social relationships, ability to engage with age-appropriate activities (e.g. play, school attendance); existential concerns - worry about death, and loss of ambitions; health care quality - child- and adolescent-friendly services. Priority psycho-social concerns and health service factors varied by age. **CONCLUSION:** This study bridges an important knowledge gap regarding symptoms, concerns and outcomes that matter to children living with life-limiting conditions and their families and informs service development and evaluation.

<https://pubmed.ncbi.nlm.nih.gov/32081084/>

**Ong, T., Liu, C. C., Elder, L., Hill, L., Abts, M., Dahl, J. P., Evans, K. N., Parikh, S. R., Soares, J. J., Striegl, A. M., Whitlock, K. B. and Johnson, K. E. (2020). "The Trach Safe Initiative: A Quality Improvement Initiative to Reduce Mortality among Pediatric Tracheostomy Patients." *Otolaryngol Head Neck Surg* 163(2): 221-231.**

**OBJECTIVE:** To describe the Trach Safe Initiative and assess its impact on unanticipated tracheostomy-related mortality in outpatient tracheostomy-dependent children (TDC). **METHODS:** An interdisciplinary team including parents and providers

designed the initiative with quality improvement methods. Three practice changes were prioritized: (1) surveillance airway endoscopy prior to hospital discharge from tracheostomy placement, (2) education for community-based nurses on TDC-focused emergency airway management, and (3) routine assessment of airway events for TDC in clinic. The primary outcome was annual unanticipated mortality after hospital discharge from tracheostomy placement before and after the initiative. RESULTS: In the 5 years before and after the initiative, 131 children and 155 children underwent tracheostomy placement, respectively. At the end of the study period, the institution sustained Trach Safe practices: (1) surveillance bronchoscopies increased from 104 to 429 bronchoscopies, (2) the course trained 209 community-based nurses, and (3) the survey was used in 488 home ventilator clinic visits to identify near-miss airway events. Prior to the initiative, 9 deaths were unanticipated. After Trach Safe implementation, 1 death was unanticipated. Control chart analysis demonstrates significant special-cause variation in reduced unanticipated mortality. DISCUSSION: We describe a system shift in reduced unanticipated mortality for TDC through 3 major practice changes of the Trach Safe Initiative. IMPLICATION FOR PRACTICE: Death in a child with a tracheostomy tube at home may represent modifiable tracheostomy-related airway events. Using Trach Safe practices, we address multiple facets to improve safety of TDC out of the hospital.

<https://pubmed.ncbi.nlm.nih.gov/32204663/>

Ou, J. Y., Hanson, H. A., Ramsay, J. M., Kaddas, H. K., Pope, C. A., 3rd, Leiser, C. L., VanDerslice, J. and Kirchhoff, A. C. (2020). "Fine Particulate Matter Air Pollution and Mortality among Pediatric, Adolescent, and Young Adult Cancer Patients." Cancer Epidemiol Biomarkers Prev, 10.1158/1055-9965.epi-19-1363.

BACKGROUND: Air pollution is a carcinogen and causes pulmonary and cardiac complications. We examined the association of fine particulate matter pollution (PM<sub>2.5</sub>) and mortality from cancer and all causes among pediatric, adolescent, and young adult (AYA) patients with cancer in Utah, a state with considerable variation in PM<sub>2.5</sub>. METHODS: We followed 2,444 pediatric (diagnosed ages 0-14) and 13,459 AYA (diagnosed ages 15-39) patients diagnosed in 1986-2015 from diagnosis to 5 and 10 years postdiagnosis, death, or emigration. We measured average monthly PM<sub>2.5</sub> by ZIP code during follow-up. Separate pediatric and AYA multivariable Cox models estimated the association of PM<sub>2.5</sub> and mortality. Among AYAs, we examined effect modification of PM<sub>2.5</sub> and mortality by stage while controlling for cancer type. RESULTS: Increases in PM<sub>2.5</sub> per 5 µg/m<sup>3</sup> were associated with cancer mortality in pediatric lymphomas and central nervous system (CNS) tumors at both time points, and all cause mortality in lymphoid leukemias [HR(5-year) = 1.32 (1.02-1.71)]. Among AYAs, PM<sub>2.5</sub> per 5 µg/m<sup>3</sup> was associated with cancer mortality in CNS tumors and carcinomas at both time points, and all cause mortality for all AYA cancer types [HR(5-year) = 1.06 (1.01-1.13)]. PM<sub>2.5</sub> ≥12 µg/m<sup>3</sup> was associated with cancer mortality among breast [HR(5-year) = 1.50 (1.29-1.74); HR(10-year) = 1.30 (1.13-1.50)] and colorectal cancers [HR(5-year) = 1.74 (1.29-2.35); HR(10-year) = 1.67 (1.20-2.31)] at both time points. Effect modification by stage was significant, with local tumors at highest risk. CONCLUSIONS: PM<sub>2.5</sub> was associated with mortality in pediatric and AYA patients with specific cancers. IMPACT: Limiting PM<sub>2.5</sub> exposure may be important for young cancer patients with certain cancers.

<https://pubmed.ncbi.nlm.nih.gov/32404444/>

Park, S. Y. and Ju, H. O. (2020). "Development of an Instrument to Measure Stress in Korean Nurses Performing End-of-Life Care for Children." J Pediatr Nurs 54: e84-e90.

**PURPOSE:** This study aims to develop a scale to assess the stress of nurses caring for terminally ill children and to test the validity and reliability of the scale. **BACKGROUND:** Nurses caring for children experience various stressors that are different from those experienced by nurses caring for adult patients. It is important to understand the level of stress of nurses caring for dying children and their families. Instruments to measure these stress levels, however, are not available. **DESIGN:** This study used a methodological approach. **METHOD:** The initial items were identified through literature reviews and in-depth interviews. Content validation of the items was evaluated by seven experts. Participants were 357 pediatric nurses working at 11 institutions in six cities. Data were analyzed using item analysis, exploratory and confirmatory factor analysis, internal consistency, and test-retest. This study followed the STROBE checklist. **FINDINGS:** The final scale consisted of 22 items chosen and classified into 5 factors (psychological difficulties, conflict with parents, difficulties in communication, lack of end-of-life care knowledge, and restricted working environment), which explained 61.13% of the total variance. The 5-subscale model was validated by confirmatory factor analysis. Cronbach's alpha for the total item was 0.90, and the intra-class correlation coefficient was 0.89. **CONCLUSION:** This scale can be used to contribute toward the assessment of stress among nurses performing end-of-life care for children. **PRACTICE IMPLICATIONS:** This scale will contribute to the improvement of the quality of life of not only nurses, but also children and their families in pediatric settings.

<https://pubmed.ncbi.nlm.nih.gov/32553475/>

Patterson, M. C., Garver, W. S., Giugliani, R., Imrie, J., Jahnova, H., Meaney, F. J., Nadjar, Y., Vanier, M. T., Moneuse, P., Morand, O., Rosenberg, D., Schwierin, B. and Héron, B. (2020). "Long-term survival outcomes of patients with Niemann-Pick disease type C receiving miglustat treatment: A large retrospective observational study." J Inherit Metab Dis, 10.1002/jimd.12245.

Miglustat has been indicated for the treatment of Niemann-Pick disease type C (NP-C) since 2009. The aim of this observational study was to assess the effect of miglustat on long-term survival of patients with NP-C. Data for 789 patients from five large national cohorts and from the NPC Registry were collected and combined. Miglustat-treated and untreated patients overall and within sub-groups according to age-at-neurological-onset, that is, early infantile-onset (<2 years), late infantile-onset (2 to <6 years), juvenile-onset (6 to <15 years), and adolescent/adult-onset ( $\geq 15$  years) were analysed and compared. Survival was analysed from the time of first neurological manifestation (Neurological onset group, comprising 669 patients) and from diagnosis (Diagnosis group, comprising 590 patients) using a Cox proportional hazard model adjusted for various covariates. Overall, 384 (57.4%) patients in the Neurological onset group and 329 (55.8%) in the Diagnosis group were treated with miglustat. Miglustat treatment was associated with a significant reduction in risk of mortality in both groups (entire Neurological onset group, Hazard ratio [HR] = 0.51; entire Diagnosis group, HR = 0.44; both  $P < .001$ ). The effect was observed consistently in all age-at-neurological-onset

sub-groups (HRs = 0.3 to 0.7) and was statistically significant for late infantile-onset patients in both groups (Neurological onset group, HR = 0.36,  $P < .05$ ; Diagnosis group, HR = 0.32,  $P < .01$ ), and juvenile-onset patients in the Diagnosis group only (HR = 0.30,  $P < .05$ ). Despite the limitations of the data that urge cautious interpretation, the findings are consistent with a beneficial effect of miglustat on survival in patients with NP-C.

<https://pubmed.ncbi.nlm.nih.gov/32324281/>

**Patterson, M. C., Mengel, E., Vanier, M. T., Moneuse, P., Rosenberg, D. and Pineda, M. (2020). "Treatment outcomes following continuous miglustat therapy in patients with Niemann-Pick disease Type C: a final report of the NPC Registry." *Orphanet J Rare Dis* 15(1): 104.**

**BACKGROUND:** Niemann-Pick disease Type C (NP-C) is a rare, progressive neurodegenerative disorder characterized by progressive neurodegeneration and premature death. We report data at closure of the NPC Registry that describes the natural history, disease course and treatment experience of NP-C patients in a real-world setting. **METHODS:** The NPC Registry was a prospective observational cohort study that ran between September 2009 and October 2017. Patients with a confirmed diagnosis of NP-C were enrolled regardless of treatment status. All patients underwent clinical assessments and medical care as determined by their physicians; data were collected through a secure internet-based portal. **RESULTS:** At closure on October 19, 2017, 472 patients from 22 countries were enrolled in the NPC Registry. Mean (standard deviation) age at enrollment was 21.2 (15.0) years, and 51.9% of patients were male. First neurological symptom onset occurred during the early-infantile (< 2 years), late-infantile (2 to < 6 years), juvenile (6 to < 15 years), or adolescent/adult ( $\geq 15$  years) periods in 13.5, 25.6, 31.8, and 29.1% of cases, respectively. The most frequent neurological manifestations prior to enrollment included ataxia (67.9%), vertical supranuclear gaze palsy (67.4%), dysarthria (64.7%), cognitive impairment (62.7%), dysphagia (49.1%), and dystonia (40.2%). During infancy, splenomegaly and hepatomegaly were frequent ( $n = 199/398$  [50%] and  $n = 147/397$  [37.0%], respectively) and persisted in most affected patients. Of the 472 enrolled patients, 241 were continuously treated with miglustat during the NPC Registry observation period, of whom 172 of these 241 patients were treated continuously for  $\geq 12$  months. A composite disability score that assesses impairment of ambulation, manipulation, language, and swallowing was highest in the early-infantile population and lowest in the adolescent/adult population. Among the continuous miglustat therapy population, 70.5% of patients had improved or had stable disease (at least 3 of the 4 domains having a decreased or unchanged score between enrollment and last follow-up). The NPC Registry did not identify any new safety signals associated with miglustat therapy. **CONCLUSIONS:** The profiles of clinical manifestations in the final NPC Registry dataset agreed with previous clinical descriptions. Miglustat therapy was associated with a stabilization of neurological manifestations in most patients. The safety and tolerability of miglustat therapy was consistent with previous reports.

<https://pubmed.ncbi.nlm.nih.gov/32334605/>

**Patterson, P., McDonald, F. E. J., Costa, D. S. J., Tindle, R., Allison, K. R. and Morris, S. E. (2020). "Initial validation of a needs instrument for young people bereaved by familial cancer." *Support Care Cancer* 28(8): 3637-3648.**

**OBJECTIVE:** This study aimed to validate the Bereaved Cancer Needs Instrument (BCNI), an instrument designed to assess the unmet psychosocial needs of adolescents and young adults (AYAs, 12-25 years) who have experienced the death of a parent or sibling to cancer. **METHODS:** In total, 335 participants aged 12 to 25 ( $M = 15.80$ ,  $SD = 3.32$ ) who had experienced the death of a parent ( $N = 297$ ) or sibling ( $N = 38$ ) from cancer took part in this study. Participants completed the BCNI, the Kessler-10 psychological distress scale (K10), and several items assessing the acceptability of the BCNI. **RESULTS:** Exploratory factor analysis indicated that a seven-factor structure best fit the BCNI, accounting for 56.65% of the variance in unmet psychosocial needs of cancer-bereaved AYAs. The measure had good psychometric properties, high levels of internal consistency for all domains, and correlated strongly with the K10 ( $r = .59$ ,  $p < .001$ ). Item response theory analysis demonstrated that the response scale was appropriate, with strong discrimination indices. Analyses also indicated the potential to reduce the BCNI from 58 items to a 37-item short-form, although this will require further validation. **CONCLUSIONS:** The BCNI is the first psychometrically validated instrument to identify the unmet psychosocial needs of bereaved AYAs who have experienced the death of a parent or sibling to cancer. The instrument can be used in research and health care settings to identify the unmet needs of young people bereaved by cancer and provide targeted support to reduce psychological distress. <https://pubmed.ncbi.nlm.nih.gov/31811484/>

**Penumarthy, N. L., Goldsby, R. E., Shiboski, S. C., Wustrack, R., Murphy, P. and Winestone, L. E. (2020). "Insurance impacts survival for children, adolescents, and young adults with bone and soft tissue sarcomas." *Cancer Med* 9(3): 951-958.**

**BACKGROUND:** While racial/ethnic survival disparities have been described in pediatric oncology, the impact of income has not been extensively explored. We analyzed how public insurance influences 5-year overall survival (OS) in young patients with sarcomas. **METHODS:** The University of California San Francisco Cancer Registry was used to identify patients aged 0-39 diagnosed with bone or soft tissue sarcomas between 2000 and 2015. Low-income patients were defined as those with no insurance or Medicaid, a means-tested form of public insurance. Survival curves were computed using the Kaplan-Meier method and compared using log-rank tests and Cox models. Causal mediation was used to assess whether the association between public insurance and mortality is mediated by metastatic disease. **RESULTS:** Of 1106 patients, 39% patients were classified as low-income. Low-income patients were more likely to be racial/ethnic minorities and to present with metastatic disease (OR 1.96, 95% CI 1.35-2.86). Low-income patients had significantly worse OS (61% vs 71%). Age at diagnosis and extent of disease at diagnosis were also independent predictors of OS. When stratified by extent of disease, low-income patients consistently had significantly worse OS (localized: 78% vs 84%, regional: 64% vs 73%, metastatic: 23% vs 30%, respectively). Mediation analysis indicated that metastatic disease at diagnosis mediated 15% of the effect of public insurance on OS. **CONCLUSIONS:** Low-income patients with bone and soft tissue sarcomas had decreased OS regardless of disease stage at presentation. The mechanism by which insurance status impacts survival requires additional investigation, but may be through reduced access to care. <https://pubmed.ncbi.nlm.nih.gov/31838786/>

Pestian, T., Thienprayoon, R., Grossoehme, D., Friebert, S. and Humphrey, L. (2020). "Safety in Pediatric Hospice and Palliative Care: A Qualitative Study." *Pediatr Qual Saf* 5(4): e328.

**INTRODUCTION:** Patient safety is extensively studied in both adults and pediatric medicine; however, knowledge is limited regarding particular safety events in pediatric hospice and palliative care (HPC). Additionally, pediatric HPC lacks a unified definition of safe care. This qualitative study sought to explore caregiver views regarding safe care in pediatric HPC. **METHODS:** This is a secondary analysis of qualitative data from a multisite study utilizing semi-structured interview data to evaluate parental perspectives of quality in pediatric home-based HPC programs across 3 different pediatric tertiary care hospitals. Eligible participants included parents and caregivers of children who were enrolled in a pediatric home-based hospice and palliative care program (HBHPC) from 2012 to 2016. The analysis was done using grounded theory methodology. **RESULTS:** Forty-three parents participated in 39 interviews across all 3 sites; 19 families were bereaved. Responses to the prompt regarding safe care produced 8 unique domains encompassing parental definitions of safe care in pediatric HPC. **DISCUSSION:** Parents of children in HPC programs describe "safe care" in novel ways, some of which echo Maslow's hierarchy of needs. The use of traditional hospital safety measures for patients receiving HPC could undermine the patient's goals or dignity, ultimately leading to harm to the patient. **CONCLUDING SUMMARY:** Patients' and families' unique goals and values must be considered when defining safety for children in this population. Future studies should continue to explore family perspectives of safety in the hospital and ambulatory settings and seek to identify measurable indicators in safety which are truly patient- and family-centered.  
<https://pubmed.ncbi.nlm.nih.gov/32766499/>

Poort, H., Zupanc, S. N., Leiter, R. E., Wright, A. A. and Lindvall, C. (2020). "Documentation of Palliative and End-of-Life Care Process Measures Among Young Adults Who Died of Cancer: A Natural Language Processing Approach." *J Adolesc Young Adult Oncol* 9(1): 100-104.

Few studies have investigated palliative and end-of-life care processes among young adults (YAs), aged 18-34 years, who died of cancer. This retrospective study used a natural language processing algorithm to identify documentation and timing of four process measures in YA cancer decedents' medical records: palliative care involvement, discussions of goals of care, code status, and hospice. Among 2878 YAs, 138 had a recorded date of death. In this group, 54.3% had at least one process measure documented early (31-180 days before death), 18.0% had only late documentation of process measures (0-30 days), and 27.5% had none documented.  
<https://pubmed.ncbi.nlm.nih.gov/31411524/>

Raed, M., Grossoehme, D. H., Brown, M. and Friebert, S. (2020). "Hospital to home transport at end of life: Survey of clinician experience." *Palliat Med* 34(3): 424-429.

**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://pubmed.ncbi.nlm.nih.gov/31431157/>

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 3.6 months (95% confidence interval (CI), 2.3-4.8 months). 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://pubmed.ncbi.nlm.nih.gov/31174104/>

Roeland, E. J., Lindley, L. C., Gilbertson-White, S., Saeidzadeh, S., Currie, E. R., Friedman, S., Bakitas, M. and Mack, J. W. (2020). "End-of-life care among adolescent and young adult patients with cancer living in poverty." *Cancer* 126(4): 886-893.

**BACKGROUND:** To the authors' knowledge, end-of-life (EOL) care outcomes among adolescents and young adults (AYAs) with cancer who are living in poverty remain poorly understood. The primary aim of the current study was to examine the effect of poverty on EOL care for AYA patients with cancer. **METHODS:** The authors conducted a multisite, retrospective study of AYA patients with cancer aged 15 to 39 years who died between January 2013 and December 2016 at 3 academic sites. Medical record-based EOL care outcomes included hospice referral, palliative care (PC) consultation, cancer treatment within the last month of life, and location of death. Two measures of poverty were applied: 1) zip code with a median income  $\leq 200\%$  of the federal poverty level; and 2) public insurance or lack of insurance. Logistic regression analyses were conducted. **RESULTS:** A total of 252 AYA cancer decedents were identified. Approximately 41% lived in a high-poverty zip code and 48% had public insurance or lacked insurance; approximately 70% had at least 1 poverty indicator. Nearly 40% had a hospice referral, 60% had a PC consultation (76% on an inpatient basis), 38% received EOL cancer treatment, and 39% died in the hospital. In bivariable analyses, AYA patients living in low-income zip codes were found to be less likely to enroll in hospice ( $P \leq .01$ ), have an early PC referral ( $P \leq .01$ ), or receive EOL cancer treatment ( $P = .03$ ), although only EOL cancer treatment met statistical significance in multivariable models. No differences with regard to location of death ( $P = .99$ ) were observed. **CONCLUSIONS:** AYA patients with cancer experience low rates of hospice referral and high rates of in-hospital death regardless of socioeconomic status. Future studies should evaluate early inpatient PC referrals as a possible method for improving EOL care.

<https://pubmed.ncbi.nlm.nih.gov/31724747/>

Sanford, E. F., Clark, M. M., Farnaes, L., Williams, M. R., Perry, J. C., Ingulli, E. G., Sweeney, N. M., Doshi, A., Gold, J. J., Briggs, B., Bainbridge, M. N., Feddock, M., Watkins, K., Chowdhury, S., Nahas, S. A., Dimmock, D. P., Kingsmore, S. F. and Coufal, N. G. (2019). "Rapid Whole Genome Sequencing Has Clinical Utility in Children in the PICU." *Pediatr Crit Care Med* 20(11): 1007-1020.

**OBJECTIVES:** Genetic disorders are a leading contributor to mortality in the neonatal ICU and PICU in the United States. Although individually rare, there are over 6,200 single-gene diseases, which may preclude a genetic diagnosis prior to ICU admission. Rapid whole genome sequencing is an emerging method of diagnosing genetic conditions in time to affect ICU management of neonates; however, its clinical utility has yet to be adequately demonstrated in critically ill children. This study evaluates next-generation sequencing in pediatric critical care. **DESIGN:** Retrospective cohort study. **SETTING:** Single-center PICU in a tertiary children's hospital. **PATIENTS:** Children 4 months to 18 years admitted to the PICU who were nominated between July 2016 and May 2018. **INTERVENTIONS:** Rapid whole genome sequencing with targeted phenotype-driven analysis was performed on patients and their parents, when parental samples were available. **MEASUREMENTS AND MAIN RESULTS:** A molecular

diagnosis was made by rapid whole genome sequencing in 17 of 38 children (45%). In four of the 17 patients (24%), the genetic diagnoses led to a change in management while in the PICU, including genome-informed changes in pharmacotherapy and transition to palliative care. Nine of the 17 diagnosed children (53%) had no dysmorphic features or developmental delay. Eighty-two percent of diagnoses affected the clinical management of the patient and/or family after PICU discharge, including avoidance of biopsy, administration of factor replacement, and surveillance for disorder-related sequelae. CONCLUSIONS: This study demonstrates a retrospective evaluation for undiagnosed genetic disease in the PICU and clinical utility of rapid whole genome sequencing in a portion of critically ill children. Further studies are needed to identify PICU patients who will benefit from rapid whole genome sequencing early in PICU admission when the underlying etiology is unclear.

<https://pubmed.ncbi.nlm.nih.gov/31246743/>

**Schmidt, P., Hartenstein-Pinter, A., Wager, J., Hasan, C. and Zernikow, B. (2020). "Addressing multidrug resistant pathogens in pediatric palliative care patients-the nurses point of view: A qualitative study." *Palliat Med* 34(3): 349-357.**

BACKGROUND: Multidrug resistant pathogens are a large-scale healthcare issue. In particular, children with life-limiting conditions have a significantly increased risk of multidrug resistant pathogen colonization. Official hygiene requirements recommend children, who are colonized with multidrug resistant pathogens, to be isolated. In the context of pediatric palliative care, such isolation adversely affects the aim of social participation. To overcome this challenge of conflicting interests on a pediatric palliative care inpatient unit, a hygiene concept for patients colonized with multidrug resistant pathogens, called PALLINI, was implemented. AIM: The aim of this study was to identify the nurses' attitudes and opinions toward PALLINI. METHODS: Nurses (N = 14) from the pediatric palliative care unit were queried in guideline-oriented interviews. Interviews were analyzed qualitatively by means of content analysis. RESULTS: The following four categories were identified: (1) safety, (2) effort, (3) quality of care, and (4) participation. All categories demonstrated ambivalence by nursing staff regarding PALLINI. Ambivalence arose from guaranteeing infection control versus noncompliance by the families, additional workload for patients with multidrug resistant pathogens versus lack of resources, impaired relationship with the parents versus enabling better care for the child, as well as enabling some limited contact versus the larger goal of genuine social participation. Despite this, nurses reported the importance of arranging everyday-life for the patients so that they experience as much social participation as possible. CONCLUSION: The implementation of a new hygiene concept is challenging. Despite positive reception of PALLINI from the nurses, ambivalence remained. Addressing these ambivalences may be critical to best implement the new hygiene concept.

<https://pubmed.ncbi.nlm.nih.gov/31659938/>

**Schmidt, P., Hasan, C., Simon, A., Geffers, C., Wager, J. and Zernikow, B. (2020). "Multidrug-resistant bacteria in a paediatric palliative care inpatient unit: results of a one year surveillance." *GMS Hyg Infect Control* 15: Doc03.**

Aim: Nosocomial infections (NIs) and multidrug resistant (MDR) pathogens are an important paediatric healthcare issue. In vulnerable patients such as children with life-

limiting conditions, MDR infections can be life-threatening. Additionally, these children have a significantly increased risk for colonisation with MDR pathogens. Therefore, it is vital to prevent new colonisations with MDR pathogens in this vulnerable patient group. However, little is known about colonisation with MDR pathogens and NIs in inpatient units for paediatric palliative care (PPC). The aim of this study was to investigate the prevalence of colonisation with MDR pathogens and the incidence of NIs in a PPC unit. Methods: Evaluation of surveillance data of a PPC unit. All patients admitted to a PPC unit from 1(st) April 2012 to 31(st) March 2013 were screened for MDR pathogens upon admission. Patients who exhibited clinical signs of an infection during their inpatient stay were screened again. Results: During the study period, 198 cases were admitted to the unit. Those cases represent 118 patients. 18% of the patients were colonised with MDR pathogens. The most common MDR pathogens were *E. coli* (8.1%) and *Pseudomonas ssp.* (8.1%). In addition, 58% of patients with tracheostomy had MDR pathogens in their tracheal secretions. The incidence density of NIs was 0.99 per 1000 inpatient treatment days with no NI caused by MDR pathogens. Conclusion: Due to a high prevalence, it is reasonable to screen PPC patients for MDR pathogen colonisation before or during admission. Special attention must be given to patients with tracheostomy. Our results provide preliminary evidence that participation in social activities in a PPC unit for patients colonised with MDR pathogens is safe if hygiene concepts are applied.

<https://pubmed.ncbi.nlm.nih.gov/32269914/>

**Singh, J., Lanzarini, E. and Santosh, P. (2020). "Autonomic dysfunction and sudden death in patients with Rett syndrome: a systematic review." *J Psychiatry Neurosci* 45(3): 150-181.**

**BACKGROUND:** Rett syndrome (RTT), a debilitating neuropsychiatric disorder that begins in early childhood, is characterized by impairments in the autonomic nervous system that can lead to sudden unexpected death. This study explores the mechanisms of autonomic dysfunction to identify potential risk factors for sudden death in patients with RTT. **METHODS:** Following the Reporting Items for Systematic Review and Meta-Analyses (PRISMA) criteria, we undertook comprehensive systematic reviews using the PubMed, Scopus, Cochrane, PsycINFO, Embase and Web of Science databases. **RESULTS:** We identified and critically appraised 39 articles for autonomic dysfunction and 5 for sudden death that satisfied the eligibility criteria. Following thematic analysis, we identified 7 themes: breathing irregularities, abnormal spontaneous brainstem activations, heart rate variability metrics, QTc changes, vagal imbalance, fluctuation in peptides and serotonergic neurotransmission. We grouped these 7 themes into 3 final themes: (A) brainstem modulation of breathing, (B) electrical instability of the cardiovascular system and (C) neurochemical changes contributing to autonomic decline. We described key evidence relating to each theme and identified important areas that could improve the clinical management of patients with RTT. **LIMITATIONS:** The heterogeneity of the methods used to assess autonomic function increased the difficulty of making inferences from the different studies. **CONCLUSION:** This study identified the important mediators of autonomic dysfunction and sudden death in patients with RTT. We proposed brainstem mechanisms and emphasized risk factors that increase brainstem vulnerability. We discussed clinical management to reduce sudden death and future directions for this vulnerable population.

<https://pubmed.ncbi.nlm.nih.gov/31702122/>

Smith, S. and Rahman, O. (2020). Post Intensive Care Syndrome (PICS). StatPearls. Treasure Island (FL), StatPearls Publishing Copyright © 2020, StatPearls Publishing LLC.

While the short-term outcomes of ICU patients have dramatically improved over the last half-century, it is increasingly recognized that many ICU survivors experience declines in physical and cognitive functioning that persist well beyond their acute hospitalization. Psychiatric sequelae, including anxiety, depression, and post-traumatic stress disorder (PTSD) are also prevalent among both ICU survivors and their family members. Attendees of a 2010 meeting of the Society of Critical Care Medicine coined the term Post Intensive Care Syndrome (PICS) to describe new and persistent declines in physical, cognitive, and mental health functioning that follow an ICU stay and for which other causes, such as traumatic brain injury (TBI) or cerebrovascular accident (CVA), have been excluded. The term PICS-F is applied to the close family members of ICU patients who experience subsequent adverse mental health outcomes, the most common of which are sleep deprivation, anxiety, depression, and complicated grief. In the last few decades, there has been a rise in the rate of pediatric ICU (PICU) utilization. In contrast, the mortality in this population has steadily fallen, resulting in a growing number of pediatric ICU survivors at risk for the impairments of PICS. The impacts of impairments following an ICU stay in pediatric patients deserve special attention as these occur within the already dynamic state of childhood development. Additionally, because even healthy children are inherently dependent upon the support of their parents and other caregivers, a child's recovery from a PICU stay inevitably impacts the entire family unit. Re-integration into school and other peer groups is a particular challenge for pediatric ICU survivors, while their siblings also face extraordinary social and emotional stressors. At a time that would otherwise represent peak economic productivity, parents of critically ill children often must cut back on work hours or withdraw from employment completely, resulting in financial consequences that persist long after the illness. For this reason, the PICS-pediatric (PICS-p) framework includes the fourth domain of social health applicable to all family members of the PICU patient. <https://pubmed.ncbi.nlm.nih.gov/32644390/>

**Starr, L. T., Ulrich, C. M., Appel, S. M., Junker, P., O'Connor, N. R. and Meghani, S. H. (2020). "Goals-of-Care Consultations Are Associated with Lower Costs and Less Acute Care Use among Propensity-Matched Cohorts of African Americans and Whites with Serious Illness." *J Palliat Med* 23(9): 1204-1213.**

Background: African Americans receive more aggressive end-of-life care than Whites. Little is known about how palliative care consultation to discuss goals-of-care ("PCC") is associated with acute care utilization and costs by race. Objective: To compare future acute care costs and utilization between propensity-matched cohorts of African Americans with and without PCC, and Whites with and without PCC. Design: Secondary analysis of a retrospective cohort study. Setting/Subjects: Thirty-five thousand one hundred and fifty-four African Americans and Whites age 18+ admitted for conditions other than childbirth or rehabilitation, who were not hospitalized at the end of the study, and did not die during index hospitalization (hospitalization during which the first PCC occurred). Measurements: Accumulated mean acute care costs and utilization (30-day readmissions, future hospital days, future intensive care unit

[ICU] admission, future number of ICU days) after discharge from index hospitalization. Results: No significant difference between African Americans with or without PCC in mean future acute care costs (\$11,651 vs. \$15,050,  $p = 0.09$ ), 30-day readmissions ( $p = 0.58$ ), future hospital days ( $p = 0.34$ ), future ICU admission ( $p = 0.25$ ), or future ICU days ( $p = 0.30$ ). There were significant differences between Whites with PCC and those without PCC in mean future acute care costs (\$8,095 vs. \$16,799,  $p < 0.001$ ), 30-day readmissions (10.2% vs. 16.7%,  $p < 0.0001$ ), and future days hospitalized (3.7 vs. 6.3 days,  $p < 0.0001$ ). Conclusions: PCC decreases future acute care costs and utilization in Whites and, directionally but not significantly, in African Americans. Research is needed to explain why utilization and cost disparities persist among African Americans despite PCC.

<https://pubmed.ncbi.nlm.nih.gov/32345109/>

**Starr, L. T., Ulrich, C. M., Junker, P., Appel, S. M., O'Connor, N. R. and Meghani, S. H. (2020). "Goals-of-Care Consultation Associated With Increased Hospice Enrollment Among Propensity-Matched Cohorts of Seriously Ill African American and White Patients." *J Pain Symptom Manage*, 10.1016/j.jpainsymman.2020.05.020.**

CONTEXT: African Americans are less likely to receive hospice care and more likely to receive aggressive end-of-life care than whites. Little is known about how palliative care consultation (PCC) to discuss goals of care is associated with hospice enrollment by race. OBJECTIVES: To compare enrollment in hospice at discharge between propensity-matched cohorts of African Americans with and without PCC and whites with and without PCC. METHODS: Secondary analysis of a retrospective cohort study at a high-acuity hospital; using stratified propensity-score matching for 35,154 African Americans and whites aged 18+ admitted for conditions other than childbirth or rehabilitation, who were not hospitalized at end of study, and did not die during index hospitalization (hospitalization during which first PCC occurred). RESULTS: Compared with African Americans without PCC, African Americans with PCC were 15 times more likely to be discharged to hospice from index hospitalization (2.4% vs. 36.5%;  $P < 0.0001$ ). Compared with white patients without PCC, white patients with PCC were 14 times more likely to be discharged to hospice from index hospitalization (3.0% vs. 42.7%;  $P < 0.0001$ ). CONCLUSION: In propensity-matched cohorts of seriously ill patients, PCC to discuss goals of care was associated with significant increases in hospice enrollment at discharge among both African Americans and whites. Research is needed to understand how PCC influences decision making by race, how PCC is associated with postdischarge hospice outcomes such as disenrollment and hospice lengths of stay, and if PCC is associated with improving racial disparities in end-of-life care.

<https://pubmed.ncbi.nlm.nih.gov/32454185/>

**Stilwell, P., Bhatt, A., Mehta, K., Carter, B., Bisset, M., Soanes, L. and Shankar, A. (2020). "Preferred place of death in paediatric, teenage and young adult haemato-oncology patients: a retrospective review." *BMJ Support Palliat Care*, 10.1136/bmjspcare-2019-002005.**

OBJECTIVES: Identifying the preferred place of death for children/young people with cancer and determining whether this is achieved is pertinent to inform palliative care service provision. The aims of this retrospective case series review were to determine

where children/young people with cancer want to die and whether their preferred place of death was achieved. METHODS: Clinical/demographic details, including preferred and actual places of death, were recorded for 121 patients who died between 2012 and 2016 at a tertiary haematology-oncology centre. A logistic regression model was used to determine the odds of achieving the preferred place of death in patient subgroups. RESULTS: 74 (61%) patients had a documented discussion regarding place of death preference. Where a preferred location was identified, 72% achieved it. All patients who wanted to die in the hospital (n=17) or a hospice (n=9) did, but only 58% of patients who wanted to die at home (n=40) achieved this. Of the 42% (n=17) who wanted to die at home but did not, 59% of these were due to rapid deterioration in clinical status shortly after the discussion. Having supportive treatment in the last month of life was associated with increased odds of achieving the preferred place of death versus those who were undergoing chemotherapy/radiotherapy (OR 3.19, 95% CI 1.04 to 9.80, p value=0.04). CONCLUSION: Where hospice/hospital was chosen as the preferred place of death, this was always achieved. Achieving home as the preferred place of death was more challenging and frequently prevented by rapid clinical deterioration. Clinicians should be encouraged to address end-of-life preferences at an early stage, with information provided adequately. Further research should explore implications of these findings on both end-of-life experience and overall service provision.

<https://pubmed.ncbi.nlm.nih.gov/32209568/>

**Tatlidil, I., Ture, H. S. and Akhan, G. (2020). "Factors affecting mortality of refractory status epilepticus." *Acta Neurol Scand* 141(2): 123-131.**

OBJECTIVE: The aim of this study was to determine the factors affecting the mortality of refractory status epilepticus (RSE) in comparison with non-refractory status epilepticus (non-RSE). MATERIAL-METHOD: Included in this retrospective study were 109 status epilepticus cases who were hospitalized in the neurological intensive care unit Katip Celebi University. Fifty-two were RSE and 57 were non-RSE. All clinical data were gathered from the hospital archives. Factors which may cause mortality were categorized for statistical analysis. RESULTS: While elderly age, continuous clinical seizure activity, absence of former seizure, infection, prolonged stay of ICU, anesthesia, and cardiac comorbidity were significantly related to mortality in the RSE subgroup, potentially fatal accompanying diseases were significantly related to mortality in the non-RSE subgroup. No significant relationship was found between mortality and refractoriness. Multivariate analysis revealed that a Glasgow Coma Score (GCS) at presentation of 8 or lower was the independent predictor of mortality both in the general SE population (P = .017) and in the RSE subgroup (P = .007). Intubation (P = .011) and hypotension (P = .011) were the other independent predictors of mortality in the general SE population. No independent predictor of mortality was detected in the non-RSE subgroup. DISCUSSION/CONCLUSION: Intubation, hypotension, and a low GCS at presentation could be the main factors which could alert clinicians of an increased risk of mortality in SE patients. Although non-RSE and RSE had similar rates of mortality in the ICU, the mortality-related factors of SE vary in the RSE and the non-RSE subgroups.

<https://pubmed.ncbi.nlm.nih.gov/31550052/>

van der Heul, A. M. B., Cuppen, I., Wadman, R. I., Asselman, F., Schoenmakers, M., van de Woude, D. R., Gerrits, E., van der Pol, W. L. and van den Engel-Hoek, L. (2020). "Feeding and Swallowing Problems in Infants with Spinal Muscular Atrophy Type 1: an Observational Study." J Neuromuscul Dis 7(3): 323-330.

**BACKGROUND:** Infantile hereditary proximal spinal muscular atrophy (SMA) type 1 is characterized by onset in the first 6 months of life and severe and progressive muscle weakness. Dysphagia is a common complication but has not been studied in detail. **OBJECTIVE:** To study feeding and swallowing problems in infants with SMA type 1, and to explore the relation between these problems and functional motor scores. **METHODS:** We prospectively included 16 infants with SMA type 1 between September 2016 and October 2018. Eleven infants received palliative care and five infants best supportive care in combination with nusinersen. We compiled and used an observation list with feeding related issues and observed feeding sessions during inpatient and outpatient visits. The Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHOP INTEND) was used as a measure of motor function. **RESULTS:** All infants in the palliative care group (median onset of disease 14 days (range 1-56); median inclusion in the study 52 days (range 16-252) demonstrated symptoms of fatigue during feeding and unsafe swallowing. Symptoms were short nursing sessions (10-15 minutes), and not being able to finish the recommended feeding volumes (72%); increased frequency of feeding sessions (55%); coughing when drinking or eating (91%), and wet breathing during and after feeding (64%). Two out of five infants in the nusinersen group (median onset of disease 38 days (range 21-90); inclusion in the study at 63 days (range 3-218) were clinically pre-symptomatic at the start of treatment. The other three infants showed symptoms of fatigue and unsafe swallowing at inclusion in the study. These symptoms initially decreased after the start of the treatment, but (re)appeared in all five infants between the ages of 8 to 12 months, requiring the start tube of feeding. In the same period motor function scores significantly improved (median increase CHOP INTEND 16 points). **CONCLUSION:** Impaired feeding and swallowing remain important complications in infants with SMA type 1 after the start of nusinersen. Improvement of motor function does not imply similar gains in bulbar function.

<https://pubmed.ncbi.nlm.nih.gov/32333596/>

Venkatasalu, M. R., Murang, Z. R., Ramasamy, D. T. R. and Dhaliwal, J. S. (2020). "Oral health problems among palliative and terminally ill patients: an integrated systematic review." BMC Oral Health 20(1): 79.

**BACKGROUND:** High incidence of treatable oral conditions has been reported among palliative patients. However, a large proportion of palliative patients lose their ability to communicate their sufferings. Therefore, it may lead to under-reporting of oral conditions among these patients. This review systematically synthesized the published evidence on the presence of oral conditions among palliative patients, the impact, management, and challenges in treating these conditions. **METHODS:** An integrative review was undertaken with defined search strategy from five databases and manual search through key journals and reference list. Studies which focused on oral conditions of palliative patients and published between years 2000 to 2017 were included. **RESULTS:** Xerostomia, oral candidiasis and dysphagia were the three most common oral conditions among palliative patients, followed by mucositis, orofacial pain,

taste change and ulceration. We also found social and functional impact of having certain oral conditions among these patients. In terms of management, complementary therapies such as acupuncture has been used but not well explored. The lack of knowledge among healthcare providers also posed as a challenge in treating oral conditions among palliative patients. **CONCLUSIONS:** This review is first in its kind to systematically synthesize the published evidence regarding the impact, management and challenges in managing oral conditions among palliative patients. Although there is still lack of study investigating palliative oral care among specific group of patients such as patients with dementia, geriatric or pediatric advanced cancer patients, this review has however provided baseline knowledge that may guide health care professionals in palliative settings.

<https://pubmed.ncbi.nlm.nih.gov/32188452/>

**Walters, A. and Grosse, J. (2020). "Is This My Home? A Palliative Care Journey Through Life and Death in the NICU: A Case Report." Adv Neonatal Care 20(2): 127-135.**

**BACKGROUND:** With advancements in neonatology, patients in the neonatal intensive care unit (NICU) are living in the hospital with complex life-limiting illnesses until their first birthday or beyond. As palliative care (PC) becomes a standard of care in neonatology, a level IV NICU developed an interdisciplinary PC team with the mission to ease the physical, mental, and moral distress of the patients, families, and staff. This case report highlights the teamwork and long-term palliative care and ultimately end-of-life care that an infant received by this dedicated NICU palliative care team. **CLINICAL FINDINGS:** This case discusses a premature ex-27-week gestation male infant who initially presented to the emergency department at 5 months of age with significant tachypnea, increased work of breathing, and poor appetite. **PRIMARY DIAGNOSIS:** The primary diagnosis was severe pulmonary vein stenosis resulting in severe pulmonary hypertension. **INTERVENTIONS:** The severity of the infant's pulmonary vein stenosis was incurable. He required substantial life-extending surgical procedures and daily intensive care interventions. In addition to his life-extending therapies, the infant and his family received palliative care support by the NICU PC team and the hospital-wide PC team (REACH team) throughout his admission. This was specialized care that focused on easing pain and suffering while also addressing any social/emotional needs in the infant, his family, and in the hospital staff. The PC teams also focused on protecting the families' goals of care, memory making, and providing a positive end-of-life experience for the infant and his family. The infant's end-of-life care involved providing adequate pain and symptom management, education, and communication to his family about the dying process and allowing unlimited family time before and after his death. **OUTCOMES:** After 11 months in the NICU and despite aggressive therapies, he required more frequent trips to the cardiac catheterization laboratory for restenosis of his pulmonary veins. He was dependent on iNO to treat his pulmonary hypertension and he continued to require an ICU ventilator. His parents ultimately decided to pursue comfort care. He died peacefully in his mother's arms. **PRACTICE RECOMMENDATIONS:** The American Academy of Pediatrics and the National Association of Neonatal Nurses both have statements recommending that palliative care be standard of care in NICUs. Establishing a NICU-dedicated interdisciplinary PC team can improve outcomes for infants and families living in the NICU with complex life-limiting illnesses.

<https://pubmed.ncbi.nlm.nih.gov/31917697/>

Weaver, M. S., Hanna, R., Hetzel, S., Patterson, K., Yuroff, A., Sund, S., Schultz, M., Schroth, M. and Halanski, M. A. (2020). "A Prospective, Crossover Survey Study of Child- and Proxy-Reported Quality of Life According to Spinal Muscular Atrophy Type and Medical Interventions." *J Child Neurol* 35(5): 322-330.

BACKGROUND: Spinal muscular atrophy is an autosomal-recessive, progressive neuromuscular disease associated with extensive morbidity. Children with spinal muscular atrophy have potentially increased life spans due to improved nutrition, respiratory support, and novel pharmaceuticals. OBJECTIVES: To report on the quality of life and family experience for children with spinal muscular atrophy with attentiveness to patient- and proxy-concordance and to stratify quality of life reports by spinal muscular atrophy type and medical interventions. METHODS: A prospective, crossover survey study inclusive of 58 children (26 spinal muscular atrophy type I, 23 type II, 9 type III) and their family caregivers at a free-standing Midwestern children's hospital. Twenty-eight families completed the 25-item PedsQL 3.0 Neuromuscular Module. Forty-four participants completed the 36-item PedsQL Family Impact Module and 47 completed the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) questionnaire. RESULTS: The PedsQL Family Impact Module demonstrated significant differences between spinal muscular atrophy types I and II in functioning domains including physical, emotional, social, and family relations ( $P < .03$ ). Child self-report and proxy report surveys demonstrated significant differences between spinal muscular atrophy types in the communication domains ( $P < .003$ ). Children self-reported their quality of life higher than proxy report of child quality of life. Gastrostomy tube ( $P = .001$ ) and ventilation support ( $P = .029$ ) impacted proxy-reported quality of life perspectives, whereas nusinersen use did not. Spinal surgery was associated with improved parental quality of life and family impact ( $P < .03$ ). CONCLUSIONS: The measurement and monitoring of quality of life for children with spinal muscular atrophy and their families represents an implementable priority for care teams.

<https://pubmed.ncbi.nlm.nih.gov/32009500/>

Wilson, R. E., Rao, P. K., Cunningham, A. J., Dewey, E. N., Krishnaswami, S. and Hamilton, N. A. (2020). "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://pubmed.ncbi.nlm.nih.gov/31446187/>

**Ye, V. C., Shah, A. H., Sur, S., Achua, J. K., Wang, S., Ibrahim, G. M., Bhatia, S. and Ragheb, J. (2020). "Long-term outcomes after surgery for catastrophic epilepsy in infants: institutional experience and review of the literature." *J Neurosurg Pediatr*, 10.3171/2020.1.peds19537: 1-8.**

OBJECTIVE: Uncontrolled epilepsy is associated with serious deleterious effects on the neurological development of infants and has been described as "catastrophic epilepsy." Recently, there has been increased emphasis on early surgical interventions to preserve or rescue neurodevelopmental outcomes in infants with early intractable epilepsy. The enthusiasm for early treatments is often tempered by concerns regarding the morbidity of neurosurgical procedures in very young patients. Here, the authors report outcomes following the surgical management of infants (younger than 1 year). METHODS: The authors performed a retrospective review of patients younger than 1 year of age who underwent surgery for epilepsy at Miami (Nicklaus) Children's Hospital and Jackson Memorial Hospital between 1994 and 2018. Patient demographics, including the type of interventions, were recorded. Seizure outcomes (at last follow-up and at 1 year postoperatively) as well as complications are reported. RESULTS: Thirty-eight infants (median age 5.9 months) underwent a spectrum of surgical interventions, including hemispherectomy (n = 17), focal resection (n = 13), and multilobe resections (n = 8), with a mean follow-up duration of 9.1 years. Hemimegalencephaly and cortical dysplasia were the most commonly encountered pathologies. Surgery for catastrophic epilepsy resulted in complete resolution of seizures in 68% (n = 26) of patients, and 76% (n = 29) had a greater than 90% reduction in seizure frequency. Overall mortality and morbidity were 0% and 10%, respectively. The latter included infections (n = 2), infarct (n = 1), and immediate reoperation for seizures (n = 1). CONCLUSIONS: Surgical intervention for catastrophic epilepsy in infants remains safe, efficacious, and durable. The authors' work provides the longest follow-up of such a series on infants to date and compares favorably with previously published series.

<https://pubmed.ncbi.nlm.nih.gov/32330892/>

**Zuniga-Villanueva, G., Widger, K., Medeiros, C., Trenholm, M. and Streuli, J. C. (2020). "Specialized Pediatric Palliative Care in Neonates with Life-Limiting Illness: A Systematic Review." *Am J Perinatol*, 10.1055/s-0040-1710031.**

OBJECTIVE: The aim of this study is to assess the impact of specialized pediatric palliative care (PPC) on neonates with life-limiting conditions compared to standard care. STUDY DESIGN: MEDLINE, PsycINFO, Cochrane Central Register of Controlled Trials, Web of Science, CINAHL, Scopus, and Embase databases were

searched from January 2000 to September 2018. Randomized clinical trials, experimental or observational studies, and secondary administrative database analyses published in English, Spanish, French, and German were included. Two independent reviewers extracted data, and used the Newcastle-Ottawa Scale and the Cochrane Risk of Bias Tool for quality analysis. Discrepancies were resolved as a team. RESULTS: From the 37,788 records obtained, only eight articles met the inclusion criteria. A meta-analysis was not possible due to the heterogeneity in how the outcomes were defined; however, a qualitative synthesis of the results was possible; organizing outcomes into eight different categories: psychological, social and spiritual support; communication; location of care; symptom management; bereavement care; predicted versus actual neonatal outcomes; and parental coping, stress, and satisfaction. CONCLUSION: Specialized versus may have an impact on neonates with life-limiting conditions and their families. More studies that evaluate the impact of specialized versus in neonates with sound statistical analysis is warranted. <https://pubmed.ncbi.nlm.nih.gov/32330969/>

## **Pain & Symptom Control**

Ávila-Castro, D., Ortiz-Torres, G., Sánchez-Jara, B., Valle-Cárdenas, T., Aquino-Fernández, E., González-Ávila, A. I. and Majluf-Cruz, A. (2020). "Proposal for the management of COVID-19-associated coagulopathy in children." Gac Med Mex 156(4): 344-353.

SARS-CoV-2 infection (COVID-19) has become a pandemic with a high case fatality rate that mainly affects adults. Most severely ill adult patients develop a coagulopathy that was not described until recently, and which is currently considered a main cause of death. Everything indicates that a similar phenomenon also occurs in children with COVID-19. Anticoagulant treatment has become one of the therapeutic foundations for this infection; however, its implementation in children can be difficult since, until recently, it was not considered in the pediatric population. Evidence regarding the use of anticoagulants in COVID-19 is rapidly generated, changes constantly, it is often difficult to interpret, and can be contradictory. After an extensive review of the published literature, a proposal was generated that offers suggestions for anticoagulant treatment, considering available resources in Mexico.

<https://pubmed.ncbi.nlm.nih.gov/32831339/>

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://pubmed.ncbi.nlm.nih.gov/31195077/>

Billeau, H., Olivier, C., Lemelle, L. and Wascheul, S. (2020). "[Cross-cultural experience of knowledge sharing in relation to pain]." Rev Infirm 69(257): 32-34.

Health professionals working in paediatric oncology met in Bamako, Mali, as part of a healthcare partnership between the Gabriel-Touré Hospital in Bamako and the Curie Institute in Paris. Open to dialogue and intercultural encounters, the hospital medical

and paramedical teams exchanged views on their practices with a particular focus on pain management.

<https://pubmed.ncbi.nlm.nih.gov/32146963/>

Clerici, C. A., Pagani Bagliacca, E., Veneroni, L., Podda, M., Silva, M., Gasparini, P., Luksch, R., Terenziani, M., Casanova, M., Spreafico, F., Meazza, C., Biassoni, V., Schiavello, E., Chiaravalli, S., Proserpio, T., Massimino, M. and Ferrari, A. (2020). "Adolescents with Terminal Cancer: Making Good Use of Illusions." J Adolesc Young Adult Oncol, 10.1089/jayao.2020.0069.

The terminal stage of disease in teenagers is extremely complex to manage. In this study, we share some stories of terminally ill adolescent patients who made use of illusion as a way to overcome their anguish in their final stages of illness. These experiences show how young patients can cope better with terminal illness by resorting to a nonrational and fictional dimension that can serve them as a psychological compromise, helping them tolerate their real everyday life by suspending their critical senses for a while. Illusions can serve as a resource for young patients and a potentially useful tool for medical professionals.

<https://pubmed.ncbi.nlm.nih.gov/32716666/>

De Rose, D. U., Piersigilli, F., Ronchetti, M. P., Santisi, A., Bersani, I., Dotta, A., Danhaive, O. and Auriti, C. (2020). "Novel Coronavirus disease (COVID-19) in newborns and infants: what we know so far." Ital J Pediatr 46(1): 56.

Recently, an outbreak of viral pneumonitis in Wuhan, Hubei, China successively spread as a global pandemic, led to the identification of a novel betacoronavirus species, the 2019 novel coronavirus, successively designated 2019-nCoV then SARS-CoV-2). The SARS-CoV-2 causes a clinical syndrome designated coronavirus disease 2019 (COVID19) with a spectrum of manifestations ranging from mild upper respiratory tract infection to severe pneumonitis, acute respiratory distress syndrome (ARDS) and death. Few cases have been observed in children and adolescents who seem to have a more favorable clinical course than other age groups, and even fewer in newborn babies. This review provides an overview of the knowledge on SARS-CoV-2 epidemiology, transmission, the associated clinical presentation and outcomes in newborns and infants up to 6 months of life.

<https://pubmed.ncbi.nlm.nih.gov/32349772/>

De Zen, L., Della Paolera, S., Del Rizzo, I., Taucar, V., Skabar, A. and Barbi, E. (2020). "Home Intranasal Dexmedetomidine for Refractory Dystonia in Pediatric Palliative Care." J Pain Symptom Manage 59(6): e3-e5.

<https://pubmed.ncbi.nlm.nih.gov/32145338/>

Dechnik, A. and Traube, C. (2020). "Delirium in hospitalised children." Lancet Child Adolesc Health 4(4): 312-321.

Delirium is a syndrome characterised by an acute and fluctuating alteration in cognition and awareness. It occurs frequently in children with serious medical illness, and is associated with adverse outcomes such as increased length of hospital stay, duration of mechanical ventilation, hospital costs, and mortality. Delirium-especially the

hypoactive subtype-is often overlooked by paediatric practitioners, but can be reduced by mitigating risks and effectively managed if detected early. Non-modifiable risk factors of delirium include young age (age <2 years), cognitive or neurological disabilities, need for invasive mechanical ventilation, severe underlying illness and pre-existing chronic conditions, and poor nutritional status. Routine bedside screening using validated tools can enable early detection of delirium. To reduce delirium in hospitalised children, health-care providers should optimise the hospital environment (eg, by reducing sleep disruption and keeping the child stimulated during the day), improve pain management, and decrease sedation (particularly use of benzodiazepines).

<https://pubmed.ncbi.nlm.nih.gov/32087768/>

**Dezfouli, S. M. M. and Khosravi, S. (2020). "Pain in child patients: A review on managements." *Eur J Transl Myol* 30(2): 8712.**

Pain has been known as one of the major universal health concerns about ill children, because of its morbidity and potential mortality. Pain suitable evaluation is a challenge in children because the verbalization is difficult. Low clinical information, few pediatric researches, and the worry of opioid side effects make difficult to provide satisfactory treatments. Many pharmacologic and non-pharmacologic strategies to manage pain exist for pediatric pain treatment. The purpose of this review article is to describe exhaustively pain mechanism, evaluation and management by review literature from January 2000 to January 2019 using PubMed, EMBASE, MEDLINE, LILACS databases. Pharmacological and integrative non-pharmacological therapies has been indicated in acute and chronic pain treatment. Opioids and opioid-sparing agents target nociceptive and neuropathic pain. With due attention to available results, an early combination of pharmacological and integrative non pharmacological treatments are indicated in children pain management.

<https://pubmed.ncbi.nlm.nih.gov/32782752/>

**Dipasquale, V., Gottrand, F., Sullivan, P. B. and Romano, C. (2020). "Top-ten tips for managing nutritional issues and gastrointestinal symptoms in children with neurological impairment." *Ital J Pediatr* 46(1): 35.**

The prevalence of children with neurological impairment (NI) presenting feeding difficulties and gastrointestinal symptoms is rising. The most recent guidelines recommend early nutritional assessment and intervention in order to prevent undernutrition and growth failure, along with the proper diagnosis and treatment of some frequent gastrointestinal symptoms, such as gastroesophageal reflux disease (GERD) and constipation, which can further worsen the feeding process and nutritional status. Nonetheless, the nutritional issues and growth deficits of children with NI are often considered to be of low priority or under recognised by healthcare providers. The present article proposes ten top tips that highlight the major points along the nutritional management pathway of NI children. The implementation of these tips in all healthcare settings could potentially improve patient outcomes and reduce morbidity and mortality.

<https://pubmed.ncbi.nlm.nih.gov/32216797/>

Doherty, M., Power, L., Attala, M. and Vadeboncoeur, C. (2020). "Use of oral cannabis extracts in the pediatric palliative care setting: A retrospective chart review." *Palliat Med* 34(3): 435-437.

<https://pubmed.ncbi.nlm.nih.gov/32103704/>

Doherty, M., Power, L. and Thabet, C. (2020). "Delivering Hospital-Based Pediatric Palliative Care: The Symptoms, Interventions, and Outcomes for Children With Cancer in Bangladesh." *JCO Glob Oncol* 6: 884-891.

**PURPOSE:** The majority of pediatric cancer deaths occur in low- and middle-income countries (LMICs). Pediatric palliative care (PPC) focuses on relieving physical, psychosocial, and spiritual suffering throughout the continuum of cancer care and is considered integral to cancer care for children in all settings. There is limited evidence from LMICs about the characteristics, symptoms, and outcomes of children with cancer who receive PPC, which is needed to define the global need and guide the development of these services. **METHODS:** This retrospective review of clinical records of children who received PPC was conducted during a pilot project (January 2014-August 2015) that implemented a PPC team at a tertiary hospital in Dhaka, Bangladesh. Clinical data on diagnosis, symptoms, treatment status, deaths, and key palliative care interventions were collected and analyzed using descriptive statistics. **RESULTS:** There were 200 children who received PPC during the pilot project. The most common diagnoses were acute lymphoblastic leukemia (62%) and acute myeloid leukemia (11%). Psychosocial support for children (n = 305; 53%) and management of physical symptoms (n = 181; 31%) were the most common types of interventions provided. The most frequently recorded symptoms were pain (n = 60; 30%), skin wounds (n = 16; 8%), and weakness (n = 9; 5%). The most common medications prescribed were morphine (n = 32) and paracetamol (n = 21). **CONCLUSION:** A hospital-based PPC service addresses pain and symptom concerns as well as psychosocial needs for children with cancer and their families in a setting where resources are limited. Health care facilities should incorporate palliative care into the care of children with cancer to address the needs of children and their families.

<https://pubmed.ncbi.nlm.nih.gov/32589466/>

Donovan, L. A., Slater, P. J., Baggio, S. J., McLarty, A. M. and Herbert, A. R. (2019). "Perspectives Of Health Professionals And Educators On The Outcomes Of A National Education Project In Pediatric Palliative Care: The Quality Of Care Collaborative Australia." *Adv Med Educ Pract* 10: 949-958.

**PURPOSE:** Demand for generalist health professional knowledge and skills in pediatric palliative care (PPC) is growing in response to heightened recognition of the benefits of a palliative approach across the neonatal, pediatric, adolescent and young adult lifespan. This study investigates factors that enhanced PPC workforce capability and education outcomes in metropolitan and regional areas through the integration of dedicated educator roles within specialist pediatric palliative care (SPPC) teams through a national education project. **METHODS:** Cross-sectional, prospective qualitative study guided by the Consolidated Criteria for Reporting Qualitative Studies. The study drew on Discovery Interview methodology and transcripts subjected to inductive thematic analysis. A convenience sample (n=16) of health professionals and

educators were recruited from specialist tertiary and regional services providing PPC in Australia. RESULTS: Four themes emerged related to outcomes of the national PPC education project: (1) building capability in PPC, (2) developing inter-professional partnerships, (3) sustaining staff well-being, and (4) learning from children and families. Dedicated educator roles in SPPC services enhanced workforce capability through education and ongoing mentoring, built collaborative relationships between the complex network of care providers for children with a life-limiting condition (LLC) and their families, and improved quality and access to PPC. Delivery of education evolved from didactic to interactive engagement and coincided with development of a mentoring model between SPPC clinicians and generalist health and social care providers. CONCLUSION: This study contributes to a growing body of knowledge on innovative and responsive mechanisms for enhancing workforce capability in PPC and provides additional evidence to support funding of dedicated educator roles in specialist PPC services.

<https://pubmed.ncbi.nlm.nih.gov/31807110/>

**Dulin, J. D. and Coyne, P. J. (2020). "Nebulized Vasopressin for the Control of Hematemesis and Hemoptysis in a Child With Recurrent, Refractory Stage III Burkitt Lymphoma." J Palliat Care 35(2): 71-74.**

BACKGROUND: Bleeding occurs with some regularity at the end of life. Patients often endure fatigue, weakness, pain, dyspnea and anxiety. These symptoms are magnified in visually apparent bleeds. Management can be particularly challenging as we attempt to balance therapies with goals of care. Children are at risk for such complications and symptoms; providers must ensure comfort for both the patient and family. CASE DESCRIPTION: A 7-year-old male with recurrent, refractory Burkitt lymphoma was frequently hospitalized for palliative chemotherapy and disease complications. On his final admission, he experienced gross hemoptysis and hematemesis: he was short of breath, fatigued and anxious due to his blood loss. His and his family's angst were heightened by "seeing" his bleed. Potential, especially invasive, treatments were limited by our goals to promote comfort, limit interventions, maintain alertness, poor intravenous access and a small bowel obstruction. Nebulized vasopressin, 10 units in 4ml of normal saline given over 10 minutes provided JC with needed relief. His bleeding remitted and he tolerated its administration. CONCLUSION: There are many treatments for hemorrhage; however, given the challenges of goals of care, administration, side-effects and tolerability, further investigation into nebulized vasopressin as a potential therapy for hemoptysis and hematemesis at the end-of-life is warranted.

<https://pubmed.ncbi.nlm.nih.gov/31680640/>

**Eche, I. J., Eche, I. M. and Aronowitz, T. (2020). "An Integrative Review of Factors Associated With Symptom Burden at the End of Life in Children With Cancer." J Pediatr Oncol Nurs 37(4): 284-295.**

Children with cancer experience multiple symptoms at end of life (EOL) that impair their health-related quality of life. Using the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines, this integrative literature review comprehensively summarized symptom experiences of children with cancer at EOL. The Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and Academic Premier were searched between January 2007 to September 2019 for articles

published in English using the MeSH terms: symptom burden or distress AND children with cancer or pediatric cancer or cancer children or oncology and pediatrics AND EOL care or palliative care or death or dying or terminally ill. The inclusion criteria were the following: (a) study designs [randomized controlled trials, nonexperimental, secondary analysis (if aims were distinct from primary studies) and qualitative]; (b) participants <18 years old (died of cancer, had no realistic chance of cure, or had advanced cancer); and (c) focused on symptom experiences/burden at EOL. Exclusion criteria were non research articles, systematic reviews, case studies, reports, and studies that focused on cancer survivors and/or those receiving curative therapies. Twenty-seven articles met inclusion criteria. The most prevalent symptoms-pain, fatigue, dyspnea, and loss of appetite were associated with impairments in health-related quality of life. Children with brain tumors experienced higher symptom burden compared to those with hematologic/solid malignancies. Children who received cancer-directed therapies experienced disproportionate symptoms and were more likely to die in the intensive care unit compared with those who did not receive cancer-directed therapies. Most common location of death was home. This integrative review indicated that children with cancer were polysymptomatic at EOL. Strategies facilitating effective symptom management at EOL are needed.

<https://pubmed.ncbi.nlm.nih.gov/32153227/>

**Fatollahzade, M., Parvizi, S., Kashaki, M., Haghani, H. and Alinejad-Naeini, M. (2020). "The effect of gentle human touch during endotracheal suctioning on procedural pain response in preterm infant admitted to neonatal intensive care units: a randomized controlled crossover study." J Matern Fetal Neonatal Med, 10.1080/14767058.2020.1755649: 1-7.**

Background: Neonates in the neonatal intensive care unit are frequently subjected to painful procedures. Non-pharmacological pain control techniques are useful for reducing procedural pain. Touch as one of the aspects of developmental care used to reduce neonatal pain. The purpose of this study was to determine the effect of gentle human touch during endotracheal suctioning on procedural pain response in preterm neonates. Methods: This was a clinical trial study with a crossover design. The study was conducted in a level III NICU in a hospital, affiliated to Iran University of Medical Sciences. Thirty-four neonates were enrolled in this study based on inclusion criteria. The samples were randomly received a sequence of suctioning with/without or suctioning without/with gentle human touch. Preterm Infant Pain Profile (PIPP) was used to collect the data. SPSS version 22 for Windows (SPSS Inc., Chicago, IL, USA) was used for statistical analysis. Results: 85.3% of neonates experienced moderate and 8.8% severe pain during suctioning without intervention, and only 64.7% of them experienced moderate and 2.9% severe pain during suctioning with intervention. The results of the paired t-test show that there is a statistically significant difference between the mean scores of pain in non intervention and intervention cases ( $p < .002$ ), and the mean pain score substantially reduced in cases with intervention. Conclusions: Results from this study showed that the pain due to suctioning procedure is considerably reduced by applying Gentle Human Touch. And nurses can use this method as one of the non-pharmacological methods of pain management.

<https://pubmed.ncbi.nlm.nih.gov/32316790/>

Friedrichsdorf, S. J. and Postier, A. C. (2019). "Recent advances in pain treatment for children with serious illness." *Pain Manag* 9(6): 583-596.

Pain is a common distressing symptom in children receiving pediatric palliative care. Both in children with cancer, but especially in children with progressive neurodegenerative and chromosomal conditions with CNS impairment pain is common, and often under-recognized and undertreated. Multimodal analgesia for children with serious illness acts synergistically for more effective pediatric pain and symptom control with fewer side effects than a single analgesic or modality. Successful pain treatment and prevention usually include integrative 'nonpharmacological' therapies, rehabilitation, psychology and spirituality in addition to pharmacology and regional anesthesia. This review article will address these effective components of multimodal pediatric analgesia and present starting doses of basic analgesia, opioids and adjuvants analgesia in infants, children and adolescents with serious illness.  
<https://pubmed.ncbi.nlm.nih.gov/31735116/>

Gao, J. Y., Qian, J., Wang, X. J., Li, B. R., Ren, H., Ning, B. T., Zhang, J., Xiang, L. and Wang, Y. (2020). "[Effect of sedation weaning pattern on withdrawal syndrome in pediatric intensive care unit]." *Zhonghua Er Ke Za Zhi* 58(4): 284-289.

Objective: To investigate the sedation weaning strategies in critically ill patients with mechanical ventilation in pediatric intensive care unit (PICU) and to explore the effect of different sedative weaning patterns on withdrawal syndrome. Methods: A single-center prospective cohort study was conducted from April 1, 2016 to April 30, 2017. One hundred and twelve patients who required mechanical ventilation and benzodiazepines and (or) opioids for at least 5 consecutive days in PICU of Shanghai Children's Medical Center were enrolled. Twenty patients (17.9%) had an intermittent weaning pattern, defined as a 50% or greater increase in daily benzodiazepine and (or) opioid dose after the start of weaning, and the remaining 92 cases (82.1%) had a steady weaning pattern. The demographic and clinical features, duration and dose of sedative and analgesics, and the incidence of withdrawal syndrome were evaluated. Mann-Whitney U test was used for comparison about clinical features between different weaning pattern groups and children with withdrawal syndrome or not. Logistic regression was used to explore the risk factors of withdrawal syndrome. Results: Among the 112 patients, 46 (41.1%) had withdrawal syndrome. The patients with the intermittent weaning pattern had a high score of pediatric risk of mortality **III** (PRISM-**III**) (10.0 (3.5, 12.0) vs. 6.0 (2.0, 10.0), U=654.50, P=0.043) and were prone to re-intubation (35.0% (7/20) vs. 7.6% (7/92), P=0.003). The patients with withdrawal syndrome had longer duration of sedation (19.5 (16.8, 24.3) vs. 10.0 (7.0, 17.3) days, U=743.50, P<0.01), higher incidence of intermittent weaning pattern (32.6% (15/46) vs. 7.6% (5/66),  $\chi^2=11.58$ , P=0.001), longer PICU hospitalization (19.0 (15.8, 25.3) vs. 12.0 (8.8, 17.0) days, U=755.00, P<0.01) and higher cost (89 (57,109) vs. 53 (32, 79) thousand yuan, U=804.00, P<0.01). Logistic regression showed that intermittent weaning pattern (odds ratio (OR)=4.85, 95% confidence interval (CI) 1.39-16.91, P=0.013), perioperative period of liver transplantation (OR=6.97, 95%CI 1.25-39.04, P=0.027) and a cumulative dose of midazolam  $\geq 34.7$  mg/kg (OR=8.12, 95%CI 3.09-21.37, P<0.01) were risk factors of withdrawal syndrome. Conclusions: Withdrawal syndrome is more likely to occur in children who are intermittently weaned from sedation. Steady weaning strategy may help prevent iatrogenic withdrawal syndrome.

<https://pubmed.ncbi.nlm.nih.gov/32234134/>

García-López, I., Cuervas-Mons Vendrell, M., Martín Romero, I., de Noriega, I., Benedí González, J. and Martino-Alba, R. (2020). "Off-Label and Unlicensed Drugs in Pediatric Palliative Care: A Prospective Observational Study." J Pain Symptom Manage, 10.1016/j.jpainsymman.2020.06.014.

CONTEXT: Off-label and unlicensed use of drugs is a widespread practice in pediatric care because of the lack of specific efficacy and safety data and the absence of formulations adapted to the needs of these individuals. Pediatric patients with a life-limiting illness frequently receive drugs under these conditions, although no studies have established the prevalence of this practice. OBJECTIVES: To describe the prevalence, indications, and most common uses of off-label and unlicensed drugs in a pediatric palliative care unit (PPCU). METHODS: A prospective cross-sectional observational study carried out between January and October 2019. RESULTS: About 85 patients involving 1198 prescriptions were analyzed. A total of 39.6% were off label, and 12.9% were unlicensed. All received at least one off-label drug, with a median of five per patient (interquartile range 3-7), and 81.2% received at least one unlicensed drug. A total of 36.1% of the prescriptions were considered off label because of indication, 33.8% because of dosage, and 26.6% because of age. The main drugs used off label were oral morphine, oral levetiracetam, inhaled albuterol, sublingual ondansetron, oral tizanidine, sublingual fentanyl, and oral diazepam. The main symptoms treated with off-label drugs were dyspnea, pain, and nausea/vomiting. CONCLUSION: More than half of the prescriptions in this PPCU were off label or unlicensed. Treatment indication was one of the main reasons for off-label use. Administration of compounded preparations was common in patients with a life-limiting illness.

<https://pubmed.ncbi.nlm.nih.gov/32569831/>

Garten, L. and Bühner, 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://pubmed.ncbi.nlm.nih.gov/31056417/>

Genik, L. M., McMurtry, C. M., Marshall, S., Rapoport, A. and Stinson, J. (2020). "Massage therapy for symptom reduction and improved quality of life in children with cancer in palliative care: A pilot study." Complement Ther Med 48: 102263.

BACKGROUND: For children with cancer in palliative care, pain and worry are common and frequently under-managed, which negatively impacts quality of life (QOL). Massage therapy (MT) can lead to reduced pain in children with chronic illnesses. Children with cancer have experienced lower anxiety after MT. No studies have examined the effects

of MT in pediatric oncology patients receiving palliative care. OBJECTIVE: Conduct a MT intervention to determine intervention acceptability and initial effects on ratings of pain, worry reduction, and quality of life. DESIGN: Pre-post single group pilot study. SETTING/SUBJECTS: Eight children with cancer (age 10-17) and one of their parents were recruited from a palliative care service. PROCEDURE/MEASUREMENTS: Baseline (one week prior to intervention): demographics, MT expectations, QOL, and pain measures. Intervention (one month): MT was provided once per week, with children's pain and worry ratings occurring immediately before and after each MT session. Follow Up (4-6 weeks after baseline): QOL, pain, and MT/study acceptability questionnaires. RESULTS: Participants reported significant decreases in pain following two MT sessions, and worry following one session. No significant changes in pain symptoms and QOL were found between baseline and follow up. Participants positively endorsed the study and the MT intervention, and there were no adverse effects reported. CONCLUSIONS: MT may lead to immediate decreases in pain and worry in children with cancer who are receiving palliative care, however the effects may not be sustained long term. Difficulties regarding protocol feasibility including recruitment and study compliance remain important considerations for future work.

<https://pubmed.ncbi.nlm.nih.gov/31987232/>

**Goldman, R. D. (2020). "Coronavirus disease 2019 in children: Surprising findings in the midst of a global pandemic." *Can Fam Physician* 66(5): 332-334.**

Question Coronavirus disease 2019 (COVID-19) is affecting millions of people worldwide. It seems that it affects mostly adults older than 40 years of age, and the death rate is highest for older individuals in the population. What should I tell parents worried about their children contracting the coronavirus (SARS-CoV-2) causing COVID-19, and what symptoms should I look for to determine if there is a need to test for the virus? Answer The COVID-19 global pandemic affects all ages. Severe respiratory manifestations have been the mainstay of illness in adults, with what seems to be rapid deterioration necessitating mechanical ventilation. Only 5% of those tested and found to have COVID-19 have been younger than 19 years, possibly owing to limited testing, as the symptoms in children are usually mild. Symptoms in children include fever, dry cough, rhinorrhea, sore throat, and fatigue, and in 10% diarrhea or vomiting. Rarely dyspnea or hypoxemia were also described. Blood tests and imaging have been shown to be of little value in children and should only be ordered for those in whom you would normally order these investigations for viral-like illness. No specific therapy is available and supportive care with rest, fluids, and antipyretics for children is the recommended approach. Ibuprofen or acetaminophen for fever and pain can be given. Antiviral and immunomodulatory treatment is not recommended at this time for otherwise healthy children, and corticosteroids should also not be used. Children with immunocompromised states should be isolated and avoid contact with others.

<https://pubmed.ncbi.nlm.nih.gov/32404451/>

**Greenfield, K., Holley, S., Schoth, D. E., Harrop, E., Howard, R. F., Bayliss, J., Brook, L., Jassal, S. S., Johnson, M., Wong, I. and Liossi, C. (2020). "A mixed-methods systematic review and meta-analysis of barriers and facilitators to paediatric symptom management at end of life." *Palliat Med* 34(6): 689-707.**

**BACKGROUND:** Symptom management for infants, children and young people at end of life is complex and challenging due to the range of conditions and differing care needs of individuals of different ages. A greater understanding of these challenges could inform the development of effective interventions. **AIM:** To investigate the barriers and facilitators experienced by patients, carers and healthcare professionals managing symptoms in infants, children and young people at end of life. **DESIGN:** A mixed-methods systematic review and meta-analysis was undertaken (PROSPERO ID: CRD42019124797). **DATA SOURCES:** The Cochrane Library, PROSPERO, CINAHL, MEDLINE, PsycINFO, Web of Science Core Collection, ProQuest Dissertations & Theses Database, Evidence Search and OpenGrey were electronically searched from the inception of each database for qualitative, quantitative or mixed-methods studies that included data from patients, carers or healthcare professionals referring to barriers or facilitators to paediatric end-of-life symptom management. Studies underwent data extraction, quality appraisal, narrative thematic synthesis and meta-analysis. **RESULTS:** A total of 64 studies were included (32 quantitative, 18 qualitative and 14 mixed-methods) of medium-low quality. Themes were generated encompassing barriers/facilitators experienced by carers (treatment efficacy, treatment side effects, healthcare professionals' attitudes, hospice care, home care, families' symptom management strategies) and healthcare professionals (medicine access, treatment efficacy, healthcare professionals' demographics, treatment side effects, specialist support, healthcare professionals' training, health services delivery, home care). Only one study included patients' views. **CONCLUSION:** There is a need for effective communication between healthcare professionals and families, more training for healthcare professionals, improved symptom management planning including anticipatory prescribing, and urgent attention paid to the patients' perspective. <https://pubmed.ncbi.nlm.nih.gov/32228216/>

**Haupt, T. S., Smyth, M. and Gregoire, M. C. (2019). "A Scoping Review of Transdermal Buprenorphine Use for Non-surgical Pain in the Pediatric Population." *Cureus* 11(10): e5954.**

A preliminary evaluation to review the scope and quality of evidence surrounding transdermal buprenorphine use in the pediatric setting for non-surgical pain was conducted. Our review revealed limited data available on the use of transdermal buprenorphine in pediatric patients. Most studies surrounding this subject involve accidental ingestion of buprenorphine and its use in the treatment of neonatal abstinence syndrome. While indicated for use only in adult populations, small studies have shown encouraging results in reducing pain in children with few, if any, adverse effects. This is reassuring from a clinical perspective, as we hope to highlight the available evidence and invite researchers to expand future studies. Through this review, we have identified significant gaps in the literature surrounding the safety and use of buprenorphine in the pediatric population. To our knowledge, there are no major studies investigating this subject, and it is our hope that future studies will explore the use of transdermal buprenorphine as an alternative pain management technique in pediatrics. The intent of our scoping review is to highlight the lack of research in this area; therefore, future studies may be conducted to support its use in North America. <https://pubmed.ncbi.nlm.nih.gov/31803545/>

Herr, K., Coyne, P. J., Ely, E., Gélinas, C. and Manworren, R. C. B. (2019). "Pain Assessment in the Patient Unable to Self-Report: Clinical Practice Recommendations in Support of the ASPMN 2019 Position Statement." Pain Manag Nurs 20(5): 404-417.

Pain is a subjective experience, unfortunately, some patients cannot provide a self-report of pain verbally, in writing, or by other means. In patients who are unable to self-report pain, other strategies must be used to infer pain and evaluate interventions. In support of the ASPMN position statement "Pain Assessment in the Patient Unable to Self-Report", this paper provides clinical practice recommendations for five populations in which difficulty communicating pain often exists: neonates, toddlers and young children, persons with intellectual disabilities, critically ill/unconscious patients, older adults with advanced dementia, and patients at the end of life. Nurses are integral to ensuring assessment and treatment of these vulnerable populations.  
<https://pubmed.ncbi.nlm.nih.gov/31610992/>

Hornemann, F., Le Duc, D., Roth, C., Pfäffle, R., Huhle, D. and Merckenschlager, A. (2020). "Childhood Dystonia-Parkinsonism Following Infantile Spasms-Clinical Clue to Diagnosis in Early Beta-Propeller Protein-Associated Neurodegeneration." Neuropediatrics 51(1): 22-29.

INTRODUCTION: Beta-propeller protein-associated neurodegeneration (BPAN) is a very rare, X-linked dominant (XLD) inherited member of the neurodegeneration with brain iron accumulation (NBIA) disease family. CASE REPORT: We present a female case of BPAN with infantile spasms in the first year, Rett-like symptomatology, focal epilepsy, and loss of motor skills in childhood. Menarche occurred at the age of 9, after precocious pubarche and puberty. Dystonia-parkinsonism as extrapyramidal sign at the age of 10 years resulted in radiological and genetic work-up. RESULTS: Burke-Fahn-Marsden Dystonia Rating Scale (BFMDRS) measured 66/120 points in body part-related dystonia symptoms. Cerebrospinal fluid examination showed dopamine depletion. T2 and B0 sequences of the diffusion-weighted magnetic resonance imaging showed susceptibility artifacts with NBIA-typical hypointense globus pallidus (GP) and substantia nigra (SN). Next-generation sequencing revealed a BPAN-causing pathogenic variant in WDR45 (WD repeat-containing protein 45) gene (c.830 + 1G > A, XLD, heterozygous, de novo). Skewed X-inactivation was measured (2:98). CONCLUSIONS: Autophagy-related X-linked BPAN disease might still be underdiagnosed in female cases of infantile spasms. Skewed X-inactivation will have mainly influenced the uncommon, very early childhood neurodegenerative symptomatology in the present BPAN case. Oral levodopa substitution led to improvement in sleep disorder, hypersalivation, and swallowing. Reduced white matter and hypointense signals in SN and GP on susceptibility sequences in magnetic resonance imaging are characteristic radiological findings of advanced disease in NBIA. No BPAN-typical halo sign in T1-weighted scan at midbrain level was seen at the age of 11 years. NBIA panel is recommended for early diagnosis.  
<https://pubmed.ncbi.nlm.nih.gov/31505688/>

Husari, K. S., Labiner, K., Huang, R. and Said, R. R. (2020). "New-Onset Refractory Status Epilepticus in Children: Etiologies, Treatments, and Outcomes." Pediatr Crit Care Med 21(1): 59-66.

**OBJECTIVES:** To elucidate etiologies, treatment, functional and neurocognitive outcomes of children with new-onset refractory status epilepticus. **DESIGN:** A single-center retrospective study. **SETTING:** A tertiary care children's hospital. **PATIENTS:** All patients between 1 month and 21 years old admitted with new-onset refractory status epilepticus between January 2004 and July 2017. **INTERVENTIONS:** None. **MEASUREMENTS AND MAIN RESULTS:** Clinical presentation, laboratory data, imaging studies, and treatments were collected during hospitalization. Outcomes were assessed at hospital discharge and follow-up in the outpatient neurology clinic based on functional and neurocognitive outcomes as well as development of epilepsy. A total of 674 unique patients presented with status epilepticus of which 40 had new-onset refractory status epilepticus. Patients were classified into either refractory status epilepticus or super-refractory status epilepticus. The etiology of most children with new-onset refractory status epilepticus remained cryptogenic. The most common identified etiology was viral (20%). None of the patients had a contributory positive neuronal antibody test. Several treatments were tried including immunotherapy which was used in half of the patients. Five patients died (12.5%) during the acute phase of their disease, with four lost to follow-up. Twenty out of the remaining 31 patients (65%) developed epilepsy and 18 (58%) had persistent neurocognitive impairment. There was no statistical significant difference in various outcome measures and various etiologies, patients' characteristics, and treatments. **CONCLUSIONS:** In this single-center cohort, more than half of the children with new-onset refractory status epilepticus did not have an identifiable etiology. Unlike adult patients, the presence of positive neuronal antibody syndrome was rare. There was no difference in outcome between those with or without an identifiable etiology. As expected, patients with super-refractory status epilepticus had worse functional and neurocognitive outcomes. More standardized diagnostic and treatment algorithms are needed along with prospective multicenter studies.

<https://pubmed.ncbi.nlm.nih.gov/31568262/>

Iodice, A. and Pisani, F. (2019). "Status dystonicus: management and prevention in children at high risk." *Acta Biomed* 90(3): 207-212.

**BACKGROUND:** Status dystonicus (SD) is a movement disorder emergency associated with significant morbidity and life-threatening events that requires immediate and effective treatment. Nevertheless, SD is currently an under-recognized and undertreated condition, partly due to the lack of a standard definition and because it can be the acute complicated course of both primary and secondary dystonias. In subjects with SD, due to the delay of identification and lacking prevention of trigger and precipitant factors, intensive care management is consistently required. **OBJECTIVES:** We performed a critical review of this topic, outlining clinical features and linked genetic disorders to recognize subject at higher risk of SD, describing precipitant and trigger factors and proposing potential pharmacological treatment strategies in order to prevent hospitalization. **RESULTS:** Genetic predisposition included: primary dystonias particularly in the case of TOR1A mutation; epileptic encephalopathy such as ARX and GNAO1 genetic variants and neurodegenerative disorders as PANK2. Early recognition of SD should be oriented by the following sign and symptoms: fever, tachycardia, respiratory change, hypertension, sweating and autonomic instability, elevated serum CK. Pain, fever and dehydration are main trigger factors that have to be prevented or quickly controlled. Achieving sleep could be the first therapeutic option in

those with high risk of developing SD. Recently, enteral or transdermal clonidine as safety and efficacy therapeutic alternative was proposed. CONCLUSION: Recognizing high risk children for Status dystonicus from the onset of subtle signs and avoiding trigger factors could drive towards better management avoiding intensive treatments. <https://pubmed.ncbi.nlm.nih.gov/31580306/>

Jibb, L., Nathan, P. C., Breakey, V., Fernandez, C., Johnston, D., Lewis, V., McKillop, S., Patel, S., Sabapathy, C., Strahlendorf, C., Victor, J. C., Moretti, M. E., Nguyen, C., Hundert, A., Cassiani, C., El-Khechen Richandi, G., Insull, H., Hamilton, R., Fang, G., Kuczynski, S. and Stinson, J. (2020). "Pain Squad+ smartphone app to support real-time pain treatment for adolescents with cancer: protocol for a randomised controlled trial." *BMJ Open* 10(3): e037251.

INTRODUCTION: Pain negatively affects the health-related quality of life (HRQL) of adolescents with cancer. The Pain Squad+ smartphone-based application (app), has been developed to provide adolescents with real-time pain self-management support. The app uses a validated pain assessment and personalised pain treatment advice with centralised decision support via a registered nurse to enable real-time pain treatment in all settings. The algorithm informing pain treatment advice is evidence-based and expert-vetted. This trial will longitudinally evaluate the impact of Pain Squad+, with or without the addition of nurse support, on adolescent health and cost outcomes. METHODS AND ANALYSIS: This will be a pragmatic, multicentre, waitlist controlled, 3-arm parallel-group superiority randomised trial with 1:1:1 allocation enrolling 74 adolescents with cancer per arm from nine cancer centres. Participants will be 12 to 18 years, English-speaking and with  $\geq 3/10$  pain. Exclusion criteria are significant comorbidities, end-of-life status or enrolment in a concurrent pain study. The primary aim is to determine the effect of Pain Squad+, with and without nurse support, on pain intensity in adolescents with cancer, when compared with a waitlist control group. The secondary aims are to determine the immediate and sustained effect over time of using Pain Squad+, with and without nurse support, as per prospective outcome measurements of pain interference, HRQL, pain self-efficacy and cost. Linear mixed models with baseline scores as a covariate will be used. Qualitative interviews with adolescents from all trial arms will be conducted and analysed. ETHICS AND DISSEMINATION: This trial is approved by the Hospital for Sick Children Research Ethics Board. Results will provide data to guide adolescents with cancer and healthcare teams in treating pain. Dissemination will occur through partnerships with stakeholder groups, scientific meetings, publications, mass media releases and consumer detailing. TRIAL REGISTRATION NUMBER: NCT03632343 (ClinicalTrials.gov). <https://pubmed.ncbi.nlm.nih.gov/32184315/>

Lonnqvist, P. A. (2020). "Pediatric pain review: what has happened since the First World Congress on Pediatric Pain in 1988? The past, the present and the future." *Minerva Anestesiol*, 10.23736/s0375-9393.20.14391-8.

The present text summarizes the development within the field of pediatric pain during the last 30 years, with a special focus on pediatric postoperative pain. Insights concerning pain ontogeny, how pain influences the neuro-endocrine stress response and the induction of a "pain memory" is discussed as well as established and new options with regards to treatment of postoperative pain. Lastly, some aspects

concerning future development within this field is discussed. It is now well-established that even the unborn fetus reacts with behavioral responses indicative of pain and is also capable of producing a neuro-endocrine stress response if subjected to a painful stimulus. These responses can successfully be treated by opioid administration. The babies stress response is proportional to the magnitude of the surgical procedure and various ways to provide better pain relief to babies undergoing major surgery has been shown to reduce morbidity and mortality. A wide variety of different options exist to treat postoperative pain both in infants and older children. The use of regional anesthetic techniques should be used whenever possible and combined with appropriate systemic options, thereby producing multi-modal analgesia. However, new concepts and drugs are unfortunately few and, thus, progress often lies in using established drugs in more efficient ways. The concept of Enhanced Recovery After Surgery (ERAS) also provides a framework where high-quality postoperative pain relief is of essence for the best possible outcome after both minor and major surgery.  
<https://pubmed.ncbi.nlm.nih.gov/32251575/>

**Maeda, S., Kato, I., Umeda, K., Hiramatsu, H., Takita, J., Adachi, S. and Tsuneto, S. (2020). "Continuous deep sedation at the end of life in children with cancer: experience at a single center in Japan." *Pediatr Hematol Oncol* 37(5): 365-374.**

Continuous deep sedation (CDS) is used to alleviate unbearable and otherwise refractory symptoms in patients dying of cancer. No data are available concerning CDS in children from Japan to date. This study primarily aimed to describe experience in CDS in child cancer patients at Kyoto University Hospital. The secondary aims were to identify the characteristics of patients who received CDS, and to assess ability in daily living at the end of life. A retrospective chart review was performed for child cancer patients who died at the institute between 2008 and 2017. The data of 35 patients were analyzed. Nine (26%) patients had received CDS. Indications for CDS were dyspnea (56%), agitation (22%), seizures (22%), and pain (11%). Midazolam was used in all nine cases. In eight (89%) patients, opioids were also prescribed. In seven (78%) patients, CDS was performed for < 48 hours. In all nine cases, consent was obtained from the parent(s) but not from the children. CDS was more likely in patients with solid tumors ( $p = 0.018$ ) and those who had received no respite sedation ( $p = 0.002$ ). Patients without central nervous system symptoms tended to maintain their capacity for oral intake and verbal communication until a few days prior to death. This is the first report on CDS in child cancer patients from Japan. In the CDS literature, cross-study differences are evident for incidence, target symptoms, duration, and the decision-making process. Further international discussion is warranted concerning indications for CDS and the decision-making process.

<https://pubmed.ncbi.nlm.nih.gov/32379512/>

**McNair, C., Chinian, N., Shah, V., McAllister, M., Franck, L. S., Stevens, B., Burry, L. and Taddio, A. (2020). "Metasynthesis of Factors That Influence Parents' Participation in Pain Management for Their Infants in the NICU." *J Obstet Gynecol Neonatal Nurs* 49(3): 263-271.**

OBJECTIVE: To metasynthesize the results of qualitative studies on the factors that affect parents' participation in pain management for their infants during procedures in the NICU. DATA SOURCES: We conducted a literature search for articles published

from 1976 through November 2019 using MeSH terminology in the following databases: MEDLINE, CINAHL Plus, EMBASE, PubMed, PsycINFO, Cochrane, Scopus, and Web of Science. All qualitative studies in which researchers explored parental participation and education in the NICU were included. **STUDY SELECTION:** A total of 29,937 articles were returned. Once we removed duplicates and limited results to qualitative studies, 48 articles remained. We excluded 41 articles because the studies reported were not conducted in NICUs, involved neonatal palliative care, or were review or opinion articles. We included seven articles for review. **DATA EXTRACTION:** Two authors reviewed all articles using the Critical Appraisal Skills Programme tool to assess study quality and independently scored each study. We reviewed and extracted authors, publication date, type of study, sample size, results, themes, and quotes and included these data elements in the analysis. **DATA SYNTHESIS:** We used a thematic synthesis technique to review the qualitative data, entered codes into NVivo software, and compared codes to create descriptive themes. From these descriptive themes, we generated four analytic themes: Learning to Parent a Hospitalized Infant, Stress and Anxiety, Health Care Providers as Gatekeepers, and NICU Environment. **CONCLUSION:** The four themes identified in this qualitative metasynthesis represent the factors that affect parents' abilities to participate in their infants' pain management. Further research is recommended to develop interventions that address these factors to optimize parents' participation in pain management for their infants during procedures in the NICU.  
<https://pubmed.ncbi.nlm.nih.gov/32277879/>

**Mollakazemi, M. J., Biswal, D., Elayi, S. C., Thyagarajan, S. and Evans, J. (2019). "Synchronization of Autonomic and Cerebral Rhythms During Listening to Music: Effects of Tempo and Cognition of Songs." *Physiol Res* 68(6): 1005-1019.**

A large number of studies document cardiorespiratory changes occurring while listening to music. Less is known, however, about the interaction between cardiorespiratory and cerebral electrical rhythms during listening to music and how cognition and acoustic structural aspects of songs influence that interaction. We focused on tempo as a structural feature of songs, since tempo is a major determinant of physiological responses to music, and on familiarity and randomization of phase of local spectra of known and unknown songs for cognition. Our results indicated an overall increase in the degree of synchronization among cardiorespiratory variables (Heart rate (RR), systolic and diastolic blood pressure (SBP, DBP), respiration) and between cardiorespiratory and cerebral (EEG) oscillations during all songs. We also observed a marked decrease in respiratory frequency bandwidth and increase in respiratory rate while listening to songs, and slow song produced the most periodic breathing. Compared with slow tempo, during fast song, DBP and cerebral oscillations became less synchronized with high frequency components of RR suggesting that the processes causing the previously known reduction in vagal activity with increase in tempo also may have caused the decrease in these synchronizations. Cognition of songs affected the SBP coherencies the most. DBP was synchronized with respiration more than all other measured variables in response to auditory stimuli. Results indicate an overall increase in the degree of synchronization among a variety of cerebral electrical and autonomically driven cardiovascular rhythms. It is possible that this significant increase in synchronizations underlies the widely reported pleasurable and palliative effects of listening to music.

<https://pubmed.ncbi.nlm.nih.gov/31711295/>

Mustafa, N. M. and L, A. S. (2020). "Characterisation of COVID-19 Pandemic in Paediatric Age Group: A Systematic Review and Meta-Analysis." *J Clin Virol* 128: 104395.

BACKGROUND: Coronavirus disease 2019 (COVID-19) is a pandemic first originated in Wuhan the capital of Hubei province, China in December 2019 and then spread globally. It is caused by SARS-CoV-2. Until 1(st) April 2020, the number of cases worldwide was recorded to be 823,626 with 40,598 deaths. Most of the reported cases were adults with few cases described in children and neonates. OBJECTIVES: We performed a systematic review and meta-analysis to analyse the disease characterisation in paediatric age group including the possibility of vertical transmission to the neonates. METHODS: Articles published up to 2(nd) April 2020 in PubMed and google Scholar were considered for this study. FINDINGS: The most frequently reported symptoms were cough 49% (95% CI: 42 - 55%) and fever 47% (95% CI: 41-53%). Lymphopenia and increased Procalcitonin were recorded in (21%, 95% CI: 12 - 30%) and (28%, 95% CI: 18 - 37%) respectively. No sex difference for COVID-19 was found in paediatric age group ( $p = 0.7$ ). Case fatality rate was 0%. Four out of 58 neonates (6.8%) born to COVID-19 confirmed mothers tested positive for the disease. CONCLUSION: The disease trajectory in Paediatric patients has good prognosis compared to adults. Intensive care unit and death are rare. Vertical transmission and virus shedding in breast milk are yet to be established.

<https://pubmed.ncbi.nlm.nih.gov/32417675/>

Norman, C. and Maynard, L. (2019). "Buccal opioids for breakthrough pain in children with life-limiting conditions receiving end-of-life care." *Int J Palliat Nurs* 25(10): 472-479.

BACKGROUND: Many palliative care health settings that care for children and young people (CYP) at the end of life use the buccal mucosa as a route of drug administration to manage the sudden onset of symptoms, such as seizures, agitation and dyspnoea, and for breakthrough pain management. The buccal route is a minimally invasive method that delivers fast symptom relief and is useful for those with swallowing impairment or reduced enteral absorption. AIM: This paper reports on a small retrospective study involving 26 CYP who received end-of-life care between January and December 2017 to review the advantages and disadvantages of using buccal opioids for breakthrough pain relief with a focus on diamorphine as the preferred opioid. METHOD: A retrospective case note review. FINDINGS: This paper shares the clinical practice experiences from one UK organisation of care for CYP at the end of their lives and contributes to the growing body of pharmacological evidence. CONCLUSION: Buccal opioids, specifically buccal diamorphine, are an effective strategy to treat breakthrough pain or dyspnoea in CYP.

<https://pubmed.ncbi.nlm.nih.gov/31755841/>

Oostendorp, L. J., Rajapakse, D., Kelly, P., Crocker, J., Dinsdale, A., Fraser, L. and Bluebond-Langner, M. (2019). "Documentation of breakthrough pain in narrative clinical records of children with life-limiting conditions: Feasibility of a retrospective review." *J Child Health Care* 23(4): 564-578.

This study explored the feasibility of generating reliable information on the frequency, nature and management of breakthrough pain (BTP) in children with life-limiting conditions and life-threatening illnesses (LTIs) from narrative clinical records. In the absence of standardized ways for documenting BTP, we conducted a consensus exercise to develop a glossary of terms that could denote BTP in the records. Thirteen clinicians who contributed to the records reached consensus on 45 terms which could denote BTP, while emphasizing the importance of contextual information. The results of this approach together with guidance for improving the reliability of retrospective reviews informed a data extraction instrument. A pilot test of this instrument showed poor agreement between raters. Given the challenges encountered, we do not recommend a retrospective review of BTP using narrative records. This study highlighted challenges of data extraction for complex symptoms such as BTP from narrative clinical records. For both clinical and research purposes, the recording of complex symptoms such as BTP would benefit from clear criteria for applying definitions, a more structured format and the inclusion of validated assessment tools. This study also showed the value of consensus exercises in improving understanding and interpretation of clinical notes within a service.

<https://pubmed.ncbi.nlm.nih.gov/30463428/>

**Piette, V., Beernaert, K., Cohen, J., Pauwels, N. S., Scherrens, A. L., van der Werff Ten Bosch, J. and Deliens, L. (2020). "Healthcare interventions improving and reducing quality of life in children at the end of life: a systematic review." *Pediatr Res*, 10.1038/s41390-020-1036-x.**

**BACKGROUND:** Children with serious illness suffer from symptoms at the end of life that often fail to be relieved. An overview is required of healthcare interventions improving and decreasing quality of life (QOL) for children with serious illness at the end of life. **METHODS:** A systematic review was performed in five databases, January 2000 to July 2018 without language limit. Reviewers selected quantitative studies with a healthcare intervention, for example, medication or treatment, and QOL outcomes or QOL-related measures, for example, symptoms, for children aged 1-17 years with serious illness. One author assessed outcomes with the QualSyst and GRADE (Grades of Recommendation, Assessment, Development, and Evaluation) Framework; two authors checked a 25% sample. QOL improvement or reduction was categorized. **RESULTS:** Thirty-six studies met the eligibility criteria studying 20 unique interventions. Designs included 1 randomized controlled trial, 1 cross-sectional study, and 34 cohort studies. Patient-reported symptom monitoring increased QOL significantly in cancer patients in a randomized controlled trial. Dexmedetomidine, methadone, ventilation, pleurodesis, and palliative care were significantly associated with improved QOL, and chemotherapy, stem cell transplant, and hospitalization with reduced QOL, in cohort studies. **CONCLUSIONS:** Use of patient-controlled symptom feedback, multidisciplinary palliative care teams with full-time practical support, inhalation therapy, and off-label sedative medication may improve QOL. Curative therapy may reduce QOL. **IMPACT:** QOL for children at the end of life may be improved with patient-controlled symptom feedback, multidisciplinary palliative care teams with full-time practical support, inhalation therapy, and off-label sedative medication. QOL for children at the end of life may be reduced with therapy with a curative intent, such as curative chemotherapy or stem cell transplant. A comprehensive overview of current

evidence to elevate currently often-failing QOL management for children at the end of life. New paradigm-level indicators for appropriate and inappropriate QOL management in children at the end of life. New hypotheses for future research, guided by the current knowledge within the field. Various healthcare interventions (as described above) could or might be employed as tools to provide relief in QOL management for children with serious illness, such as cancer, at the end of life, and therefore could be discussed in pediatrician end-of-life training to limit the often-failed QOL management in this population, cave the one-size-fits-all approach for individual cases. Multidisciplinary team efforts and 24/7 presence, especially practical support for parents, might characterize effective palliative care team interventions for children with serious illness at the end of life, suggesting a co-regulating link between well-being of the child partly to that of the parents Hypothesis-oriented research is needed, especially for children with nonmalignant disorders, such as genetic or neurological disorders at the end of life, as well as QOL outcomes for intervention research and psychosocial or spiritual outcomes.

<https://pubmed.ncbi.nlm.nih.gov/32645707/>

**Piva, J. and Fontela, P. (2020). "Children With Complex Chronic Conditions: A Multifaceted Contemporary Medical Challenge Not Restricted to PICUs." Pediatr Crit Care Med 21(3): 298-299.**

<https://pubmed.ncbi.nlm.nih.gov/32142032/>

**Quirk, K., Wright, J., Marks, A. and Smith, M. A. (2020). "Sublingual Buprenorphine for Pediatric Cancer Pain: A Case Report and Review of the Literature." J Pain Symptom Manage, 10.1016/j.jpainsymman.2020.07.029.**

Pain is a common symptom in pediatric patients with cancer, and most patients in palliative care will receive opioids. Traditional opioids have several drawbacks, including their adverse effects, inconsistent or diminishing efficacy, and limited available routes of administration. Buprenorphine is an attractive option for pain management because of its safety profile, unique pharmacology, and availability in transdermal, buccal, parenteral, and sublingual (SL) dosage forms. Unfortunately, data supporting the use of buprenorphine in pediatric pain patients, particularly SL buprenorphine, are lacking. This case report describes the feasibility of SL buprenorphine use in pediatric patients with complex cancer-related pain.

<https://pubmed.ncbi.nlm.nih.gov/32739561/>

**Smith, A. and Jane Brimble, M. (2020). "Use of subcutaneous fluids in palliative care with children: a case study." Nurs Child Young People 32(4): 26-30.**

Quality of life is a major consideration in children's palliative care, particularly at the end of life. Optimal symptom management is crucial in maintaining quality of life, with the aim being to ensure the child is as comfortable as possible. Ensuring adequate hydration will often be part of symptom management but may be associated with several practical and ethical challenges. Subcutaneous fluid administration in children's palliative care is relatively uncommon, so there is a lack of evidence on the topic. This article demonstrates that it is feasible to use subcutaneous fluid therapy in the children's hospice setting to address patients' hydration needs and manage their

symptoms. It presents a case study of a child who received subcutaneous fluids in a children's hospice for dehydration and myoclonus. It uses the case study to discuss subcutaneous fluid therapy in the children's palliative care setting, including its indications and contraindications, administration, complications and important factors to consider. <https://pubmed.ncbi.nlm.nih.gov/32537962/>

Smith, L. K., Dickens, J., Bender Atik, R., Bevan, C., Fisher, J. and Hinton, L. (2020). "Parents' experiences of care following the loss of a baby at the margins between miscarriage, stillbirth and neonatal death: a UK qualitative study." *Bjog* 127(7): 868-874.

OBJECTIVE: To explore the healthcare experiences of parents whose baby died either before, during or shortly after birth between 20(+0) and 23(+6) weeks of gestation in order to identify practical ways to improve healthcare provision. DESIGN: Qualitative interview study. SETTING: England through two parent support organisations and four NHS Trusts. SAMPLE: A purposive sample of parents. METHODS: Thematic analysis of semi-structured in-depth narrative interviews. MAIN OUTCOME MEASURES: Parents' healthcare experiences. RESULTS: The key overarching theme to emerge from interviews with 38 parents was the importance of the terminology used to refer to the death of their baby. Parents who were told they were 'losing a baby' rather than 'having a miscarriage' were more prepared for the realities of labour, the birth experience and for making decisions around seeing and holding their baby. Appropriate terminology validated their loss, and impacted on parents' health and wellbeing immediately following bereavement and in the longer term. CONCLUSION: For parents experiencing the death of their baby at the margins between miscarriage, stillbirth and neonatal death, ensuring the use of appropriate terminology that reflects parents' preferences is vital. This helps to validate their loss and prepare them for the experiences of labour and birth. Reflecting parents' language preferences combined with compassionate bereavement care is likely to have a positive impact on parents' experiences and improve longer-term outcomes. TWEETABLE ABSTRACT: Describing baby loss shortly before 24 weeks of gestation as a 'miscarriage' does not prepare parents for labour and birth, seeing their baby and making memories. <https://pubmed.ncbi.nlm.nih.gov/31976622/>

Smyth, M., Haupt, T. S. and Gregoire, M. C. (2020). "Retrospective Review of the Use of Transdermal Buprenorphine Patches (Butrans) in a Pediatric Population." *J Palliat Med* 23(8): 1094-1097.

Background: Buprenorphine is an opioid medication used for the treatment of moderate to severe pain. In Canada, buprenorphine is not indicated for use in the pediatric population and literature surrounding its use in pediatrics is limited. Our aim was to evaluate the safety of transdermal buprenorphine in a pediatric palliative care setting. Methods: Our study was performed at the IWK Health Centre. Medical records of 11 patients were examined for specific clinical characteristics. The study focused primarily on descriptive results; standard data analyses were not performed. Results: Buprenorphine was found to be well tolerated in our patient population. There were no adverse effects reported in 8 of 11 patients during their treatment with buprenorphine. The remaining 3 patients described mild adverse effects in the form of skin irritation which resolved with topical steroid treatment. Efficacy was reported as anecdotal

quotes from patient records. Conclusion: In this study, the use of buprenorphine in this setting was safe in a small group of patients, with the only mild adverse effect noted being a contact dermatitis in 3 patients which resolved quickly. Other studies have also demonstrated buprenorphine to be a safe and an effective opioid for the treatment of severe pain at the end of life in a pediatric population. Given these results, the implementation of buprenorphine in pediatrics may be safe for use in patients who are unable to tolerate traditional opioid analgesic therapies.

<https://pubmed.ncbi.nlm.nih.gov/31770045/>

**Song, L., Liu, F., Liu, Y., Zhang, R., Ji, H. and Jia, Y. (2020). "Clonazepam add-on therapy for drug-resistant epilepsy." *Cochrane Database Syst Rev* 4(4): Cd012253.**

**BACKGROUND:** This is an updated version of the original Cochrane Review published in 2018, Issue 5. Epilepsy affects over 70 million people worldwide, and nearly a quarter of patients with seizures have drug-resistant epilepsy. People with drug-resistant epilepsy have increased risks of premature death, injuries, psychosocial dysfunction, and a reduced quality of life. **OBJECTIVES:** To assess the efficacy and tolerability of clonazepam when used as an add-on therapy for adults and children with drug-resistant focal onset or generalised onset epileptic seizures, when compared with placebo or another antiepileptic agent. **SEARCH METHODS:** For the latest update we searched the following databases on 4 June 2019: Cochrane Register of Studies (CRS Web), MEDLINE (Ovid) 1946 to 3 June, 2019. The Cochrane Register of Studies (CRS Web) includes the Cochrane Epilepsy Group Specialized Register, the Cochrane Central Register of Controlled Trials (CENTRAL), and randomised or quasi-randomised, controlled trials from Embase, ClinicalTrials.gov and the World Health Organization International Clinical Trials Registry Platform (ICTRP). **SELECTION CRITERIA:** Double-blind randomised controlled studies of add-on clonazepam in people with resistant focal or generalised onset seizures, with a minimum treatment period of eight weeks. The studies could be of parallel or cross-over design. **DATA COLLECTION AND ANALYSIS:** Two review authors independently selected studies for inclusion, extracted relevant data, and assessed trial quality. We contacted study authors for additional information. **MAIN RESULTS:** We found no double-blind randomised controlled trials which met the inclusion criteria. **AUTHORS' CONCLUSIONS:** There is no evidence from double-blind randomised controlled trials for or against the use of clonazepam as an add-on therapy for adults and children with drug-resistant focal or generalised onset epileptic seizures. Since the last version of this review no new studies have been found.

<https://pubmed.ncbi.nlm.nih.gov/32309880/>

**Ubeda Tikkanen, A., Buxton, K., Ullrich, C. K., Stone, S. S. and Nimec, D. L. (2019). "The Palliative Use of Intrathecal Baclofen in Niemann-Pick Disease Type C." *Pediatrics* 144(5).**

Niemann-Pick disease type C is a rare progressive genetic disorder that leads to the abnormal accumulation of lipids within various tissues of the body, including brain tissue and liver. There is a rapid progression of the disease, resulting in severe disability in only a few years after the first symptoms, and survival is not much longer. Spasticity, dystonia, and chronic pain are common findings that severely impact quality of life in these patients. Analgesic management with traditional pain medications is not always effective, and the risk for secondary effects in medically complex patients is high. Liver

function is also a limiting factor in these patients. This is a case report of a boy with advanced Niemann-Pick disease type C with developmental regression, cataplexia, and seizures. His severe spasticity made positioning and care difficult, and intense pain required multiple hospitalizations. He had unsuccessfully trialed multiple drugs. An intrathecal baclofen pump was placed without surgical complications and resulted in positive clinical effects. Baclofen pumps have classically been used for spasticity management in adults and children with nonprogressive diseases such as cerebral palsy or spinal cord injury with relatively long life expectancies. In adults, they have been used in patients with multiple sclerosis; however, use in pediatric neurodegenerative diseases has scarcely been reported. The use of intrathecal baclofen in palliative settings might provide an additional resource to provide comfort and quality of life for children with neurodegenerative diseases not only at end-of-life stages but also earlier on.

<https://pubmed.ncbi.nlm.nih.gov/31649137/>

van den Akker, C. H. P., van Goudoever, J. B., Shamir, R., Domellöf, M., Embleton, N. D., Hojsak, I., Lapillonne, A., Mihatsch, W. A., Berni Canani, R., Bronsky, J., Campoy, C., Fewtrell, M. S., Fidler Mis, N., Guarino, A., Hulst, J. M., Indrio, F., Kolaček, S., Orel, R., Vandenplas, Y., Weizman, Z. and Szajewska, H. (2020). "Probiotics and Preterm Infants: A Position Paper by the European Society for Paediatric Gastroenterology Hepatology and Nutrition Committee on Nutrition and the European Society for Paediatric Gastroenterology Hepatology and Nutrition Working Group for Probiotics and Prebiotics." *J Pediatr Gastroenterol Nutr* 70(5): 664-680.

More than 10,000 preterm infants have participated in randomised controlled trials on probiotics worldwide, suggesting that probiotics in general could reduce rates of necrotising enterocolitis (NEC), sepsis, and mortality. Answers to relevant clinical questions as to which strain to use, at what dosage, and how long to supplement are, however, not available. On the other hand, an increasing number of commercial products containing probiotics are available from sometimes suboptimal quality. Also, a large number of units around the world are routinely offering probiotic supplementation as the standard of care despite lacking solid evidence. Our recent network meta-analysis identified probiotic strains with greatest efficacy regarding relevant clinical outcomes for preterm neonates. Efficacy in reducing mortality and morbidity was found for only a minority of the studied strains or combinations. In the present position paper, we aim to provide advice, which specific strains might potentially be used and which strains should not be used. In addition, we aim to address safety issues of probiotic supplementation to preterm infants, who have reduced immunological capacities and occasional indwelling catheters. For example, quality reassurance of the probiotic product is essential, probiotic strains should be devoid of transferable antibiotic resistance genes, and local microbiologists should be able to routinely detect probiotic sepsis. Provided all safety issues are met, there is currently a conditional recommendation (with low certainty of evidence) to provide either *Lactobacillus rhamnosus* GG ATCC53103 or the combination of *Bifidobacterium infantis* Bb-02, *Bifidobacterium lactis* Bb-12, and *Streptococcus thermophilus* TH-4 in order to reduce NEC rates.

<https://pubmed.ncbi.nlm.nih.gov/32332478/>

Wang, J., Qi, H., Bao, L., Li, F. and Shi, Y. (2020). "A contingency plan for the management of the 2019 novel coronavirus outbreak in neonatal intensive care units." Lancet Child Adolesc Health 4(4): 258-259.  
<https://pubmed.ncbi.nlm.nih.gov/32043976/>

Weaver, M. S., Robinson, J. and Wichman, C. (2020). "Aromatherapy improves nausea, pain, and mood for patients receiving pediatric palliative care symptom-based consults: A pilot design trial." Palliat Support Care 18(2): 158-163.

**OBJECTIVE:** The role of aromatherapy in supportive symptom management for pediatric patients receiving palliative care has been underexplored. This pilot study aimed to measure the impact of aromatherapy using validated child-reported nausea, pain, and mood scales 5 minutes and 60 minutes after aromatherapy exposure. **METHODS:** The 3 intervention arms included use of a symptom-specific aromatherapy sachet scent involving deep breathing. The parallel default control arm (for those children with medical exclusion criteria to aromatherapy) included use of a visual imagery picture envelope and deep breathing. Symptom burden was sequentially assessed at 5 and 60 minutes using the Baxter Retching Faces scale for nausea, the Wong-Baker FACES scale for pain, and the Children's Anxiety and Pain Scale (CAPS) for anxious mood. Ninety children or adolescents (mean age 9.4 years) at a free-standing children's hospital in the United States were included in each arm (total n = 180). **RESULTS:** At 5 minutes, there was a mean improvement of 3/10 (standard deviation [SD] 2.21) on the nausea scale; 2.6/10 (SD 1.83) on the pain scale; and 1.6/5 (SD 0.93) on the mood scale for the aromatherapy cohort ( $p < 0.0001$ ). Symptom burden remained improved at 60 minutes post-intervention ( $<0.0001$ ). Visual imagery with deep breathing improved self-reports of symptoms but was not as consistently sustained at 60 minutes. **SIGNIFICANCE OF RESULTS:** Aromatherapy represents an implementable supportive care intervention for pediatric patients receiving palliative care consults for symptom burden. The high number of children disqualified from the aromatherapy arm because of pulmonary or allergy indications warrants further attention to outcomes for additional breathing-based integrative modalities.  
<https://pubmed.ncbi.nlm.nih.gov/31423959/>

Weaver, M. S. and Wiener, L. (2020). "Applying Palliative Care Principles to Communicate With Children About COVID-19." J Pain Symptom Manage 60(1): e8-e11.

Children are seeing rapid changes to their routines and facing an unpredictable future. Palliative care teams may consider expanding their communication training and skill sets to help families consider caring ways to communicate with their children and grandchildren about the coronavirus. Palliative care teams are wise to encourage families to ground their communication with children on key values: honesty and trust, self-compassion, safety, sensitivity, connection, preparedness, community building, recognition of death as a part of the life cycle, and legacy.  
<https://pubmed.ncbi.nlm.nih.gov/32240751/>

## Psychosocial & Family Issues

Aftyka, A., Rozalska, I. and Milanowska, J. (2020). "Is post-traumatic growth possible in the parents of former patients of neonatal intensive care units?" Ann Agric Environ Med 27(1): 106-112.

**INTRODUCTION:** The birth of a sick child, as well as the infant's subsequent hospitalization in an neonatal intensive care unit (NICU), is undoubtedly stressful for the parents of the infant. Most studies conducted in groups of parents of such children focus on the assessment of the negative changes in their functioning due to such stress. The authors were interested in positive changes in the psychological functioning of parents that may occur after traumatic experiences. These changes are referred to as post-traumatic growth (PTG). **OBJECTIVE:** The aim of this study was to examine whether parents experience post-traumatic growth and to determine the predictors of PTG in fathers and mothers, depending on the coping strategy adopted. **MATERIAL AND METHODS:** The study involved 82 parents, whose children were previously hospitalized in neonatal intensive care unit. The methods used included the following standardized psychological tests: the Post-traumatic Growth Inventory, the Impact of Event Scale-Revised, and the COPE Inventory. Socio-demographic and medical data were also collected. **RESULTS:** Analysis of the data proved that the illness and hospitalization of a child are significantly associated with the occurrence of post-traumatic growth in parents. PTG in mothers is higher than in fathers. Predictors of PTG in fathers include the use of strategies aimed at seeking emotional support and positive reinterpretation and growth, while in the group of mothers, seeking emotional support, religious coping and planning were the coping strategies used. **CONCLUSIONS:** Research on post-traumatic growth should be expanded. Knowledge of the predictors of positive growth in a difficult situation can contribute to the widespread implementation of primary and secondary prevention of post-traumatic stress symptoms as well as increase positive changes in individuals who have experienced traumatic events.

<https://pubmed.ncbi.nlm.nih.gov/32208588/>

Ainscough, T., Fraser, L., Taylor, J., Beresford, B. and Booth, A. (2019). "Bereavement support effectiveness for parents of infants and children: a systematic review." BMJ Support Palliat Care, 10.1136/bmjspcare-2019-001823.

**OBJECTIVES:** This systematic review aims to assess the effectiveness of bereavement support interventions (BSIs) for parents of an infant or a child who has died from a medical condition or in unforeseen circumstances. **METHODS:** A systematic search of MEDLINE, PsycINFO, Embase and CINAHL (1980 to January 2018) was performed to identify studies investigating BSIs for the parents of children who died between the ages of 24 weeks gestation and 30 years. Due to significant clinical and methodological heterogeneity between studies, a narrative synthesis was performed. **RESULTS:** The database searches returned 24 550 records, with a further 6 identified through other sources. Of these, eight studies, reported in nine papers, met the inclusion criteria. Most studies were conducted in the USA (n=5) and in perinatal/neonatal deaths (n=6). Five of the included studies were randomised controlled trials and three were non-randomised comparative studies. Interventions were delivered to groups, individuals or

families. Outcomes of interest were grief, mental health, physical health and 'others'. There were major concerns over the quality of study methods and reporting. Only three of the nine studies reported a significant difference between experimental and control arm participants in any outcomes, despite a total of 23 outcomes being measured. CONCLUSIONS: Poor methodology and reporting of the few studies which have assessed BSIs for parents limit any conclusions on their effectiveness. Agreement on core outcomes and more robust study methodology are required in this neglected area of research.

<https://pubmed.ncbi.nlm.nih.gov/31582385/>

**Alzawad, Z., Lewis, F. M., Kantrowitz-Gordon, I. and Howells, A. J. (2020). "A Qualitative Study of Parents' Experiences in the Pediatric Intensive Care Unit: Riding a Roller Coaster." *J Pediatr Nurs* 51: 8-14.**

PURPOSE: Post-traumatic stress disorder rates in parents following PICU admission ranged between 12.2% and 42%. Despite the numbers affected and the magnitude of parents' distress, little is known about parents' experience in the PICU that could be a source of their stress. This study sought to describe parents' experience of the PICU during their child's stay, including their perceived stressors. DESIGN AND METHODS: Single occasion interviews with 15 parents of children with complex medical conditions admitted for 48 or more hours to a tertiary PICU in the USA. Interviews were inductively coded using methods adapted from Grounded Theory. RESULTS: Riding a Roller Coaster was the core construct that explained parents' experiences. Analyses revealed four domains: Being in a New Stressful World, My Brain Is Burning All the Time, Going through a Hurricane of Emotions, and Being in a Safe Place with Great People. CONCLUSION: Despite outstanding medical services, parents were traumatized by seeing their child in a life-threatening situation and were buffeted by a tidal wave of emotions. Parents lived in a constant state of uncertainty, helplessness and fear, not knowing if their child would survive or have devastating outcomes or permanent disabilities. PRACTICE IMPLICATIONS: Supporting parents during their emotional roller coaster ride requires targeted services throughout the child's illness trajectory, including ways to interpret what is happening in the PICU, helping parents self-regulate their stress, and offering services around parents' fears, concerns, and strategies to manage their uncertainty and feelings of helplessness.

<https://pubmed.ncbi.nlm.nih.gov/31835065/>

**Arias-Rojas, M., Carreño-Moreno, S. and Posada-López, C. (2019). "Uncertainty in illness in family caregivers of palliative care patients and associated factors." *Rev Lat Am Enfermagem* 27: e3200.**

OBJECTIVE: to describe the level of uncertainty in illness in family caregivers of palliative care patients and detect associations between the profile of the caregiver and the levels of uncertainty. METHOD: descriptive correlational study conducted with 300 family caregivers of hospitalized patients. The sociodemographic characterization of caregiver and patient was used to assess the caregiver profile, as well as the Uncertainty in Illness scale for family caregivers. Spearman's Rho correlation test was applied to detect associations. RESULTS: the average score of illness uncertainty was 91.7 points. The analysis showed significant correlations between the level of uncertainty and patient dependence ( $r=0.18$ ,  $p=0.001$ ), symptom assessment ( $r=0.312$ ,

$p < 0.001$ ), length of service as a caregiver ( $r = 0.131$ ,  $p = 0.023$ ), perception of support from health professionals ( $r = -0.16$ ,  $p = 0.048$ ), family ( $r = -0.145$ ,  $p = 0.012$ ) and religious support ( $r = -0.131$ ,  $p = 0.050$ ). CONCLUSIONS: there were high levels of uncertainty in caregivers about their patient's illness. These levels are associated with the health condition and symptoms of the patient who is cared for, the length of service as a caregiver and the perceived support from health professionals, family and religion.

<https://pubmed.ncbi.nlm.nih.gov/31618393/>

**Baumann, I., Künzel, J., Goldbeck, L., Tutus, D. and Niemitz, M. (2020). "Prolonged Grief, Posttraumatic Stress, and Depression Among Bereaved Parents: Prevalence and Response to an Intervention Program." *Omega (Westport)*, 10.1177/0030222820918674: 30222820918674.**

Bereaved parents may experience diverse psychological symptoms. Possible interventions are not yet well established. In this study, the psychological symptoms of 323 bereaved parents (mean age = 39.97, SD = 7.21, 52.0% female), referred to a 4-week family-oriented rehabilitation (FOR) program, were assessed. The baseline assessments indicated that 160 (49.5%) parents showed symptoms of prolonged grief disorder (PGD). Complicated grief was indicated in 272 (84.2%), depression in 191 (59.1%), and posttraumatic stress disorder in 242 (74.9%) parents. Mothers were at higher risk of complicated grief ( $p \leq .001$ ), depression ( $p = .029$ ), and posttraumatic stress disorder ( $p = .004$ ), compared to fathers. Significant remissions of symptoms between admission and discharge from the program are presented as symptoms of complicated grief, depression, and posttraumatic stress. The effect sizes ranged between  $d = 0.68$  and  $1.22$ . In addition, significantly fewer parents fulfilled PGD criteria on discharge from the FOR program ( $p \leq .001$ ). The special FOR program appears promising with regard to improving the bereaved parents' mental health.

<https://pubmed.ncbi.nlm.nih.gov/32290762/>

**Bogetz, J. F., Revette, A., Rosenberg, A. R. and DeCoursey, D. (2020). "I Could Never Prepare for Something Like the Death of My Own Child": Parental Perspectives on Preparedness at End of Life for Children With Complex Chronic Conditions." *J Pain Symptom Manage*, 10.1016/j.jpainsymman.2020.06.035.**

CONTEXT: Children with complex chronic conditions (CCCs) have high morbidity and mortality. While these children often receive palliative care services, little is known about parental preparedness for their child's end of life (EOL). OBJECTIVES: This study aimed to elucidate aspects important to preparedness at EOL among bereaved parents of children with CCCs. METHODS: In this cross-sectional study, parents of children who received care at Boston Children's Hospital and died between 2006 and 2015 completed 21 open-response items querying communication, decision-making, and EOL experiences as part of the Survey of Caring for Children with CCCs. Additional demographic data were extracted from the child's medical record. An iterative multistage thematic analysis of responses was utilized to identify key contexts, conditions, and themes pertaining to preparedness. RESULTS: One hundred ten of 114 parents responded to open-ended items; 63% ( $n = 69$ ) had children with congenital or central nervous system progressive primary conditions for a median of 7.5 years (IQR 0.8-18.1) before death. Seventy-one percent ( $n = 78/110$ ) had palliative care involvement and 65% ( $n = 69/106$ ) completed advance care planning. Parents

described preparedness as a complex concept that extended beyond "readiness" for their child's death. Three domains emerged that contributed to parents' lack of preparedness: 1) chronic illness experiences; 2) pretense of preparedness; and 3) circumstances and emotions surrounding their child's death. CONCLUSIONS: Most bereaved parents of children with CCCs described feeling unprepared for their child's EOL, despite palliative care and advance care planning, suggesting preparedness is a nuanced concept beyond "readiness." More research is needed to identify supportive elements among parents facing their child's EOL.

<https://pubmed.ncbi.nlm.nih.gov/32629083/>

**Boyden, J. Y., Ersek, M., Deatrick, J. A., Widger, K., LaRagione, G., Lord, B. and Feudtner, C. (2020). "What Do Parents Value Regarding Pediatric Palliative and Hospice Care in the Home Setting?" *J Pain Symptom Manage*, 10.1016/j.jpainsymman.2020.07.024.**

CONTEXT: Children with life-shortening serious illnesses and medically-complex care needs are often cared for by their families at home. Little, however, is known about what aspects of pediatric palliative and hospice care in the home setting (PPHC@Home) families value the most. OBJECTIVES: To explore how parents rate and prioritize domains of PPHC@Home as the first phase of a larger study that developed a parent-reported measure of experiences with PPHC@Home. METHODS: Twenty domains of high-value PPHC@Home, derived from the National Consensus Project's Guidelines for Quality Palliative Care, the literature, and a stakeholder panel, were evaluated. Using a discrete choice experiment, parents provided their ratings of the most and least valued PPHC@Home domains. We also explored potential differences in how subgroups of parents rated the domains. RESULTS: Forty-seven parents participated. Overall, highest-rated domains included Physical aspects of care: Symptom management, Psychological/emotional aspects of care for the child, and Care coordination. Lowest-rated domains included Spiritual and religious aspects of care and Cultural aspects of care. In exploratory analyses, parents who had other children rated the Psychological/emotional aspects of care for the sibling(s) domain significantly higher than parents who did not have other children ( $P = 0.02$ ). Furthermore, bereaved parents rated the Care giver support at the end of life domain significantly higher than parents who were currently caring for their child ( $P = 0.04$ ). No other significant differences in domain ratings were observed. CONCLUSION: Knowing what parents value most about PPHC@Home provides the foundation for further exploration and conversation about priority areas for resource allocation and care improvement efforts.

<https://pubmed.ncbi.nlm.nih.gov/32745574/>

**Bradford, N., Rolfe, M., Ekberg, S., Mitchell, G., Beane, T., Ferranti, K. and Herbert, A. (2020). "Family meetings in paediatric palliative care: an integrative review." *BMJ Support Palliat Care*, 10.1136/bmjspcare-2020-002333.**

OBJECTIVE: Our aim was to synthesise the available evidence surrounding the structure, processes and outcomes of family meetings in the paediatric palliative care literature. METHODS: We undertook an integrative literature review informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The protocol was registered with PROSPERO (CRD42019138938). Electronic databases

were systematically search using keywords and hand searching of reference articles and grey literature was also completed. RESULTS: Ten empirical studies and five theoretical articles were included in the synthesis. Empirical studies provided more information about meeting structure, whereas theoretical articles more frequently described a desired process for planning and undertaking meetings. No articles identified how the success of a meeting was defined or made recommendations for doing so. Despite reports that family meetings are commonly occurring, few articles described outcomes from either the family or clinician perspectives. CONCLUSIONS: Family meetings are essential communication strategies commonly used in paediatric palliative care, yet there is little guidance about how meetings should be organised and conducted, who should participate and when they should occur. The limited data available on the outcomes of family meetings suggest improvements are required to meet the needs of families. We present a framework that synthesises the available evidence. The framework offers an overview of the elements to consider when planning for and undertaking family meetings in paediatric palliative care and may be useful for both clinicians and researchers.

<https://pubmed.ncbi.nlm.nih.gov/32680893/>

**Bratica, R. B. (2020). "A baby born too soon." *Fam Syst Health* 38(1): 90.**

Presents a poem about a mother's response to the death of her premature baby. (PsycInfo Database Record (c) 2020 APA, all rights reserved).

<https://pubmed.ncbi.nlm.nih.gov/32202837/>

**Brouwer, M., Maeckelberghe, E. L. M., van der Heide, A., Hein, I. and Verhagen, E. (2020). "Barriers in care for children with life-threatening conditions: a qualitative interview study in the Netherlands." *BMJ Open* 10(6): e035863.**

OBJECTIVE: To identify barriers, as perceived by parents, to good care for children with life-threatening conditions. DESIGN: In a nationwide qualitative study, we held in-depth interviews regarding end-of-life care with parents of children (aged 1 to 12 years) who were living with a life-threatening illness or who had died after a medical trajectory (a maximum of 5 years after the death of the child). Sampling was aimed at obtaining maximum variety for a number of factors. The interviews were transcribed and analysed. SETTING: The Netherlands. PARTICIPANTS: 64 parents of 44 children. RESULTS: Parents identified six categories of difficulties that create barriers in the care for children with a life-threatening condition. First, parents wished for more empathetic and open communication about the illness and prognosis. Second, organisational barriers create bureaucratic obstacles and a lack of continuity of care. Third, parents wished for more involvement in decision-making. Fourth, parents wished they had more support from the healthcare team on end-of-life decision-making. Fifth, parents experienced a lack of attention for the family during the illness and after the death of their child. Sixth, parents experienced an overemphasis on symptom-treatment and lack of attention for their child as a person. CONCLUSIONS: The barriers as perceived by parents focussed almost without exception on non-medical aspects: patient-doctor relationships; communication; decision-making, including end-of-life decision-making; and organisation. The perceived barriers indicate that care for children with a life-threatening condition focusses too much on symptoms and not enough on the human beings behind these symptoms.

<https://pubmed.ncbi.nlm.nih.gov/32595157/>

**Burns, M., Griese, B., King, S. and Talmi, A. (2020). "Childhood bereavement: Understanding prevalence and related adversity in the United States." Am J Orthopsychiatry 90(4): 391-405.**

The death of a parent or sibling during childhood is an adverse experience that increases risk for future behavioral health, academic, and relational problems, as well as earlier mortality. Efforts to estimate childhood bereavement prevalence rates have been hampered by methodological, reporting, and data source limitations. In the absence of national tracking systems in the United States, a quantitative statistical model has been introduced with the aim of estimating the prevalence of this public health issue to aid in needs assessment and service provision. A hybrid of binomial probability and life table methods was applied to develop the Childhood Bereavement Estimation Model (CBEM), which utilizes U.S. vital statistics data to generate current and projected estimates of the number of youth impacted by the death of a parent or sibling. National and state CBEM estimates are reported. Notable differences among geographies and associated public health implications are discussed, contextualizing childhood bereavement among other social determinants of health and calling for a more comprehensive approach to this underresourced issue. Nationally, CBEM Projected Estimates reveal that 6.99% of children-nearly 5.0 million-have or will have experienced the death of a parent or sibling by age 18. For youth under 25, this estimate more than doubles to almost 12.9 million. The CBEM offers social service professionals a tool for raising awareness about the magnitude of childhood bereavement and assessing the need for grief services within specific localities to ultimately equip communities in developing effective preventive interventions that are inclusive and accessible. (PsycInfo Database Record (c) 2020 APA, all rights reserved).

<https://pubmed.ncbi.nlm.nih.gov/31999137/>

**Cai, S., Guo, Q., Luo, Y., Zhou, Y., Abbas, A., Zhou, X. and Peng, X. (2020). "Spiritual needs and communicating about death in nonreligious theistic families in pediatric palliative care: A qualitative study." Palliat Med 34(4): 533-540.**

**BACKGROUND:** Spiritual support should be offered to all patients and their families regardless of their affiliated status with an organized religion. **AIM:** To understand nonreligious theistic parents' spirituality and to explore how parents discuss death with their terminally ill children in mainland China. **DESIGN:** Qualitative study. **SETTING/PARTICIPANTS:** This study was conducted in the hematology oncology center at Beijing Children's Hospital. Participants in this study included 16 bereaved parents. **RESULTS:** Participants described themselves as nonreligious but showed a tendency toward a particular religion. Parents sought religious support in the face of the life-threatening conditions that affected their child and regarded the religious belief as an important way to get psychological and spiritual comfort after experiencing the death of their child. Religious support could partially address parents' spiritual needs. Parents' spiritual needs still require other supports such as bereavement services, death education, and family support groups. Some parents stated that it was difficult to find a way to discuss death with their children. For patients who come from nonreligious theistic families, their understanding of death was more complex and may be related to atheism. **CONCLUSION:** Religious support could be an element of

spiritual support for nonreligious theistic parents of terminally ill children. Multiple strategies including religious supports and nonreligious supports should be rationally integrated into spiritual support of nonreligious theistic family. Patient's personal belief in death should be assessed before discussing death with them.

<https://pubmed.ncbi.nlm.nih.gov/31971068/>

**Cai, S., Guo, Q., Luo, Y., Zhou, Y., Abbas, A., Zhou, X. and Peng, X. (2020). "Spiritual needs and communicating about death in nonreligious theistic families in pediatric palliative care: A qualitative study." *Palliat Med* 34(4): 533-540.**

**BACKGROUND:** Spiritual support should be offered to all patients and their families regardless of their affiliated status with an organized religion. **AIM:** To understand nonreligious theistic parents' spirituality and to explore how parents discuss death with their terminally ill children in mainland China. **DESIGN:** Qualitative study. **SETTING/PARTICIPANTS:** This study was conducted in the hematology oncology center at Beijing Children's Hospital. Participants in this study included 16 bereaved parents. **RESULTS:** Participants described themselves as nonreligious but showed a tendency toward a particular religion. Parents sought religious support in the face of the life-threatening conditions that affected their child and regarded the religious belief as an important way to get psychological and spiritual comfort after experiencing the death of their child. Religious support could partially address parents' spiritual needs. Parents' spiritual needs still require other supports such as bereavement services, death education, and family support groups. Some parents stated that it was difficult to find a way to discuss death with their children. For patients who come from nonreligious theistic families, their understanding of death was more complex and may be related to atheism. **CONCLUSION:** Religious support could be an element of spiritual support for nonreligious theistic parents of terminally ill children. Multiple strategies including religious supports and nonreligious supports should be rationally integrated into spiritual support of nonreligious theistic family. Patient's personal belief in death should be assessed before discussing death with them.

<https://pubmed.ncbi.nlm.nih.gov/31971068/>

**Callahan, K., Steinwurtzel, R., Brumarie, L., Schechter, S. and Parravicini, E. (2019). "Early palliative care reduces stress in parents of neonates with congenital heart disease: validation of the "Baby, Attachment, Comfort Interventions". " *J Perinatol* 39(12): 1640-1647.**

**OBJECTIVE:** To test our hypothesis that an innovative method of early palliative care called "Baby, Attachment, Comfort Interventions" reduces psychological distress in parents of neonates with congenital heart disease. **STUDY DESIGN:** Prospective cohort study of parents of neonates with congenital heart disease. Distress was evaluated at admission and discharge using Neonatal Unit Parental Stressor Scale and Depression Anxiety Stress Index-21. Control parents received standard of care. Intervention parents received interdisciplinary interventions aimed at improving neonatal comfort and parenting experience. **RESULTS:** Seventy-seven parents participated. Stress decreased in the intervention group (26 parents) but not in the control group (51 parents). There was no decrease in anxiety or depression in either group. **CONCLUSION:** Early palliative care reduces stress in parents of neonates with

congenital heart disease. Further work is needed to address depression/anxiety in this group of high-risk parents.

<https://pubmed.ncbi.nlm.nih.gov/31488903/>

**Collins, A., Burchell, J., Remedios, C. and Thomas, K. (2020). "Describing the psychosocial profile and unmet support needs of parents caring for a child with a life-limiting condition: A cross-sectional study of caregiver-reported outcomes." *Palliat Med* 34(3): 358-366.**

**BACKGROUND:** There is a lack of studies examining the prevalence and severity of psychosocial distress in parents caring for a child with life-limiting condition. More research is also needed to better understand the experience, support needs and quality-of-life of this population. **AIM:** To describe the experience and support needs of caring for children with life-limiting conditions and examine the level of distress and quality-of-life experienced by parents. **DESIGN:** Cross-sectional, prospective, quantitative study guided by an advisory group. Participants completed a survey that included demographics and self-report outcome measures of unmet support needs, appraisal of caregiving, psychological distress and quality-of-life. Bivariate correlation analyses were performed to examine for associations between measures.

**SETTING/PARTICIPANTS:** Parents currently caring for one or more children ( $\leq 18$  years) with a life-limiting condition and registered with a paediatric palliative care service (Australia). **RESULTS:** In total, 143 parents (88% female) completed the questionnaire (36% RR). Compared with population norms, participants reported low quality-of-life, high carer burden and high psychological distress. Almost half (47%) of the sample met the criteria for one or more diagnoses of clinically elevated stress, anxiety or depression. There were significant associations between the psychosocial outcome variables; carer strain and depression had the strongest correlations with quality-of-life ( $r = -.63$ ,  $p < .001$ , for both). Participants also reported multiple unmet needs related to emotional and practical support. **CONCLUSIONS:** This study contributes to the growing body of evidence on paediatric palliative care, specifically that parents caring for a child with a life-limiting condition report high levels of distress and burden, low quality-of-life and need more emotional and practical support targeted at their unmet needs. Paediatric palliative care services should routinely assess parent mental health and provide appropriate support.

<https://pubmed.ncbi.nlm.nih.gov/32103697/>

**D, Ó. C., Prizeman, G., Korn, B., Donnelly, S. and Hynes, G. (2019). "Dying in acute hospitals: voices of bereaved relatives." *BMC Palliat Care* 18(1): 91.**

**BACKGROUND:** Internationally there is an increasing concern about the quality of end-of-life care (EoLC) provided in acute hospitals. More people are cared for at end of life and die in acute hospitals than in any other healthcare setting. This paper reports the views of bereaved relatives on the experience of care they and the person that died received during their last admission in two university adult acute tertiary hospitals.

**METHODS:** Relatives of patients who died were invited to participate in a post-bereavement postal survey. An adapted version of VOICES (Views of Informal Carers - Evaluation of Services) questionnaire was used. VOICES MaJam has 36 closed questions and four open-ended questions. Data were gathered in three waves and analysed using SPSS and NVivo. 356 respondents completed the survey (46%

response rate). RESULTS: The majority of respondents (87%: n = 303) rated the quality of care as outstanding, excellent or good during the last admission to hospital. The quality of care by nurses, doctors and other staff was highly rated. Overall, care needs were well met; however, findings identified areas of care which could be improved, including communication and the provision of emotional and spiritual support. In addition, relatives strongly endorsed the provision of EoLC in single occupancy rooms, the availability of family rooms on acute hospital wards and the provision of bereavement support. CONCLUSIONS: This research provides a powerful snapshot in time into what works well and what could be improved in EoLC in acute hospitals. Findings are reported under several themes, including the overall quality of care, meeting care needs, communication, the hospital environment and support for relatives. Results indicate that improvements can be made that build on existing good practice that will enhance the experience of care for dying persons and their relatives. The study adds insights in relation to relative's priorities for EoLC in acute hospitals and can advance care providers', policy makers' and educationalists' priorities for service improvement.

<https://pubmed.ncbi.nlm.nih.gov/31672137/>

**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://pubmed.ncbi.nlm.nih.gov/31079074/>

**Darlington, A. S., Randall, D., Leppard, L. and Koh, M. (2020). "Palliative and end of life care for a child: Understanding parents' coping strategies." *Acta Paediatr*, 10.1111/apa.15429.**

AIM: Understanding of coping strategies that parents use before the death of their child is crucial and will enable us to best provide support. The current study aimed to explore parents' coping strategies, and map these onto an existing theoretical framework. METHODS: Bereaved parents and parents of a child with a life-limiting/threatening condition were interviewed to investigate coping strategies, recruited through Intensive Care Units (2 Neonatal, 2 Paediatric, 1 Paediatric Cardiac) and a children's hospice. Analysis focused on coping strategies and mapping these onto the framework. RESULTS: 24 parents of 20 children were interviewed and identified. Parents use a variety of coping strategies (n = 25) such as humour, staying positive, advocating and staying strong for others, expressing emotions and preparing, while also living life to the full, supported by others. The themes were successfully mapped onto the theoretical framework, which focuses on the constructs of approach and avoidance, as well as coping for self and others. CONCLUSION: The findings have provided a detailed account of the breadth and depth of coping strategies parents use, including those classed as avoidance. The strategies were successfully mapped onto the theoretical framework. Future research should investigate changes over times, and associations to negative long-term outcomes.

<https://pubmed.ncbi.nlm.nih.gov/32564398/>

**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 in-curable 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://pubmed.ncbi.nlm.nih.gov/31044306/>

**Denhup, C. (2019). "Bereavement care to minimize bereaved parents' suffering in their lifelong journey towards healing." Appl Nurs Res 50: 151205.**

This article presents select findings from an interpretive phenomenological study which aimed to describe the lived experience of parental bereavement. Six parents, each of whom experienced the death of a child due to cancer at least one year prior,

participated in conversational interviews to share what it has been like for them since their child's death. Heideggerian (1962) phenomenology provided the philosophical underpinnings of the study, while van Manen's (1997) phenomenological method guided data collection and analysis. From this methodological approach, a structure of the meaning of parental bereavement experience was revealed. Profound suffering emerged as one essential theme. Pertinent findings related to this theme are discussed. Parents share ways others might minimize their suffering and provide support in their lifelong journey towards healing. Findings will enhance nurses' practice of providing bereavement care, which is an expectation of quality palliative care.  
<https://pubmed.ncbi.nlm.nih.gov/31677927/>

Dermer, E., Spahr, A., Tran, L. T., Mirchi, A., Pelletier, F., Guerrero, K., Ahmed, S., Brais, B., Braverman, N., Buhas, D., Chandratre, S., Chenier, S., Chrestian, N., Desmeules, M., Dilenge, M. E., Laflamme, J., Larbrisseau, A., Legault, G., Lim, K. Y., Maftai, C., Major, P., Malvey-Dorn, E., Marois, P., Mitchell, J., Nadeau, A., Osterman, B., Paradis, I., Pohl, D., Reggin, J., Riou, E., Roedde, G., Rossignol, E., Sébire, G., Shevell, M., Srour, M., Sylvain, M., Tarnopolsky, M., Venkateswaran, S., Sullivan, M. and Bernard, G. (2020). "Stress in Parents of Children With Genetically Determined Leukoencephalopathies: A Pilot Study." *J Child Neurol*, 10.1177/0883073820938645: 883073820938645.

Genetically determined leukoencephalopathies comprise a group of rare inherited white matter disorders. The majority are progressive diseases resulting in early death. We performed a cross-sectional pilot study including 55 parents from 36 families to assess the level of stress experienced by parents of patients with genetically determined leukoencephalopathies, aged 1 month to 12 years. Thirty-four mothers and 21 fathers completed the Parenting Stress Index-4th Edition. One demographic questionnaire was completed per family. Detailed clinical data was gathered on all patients. Statistical analysis was performed with total stress percentile score as the primary outcome. Mothers and fathers had significantly higher stress levels compared with the normative sample; 20% of parents had high levels of stress whereas 11% had clinically significant levels of stress. Mothers and fathers had comparable total stress percentile scores. We identified pediatric behavioral difficulties and gross motor function to be factors influencing stress in mothers. Our study is the first to examine parental stress in this population and highlights the need for parental support early in the disease course. In this pilot study, we demonstrated that using the Parenting Stress Index-4th Edition to assess stress levels in parents of patients with genetically determined leukoencephalopathies is feasible, leads to valuable and actionable results, and should be used in larger, prospective studies.  
<https://pubmed.ncbi.nlm.nih.gov/32720856/>

Dionne-Odom, J. N., Currie, E. R., Johnston, E. E. and Rosenberg, A. R. (2019). "Supporting Family Caregivers of Adult and Pediatric Persons with Leukemia." *Semin Oncol Nurs* 35(6): 150954.

OBJECTIVES: To describe the needs and formal assessment of family caregivers and ways to intervene to alleviate distress and enhance caregiving skills in the setting of adult and pediatric leukemia. DATA SOURCES: Literature review, clinical practice observations and experiences. CONCLUSION: While rapid treatment advances in

leukemia are a welcome development, the reliance on complex care delivered by family members across settings continues to grow and, concomitantly, so does the risk of mental, physical, and economic burden. IMPLICATIONS FOR NURSING PRACTICE: Oncology nurses and other clinicians should systematically incorporate screening and assessment services so that educational and referral needs are identified and intervened upon.

<https://pubmed.ncbi.nlm.nih.gov/31753704/>

Donovan, L. A., Wakefield, C. E., Russell, V., Fardell, J., Mallitt, K. A., Hetherington, K. and Cohn, R. (2019). "Variables associated with grief and personal growth following the death of a child from cancer: A mixed method analysis." Death Stud, 10.1080/07481187.2019.1682087: 1-12.

This mixed method study explored parent and child characteristics that impact grief and personal growth in parents (n = 119) after a child dies from cancer in Australia. Medical components of a child's cancer care including radiation treatment, referral to palliative care, and location of death had a significant impact on levels of grief. Parents' gender, religious affiliation, and education level had a significant impact on levels of personal growth. This study further enhances our understanding of the impact of specific parent and child characteristics throughout a child's cancer treatment and end of life that may influence their families' experience of bereavement.

<https://pubmed.ncbi.nlm.nih.gov/31656129/>

Dunbar, H. and Carter, B. (2020). "Experiencing place identity and place belongingness at a children's hospice: Parents' perspectives." J Child Health Care, 10.1177/1367493520915134: 1367493520915134.

Children's hospices are key players in the provision of palliative care services for families with children with life-limiting conditions (LLCs). However, evidence suggests that some of the negative terminology/language which surrounds the notions of palliative and hospice care may contribute to the lack of uptake of hospice services by families. This article reports two elements of place bonding: parents' experiences of place identity and place belongingness at a children's hospice in a region in England. Underpinned by a constructivist grounded theory methodology, focus groups were undertaken with 24 parents of children with LLCs accessing a children's hospice. Despite initial reservations associated with the identity of the hospice, parents described how and why their view changed and therefore consequently how they were able to experience the hospice differently. This article demonstrates how parents' views of the identity of the hospice change and how the hospice becomes a place where parents experience a sense of belongingness.

<https://pubmed.ncbi.nlm.nih.gov/32216572/>

Dutta, O., Tan-Ho, G., Choo, P. Y., Low, X. C., Chong, P. H., Ng, C., Ganapathy, S. and Ho, A. H. Y. (2020). "Trauma to Transformation: the lived experience of bereaved parents of children with chronic life-threatening illnesses in Singapore." BMC Palliat Care 19(1): 46.

BACKGROUND: In 2016, over 6.6 million children died globally, and 245 children died in Singapore. Chronic illnesses are prevalent causes of child mortality around the world.

Despite growing research that examines the lived experience of parents bereaved by their child's chronic life-threatening illness, there is no such study within the Asian context. **METHODS:** To bridge this knowledge gap, meaning-oriented, strength-focused interviews were conducted with 25 parental units (i.e. 6 couples, 13 lone mothers, 4 lone fathers, and 2 primary parental figures) who lost their child to chronic life-threatening illness in Singapore (N = 31), including those of Chinese (n = 17), Malay (n = 10) and Indian ethnicities (n = 4), between August 2017 and April 2018. **RESULTS:** Data analysis adhering to the grounded theory approach revealed 7 themes and 25 sub-themes that were organized into a Trauma-to-Transformation Model of Parental Bereavement. This model shows the major milestones in participants' lived experience of their child's chronic life-threatening illness and death, starting from the diagnosis of their child's chronic life-threatening illness and the subsequent emotional turmoil (Theme 1), the mourning of their child's death and the losses which accompanied the death (Theme 3) and participants' experience of posttraumatic growth through reflection of their journey of caregiving and child loss (Theme 5). The model further describes the deliberate behaviors or 'rituals' that helped participants to regain power over their lives (Theme 2), sustain an intimate bond with their child beyond death (Theme 4), and transcend their loss by deriving positive outcomes from their experience (Theme 6). Finally, the model denotes that the lived experiences and well-being of participants were embedded within the health-and-social-care ecosystem, and in turn impacted by it (Theme 7). **CONCLUSION:** These themes and their corresponding sub-themes are discussed, with recommendations for enhancing culturally sensitive support services for grieving Asian parents around the globe.

<https://pubmed.ncbi.nlm.nih.gov/32252753/>

**Dyregrov, A., Dyregrov, K., Pereira, M., Kristensen, P. and Johnsen, I. (2020). "Early intervention for bereaved children: What mental health professionals think." *Death Stud* 44(4): 201-209.**

People rarely specify what "early intervention" following bereavement means, so we explored the views of experienced professionals working primarily with bereaved children. In an anonymous online survey, 84 mental health professionals answered questions about the content and timeframe of early intervention. The types of interventions varied, but conversation and support were most frequent. Most considered early intervention to mean before or during the first month following the loss. Although meta-analyses show little benefit of early intervention, professionals disagree and see the need to tailor interventions to the type of death, the situation of the family, and the intensity of reactions.

<https://pubmed.ncbi.nlm.nih.gov/30556790/>

**Earle, S. and Blackburn, M. (2020). "Young adults with life-limiting or life-threatening conditions: sexuality and relationships support." *BMJ Support Palliat Care*, 10.1136/bmjspcare-2019-002070.**

**OBJECTIVE:** The research project addressed the need to support young adults with issues relating to sexuality and relationships through the development of guidance and standards for practice. **METHODS:** An action research project underpinned by an interpretivist qualitative framework. Participants were recruited to the project via three hospices in the UK. Data from four focus groups were analysed thematically using a

process of constant comparison. RESULTS: Sixteen young adults with life-limiting or life-threatening conditions aged 21-33 years participated in the study. Three significant themes were identified: sexuality and the transition to adulthood, recognising the significance of sex and relationships, and realising sexual rights. CONCLUSION: Sexuality and relationships play an important role in the transition to adulthood for people with life-limiting or life-threatening conditions living in the UK. While young adults with these conditions may have considerable support needs, it is important to balance this with the freedom to exercise choice and to make independent decisions. Sex negativity can have an adverse impact on the experiences of young adults and creates barriers. Improved ongoing access to sex education and the provision of enabling environments that afford privacy and safety are important to support young adults with sexuality and relationships.

<https://pubmed.ncbi.nlm.nih.gov/32241956/>

**Falkenburg, J. L., van Dijk, M., Tibboel, D. and Ganzevoort, R. R. (2020). "The fragile spirituality of parents whose children died in the pediatric intensive care unit." *J Health Care Chaplain* 26(3): 117-130.**

Spiritual care is recognized as a relevant dimension of health care. In the context of pediatric palliative end-of-life care, spirituality entails more than adhering to a spiritual worldview or religion. Interviews with parents whose critically ill child died in the pediatric intensive care unit revealed features of a spirituality that is fragmentary and full of contradictions. This type of spirituality, which we refer to as fragile, speaks of parents' connectedness with the deceased child and the hope of some kind of reuniting after one's own death. Acknowledging that fragments of spirituality can be part of parents' experiences in their child's end-of-life stage can be a meaningful contribution to compassionate care.

<https://pubmed.ncbi.nlm.nih.gov/31583971/>

**Fortney, C. A., Baughcum, A. E., Moscato, E. L., Winning, A. M., Keim, M. C. and Gerhardt, C. A. (2020). "Bereaved Parents' Perceptions of Infant Suffering in the NICU." *J Pain Symptom Manage* 59(5): 1001-1008.**

CONTEXT: It is challenging to provide supportive intensive care to infants in the neonatal intensive care unit (NICU), giving them every chance for survival, while also trying to minimize suffering for both the infant and parents. Parents who believe their infant is suffering may alter treatment goals based on their perceptions; however, it is unknown how parents come to believe that their infant may be suffering. OBJECTIVES: To examine bereaved parents' perceptions of infant suffering in the NICU. METHODS: Parents completed a qualitative interview exploring their perceptions of the level of suffering that their infant experienced at the end of life. Parents whose infant died in a large Midwestern Level IV regional referral NICU from July 2009 to July 2014 were invited to participate. Thirty mothers and 16 fathers from 31 families (31 of 249) participated in telephone interviews between three months and five years after their infant's death. RESULTS: Four themes emerged from the qualitative analysis: 1) the presence/absence of suffering, 2) indicators of suffering, 3) temporal components of suffering (trajectory), and 4) influence of perceived suffering on parents, infants, and clinical decision making. CONCLUSION: Parents used signs exhibited by infants, as well as information they received from the health care team to form their perceptions of

suffering. Perceived suffering followed different trajectories and influenced the decisions that parents made for their infant. Soliciting parent perspectives may lead to improvements in the understanding of infant well-being, particularly suffering, as well as how parents rely on these perceptions to make treatment decisions for their infant.

<https://pubmed.ncbi.nlm.nih.gov/31837457/>

**Fra, J. (2019). "[Supporting parents after the death of a premature twin]." *Soins Pédiatr Pueric* 40(310): 31-33.**

The death of a twin hospitalised in neonatal intensive care presents several issues that the children's nurse must take into account. Identifying the elements which characterise the issues around supporting families confronted at the same time with the grieving and bonding processes enables suitable actions to be put in place.

<https://pubmed.ncbi.nlm.nih.gov/31543232/>

**Fraser, L. K., Murtagh, F. E. M., Sheldon, T., Gilbody, S. and Hewitt, C. (2020). "Health of mothers of children with a life-limiting condition: a protocol for comparative cohort study using the Clinical Practice Research Datalink." *BMJ Open* 10(7): e034024.**

**INTRODUCTION:** There are now nearly 50 000 children with a life-limiting or life-threatening condition in the UK. These include conditions where there is no reasonable hope of cure and from which they will die, as well as conditions for which curative treatment may be feasible but can fail, for example, cancer or heart failure. Having a child with a life-limiting condition involves being a coordinator and provider of healthcare in addition to the responsibilities and pressures of parenting a child who is expected to die young. This adversely affects the health and well-being of these mothers and affects their ability to care for their child, but the extent of the impact is poorly understood. This study aims to quantify the incidence and nature of mental and physical morbidity in mothers of children with a life-limiting condition, their healthcare use and to assess whether there is a relationship between the health of the mother and the child's condition. **METHODS AND ANALYSIS:** A comparative cohort study using data from the Clinical Practice Research Datalink and linked hospital data will include three groups of children and their mothers (those with a life-limiting condition, those with a chronic condition and those with no long-term health condition total=20 000 mother-child dyads). Incidence rates and incidence rate ratios will be used to quantify and compare the outcomes between groups with multivariable regression modelling used to assess the relationship between the child's disease trajectory and mother's health. **ETHICS AND DISSEMINATION:** This study protocol has approval from the Independent Scientific Advisory Committee for the UK Medicines and Healthcare products Regulatory Agency Database Research. The results of this study will be reported according to the STROBE and RECORD guidelines. There will also be a lay summary for parents which will be available to download from the Martin House Research Centre website ([www.york.ac.uk/mhrc](http://www.york.ac.uk/mhrc)).

<https://pubmed.ncbi.nlm.nih.gov/32665342/>

Garten, L., Globisch, M., von der Hude, K., Jäkel, K., Knochel, K., Krones, T., Nicin, T., Offermann, F., Schindler, M., Schneider, U., Schubert, B. and Strahleck, T. (2020). "Palliative Care and Grief Counseling in Peri- and Neonatology: Recommendations From the German PaluTiN Group." *Front Pediatr* 8: 67. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7058113/>

Gerrish, N. J. and Bailey, S. (2020). "Maternal Grief: A Qualitative Investigation of Mothers' Responses to the Death of a Child From Cancer." *Omega (Westport)* 81(2): 197-241.

This study explored bereaved mothers' responses to the death of a child from cancer, with a focus on identifying adaptive and complicated grief reactions. To understand the unique meaning of their loss, in-depth interviews were conducted with 13 mothers at two time points. Interpretative phenomenological analysis-guided by meaning-making theories of loss-revealed five master categories: the perceptions of the child's life with cancer and death from the disease, changed self-identity, coping style, developing an ongoing relationship to the deceased child, and the post-death social environment. Each of these master categories and associated subthemes provided insights into the characteristics of the bereaved mothers' adaptive and complicated grief responses to their loss. Given all the mothers evidenced multiple forms or types of these responses over time, they could not be categorized as adaptive or complicated grievers. However, the varying proportions of each of these responses highlighted differences in overall bereavement adaptation.

<https://pubmed.ncbi.nlm.nih.gov/29570031/>

Goldstein, R. D., Petty, C. R., Morris, S. E., Human, M., Odendaal, H., Elliott, A., Tobacco, D., Angal, J., Brink, L., Kinney, H. C. and Prigerson, H. G. (2019). "Pre-loss personal factors and prolonged grief disorder in bereaved mothers." *Psychol Med* 49(14): 2370-2378.

**BACKGROUND:** Identifying characteristics of individuals at greatest risk for prolonged grief disorder (PGD) can improve its detection and elucidate the etiology of the disorder. The Safe Passage Study, a study of women at high risk for sudden infant death syndrome (SIDS), prospectively examined the psychosocial functioning of women while monitoring their healthy pregnancies. Mothers whose infants died of SIDS were followed in bereavement. **METHODS:** Pre-loss data were collected from 12 000 pregnant mothers and analyzed for their associations with grief symptoms and PGD in 50 mothers whose infants died from SIDS, from 2 to 48 months after their infant's death, focusing on pre-loss risk factors of anxiety, depression, alcohol use, maternal age, the presence of other living children in the home, and previous child loss. **RESULTS:** The presence of any four risk factors significantly predicted PGD for 24 months post-loss ( $p < 0.003$ ); 2-3 risk factors predicted PGD for 12 months ( $p = 0.02$ ). PGD rates increased in the second post-loss year, converging in all groups to approximately 40% by 3 years. Pre-loss depressive symptoms were significantly associated with PGD. Higher alcohol intake and older maternal age were consistently positively associated with PGD. Predicted risk scores showed good discrimination between PGD and no PGD 6-24 months after loss (C-statistic = 0.83). **CONCLUSIONS:** A combination of personal risk factors predicted PGD in 2 years of

bereavement. There is a convergence of risk groups to high rates at 2-3 years, marked by increased PGD rates in mothers at low risk. The risk factors showed different effects on PGD.

<https://pubmed.ncbi.nlm.nih.gov/30409237/>

Goldstein, R. D., Petty, C. R., Morris, S. E., Human, M., Odendaal, H., Elliott, A. J., Tobacco, D., Angal, J., Brink, L. and Prigerson, H. G. (2020). "Transitional objects of grief." *Compr Psychiatry* 98: 152161.

BACKGROUND: Transitional objects provide security and symbolic connection with valued others when separated from them. Bereaved parents often keep, cherish and visit saved objects of their deceased child. This research examined the hypothesis that these objects behave as transitional objects of grief in bereaved mothers during three years following their infants' deaths from Sudden Infant Death Syndrome. METHODS: Questionnaires were administered asking about the presence of kept objects and mementos from their deceased infant, and the frequency, location and emotions experienced during visits to them. Diagnostic criteria for Prolonged Grief Disorder (PGD) were assessed using the Parental Bereavement Questionnaire. RESULTS: 98.6% of the mothers reported having transitional objects of grief, and most visited them more frequently than once per week regardless of PGD status. Mothers with PGD reported significantly more distress when visiting the objects, especially those visiting them privately. Mothers with PGD who felt comforted by the objects had lower risk for finding life meaningless or finding discussion about the infant intolerable. CONCLUSIONS: Transitional objects of grief are common and associated with key aspects of grief. There is a need to understand the potential therapeutic uses of transitional objects in promoting bereavement adjustment.

<https://pubmed.ncbi.nlm.nih.gov/31978784/>

Guimarães, T. M., Pacheco, S. T. A., Nunes, M. D. R. and Silva, L. F. D. (2020). "Perceptions of adolescents with cancer undergoing palliative care about their illness process." *Rev Gaucha Enferm* 41: e20190223.

OBJECTIVE: To understand the perception of adolescents with cancer undergoing palliative care about their illness process. METHOD: An exploratory and qualitative study, performed at a federal public hospital specialized in oncology disease in Rio de Janeiro, through interviews with nine adolescents aged 12 to 20 years old, from July to August 2017. Data was submitted to thematic analysis and the theoretical framework was Hildegard Peplau's Theory of Interpersonal Relationships. RESULTS: Three categories emerged: Living the difficult moment of the trajectory of the disease; Feeling the social isolation and that life has stopped; and Overcoming the difficult stage of the disease. They addressed the trajectory of the disease since the diagnosis, with the awakening of feelings of isolation and stagnation of life. Moreover, they highlighted the overcoming power of these adolescents. FINAL CONSIDERATIONS: The study made it possible to know the difficulties experienced during the course of the disease, providing subsidies for the practice of nurses to happen in a sensitive, individualized manner and focused on the individual's need thus enhancing comfort and quality of life.

<https://pubmed.ncbi.nlm.nih.gov/32520110/>

Hesse, M., Forstmeier, S., Ates, G. and Radbruch, L. (2019). "Patients' priorities in a reminiscence and legacy intervention in palliative care." *Palliat Care Soc Pract* 13: 2632352419892629.

**BACKGROUND:** Reminiscence is used in a range of different interventions in palliative care, for example, Dignity Therapy or Life Review. However, literature has focused mainly on the methodology, and little has been published on patients' priorities and primary concerns. **OBJECTIVE:** This study looks at themes emerging in a reminiscence intervention with patients confronted with a life-limiting disease. Interviews were audiotaped and transcribed verbatim. Transcripts were analysed using thematic analysis. **SETTING/SUBJECTS:** Seventeen patients who were receiving palliative care at the University Hospital Bonn participated in interviews reviewing parts or phases of their lives. **RESULTS:** Patients expressed satisfaction and a sense of well-being with the intervention. Major themes emerging in the interviews were the factors involved in the development and expression of personality, such as character-forming influences, self-image, self-awareness, and philosophy of life. Talking about personality was entangled with influences from growing up, qualification/job, partner/spouse, children, resources, twists of fate/crossroads, and coping. **CONCLUSION:** The topics emerging from the interviews differed from the scope of guiding questions in common reminiscence methods like Life Review or Dignity Therapy. The underlying motivation of patients seemed to be the search for identity and continuity in one's life.  
<https://pubmed.ncbi.nlm.nih.gov/32215373/>

Ho, A. H. Y., Dutta, O., Tan-Ho, G., Choo, P. Y., Low, X. C., Chong, P. H., Ng, C. and Ganapathy, S. (2019). "Thematic analysis of spousal interaction patterns among Asian parents of children with chronic life-threatening illness." *BMJ Open* 9(11): e032582.

**OBJECTIVE:** This is the first known study which examines the evolutionary nature of spousal interaction patterns among Asian parents of children with chronic life-threatening illness, from the time of providing care to their child through bereavement. This study is informed by earlier findings that when a child is diagnosed with a chronic life-threatening illness, parents are faced with multiple stressors, leaving them with little time to invest in their spousal relationship. **PARTICIPANTS AND SETTING:** A constructivist-phenomenological research paradigm was adopted and meaning-oriented interviews were conducted with 20 parental units (i.e., 6 couples, 12 lone mothers and 2 lone fathers) of Chinese, Malay and Indian ethnicities who lost their child to chronic life-threatening illness in Singapore. **RESULTS:** Qualitative thematic analysis of the data revealed four themes, which describe the evolutionary nature of spousal interaction patterns among Asian parents of children with chronic life-threatening illness, from caregiving through bereavement. Findings reveal participants' tendency to concentrate on pragmatic, solution-focused communication during the period of caregiving (pragmatic interaction), avoid discussion about their emotional pain as a means of protecting their spouse (partner-oriented self-regulation), respect and acknowledge their spouse's personal coping strategies (empathic responding) and show greater appreciation and emotional expression within the spousal relationship after their child's death (affective appreciation). **CONCLUSION:** Engaging in pragmatic discussions, deferring emotion-focused and potentially distressing conversations, and acknowledging their spouse's need for personal space are important coping strategies

for Asian couples facing their child's chronic life-threatening illness and in the immediate aftermath of his/her death. Bereaved couples who have processed their grief individually feel ready to share their reflections with their spouse, deriving meaning and greater relational closeness through such disclosure. These findings are discussed from a cultural lens, with recommendations for healthcare professionals working with Asian parents of children with chronic life-threatening illness.

<https://pubmed.ncbi.nlm.nih.gov/31748309/>

**Hovén, E., Hagström, J., Pöder, U., Grönqvist, H. and von Essen, L. (2020). "Parents' needs of support following the loss of a child to cancer: a Swedish, prospective, longitudinal, multi-centre study." *Acta Oncol* 59(3): 351-357.**

Introduction: Parents' needs of support following the loss of a child to cancer and whether these needs are met are not fully known. This study aimed to describe parents' needs, opportunity, and benefit of support from healthcare professionals and significant others from shortly after, up to five years after bereavement. Material and methods: Data were collected at nine months (T5, n = 20), eighteen months (T6, n = 37), and five years after the child's death (T7, n = 38). Parents answered questions via telephone about need, opportunity, and benefit of talking to psychologists, social workers, partners, and friends. Needs were examined in relation to parent and child characteristics, including sex, age, and parent posttraumatic stress symptoms (PTSS). Results: The proportion reporting a need of support from psychologists varied from 56% and 46% at T5 to 20% and 6% at T7 (mothers and fathers, respectively). All mothers and 90% of fathers reported a need of support from social workers at T5. At T7, the corresponding percentages were 30% and 6%. More mothers than fathers reported a need of support from friends at T7 ( $p = .001$ ). The proportion reporting a need of support from psychologists, social workers, and friends decreased over time (all  $p \leq .050$ ). Parents reporting a higher level of PTSS were more likely to report a need of support from social workers at T6 ( $p = .040$ ) and from psychologists ( $p = .011$ ) and social workers ( $p = .012$ ) at T7. Opportunities for support from healthcare professionals varied, most reported need of and opportunity for support from significant others. Almost all reported benefit from received support. Conclusion: Bereaved parents need and benefit of support from healthcare professionals and significant others. Results show a need for improved access to psychosocial services, even at five years post bereavement. Large-scale studies are needed to better understand the associations between parent and child characteristics and support needs.

<https://pubmed.ncbi.nlm.nih.gov/31702406/>

**Johnston, E. E., Molina, J., Martinez, I., Dionne-Odom, J. N., Currie, E. R., Crowl, T., Butterworth, L., Chamberlain, L. J., Bhatia, S. and Rosenberg, A. R. (2020). "Bereaved parents' views on end-of-life care for children with cancer: Quality marker implications." *Cancer* 126(14): 3352-3359.**

BACKGROUND: End-of-life (EOL) quality markers in adult oncology include home death and intensive care unit avoidance. Corresponding markers are lacking in pediatric oncology. This study was aimed at describing bereaved parents' perspectives of high-quality EOL care in pediatric oncology. METHODS: This study enrolled a convenience sample of 28 bereaved parents (English- or Spanish-speaking) whose children (0-21 years old) had died of cancer  $\geq 6$  months before. Semistructured interviews were

conducted to elicit parental perceptions of medically intense/quality EOL care. Interviews were recorded and transcribed verbatim (30 hours), and study team consensus and content analyses identified themes related to EOL quality markers. Related quotes were scored on a 5-point Likert scale ranging from 1 (supported comfort care) to 5 (supported medically aggressive care). RESULTS: The children died in 1998-2017 at a mean age of 10 years (SD, 5.2 years); 50% had a solid tumor, and 46% were Spanish-speaking. Themes included 1) home death preference (unless home support was inadequate; median score, 1.6), nonaggressive care (median score, 2.4), and continued anticancer therapy (median score, 3.2); 2) programs/policies that could alleviate barriers limiting a family's time with a dying child (visiting restrictions and financial strains); 3) the need to prepare the family for death (eg, what would happen to the child's body), and 4) perceived abandonment. CONCLUSIONS: This is the first qualitative study to identify quality makers for children dying of cancer from bereaved parents' perspectives. Natural death is generally preferred, and quality measures that address barriers to parents' spending time with their children, a lack of preparation for the events surrounding death, and feelings of abandonment are critical. Future studies need to validate these findings and develop targeted interventions.

<https://pubmed.ncbi.nlm.nih.gov/32383817/>

**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://pubmed.ncbi.nlm.nih.gov/31493675/>

**Kenny, M., Darcy-Bewick, S., Martin, A., Eustace-Cook, J., Hilliard, C., Clinton, F., Storey, L., Coyne, I., Murray, K., Duffy, K., Fortune, G., Smith, O., Higgins, A. and**

Hynes, G. (2020). "You are at rock bottom: A qualitative systematic review of the needs of bereaved parents as they journey through the death of their child to cancer." J Psychosoc Oncol, 10.1080/07347332.2020.1762822: 1-21.

**Problem Identification:** This systematic review will examine the social support needs of bereaved parents in the specific context of pediatric cancer by synthesizing the qualitative evidence. Social support encompasses emotional, practical, informational, and meaning-making support needs. **Literature Search:** The Joanna Briggs Institute procedures for conducting qualitative systematic reviews guided every stage of this review. Four databases (PsychInfo, CINAHL, Pubmed, and ASSIA) were systematically searched, in addition to the gray literature and scoping review. Through a five-step critical appraisal process 11 out of 668 potential articles were identified as meeting the inclusion criteria. **Data Evaluation/Synthesis:** Relevant findings were synthesized with a thematic-synthesis approach. Findings, which follow the journey of bereaved parents integrated under the core-category "Needs." This encompasses of four higher-level categories: Last days: Parent needs when caring for their dying child Rest in peace: Parent needs during the child's death Feeling abandoned: Parent needs for contact after the child's death Searching for Meaning: Parents needs when making sense of loss **Conclusion:** Informational support needs is largely unexplored in academic literature. Staff in the treating-hospital are central in offering bereavement-support to parents, who may otherwise feel that they have lost their second home (hospital) and second family (staff).

<https://pubmed.ncbi.nlm.nih.gov/32419648/>

Khraisat, O. M., Alkhaldeh, A. and Abuhammad, S. (2019). "Spirituality-focused end-of-life care among paediatric patients: evidence from Saudi Arabia?" Int J Palliat Nurs 25(12): 610-616.

**BACKGROUND:** Spirituality has been recognised as an essential aspect of patient care. **AIM:** To assess the greatest facilitators that would help to provide spirituality for paediatric end of life. **Methods:** Two hundred and fifty oncology nurses were surveyed using a spirituality and spiritual care rating questionnaire. **FINDINGS:** The greatest facilitators perceived by nurses were: believe in spirituality as a unifying force that enables one to be at peace with oneself and the world; listening and allowing patients time to discuss and explore their fears; and using art, creativity and self-expression; respect for privacy, dignity and religious and cultural beliefs of a patient. **CONCLUSIONS:** Many nursing-related facilitators to spirituality care were found. They need to be addressed and supported through education and training.

<https://pubmed.ncbi.nlm.nih.gov/31855517/>

Krick, J. A., Weiss, E. M., Snyder, A., Haldar, S., Campelia, G. D. and Opel, D. J. (2020). "Living with the Unknown: A Qualitative Study of Parental Experience of Prognostic Uncertainty in the Neonatal Intensive Care Unit." Am J Perinatol, 10.1055/s-0039-3402722.

**OBJECTIVE:** This study aims to characterize the experience of prognostic uncertainty for neonatal intensive care unit (NICU) parents. **STUDY DESIGN:** We conducted a qualitative interview study of current and former NICU parents regarding their experience with prognostic uncertainty in the NICU. Interviews were transcribed and

analyzed using a grounded theory methodology. RESULTS: Twenty-four parents were interviewed before achieving thematic saturation. Three phases of the parental experience of prognostic uncertainty emerged: shock, gray daze, and looking forward. These phases often, but not always, occurred sequentially. In shock, parents felt overwhelmed by uncertainty and were unable to visualize a future for their family. In gray daze, parents felt frustrated by the continued uncertainty. While accepting the possibility of a future for their family, they could not conceptualize a path by which to achieve it. In looking forward, parents accepted uncertainty as inevitable and incorporated it into their vision of the future. CONCLUSION: While each parent experienced the prognostic uncertainty in the neonatal intensive care unit in their own way, we found three common experiential phases. By understanding how a parent experiences prognostic uncertainty in these phases, providers may become better able to communicate and form therapeutic relationships with parents.

<https://pubmed.ncbi.nlm.nih.gov/31899927/>

**Lee, D. H., Khang, M., Shin, J., Lee, H. J. and Brown, J. A. (2020). "Life Experience of Bereaved Parents After the 2014 Sewol Ferry Disaster in South Korea." *Omega (Westport)* 80(4): 515-543.**

The aim of this study was to identify the outcomes of parental bereavement and the changes in life experience that follow the traumatic death of a teenage child. The results of the study are aimed to assist counselors and educators who work with themes of grief and loss. From 17 in-depth interviews from parents bereaved by the Sewol ferry disaster of 2014 in South Korea, three main categories were found to capture the reality for parents after the sudden and traumatic death of a teenage child: (a) personal changes, (b) changes in close relationships, and (c) changes in social life.

Recommendations for future research and potential implications were discussed.

<https://pubmed.ncbi.nlm.nih.gov/29182040/>

**Levy, K., Grant, P. C. and Kerr, C. W. (2020). "End-of-Life Dreams and Visions in Pediatric Patients: A Case Study." *J Palliat Med*, 10.1089/jpm.2019.0547.**

Background: End-of-life dreams and visions (ELDVs) are a recognized phenomenon that can occur as part of the normal dying process. Data suggest that ELDVs can provide comfort, foster discussion of waking life concerns, and lessen the fear of death. Current literature on ELDVs focuses on the prevalence, content, and effects of ELDVs exclusively in adult populations. Methods: We present the case of a 15-year-old girl with terminal glioblastoma who was enrolled in a pediatric palliative care program and later in hospice care. During her end-of-life trajectory, the patient experienced two distinct ELDV experiences, from which she recalled vivid details regarding the setting, characters, and content. These ELDV experiences afforded comfort and meaning to the patient and her family through her end-of-life trajectory as well as provided relief for her grieving family. Conclusion: In the case presented, ELDVs appear to show similar characteristics and impact in the adolescent population as described in the previous literature examining adult ELDVs. In addition, this case demonstrates the potential benefits of ELDV awareness for the bereaved. Clinicians working with pediatric and adolescent end-of-life populations should take note of the potential for ELDVs and the impact they can have on both patients and families.

<https://pubmed.ncbi.nlm.nih.gov/31977259/>

Levy, K., Grant, P. C., Tenzek, K. E., Depner, R. M., Pailer, M. E. and Beaupin, L. K. (2020). "The Experience of Pediatric Palliative Caregiving: A Qualitative Analysis From the Photographs of Meaning Program." *Am J Hosp Palliat Care* 37(5): 364-370.

The Photographs of Meaning Program for pediatric palliative caregivers (POM-PPCG) is an innovative, meaning-based intervention utilizing photovoice and social media components. In 2017, 9 pediatric palliative caregivers participated in this intervention. During the social media portion of the POM-PPCG, participants were presented with weekly themes based on a meaning-making curriculum. In response, they took photographs, applied either audio or typed narratives, and shared them via social media. Ninety-five photographs with narratives were produced during the intervention. Through thematic qualitative analysis with consensual qualitative research components, 5 themes were identified: Love, Challenges, Loss, Coping, and The New Normal. This study adds to existing literature by shedding light on the experiences of caregivers of children with palliative care needs. Findings from this research contribute not only to the innovative use of qualitative methods but also to the clinical knowledge and practice regarding the pediatric palliative caregiver experience.

<https://pubmed.ncbi.nlm.nih.gov/31578071/>

Liu, S. and Niu, W. (2020). "Anxiety and Depression Prevalence in Children, Adolescents, and Young Adults With Life-Limiting Conditions." *JAMA Pediatr* 174(2): 208.

<https://pubmed.ncbi.nlm.nih.gov/31841584/>

Lizcano Pabón, L. D. M., Moreno Fergusson, M. E. and Palacios, A. M. (2019). "Experience of Perinatal Death From the Father's Perspective." *Nurs Res* 68(5): E1-e9.

**BACKGROUND:** Although perinatal deaths are still a common pregnancy outcome in developing countries, little is known about the effect perinatal death has on fathers. **OBJECTIVE:** The aim of the study was to understand and describe the meaning of perinatal death in a sample of fathers from northeastern Colombia. **METHODS:** Using purposive and snowball sampling approaches, we identified 15 participants from northeastern Colombia who agreed to participate. We used a descriptive phenomenological design. Data were collected through in-depth, semistructured interviews. **RESULTS:** Men suffer in solitude and hide their emotions as they feel the need to be the main supporters of their partners. Three major themes emerged: experience of loss, coming to terms with an irreparable loss, and overcoming the loss. **DISCUSSION:** While women are receiving care, health staff may neglect or forget men. Men suffer alone while seeking ways of attunement with their partners' emotions to support them during the grieving process. Fathers can overcome and adjust to the loss when they transcend it and find new meaning. Men felt neglected and marginalized at

hospitals while their partners were receiving treatment. Health professionals should recognize and acknowledge the pain of fathers who face perinatal death and include them as much as possible in the standard of care. The results identify opportunities for healthcare providers in clinical and outpatient settings to acknowledge the importance of men within the context of pregnancy and to learn about their pain and suffering when they face a perinatal death.

<https://pubmed.ncbi.nlm.nih.gov/31465306/>

Lord, S., Moore, C., Beatty, M., Cohen, E., Rapoport, A., Hellmann, J., Netten, K., Amin, R. and Orkin, J. (2020). "Assessment of Bereaved Caregiver Experiences of Advance Care Planning for Children With Medical Complexity." *JAMA Netw Open* 3(7): e2010337.

**IMPORTANCE:** Advance care planning (ACP) is the process of discussing values and preferences for care to help inform medical decision-making. Children with medical complexity (CMC) often have a shortened life span with an unpredictable clinical course and timing of death; however, there is a paucity of literature that describes the experience of ACP from the perspective of bereaved family caregivers of CMC.

**OBJECTIVE:** To explore the experiences of bereaved family caregivers with ACP for CMC.

**DESIGN, SETTING, AND PARTICIPANTS:** This qualitative study included 12 interviews with 13 bereaved family caregivers of CMC whose deaths had occurred in the 5 years before study commencement (2013-2018). Participants were recruited at a single tertiary care pediatric center; CMC were treated by the Complex Care or Long-term Ventilation clinic in Toronto, Ontario, Canada. Data were collected from July to October 2018. Thematic analysis with an inductive approach was used.

**EXPOSURES:** Qualitative interviews were conducted using purposive sampling of bereaved family caregivers using semi-structured interviews that were recorded and transcribed.

Interviews were conducted until saturation was reached.

**MAIN OUTCOMES AND MEASURES:** Transcripts were analyzed to create themes that characterized caregiver experiences with ACP. **RESULTS:** A total of 13 family caregivers were interviewed in 12 interviews, all of whom were parents (12 [92%] women, 1 [8%] man) of a deceased child (aged 7 months to 12 years). Themes were divided in the 3 following categories, which align with the Donabedian model for health service quality: (1) structure of care,

(2) ACP process, and (3) end-of-life experience. Notable subthemes for this population included the importance of accounting for parental expertise in the child's care, recurrent experiences with life-threatening events, relative shock of the timing of death, and the multiple losses that caregivers experienced.

**CONCLUSIONS AND RELEVANCE:** In this study, parental experiences revealed that there are key aspects of the structure of the child's care, process around ACP, and end-of-life care experiences that provide important reflections on ACP that warrant future study.

<https://pubmed.ncbi.nlm.nih.gov/32721029/>

Lykke, C., Ekholm, O., Schmiegelow, K., Olsen, M. and Sjøgren, 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://pubmed.ncbi.nlm.nih.gov/31276811/>

**McNamara, L. C., Okoniewski, W., Maurer, S. H., Moehling, K., Hall, D. E. and Schenker, Y. (2020). "Give them the door but don't push them through it": Family Attitudes Toward Physician-Led Spiritual Care in Pediatric Palliative Medicine." *J Relig Health*, 10.1007/s10943-020-00991-z.**

Little is known about pediatric caregivers' perceptions of religious or spiritual (R/S) care provided by physicians. We conducted a qualitative, semistructured interview study to understand perceptions of pediatric caregivers toward physician-led R/S care. Participants were 20 primary caregivers whose children were hospitalized and receiving palliative care services. Interviews were audio recorded, transcribed verbatim, and analyzed using constant comparative methods. Three recurrent themes emerged regarding physician-led R/S care: (1) Most caregivers view providing R/S care as a positive sign of physician empathy, while a minority (3/20) prefer to keep R/S and medical care separate, (2) many caregivers prefer R/S care from a physician with whom they have a close relationship and/or share a faith background, and (3) physicians should open the door, but allow families to lead conversations about R/S care. Caregivers have mixed perceptions on physicians engaging in R/S care; most prefer that families set the direction of R/S care for themselves and their loved ones. Physicians should be trained to evaluate families' spiritual backgrounds and needs in ways that respectfully open the door to these conversations.

<https://pubmed.ncbi.nlm.nih.gov/32052280/>

**McNeil, M. J., Namisango, E., Hunt, J., Powell, R. A. and Baker, J. N. (2020). "Grief and Bereavement in Parents After the Death of a Child in Low- and Middle-Income Countries." *Children (Basel)* 7(5).**

While great strides have been made in improving childhood mortality, millions of children die each year with significant health-related suffering. More than 98% of these children live in low- and middle-income countries (LMICs). Efforts have been made to increase access to pediatric palliative care (PPC) services to address this suffering in LMICs through policy measures, educational initiatives, and access to essential medicines. However, a core component of high-quality PPC that has been relatively neglected in LMICs is grief and bereavement support for parents after the death of their child. This paper reviews the current literature on parental grief and bereavement in LMICs. This includes describing bereavement research in high-income countries (HICs), including its definition, adverse effect upon parents, and supportive interventions, followed by a review of the literature on health-related grief and bereavement in LMICs, specifically around: perinatal death, infant mortality, infectious disease, interventions used, and perceived need. More research is needed in grief and bereavement of parents in LMICs to provide them with the support they deserve within their specific cultural, social, and religious context. Additionally, these efforts in LMICs will help advance the field of parental grief and bereavement research as a whole.

<https://pubmed.ncbi.nlm.nih.gov/32369937/>

**Moore, B., Sprague, R., Harmon, C. M. and Davis, S. (2020). "Walk with Me: A Bridge Program for Assisting Families Expecting Babies with Fetal Anomalies and/or a Terminal Diagnosis." *Neonatal Netw* 39(1): 24-28.**

When an expectant mother hears the news that her infant has a fetal anomaly, she may feel unsure of the future. A RN recognized the needs of women (and their families) expecting infants with critical fetal diagnoses and reached out to help them through their journey-through the pregnancy, delivery, and beyond. The act of walking alongside the mothers through their experience has grown into a formal program at a specialized children's and women's hospital in the southeastern United States. This article describes the purpose of the program, how the program came into existence, and what services the program provides to this special population. The program continues to evolve, and the team members have worked with over 169 mothers to date. <https://pubmed.ncbi.nlm.nih.gov/31919290/>

**Moore, B. S., Carter, B. S., Beaven, B., House, K. and House, J. (2019). "Anticipation, Accompaniment, and a Good Death in Perinatal Care." *Yale J Biol Med* 92(4): 741-745.**

The ethics of perinatal care, and the experiences of families who receive such care, remains a nascent area of inquiry. It can be hard to see how existing "good death" constructs apply to the experiences of fetal patients and their families. In this paper, we explore two themes raised by a case at our fetal health center: anticipation and accompaniment. In this case, a mother presented to our fetal health center; her unborn son, our fetal patient, was diagnosed with life-threatening hypoplastic left heart syndrome and endocardial fibroelastosis. The parents were told that their son's life expectancy, upon birth, was short. For us, this case raised important questions around what sorts of things we might, together with the family, anticipate with respect to their son's birth and death, and what it meant to really accompany this family on their journey. Alongside conventional lessons in the philosophical literature and palliative care

practice, the process of anticipating together and of mutual accompaniment helped us to guide this family to what they ultimately determined to be a good death for their son.  
<https://pubmed.ncbi.nlm.nih.gov/31866789/>

**Morris, S., Fletcher, K. and Goldstein, R. (2019). "The Grief of Parents After the Death of a Young Child." J Clin Psychol Med Settings 26(3): 321-338.**

Research demonstrates that severe forms of grief and grief-related pathology exist in the general population. Less attention, however, has been paid to the grief of parents following the death of a young, dependent child. In this review, we summarize a search of Pubmed, PsycINFO and Web of Science from 1995 to 2017, using the terms 'parental complicated grief', 'parental traumatic grief', and 'parent Prolonged Grief Disorder', specifically addressing parental grief and identified risk factors for complicated or prolonged grief. Forty-two studies met criteria and indicate a significant burden of complicated or prolonged grief in parents of children dying from virtually any cause. It appears that the empiric literature is undermined by great variability, including the composition of samples, the causes of death studied, the psychometric measures used, and post-loss intervals. We conclude that the uniform severity of grief experiences following the death of a young child is potentially a distinct subtype of grief, deserving of attention in its own right in future research and diagnostic formulations.  
<https://pubmed.ncbi.nlm.nih.gov/30488260/>

**Na, K. S. (2020). "Anxiety and Depression Prevalence in Children, Adolescents, and Young Adults With Life-Limiting Conditions." JAMA Pediatr 174(2): 207-208.**  
<https://pubmed.ncbi.nlm.nih.gov/31841580/>

**Nilsson, S., Hård Af Segerstad, Y. and Olsson, M. (2020). "Worrying About Death: An Initial Analysis of Young Adult Cancer Patients' Needs." J Adolesc Young Adult Oncol, 10.1089/jayao.2020.0033.**

Young adults (YAs) with cancer may have a need to develop strategies to cope with their worries about death. This brief report presents findings from a pilot study on YAs' needs with regard to such issues. An anonymous, web-based questionnaire was posted with a total of 83 cancer patients taking the questionnaire (71 females and 12 males). Almost half of the participants thought about death every day. Since most of the participants had ended their treatment, this would appear to show that matters related to death remain an important issue after the YAs' cancer treatment has ended. The results show a need for YAs to talk about death, either with professionals or with peers.  
<https://pubmed.ncbi.nlm.nih.gov/32552246/>

**Obst, K. L., Due, C., Oxlad, M. and Middleton, P. (2020). "Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model." BMC Pregnancy Childbirth 20(1): 11.**

BACKGROUND: Emotional distress following pregnancy loss and neonatal loss is common, with enduring grief occurring for many parents. However, little is known about men's grief, since the majority of existing literature and subsequent bereavement care guidelines have focused on women. To develop a comprehensive understanding

of men's grief, this systematic review sought to summarise and appraise the literature focusing on men's grief following pregnancy loss and neonatal loss. **METHODS:** A systematic review was undertaken with searches completed across four databases (PubMed, PsycINFO, Embase, and CINAHL). These were guided by two research questions: 1) what are men's experiences of grief following pregnancy/neonatal loss; and 2) what are the predictors of men's grief following pregnancy/neonatal loss? Eligible articles were qualitative, quantitative or mixed methods empirical studies including primary data on men's grief, published between 1998 and October 2018. Eligibility for loss type included miscarriage or stillbirth (by any definition), termination of pregnancy for nonviable foetal anomaly, and neonatal death up to 28 days after a live birth. **RESULTS:** A final sample of 46 articles were identified, including 26 qualitative, 19 quantitative, and one mixed methods paper. Findings indicate that men's grief experiences are highly varied, and current grief measures may not capture all of the complexities of grief for men. Qualitative studies identified that in comparison to women, men may face different challenges including expectations to support female partners, and a lack of social recognition for their grief and subsequent needs. Men may face double-disenfranchised grief in relation to the pregnancy/neonatal loss experience. **CONCLUSION:** There is a need to increase the accessibility of support services for men following pregnancy/neonatal loss, and to provide recognition and validation of their experiences of grief. Cohort studies are required among varied groups of bereaved men to confirm grief-predictor relationships, and to refine an emerging socio-ecological model of men's grief. **TRIALS REGISTRATION:** PROSPERO registration number: CRD42018103981. <https://pubmed.ncbi.nlm.nih.gov/31918681/>

**Petersen, C. L. (2020). "Spiritual Care: Minimizing the Vulnerability of Parents Whose Children With Cancer Face the End of Life." *J Pediatr Oncol Nurs* 37(2): 105-115.**

There is a distinct lack of literature related to the spiritual care of parents whose children with cancer are at the end of life. This has led to a dearth in evidence about how nurses may intervene with spiritual care interventions to best support these vulnerable parents. The purpose of this scoping review was to examine the evidence regarding the value of spirituality/spiritual care in minimizing the vulnerability of parents whose children were diagnosed with cancer and who faced the end of life. The Arksey and O'Malley methodological framework guided the analysis of the reviewed quantitative and qualitative literature. Spirituality and spiritual care provided bereaved parents and parents of children with cancer with necessary support and enhanced coping to allow them to better deal with this devastating experience. Spirituality and spiritual care instilled hope, assisted in the search for meaning and purpose, and guided parents to develop continuing bonds with their child. Through skillful communication, pediatric oncology nurses may guide parents of children who face the end of life to strengthen relationships that offer support, plan activities that provide opportunities for hope and connection, and identify sources of meaning in their experiences.

<https://pubmed.ncbi.nlm.nih.gov/31718403/>

Plaza Fornieles, M., García-Marcos Barbero, P., Galera Miñarro, A. M., Barbieri, G., Bellavia, N., Bermúdez Cortés, M. D. M. and Navarro Mingorance, Á. (2020). "[Efficacy of the Paediatrics Palliative Care Team of Murcia according to the experience of the parents]." *An Pediatr (Barc)* 93(1): 4-15.

**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://pubmed.ncbi.nlm.nih.gov/31427213/>

Polita, N. B., de Montigny, F., Neris, R. R., Alvarenga, W. A., Silva-Rodrigues, F. M., Leite, A. and Nascimento, L. C. (2020). "The Experiences of Bereaved Parents After the Loss of a Child to Cancer: A Qualitative Metasynthesis." *J Pediatr Oncol Nurs*, 10.1177/1043454220944059: 1043454220944059.

This study aims to synthesize qualitative evidence about the bereavement experience of parents following the death of a child due to cancer. A qualitative metasynthesis was conducted from searching five databases. The search identified 650 articles that were independently assessed by two reviewers. Thirty-one articles were selected for full-text reading and assessed for eligibility; a total of 14 articles were included in the final sample and submitted to quality appraisal. The software NVivo® was used to organize the data and support the thematic analysis procedures. Two analytical themes were constructed: (1) losing a child and facing a rupture in identity and sense of life and (2) surviving grief and reengaging in life. The grief process was dynamic, continuous, and begun before the death of the child. Fathers and mothers reacted differently to the loss and experience of grief. The loss of a child definitively changed the parents' life and caused identity crisis and loss of life's purpose. During the process of survival, parents constructed new meanings that helped them cope with grief; they used strategies that allowed them to recover their sense of purpose in life. Synthesizing the experience of bereaved parents is essential to improve the support families of children with advanced cancer receive to better cope with their suffering and loss, before and after the child's death.

<https://pubmed.ncbi.nlm.nih.gov/32715930/>

Pollock, D., Pearson, E., Cooper, M., Ziaian, T., Foord, C. and Warland, J. (2020). "Voices of the unheard: A qualitative survey exploring bereaved parents experiences of stillbirth stigma." Women Birth 33(2): 165-174.

**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://pubmed.ncbi.nlm.nih.gov/31005574/>

Proserpio, T., Pagani Bagliacca, E., Sironi, G., Clerici, C. A., Veneroni, L., Massimino, M. and Ferrari, A. (2020). "Spirituality and Sustaining Hope in Adolescents with Cancer: The Patients' View." J Adolesc Young Adult Oncol 9(1): 36-40.

**Purpose:** The trauma of the diagnosis of cancer during adolescence may affect the young people's spiritual sphere. Projects aiming to the global care of adolescents with cancer should consider also their spiritual needs: at our center, the dedicated multidisciplinary team of professionals includes a chaplain with a specific training. This article describes, throughout the patients' dialogs, how a chaplain can help patients to give voice to their emotions and thoughts about their sense of life and illness. **Methods:** From January 2016 to December 2017, 33 adolescent patients with solid tumors had from 2 to 12 one-to-one talks with the chaplain. We selected six specific clinical cases in which some important topics were discussed between the chaplain and the patients. **Results:** Patients' own voices were reported to describe some specific spiritual issues, particularly as regards how spirituality could sustain them in their need to continue to hope. Examples of specific questions during talks were as follows: "Why doesn't God do something?"; "What is the point of all this pain?"; "Why have I become ill? Why me?"; "What do you think will happen to me after I die?" **Conclusions:** This experience underlines the importance of the inclusion of the spiritual assistant within the multidisciplinary team dedicated to young people with cancer. The daily and constantly

available presence of the chaplain in the ward, from the beginning of any treatment, can permit a good relationship with patients and help them to keep hope and move forward.

<https://pubmed.ncbi.nlm.nih.gov/31539288/>

**Raharjo, C. V., Hetherington, K., Donovan, L., Fardell, J. E., Russell, V., Cohn, R. J., Morgan, N. L., Siddiqui, J. and Wakefield, C. E. (2020). "An Evaluation of By My Side: Peer Support in Written Form is Acceptable and Useful for Parents Bereaved by Childhood Cancer." *J Pain Symptom Manage* 59(6): 1278-1286.**

CONTEXT: Cancer is the leading cause of nonaccidental death in childhood, with the death of a child representing a devastating loss for families. Peer support offers a valuable way to support parents' adjustment in bereavement. The By My Side book provides written peer support by sharing bereaved parents' stories to normalize grief experiences and reduce parents' isolation. It is available free of charge. OBJECTIVES: This project evaluated the acceptability, relevance, emotional impact, and usefulness of By My Side. DESIGN: Bereaved parents and health care professionals (HCPs) provided feedback via a questionnaire. We used descriptive statistics and qualitative analysis of open-ended responses to analyze the data. SETTING/PARTICIPANTS: We mailed a study invitation and evaluation questionnaire to parents and HCPs who ordered a copy of By My Side. RESULTS: About 24 bereaved parents and seven HCPs provided feedback. Parents thought the book's length (91.7%) and amount of information (83.3%) was just right. About 75% of parents reported that the book made them feel that their reactions to their child's death were normal and/or appropriate. Parents reported positive and negative emotional reactions to the book (e.g., 87.5% felt comforted, 87.5% felt sadness). All parents and HCPs reported that the book provided useful information about grief. About 83.4% of parents and 85.7% of HCPs would recommend it to others. CONCLUSION: By My Side was acceptable and useful to bereaved parents and HCPs. Results suggest that peer support in written form may help normalize aspects of grief and comfort parents bereaved by childhood cancer.

<https://pubmed.ncbi.nlm.nih.gov/32006611/>

**Robinson, J. E., Huskey, D., Schwartz, J. and Weaver, M. S. (2019). "The Many Roles of the Rock: A Qualitative Inquiry into the Roles and Responsibilities of Fathers of Children with Brain Tumors." *Children (Basel)* 6(10).**

A pediatric brain tumor diagnosis impacts an entire family unit, from diagnosis through curative treatment, and into survivorship or bereavement. Paternal caregiver experience has been significantly underexplored in pediatric neuro-oncology research as compared to maternal experience. This case series study explores the paternal roles, responsibilities, strengths, challenges, personal growth, and support needs of fathers of children with brain tumors receiving new palliative care consultations. In the study setting, a neuro-oncology diagnosis results in an automatic referral to the palliative care team, and thus, a convenience sampling model was employed based on consecutive palliative care consults for new childhood brain tumor diagnoses. In this study, four fathers of pediatric brain tumor patients receiving palliative care consultations responded to eight open-ended questions. Individual, voice-recorded interviews were transcribed for semantic content qualitative analysis. Analysis followed Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines. Participants completed

quantitative surveys of their information preferences and support needs. Participants defined their father role as: being a team parent, an adaptable father, supporter, provider, a present father, and protector. Role conflict due to paternal responsibilities were recognized, such as the absence from the hospital to provide financial security for the family, and yet a desire to be physically present for the child. Fathers prioritized their knowledge needs about their child's diagnosis, prognosis, and treatment above emotional needs. Fathers shared experiences of their personal growth through their child's brain tumor diagnosis and advised on preferred support formats to include both verbal and written information. Understanding how paternal caregivers of children with cancer define their roles and goals has potential to improve the care and communication delivered to families of pediatric neuro-oncology patients.

<https://pubmed.ncbi.nlm.nih.gov/31614522/>

Rusch, R., Greenman, J., Scanlon, C., Horne, K. and Jonas, D. F. (2020). "Bibliotherapy and Bereavement: Harnessing the Power of Reading to Enhance Family Coping in Pediatric Palliative Care." J Soc Work End Life Palliat Care 16(2): 85-98.

Bibliotherapy is a therapeutic intervention that could potentially be utilized by pediatric palliative care social workers to aid in providing individualized support and adaptive coping techniques through end-of-life and bereavement. Multiple modalities of implementing bibliotherapy are considered, including applications in individual and group counseling. An institutionally supported bibliotherapy program that aims to provide therapeutic and recreational texts for patients, families and clinicians is described. Suggested guidelines and book titles for use in practice with bereaved siblings and families are provided alongside targeted description for use in clinical practice.

<https://pubmed.ncbi.nlm.nih.gov/32233977/>

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://pubmed.ncbi.nlm.nih.gov/30892150/>

Sedig, L. K., Spruit, J. L., Paul, T. K., Cousino, M. K., Pituch, K. and Hutchinson, R. (2020). "Experiences at the End of Life From the Perspective of Bereaved Parents: Results of a Qualitative Focus Group Study." *Am J Hosp Palliat Care* 37(6): 424-432.

BACKGROUND: Palliative care principles are known to support the experiences of children and their families throughout the illness trajectory. However, there is little knowledge of the parental perceptions of care delivered and gaps experienced by families receiving end-of-life care. We report the most helpful aspects of care provided during the end of life and identify opportunities to improve care delivery during this critical time. METHODS: This study consists of 2 one-hour focus group sessions with 6 participants each facilitated by a clinical psychologist to explore the experiences of bereaved parents of pediatric oncology patients at the end of their child's life. The data were transcribed and coded using constant comparative analysis and evaluated for inter-rater reliability using intraclass correlation coefficient. RESULTS: Four common themes were identified through qualitative analysis: (1) valued communication qualities, (2) valued provider qualities, (3) unmet needs, and (4) parental experiences. The most prevalent of these themes was unmet needs (mentioned 51 times). Subthemes were identified and evaluated. Parents described struggling with communication from providers, loss of control in the hospital environment, and challenges associated with transition of care to hospice services. CONCLUSION: Interventions that support the complex needs of a family during end-of-life care are needed, especially with regard to coordination of care.

<https://pubmed.ncbi.nlm.nih.gov/31884806/>

Sedig, L. K., Spruit, J. L., Paul, T. K., Cousino, M. K., McCaffery, H., Pituch, K. and Hutchinson, R. (2020). "Supporting Pediatric Patients and Their Families at the End of Life: Perspectives From Bereaved Parents." *Am J Hosp Palliat Care* 37(12): 1009-1015.

BACKGROUND: Cancer remains the leading cause of death by disease for children in the United States. It is imperative to optimize measures to support patients and families facing the end of a child's life. This study asked bereaved parents to reflect on their child's end-of-life care to identify which components of decision-making, supportive services, and communication were helpful, not helpful, or lacking. METHODS: An anonymous survey about end-of-life experiences was sent to families of children treated at a single institution who died of a malignancy between 2010 and 2017. RESULTS: Twenty-eight surveys were returned for a 30.8% response rate. Most of the bereaved parents (61%) reported a desire for shared decision-making; this was described by 52% of families at the end of their child's life. There was a statistically significant association between how well death went and whether the parental perception of actual decision-making aligned with desired decision-making ( $P = .002$ ).

Families did not utilize many of the supportive services that are available including psychology and psychiatry (only 22% used). Respondents felt that additional services would have been helpful. **CONCLUSIONS:** Health care providers should strive to participate in decision-making models that align with the preferences of the patient and family and provide excellent communication. Additional resources to support families following the death of a child should be identified for families or developed and funded if a gap in available services is identified.

<https://pubmed.ncbi.nlm.nih.gov/32372700/>

**Sim, C. W., Heuse, S., Weigel, D. and Kendel, F. (2020). "If only I could turn back time-Regret in bereaved parents." *Pediatr Blood Cancer* 67(6): e28265.**

**INTRODUCTION:** Regret about loss is one of the most intense types of regret experienced in life. Little is known about the bereavement regret of parents whose child has died of cancer. Although knowledge about parents' experiences after their child's death is vital for supporting these families, parents' regret is mostly hidden from the treating clinical staff. This study aimed to explore these parents' regret themes and their impact on their future lives. **METHODS:** An explorative questionnaire was sent to bereaved parents who lost a child to cancer. A total of 26 parents responded to the questionnaire. Data were analyzed using the constant comparative method. **RESULTS:** Regret experiences were shared by almost all participants. The focus of regret issues include parenting and interaction with the child, reflection on existing values, dealing with the disease, and neglecting the remaining siblings. The regret experience had an impact on prioritizing values, future lifestyle and contacts. **CONCLUSIONS:** Regret seems to be a general phenomenon among bereaved parents and strongly influences the grieving process, in the sense of reflecting on past experiences to reorient for future actions. As this study was explorative, it is significant toward deepening the understanding of bereavement regret in future. These insights are crucial when working with affected families to help them decide important issues they can care about now and will not regret later.

<https://pubmed.ncbi.nlm.nih.gov/32196890/>

**Smith, L. K., Dickens, J., Bender Atik, R., Bevan, C., Fisher, J. and Hinton, L. (2020). "Parents' experiences of care following the loss of a baby at the margins between miscarriage, stillbirth and neonatal death: a UK qualitative study." *Bjog* 127(7): 868-874.**

**OBJECTIVE:** To explore the healthcare experiences of parents whose baby died either before, during or shortly after birth between 20(+0) and 23(+6) weeks of gestation in order to identify practical ways to improve healthcare provision. **DESIGN:** Qualitative interview study. **SETTING:** England through two parent support organisations and four NHS Trusts. **SAMPLE:** A purposive sample of parents. **METHODS:** Thematic analysis of semi-structured in-depth narrative interviews. **MAIN OUTCOME MEASURES:** Parents' healthcare experiences. **RESULTS:** The key overarching theme to emerge from interviews with 38 parents was the importance of the terminology used to refer to the death of their baby. Parents who were told they were 'losing a baby' rather than 'having a miscarriage' were more prepared for the realities of labour, the birth experience and for making decisions around seeing and holding their baby. Appropriate

terminology validated their loss, and impacted on parents' health and wellbeing immediately following bereavement and in the longer term. **CONCLUSION:** For parents experiencing the death of their baby at the margins between miscarriage, stillbirth and neonatal death, ensuring the use of appropriate terminology that reflects parents' preferences is vital. This helps to validate their loss and prepare them for the experiences of labour and birth. Reflecting parents' language preferences combined with compassionate bereavement care is likely to have a positive impact on parents' experiences and improve longer-term outcomes.

<https://pubmed.ncbi.nlm.nih.gov/31976622/>

**Snaman, J., Morris, S. E., Rosenberg, A. R., Holder, R., Baker, J. and Wolfe, J. (2020). "Reconsidering early parental grief following the death of a child from cancer: a new framework for future research and bereavement support." Support Care Cancer 28(9): 4131-4139.**

**PURPOSE:** Parents of children that die from cancer are at increased risk of significant long-term psychosocial and physical morbidities. Less, however, is known about the experience of parents early in the grief process. Currently used frameworks and instruments used to understand and assess outcomes in parents early in the grief experience are inadequate and may serve to pathologize the normal grief response. **METHODS:** Through review of the literature, previously conducted qualitative work, and extensive clinical experience working with bereaved parents, we developed a new framework for understanding, assessing, and studying parental grief during the first 2 years following the death of a child from cancer. **RESULTS:** Our novel longitudinal framework hypothesizes that short- and long-term psychosocial sequelae in parents following the death of a child from cancer depend not only on pre-death factors but on the support present through the disease experience and the oscillation between protective factors and risk factors in the post-death period. We further hypothesize that protective factors and risk factors may be modifiable, making them key potential targets for supportive interventions aimed at augmenting protective factors and diminishing the effect of risk factors. **CONCLUSION:** This is a new framework for understanding and assessing the grief experience of parents within the first 2 years of a child's death. Many questions about how best to support parents following the death of a child from cancer remain providing ample opportunities for future research and development of interventions to improve both short- and long-term outcomes in bereaved parents.

<https://pubmed.ncbi.nlm.nih.gov/31872296/>

**Song, J., Mallick, 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://pubmed.ncbi.nlm.nih.gov/31487567/>

**Sullivan, J. E., Gillam, L. H. and Monagle, P. T. (2020). "After an end-of-life decision: Parents' reflections on living with an end-of-life decision for their child." *J Paediatr Child Health* 56(7): 1060-1065.**

AIM: Parents' role as end-of-life decision-makers for their child has become largely accepted Western health-care practice. How parents subsequently view and live with the end-of-life decision (ELD) they made has not been extensively examined. To help extend understanding of this phenomenon and contribute to care, as a part of a study on end-of-life decision-making, bereaved parents were asked about the aftermath of their decision-making. METHODS: A qualitative methodology was used. Semi-structured interviews were conducted with parents who had discussed ELDs for their child who had a life-limiting condition and had died. Data were thematically analysed. RESULTS: Twenty-five bereaved parents participated. Results indicate that parents hold multi-faceted views about their decision-making experiences. An ELD was viewed as weighty in nature, with decisions judged against the circumstances that the child and parents found themselves in. Despite the weightiness, parents reflected positively on their decisions, regarding themselves as making the right decision. Consequently, parents' comments demonstrated being able to live with their decision. When expressed, regret related to needing an ELD, rather than the actual decision. The few parents who did not perceive themselves as their child's decision-maker subsequently articulated negative reactions. Enduring concerns held by some parents mostly related to non-decisional matters, such as the child's suffering or not knowing the cause of death. CONCLUSION: Results suggest that parents can live well with the ELDs they made for their child. End-of-life decision-making knowledge is confirmed and extended, and clinical support for parents informed.

<https://pubmed.ncbi.nlm.nih.gov/32073205/>

**Szabat, M. (2020). "Parental experience of hope in pediatric palliative care: Critical reflections on an exemplar of parents of a child with trisomy 18." *Nurs Inq* 27(2): e12341.**

The purpose of this study is to analyze the experience of hope that appears in a parent's blog presenting everyday life while caring for a child with Trisomy 18 (Edwards syndrome). The author, Rebekah Peterson, began her blog on 17 March 2011 and

continues to post information on her son Aaron's care. The analysis of hope in the blog is carried out using a mixed methodology: initial and focused coding using Charmaz's constructed grounded theory and elements of Colaizzi's method. Each aspect of hope is coded through the blog author's statements, from which three main aspects of hope emerge: hope for the longest possible presence of Aaron with his family, hope for control over situations, pain, and symptoms, and existential facets of hope. These various aspects reveal to what extent the experience of hope is unique. Additionally, analyzing the experience of parental hope uncovers the additional problem of inappropriate communication by health care professionals (HCPs) in intensive care units, particularly when discussing the termination of causal treatment. The problem may be solved through proper education for HCPs and serious consideration of parental involvement in order to properly elaborate guidelines on this issue. The three main aspects of parental hope discussed in this paper might expand knowledge on the issue, helping HCPs to better understand the parents' experience of care and to help sustain parental hope in pediatric palliative care.

<https://pubmed.ncbi.nlm.nih.gov/31899851/>

**Thienprayoon, R., Grosseohme, D., Humphrey, L., Pestian, T., Frimpong-Manso, M., Malcolm, H., Kitamura, E., Jenkins, R. and Friebert, S. (2020). "There's Just No Way to Help, and They Did." Parents Name Compassionate Care as a New Domain of Quality in Pediatric Home-Based Hospice and Palliative Care." *J Palliat Med* 23(6): 767-776.**

Background: To design high-quality home-based hospice and palliative care (HBHPC) systems, it is imperative to understand the perspectives of parents whose children enroll in HBHPC programs. Objective: The goal of this project was to identify and define parent/caregiver-prioritized domains of family-centered care in HBHPC by performing semistructured interviews of parents/caregivers ("parents") across Ohio whose children have received HBHPC. We hypothesized that the 10 provider-prioritized domains and their definitions, as identified in our previous research, would be modified and augmented by parents for application in the pediatric HBHPC setting. Methods: This was a qualitative study utilizing semistructured interviews of bereaved parents of children who were enrolled in a pediatric HBHPC program at the three sites from 2012 to 2016 and parents of children who were currently enrolled in these programs for at least a year. Results: Parent-prioritized thematic codes mapped to 9 of the 10 provider-prioritized domains of quality HBHPC; none mapped to the domain "Ethical and Legal Aspects of Care." Although most of the provider-prioritized domains are pertinent to parents, parents defined these domains differently, deepening our understanding and perspective of quality within each domain. An 11th domain, Compassionate Care, was created and defined based on emergent themes. Conclusions: Parent/caregiver-prioritized domains of quality in pediatric HBHPC map closely to provider-prioritized domains, but parents define these domains differently. Parents also prioritize Compassionate Care as a new domain of quality in pediatric HBHPC. Measuring the quality of care provided in HBHPC programs through this broader perspective should enable the selection of measures which are truly patient- and family-centered.

<https://pubmed.ncbi.nlm.nih.gov/31880492/>

Thornton, R., Nicholson, P. and Harms, L. (2020). "Creating Evidence: Findings from a Grounded Theory of Memory-Making in Neonatal Bereavement Care in Australia." *J Pediatr Nurs* 53: 29-35.

**PURPOSE:** Perinatal and neonatal palliative care guidelines recommend the provision of photographs and other mementos as an element of care for parents bereaved by neonatal loss. However, little is known about parents' perceptions of such bereavement interventions. This study explored the significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of loss following neonatal loss. **DESIGN AND METHODS:** We conducted semi-structured interviews with 18 bereaved parents. A grounded theory approach informed by Corbin and Strauss was used to underpin data sampling, data collection and data analysis. A constant comparative approach was used to engage in open, axial and selective coding to distil parents' stories into categories supporting a core concept. **RESULTS:** "Creating evidence" emerged as a key theme in the grounded theory of memory-making in bereavement care for parents following neonatal loss. Creating evidence involved taking photographs, creating mementos, as well as involving friends and family during the baby's time in the Neonatal Unit. **CONCLUSIONS:** Creating evidence affirmed the life of the baby and the role of the parents. Creating evidence was a significant element of memory-making that had a positive impact on parents' experience of bereavement. **PRACTICE IMPLICATIONS:** Parents should be supported to create evidence of their baby's life, through taking photos, creating mementos, and involving others in their baby's care. Such interventions provide affirmation of the baby's life and of the individual's role as a parent.

<https://pubmed.ncbi.nlm.nih.gov/32344367/>

Widding, U., Hägglöf, B., Adamsson, M. and Farooqi, A. (2020). "Parents of extremely and moderately preterm children reported long-lasting impressions of medical care and the hospital environment." *Acta Paediatr* 109(9): 1772-1777.

**AIM:** Few studies have examined the parents of moderately preterm children. The aim of this study was to investigate the experiences of parents of both extremely and moderately preterm children. **METHODS:** Qualitative telephone interviews were conducted in 2013-2014 with 13 mothers and 10 fathers of extremely preterm children and with 11 mothers and seven fathers of moderately preterm children. The children were born between 2000 and 2003. Data were analysed with a narrative approach. **RESULTS:** Parents of extremely preterm children recounted dramatic birth stories that, for most, ended positively. Parents of moderately preterm children presented more neutral birth stories, and most recounted that their children did not receive attention for prematurity from medical staff. Parents from both groups described staff members' treatment in terms of long-lasting impressions, and they were deeply affected by the hospital environment and the other parents and children admitted. Parents whose children died or were disabled recounted dramatic stories and endless fights for support. **CONCLUSION:** Parents from both groups reported long-lasting impressions of the medical staff and the hospital environment, which they found important to talk about, even a decade after the birth of their child/children.

<https://pubmed.ncbi.nlm.nih.gov/31876043/>

Wiener, L., Tager, J., Mack, J., Battles, H., Bedoya, S. Z. and Gerhardt, C. A. (2020). "Helping parents prepare for their child's end of life: A retrospective survey of cancer-bereaved parents." *Pediatr Blood Cancer* 67(2): e27993.

**BACKGROUND:** Most parents vividly recall the weeks, days, and moments preceding their child's death for years to come. Dissatisfaction with communication about their child's condition and lack of guidance can contribute to stress prior to a child's death. Based on findings from a study assessing the degree of preparation bereaved parents received and our collective clinical experience, the authors provide suggestions on end-of-life communication and guidance for parents. **METHODS:** Caregivers of a child who died from cancer were invited to complete a 46-item survey through a closed social media (Facebook) group ("Parents who lost children to cancer"). In four months' time, 131 bereaved caregivers completed the survey. Results were analyzed using descriptive statistics, chi-square analyses, and a thematic content analysis framework. The mean age of the child at the time of death was 12. **RESULTS:** Approximately 40% of the parents in this study felt unprepared for both the medical problems their child faced and how to respond to their child's emotional needs; fewer than 10% felt very prepared for either. Parents were more likely to feel unprepared when perceived suffering was high, highlighting the critical importance of communication and support from the healthcare team as an adjunct to optimal symptom control. **CONCLUSIONS:** Through quantitative and open-ended responses, this study identified specific medical and emotional issues about which parents wanted greater preparation. Future research to evaluate guidance strategies to reduce parental suffering prior to the child's death is needed.

<https://pubmed.ncbi.nlm.nih.gov/31595653/>

Youngblut, J. M. and Brooten, D. (2020). "What Children Wished They Had/Had Not Done and Their Coping in the First 13 Months after Their Sibling's Neonatal/Pediatric Intensive Care Unit/Emergency Department Death." *J Palliat Med*, 10.1089/jpm.2019.0538.

**Background:** Research on what children wished they had done differently after their sibling's death has not been reported. **Objective:** Examine what children wished they had/had not done, and their coping after a sibling's neonatal/pediatric intensive care unit/emergency department (NICU/PICU/ED) death. **Design:** Qualitative data are part of a longitudinal mixed methods study of 6- to 18-year-olds interviewed at 2, 4, 6, and 13 months after a sibling's death. **Setting/Subjects:** Ninety-five school-aged children and 37 adolescents (58% female; 30% Hispanic, 50% black, 20% white). **Measurements:** Children responded to three open-ended questions: Thinking about your sibling's death, are there things you wish you (1) had done? (2) had not done? (3) What do you do to deal with your sibling's death? Conventional content analysis procedures were used. **Results:** Children wished they had spent more time, talked and played more with their sibling, saved their sibling, taken care of their sibling more, and been able to see their sibling grow up. They wished they had not been mean/yelled at their sibling, complained/argued with mother about their sibling, and kept their feelings inside. Children coped by talking with family, friends, and the deceased; playing, reading, watching TV; avoiding thoughts about and remembering their sibling; crying, keeping calm, praying; living for their sibling. Resuming their usual activities, trying to be happy, and laughing also helped children cope. **Conclusions:** Children commented more about

what they wish they had done (n = 317) and less about what they wish they had not done (n = 107). Children talked to others and tried resuming usual activities to cope. <https://pubmed.ncbi.nlm.nih.gov/32640860/>

Zhao, X., Hu, H., Zhou, Y. and Bai, Y. (2020). "What are the long-term effects of child loss on parental health? Social integration as mediator." *Compr Psychiatry* 100: 152182.

**BACKGROUND:** Some bereaved parents experience a decreasing trajectory of grief, while others fail to adapt over the long term and persistently suffer from negative health consequences. This study investigates the mediating role of social integration in the relationship between losing an only child and parental health in a family-oriented society. **METHOD:** A sample of 1828 bereaved parents and 4739 non-bereaved parents was drawn from a 10-city survey in China. Regression methods were used to examine the impact of child loss on parental health, and Sobel test was applied to examine the mediating role of social integration. **RESULTS:** Bereaved parents who lost their only child have worse self-rated health and more negative affect than the non-bereaved parents, which lasted for years after the death of the only child. The Sobel test shows that 24.8% of the total effects on self-rated health and 6.7% of the total effects on negative affect can be explained via decreased social integration. The gender of parents and child as well as fertility intentions are important sources of heterogeneity in the Chinese culture. **LIMITATION:** The results based on cross-sectional data may only reveal correlation rather than causality. The data was retrieved from self-reported questionnaires and there is a lack of objective measures of parental health. Moreover, the detailed mechanisms behind how child loss resulted in less social integration should be further explored. **CONCLUSIONS:** Significant disparities in health outcomes and social integration were found for bereaved parents relative to the non-bereaved parents. Future work is needed to assess the health of bereaved parents, identify the vulnerable and disadvantaged groups, and design inclusive intervention programs. <https://pubmed.ncbi.nlm.nih.gov/32430143/>

## Services for Children & Young People

(2019). "Perinatal Palliative Care: ACOG COMMITTEE OPINION, Number 786." *Obstet Gynecol* 134(3): e84-e89.

Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy. With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment. The focus of this document, however, involves the provision of exclusively palliative care without intent to prolong life in the context of a life-limiting condition, otherwise known as perinatal palliative comfort care. Once a life-limiting diagnosis is suspected antenatally, the tenets of informed consent require that the pregnant patient be given information of sufficient depth and breadth to make an informed, voluntary choice for her care. Health care providers are encouraged to model effective, compassionate

communication that respects patient cultural beliefs and values and to promote shared decision making with patients. Perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions. If a patient opts to pursue perinatal palliative comfort care, a multidisciplinary team should be identified with the infrastructure and support to administer this care. The perinatal palliative care team should prepare families for the possibility that there may be differences of opinion between family members before and after the delivery of the infant, and that there may be differences between parents and the neonatal care providers about appropriate postnatal therapies, especially if the postnatal diagnosis and prognosis differ substantially from antenatal predictions. Procedures for resolving such differences should be discussed with families ahead of time.

<https://pubmed.ncbi.nlm.nih.gov/31441826/>

**Amuka, J. I., Asogwa, F. O., Ugwuanyi, R. O. and Onyechi, T. (2020). "Neonatal deaths and challenges of public health: Where do We need urgent intervention in developing countries?" *Health Care Women Int* 41(2): 227-237.**

Neonatal death is child health problem which the global community seeks to reduce to the barest minimum by 2030. In 2017, sub-Saharan Africa's average neonatal death was 27 in every 1000 successful births, while Nigeria's neonatal death rate was 32.9. The researcher's objective is to propose public health policies needed to reduce neonatal death drastically in Nigeria by 2030. The researchers sourced data from World Bank between 1993 and 2015, and used ordinary least squares method of analysis because of its simplicity. We recommended introduction of antenatal meal plus in Nigeria based on finding that poor nutrition causes neonatal death.

<https://pubmed.ncbi.nlm.nih.gov/31721659/>

**Atkinson, T. B. (2020). "Infant Mortality: Access and Barriers to Quality Perinatal Care in North Carolina." *N C Med J* 81(1): 28-31.**

This commentary evaluates access and barriers to perinatal care in North Carolina utilizing key goals the state has identified in its strategic plans, such as expanding health care access for North Carolinians, increasing access to preconception care for women and men, improving access to prenatal care, and undoing racism.

<https://pubmed.ncbi.nlm.nih.gov/31908329/>

**Atun, R., Bhakta, N., Denburg, A., Frazier, A. L., Friedrich, P., Gupta, S., Lam, C. G., Ward, Z. J., Yeh, J. M., Allemani, C., Coleman, M. P., Di Carlo, V., Loucaides, E., Fitchett, E., Girardi, F., Horton, S. E., Bray, F., Steliarova-Foucher, E., Sullivan, R., Aitken, J. F., Banavali, S., Binagwaho, A., Alcasabas, P., Antillon, F., Arora, R. S., Barr, R. D., Bouffet, E., Challinor, J., Fuentes-Alabi, S., Gross, T., Hagander, L., Hoffman, R. I., Herrera, C., Kutluk, T., Marcus, K. J., Moreira, C., Pritchard-Jones, K., Ramirez, O., Renner, L., Robison, L. L., Shalkow, J., Sung, L., Yeoh, A. and Rodriguez-Galindo, C. (2020). "Sustainable care for children with cancer: a Lancet Oncology Commission." *Lancet Oncol* 21(4): e185-e224.**

We estimate that there will be 13.7 million new cases of childhood cancer globally between 2020 and 2050. At current levels of health system performance (including access and referral), 6.1 million (44.9%) of these children will be undiagnosed. Between 2020 and 2050, 11.1 million children will die from cancer if no additional investments are made to improve access to health-care services or childhood cancer treatment. Of this total, 9.3 million children (84.1%) will be in low-income and lower-middle-income countries. This burden could be vastly reduced with new funding to scale up cost-effective interventions. Simultaneous comprehensive scale-up of interventions could avert 6.2 million deaths in children with cancer in this period, more than half (56.1%) of the total number of deaths otherwise projected. Taking excess mortality risk into consideration, this reduction in the number of deaths is projected to produce a gain of 318 million life-years. In addition, the global lifetime productivity gains of US\$2580 billion in 2020-50 would be four times greater than the cumulative treatment costs of \$594 billion, producing a net benefit of \$1986 billion on the global investment: a net return of \$3 for every \$1 invested. In sum, the burden of childhood cancer, which has been grossly underestimated in the past, can be effectively diminished to realise massive health and economic benefits and to avert millions of needless deaths.

<https://pubmed.ncbi.nlm.nih.gov/32240612/>

**Avery, J., Geist, A., D'Agostino, N. M., Kawaguchi, S. K., Mahtani, R., Mazzotta, P., Mosher, P. J., Al-Awamer, A., Kassam, A., Zimmermann, C., Samadi, M., Tam, S., Srikanthan, A. and Gupta, A. (2020). "'It's More Difficult...': Clinicians' Experience Providing Palliative Care to Adolescents and Young Adults Diagnosed With Advanced Cancer." *JCO Oncol Pract* 16(1): e100-e108.**

**PURPOSE:** Adolescents and young adults (AYAs; age 15-39 years) with advanced cancer are a population in whom quality of life is uniquely affected because of their stage of life. However, training focused on palliative care for AYAs is not routinely provided for health care providers (HCPs) in oncology. This study aims to explore the experiences of HCPs involved in introducing and providing palliative care caring for AYAs with advanced cancer and their families to understand the unique challenges HCPs experience. **METHODS:** Using a qualitative descriptive design, semistructured interviews were conducted with medical and radiation oncologists, palliative care physicians, psychiatrists, and advanced practice nurses involved in caring for AYAs diagnosed with advanced cancer (N = 19). Interviews were transcribed verbatim and analyzed using thematic analysis in combination with constant comparative analysis and theoretical sampling. **RESULTS:** There were 19 participants, 9 men and 10 women, with a median age of 45 years (range, 24-67 years). Six were palliative care physicians, 5 medical oncologists, 4 nurse practitioners, and 2 each radiation oncologists and psychiatrists. Overall, participants perceived the provision of palliative care for AYAs to be more difficult compared with older adults. Four themes emerged: (1) challenges helping AYAs/families to engage in and accept palliative care, (2) uncertainty regarding how to involve the family, (3) HCP sense of tragedy, and (4) HCP sense of emotional proximity. **CONCLUSION:** Findings from this study support the development of dedicated training for HCPs involved in palliative care for AYA.

<https://pubmed.ncbi.nlm.nih.gov/31765276/>

Bakar, M., Capano, E., Patterson, M., McIntyre, B. and Walsh, C. J. (2020). "The Role of Palliative Care in Caring for the Families of Patients With COVID-19." Am J Hosp Palliat Care 37(10): 866-868.

In palliative care, we strive to provide care to the whole patient. When we think about the whole patient, we include the people who are important in our patients' lives. Our New York City-based palliative care team has found that caring for patients' loved ones has proven to be an even more important aspect of the care we have provided during the COVID epidemic. In this article, we describe the multicomponent interdisciplinary interventions we have implemented to enhance our ability to create a therapeutic alliance with family members and facilitate the provision of goal concordant care to patients with COVID during this extremely difficult time.

<https://pubmed.ncbi.nlm.nih.gov/32508107/>

Benthien, K., Diasso, P., von Heymann, A., Nordly, M., Kurita, G., Timm, H., Johansen, C., Kjellberg, J., von der Maase, H. and Sjøgren, P. (2020). "Oncology to specialised palliative home care systematic transition: the Domus randomised trial." BMJ Support Palliat Care 10(3): 350-357.

**OBJECTIVES:** To assess the effect of a systematic, fast-track transition from oncological treatment to specialised palliative care at home on symptom burden, to explore intervention mechanisms through patient and intervention provider characteristics and to assess long-term survival and place of death. **MEASURES:** The effect of a systematic, fast-track transition from oncological treatment to specialised palliative care at home on patient symptom burden was studied in the Domus randomised clinical trial. Participants had incurable cancer and limited treatment options. The intervention was provided by specialised palliative home teams (SPT) based in hospice or hospital and was enriched with a psychological intervention for patient and caregiver dyad. Symptom burden was measured with Edmonton Symptom Assessment System (ESAS-r) at baseline, 8 weeks and 6 months follow-up and analysed with mixed models. Survival and place of death was analysed with Kaplan-Meier and Fisher's exact tests. **RESULTS:** The study included 322 patients. Tiredness was significantly improved for the Domus intervention group at 6 months while the other nine symptom outcomes were not significantly different from the control group. Exploring the efficacy of intervention provider demonstrated significant differences in favour of the hospice SPT on four symptoms and total symptom score. Patients with children responded more favourably to the intervention. The long-term follow-up demonstrated no differences between the intervention and the control groups regarding survival or home deaths. **CONCLUSIONS:** The Domus intervention may reduce tiredness. Moreover, the intervention provider and having children might play a role concerning intervention efficacy. The intervention did not affect survival or home deaths. **TRIAL REGISTRATION NUMBER:** NCT01885637.

<https://pubmed.ncbi.nlm.nih.gov/32680894/>

Bird, M., Li, L., Ouellette, C., Hopkins, K., McGillion, M. H. and Carter, N. (2019). "Use of Synchronous Digital Health

Brenner, M., O'Shea, M. P., Larkin, P. and Berry, J. (2020). "Key constituents for integration of care for children assisted with long-term home ventilation: a European study." *BMC Pediatr* 20(1): 71.

**BACKGROUND:** The number of children requiring long-term home ventilation has consistently increased over the last 25 years. Given the growing population of children with complex care needs (CCNs), this was an important area of focus within the Models of Child Health Appraised (MOCHA) project, funded by the European Union (EU) under the Horizon 2020 programme. We examined the structures and processes of care in place for children with CCNs and identified key constituents for effective integration of care for these children at the community and acute care interface across 30 EU/ European Economic Area (EEA) countries. **METHODS:** This was a non-experimental descriptive study with an embedded qualitative element. Data were collected by a Country Agent in each of the 30 countries, a local expert in child health services. Data were analysed using descriptive statistics and a thematic analysis was undertaken of the free text data provided. **RESULTS:** A total of 27 surveys were returned from a possible 30 countries (90.0%) countries. One respondent indicated that their country does not have children on long-term ventilation (LTV) in the home, therefore, responses of 26 countries (86.7%) were analysed. None of the responding countries reported that they had all of the core components in place in their country. Three themes emerged from the free text provided: 'family preparedness for transitioning to home', 'coordinated pathway to specialist care' and 'legal and governance structures'. **CONCLUSIONS:** While the clinical care of children on LTV in the acute sector has received considerable attention, the results identify the need for an enhanced focus on the care required following discharge to the community setting. The results highlight the need for a commitment to supporting care delivery that acknowledges the complexity of contemporary child health issues and the context of the families that become their primary care givers.

<https://pubmed.ncbi.nlm.nih.gov/32061253/>

Broden, E. G., Deatrck, J., Ulrich, C. and Curley, M. A. Q. (2020). "Defining a "Good Death" in the Pediatric Intensive Care Unit." *Am J Crit Care* 29(2): 111-121.

**BACKGROUND:** Societal attitudes about end-of-life events are at odds with how, where, and when children die. In addition, parents' ideas about what constitutes a "good death" in a pediatric intensive care unit vary widely. **OBJECTIVE:** To synthesize parents' perspectives on end-of-life care in the pediatric intensive care unit in order to define the characteristics of a good death in this setting from the perspectives of parents. **METHODS:** A concept analysis was conducted of parents' views of a good death in the pediatric intensive care unit. Empirical studies of parents who had experienced their child's death in the inpatient setting were identified through database searches. **RESULTS:** The concept analysis allowed the definition of antecedents, attributes, and consequences of a good death. Empirical referents and exemplar cases of care of a dying child in the pediatric intensive care unit serve to further operationalize the concept. **CONCLUSIONS:** Conceptual knowledge of what constitutes a good death from a parent's perspective may allow pediatric nurses to care for dying children in a way that promotes parents' coping with bereavement and continued bonds and memories of the deceased child. The proposed conceptual model synthesizes

characteristics of a good death into actionable attributes to guide bedside nursing care of the dying child.

<https://pubmed.ncbi.nlm.nih.gov/32114610/>

Castor, C., Hallström, I. K., Landgren, K. and Hansson, H. (2019). "Accessibility, utilisation and acceptability of a county-based home care service for sick children in Sweden." *Scand J Caring Sci* 33(4): 824-832.

**BACKGROUND:** Home care service (HCS) for sick children is a complex healthcare service, which can be organised in various models. Despite the possibility to support family everyday life, the accessibility and utilisation may still be limited. The aim of this study was to (i) determine characteristics in referrals to county-based HCS, (ii) determine characteristics of referred children and (iii) assess acceptability of parents and children in county-based HCS. **METHODS:** Data on characteristics of referrals and referred children were collected from medical records of children 0-17 years of age, referred to eight HCS units during 2015-2018. Data on parental and child overall experience, satisfaction of, safety with, and preference for care, were collected from parents by a questionnaire. Descriptive and comparative statistics were used to analyse the data. **RESULTS:** Three hundred and fifty-five referrals led to one or more periods of HCS for 171 children in various ages with a wide range of illnesses. Children with cancer (30%) composed the largest group and administration of intravenous antibiotics accounted for 56% of the care tasks. Seven per cent of the referrals were to palliative home care. Thirty-eight referrals of 34 children were refused. There was an uneven distribution of the indication for referral, acceptance rate and diagnoses of children among HCS units. Parents reported their and their child's experience with the HCS visit as highly positive and preferred home care to hospital care in over 96% of the HCS in 212 visits. **CONCLUSION:** County-based HCS constitutes a supplement to hospital care for sick children with various illnesses through different stages of acute and long-term illness and at end of life, with high levels of acceptability. Few referrals and variation in referral characteristics and acceptance rate of referrals between HCS units led to unequal and inequitable accessibility and utilisation of HCS.

<https://pubmed.ncbi.nlm.nih.gov/30865330/>

Christou, A., Alam, A., Sadat Hofiani, S. M., Rasooly, M. H., Mubasher, A., Rashidi, M. K., Dibley, M. J. and Raynes-Greenow, C. (2020). "Understanding pathways leading to stillbirth: The role of care-seeking and care received during pregnancy and childbirth in Kabul province, Afghanistan." *Women Birth*, 10.1016/j.wombi.2020.02.012.

**BACKGROUND:** The underlying pathways leading to stillbirth in low- and middle-income countries are not well understood. Context-specific understanding of how and why stillbirths occur is needed to prioritise interventions and identify barriers to their effective implementation and uptake. **AIM:** To explore the contribution of contextual, individual, household-level and health system factors to stillbirth in Afghanistan. **METHODS:** Using a qualitative approach, we conducted semi-structured in-depth interviews with women and men that experienced stillbirth, female elders, community health workers, healthcare providers, and government officials in Kabul province, Afghanistan between October-November 2017. We used thematic analysis to identify contributing factors and developed a conceptual map describing possible pathways to

stillbirth. FINDINGS: We found that low utilisation and access to healthcare was a key contributing factor, as were unmanaged conditions in pregnancy that increased women's risk of complications and stillbirth. Sociocultural factors related to the treatment of women and perceptions about medical interventions deprived women of interventions that could potentially prevent stillbirth. The quality of care from public and private providers during pregnancy and childbirth was a recurring concern exacerbated by health system constraints that led to unnecessary delays; while environmental factors linked to the ongoing conflict were also perceived to contribute to stillbirth. These pathways were underscored by social, cultural, economic factors and individual perceptions that contributed to the three-delays. DISCUSSION: Efforts are needed at the community-level to facilitate care-seeking and raise awareness of stillbirth risk factors and the facility-level to strengthen antenatal and childbirth care quality, ensure culturally appropriate and respectful care, and reduce treatment delays.

<https://pubmed.ncbi.nlm.nih.gov/32094034/>

**Cook, K. A. and Bergeron, K. (2020). "Palliative care for young adults with life-limiting conditions: public health recommendations." *BMJ Support Palliat Care*, 10.1136/bmjspcare-2019-002042.**

OBJECTIVE: To engage young adults (18-35 years of age) with life-limiting neuromuscular conditions, their parents, and health and community providers in the development of a public health approach to palliative care. A public health approach protects and improves health and wellness, maximises the quality of life when health cannot be restored and improves the quality, scope and accessibility of age-appropriate care and services. METHODS: Group concept mapping (GCM) was used to determine the most important priorities for these young adults. GCM involves three distinct phases: (1) brainstorming ideas, (2) sorting and rating ideas based on level of importance and (3) analysing and interpreting concepts maps. Online software was used to collect information for phases 1 and 2 and develop concept maps. In phase 3, a face-to-face workshop, participants analysed and interpreted the concept maps. The combination of online and face-to-face research activities offered the needed flexibility for participants to determine when and how to participate in this research. RESULTS: Through this three-phase patient engagement strategy, participants generated 64 recommendations for change and determined that improvements to programming, improvements to funding and creating a continuum of care were their most important priorities. Five subthemes of these three priorities and development of the concept map are also discussed. CONCLUSION: This research demonstrates the unique perspectives and experiences of these young adults and offers recommendations to improve services to enhance their health and well-being. Further, these young adults were integral in the development of recommendations for system changes to match their unique developmental needs.

<https://pubmed.ncbi.nlm.nih.gov/32561547/>

**Costantini, M., Sleeman, K. E., Peruselli, C. and Higginson, I. J. (2020). "Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy." *Palliat Med* 34(7): 889-895.**

BACKGROUND: Palliative care is an important component of health care in pandemics, contributing to symptom control, psychological support, and supporting triage and

complex decision making. AIM: To examine preparedness for, and impact of, the COVID-19 pandemic on hospices in Italy to inform the response in other countries. DESIGN: Cross-sectional telephone survey, in March 2020. SETTING: Italian hospices, purposively sampled according to COVID-19 regional prevalence categorised as high (>25), medium (15-25) and low prevalence (<15) COVID-19 cases per 100,000 inhabitants. A brief questionnaire was developed to guide the interviews. Analysis was descriptive. RESULTS: Seven high, five medium and four low prevalence hospices provided data. Two high prevalence hospices had experienced COVID-19 cases among both patients and staff. All hospices had implemented policy changes, and several had rapidly implemented changes in practice including transfer of staff from inpatient to community settings, change in admission criteria and daily telephone support for families. Concerns included scarcity of personal protective equipment, a lack of hospice-specific guidance on COVID-19, anxiety about needing to care for children and other relatives, and poor integration of palliative care in the acute planning response. CONCLUSION: The hospice sector is capable of responding flexibly and rapidly to the COVID-19 pandemic. Governments must urgently recognise the essential contribution of hospice and palliative care to the COVID-19 pandemic and ensure these services are integrated into the health care system response. Availability of personal protective equipment and setting-specific guidance is essential. Hospices may also need to be proactive in connecting with the acute pandemic response.

<https://pubmed.ncbi.nlm.nih.gov/32348711/>

**Dangel, T., Kmiec, T., Januszaniec, A. and Wazny, B. (2020). "Palliative care in 9 children with neurodegeneration with brain iron accumulation." *Neurol Sci* 41(3): 653-660.**

AIM: Evaluation of pediatric palliative home care of families with children suffering from neurodegeneration with brain iron accumulation (NBIA) and their parents. MATERIAL AND METHODS: The children were treated at home by a multidisciplinary team. Densitometry was used to evaluate the condition of the skeletal system. Botulinum toxin was injected into the muscles in doses between 22 and 50 units/kg. The quality of palliative care was assessed on the basis of a specially designed questionnaire for parents. RESULTS: The observations were performed on a group of 9 patients with NBIA. On admission, the median age of patients was 9 years (7-14). The average time of palliative home care was 1569 days (34 days-17 years). The median age at death (6 patients) was 11 years (7-15). The botulinum toxin injections gave the following results: reduction of spasticity and dystonia, reduction of spine and chest deformation, relief of pain and suffering, facilitation of rehabilitation and nursing, prevention of permanent contractures, and reduction of excessive salivation. Bone mineral density and bone strength index were reduced. Two patients experienced pathological fracture of the femur. The body mass index at admission varied between 9.8 and 14.9. In 7 cases, introduction of a ketogenic diet resulted in the increase of body mass and height. The ketogenic diet did not worsen the neurological symptoms. The parents positively evaluated the quality of care. CONCLUSION: Palliative home care is the optimal form of treatment for children with NBIA.

<https://pubmed.ncbi.nlm.nih.gov/31758347/>

Daniels-Howell, C. (2020). "Caring for Children With Life-Limiting Illness in Bloemfontein, South Africa: Challenging the Assumptions of the 'Good Death'." Omega (Westport), 10.1177/0030222820944099: 30222820944099.

Theories of good death focused on acceptance, control, and meaning-making inform adult palliative care in high-resource settings. As children's palliative and hospice care (CPHC) develops in resource-limited settings, critical conceptualisations of a good death for children across these diverse settings are unknown. Assessed against high-resource setting tenets of good death from carer perspectives, results suggest: carer agency is limited; advanced discussion of death does not occur; distress results from multiple burdens; basic survival is prioritised; physical pain is not an emphasised experience; and carers publicly accept death quickly while private grief continues. Hegemonic conceptions of 'good death' for children do not occur in contexts where agency is constrained and discussing death is taboo, limiting open discussion, acceptance, and control of dying experiences. Alternate forms of discourse and good death could still occur. Critical, grounded conceptualisations of good death in individual resource-limited settings should occur in advance of CPHC development to effectively relieve expansive suffering in these contexts.

<https://pubmed.ncbi.nlm.nih.gov/32703072/>

David, I. and Le Moing, S. (2019). "[Palliative care in a paediatric intrahospital mobile team]." Soins PEDIATR Pueric 40(310): 45-48.

Paediatric palliative care has been set up after extensive discussion and observations regarding the need to provide different support to children with a serious and incurable disease as well as their families. The mobile palliative care team support children and their family in this specific process and train caregivers in the palliative approach.

<https://pubmed.ncbi.nlm.nih.gov/31543235/>

Davis, J. A. M., Bass, A., Humphrey, L., Texter, K. and Garee, A. (2020). "Early Integration of Palliative Care in Families of Children with Single Ventricle Congenital Heart Defects: A Quality Improvement Project to Enhance Family Support." Pediatr Cardiol 41(1): 114-122.

Children with single ventricle congenital heart defects (SVCHD) experience a significant risk of early mortality throughout their lifespan, particularly during their first year of life. Due to the intense care needed for these children and families, pediatric palliative care (PPC) team consults should be routine; however, medical staff are often reluctant to broach the idea of PPC to families. The involvement of PPC for many carries with it an association to end-of-life (EOL) care. Setting the standard of PPC involvement from the time of admission for the first palliative surgery led to increased family support, decreased days to consult, improved acceptance and communication. The purpose of this article is to describe a quality improvement project of early integration of PPC with families of children with SVCHD. Lessons learned will be presented, including the resources needed and the barriers encountered in assimilating PPC into the standard of care for all patients with SVCHD. The single ventricle (SV) and PPC teams collaborated to enhance the support given to SV families. Education was initiated with cardiology and PPC providers to understand the goal of consistent PPC consults beginning after birth for patients with SVCHD. Parents were educated during fetal

consultation regarding the involvement of the PPC team. The SV team ensured compliance with the PPC initiative by identifying eligible patients and requesting consult orders from the primary providers. PPC consultation increased significantly over the 40 month study period to nearly 100% compliance for children with SVCHD who are undergoing pre-Fontan surgery. In addition, mean days to consult decreased dramatically during the study to a current average of 3 days into the patient's hospitalization; the data likely suggest that more PPC consults were routinely ordered versus urgently placed for unexpected complications. Data indicate that patients are being followed by the PPC team at an earlier age and stage in their SV journey which allows for more opportunity to provide meaningful support to these patients and families. The early involvement of the PPC team for children with SV physiology was operationally feasible and was accepted by families, thus allowing PPC providers to establish a therapeutic relationship early in the disease trajectory with the family. It allowed more continuity throughout the SV journey in a proactive fashion rather than a reactive manner.

<https://pubmed.ncbi.nlm.nih.gov/31676955/>

Davis, S. L., Harmon, C. M., Baker Urquhart, B., Moore, B. and Sprague, R. (2020). "Women and Infants in the Deep South Receiving Perinatal and Neonatal Palliative and Supportive Care Services." Adv Neonatal Care 20(3): 216-222.

BACKGROUND: While women in the Deep South area of the United States have higher rates of maternal and infant mortality, palliative and supportive care programs are lacking. Additionally, few studies have detailed referral triggers that are specific to the mother, infant, or pregnancy for inclusion in perinatal and neonatal palliative and supportive care programs. PURPOSE: The purpose of this retrospective, descriptive study was to examine the sociodemographic factors and referral triggers for perinatal-neonatal palliative and supportive care services for women enrolled in a newly developed perinatal-neonatal palliative and supportive care program. METHODS: Data were collected from medical records of 135 women enrolled in the program. Triggers for referral to the program were classified as fetal, maternal, or prenatal complications. RESULTS: A diverse sample of women were enrolled in the program. Most infants survived to birth and discharge from the hospital. Two-thirds of referrals were related to infant complications and 34% were for multiple complications (fetal, maternal, and/or prenatal). Triggers for referral to the program were not related to sociodemographic characteristics of women. IMPLICATIONS FOR PRACTICE: A comprehensive list of triggers that include maternal and prenatal complications, in addition to infant complications, may ensure at-risk women and infants, are enrolled in perinatal-neonatal palliative and supportive care programs early in pregnancy, regardless of sociodemographic factors. IMPLICATIONS FOR RESEARCH: Prospective research on the effectiveness of perinatal-neonatal palliative and supportive care programs in diverse populations of women is needed. This includes the examination of family health outcomes and provider perspectives.

<https://pubmed.ncbi.nlm.nih.gov/31922972/>

Dionne-Odom, J. N., Ornstein, K. A. and Kent, E. E. (2019). "What do family caregivers know about palliative care? Results from a national survey." Palliat Support Care 17(6): 643-649.

**OBJECTIVE:** Despite their key role in caring for individuals with serious, chronic illness, there have been no national studies examining family caregiver awareness and perceptions of palliative care. Hence, our objectives were to ascertain level of knowledge of palliative care among U.S. family caregivers and describe demographic variation in awareness and perceptions of palliative care. **METHOD:** Using the 2018 National Cancer Institute Health Information National Trends Survey, we identified unpaid family caregivers caring or making healthcare decisions for someone with a medical, behavioral, disability, or other condition. Respondents were asked about their awareness of the term "palliative care" and, if aware, how much they agreed with statements representing common (mis)perceptions about palliative care (e.g., "Palliative care is the same as hospice"). **RESULT:** More than one-half of caregivers (55%) had "never heard" of palliative care; 19.2% knew what palliative care was and "could explain it to someone else." In adjusted models, racial minorities (vs. whites) and those without a college degree were less likely to have heard of palliative care. Among those aware of palliative care, ~40% "strongly" or "somewhat" agreed that "Palliative care is the same as hospice"; another 10.5% "didn't know." Similarly, 40% reported that "When I think of palliative care, I automatically think of death." **SIGNIFICANCE OF RESULTS:** One-half of family caregivers of adults with serious chronic illness have never heard of palliative care. Even among those who had heard of palliative care, the majority do not distinguish it from hospice care and death. Given the role family caregivers may play in decisions to access palliative care, public messaging efforts are needed to clarify palliative care services in a way that is patient- and family-centered.

<https://pubmed.ncbi.nlm.nih.gov/30957733/>

Downing, J., Niyonzima, N., Guma, S., Batuli, M., Kiwanuka, R., Atuhe, I., Nalukwago, Z., Mwesiga, M., Phipps, W. and Ddungu, H. (2019). "Towards universal coverage-highlights from the 2nd Uganda Conference on Cancer and Palliative Care, 5-6 September 2019, Kampala, Uganda." *Ecancermedicalsecience* 13: 976.

The 2nd Uganda Conference on Cancer and Palliative Care was held in September 2019 in Kampala, Uganda under the theme: Towards Universal Coverage. It was hosted by the Uganda Cancer Institute and the Palliative Care Association of Uganda (PCAU). The conference brought together 350 delegates from eight countries. Key themes from the conference included: universal health coverage (UHC), service provision and public health; resources for achieving UHC; capacity building; human rights and engagement on the implementation of the recommendations made by the Uganda Human Rights Commission; provision of cancer and palliative care to 'hard to reach' and 'vulnerable' groups; paediatrics; health promotion and prevention; policy and advocacy and digital technology. The conference also gave opportunity to celebrate the 20th Anniversary of the work of PCAU, with a celebration dinner attended by the Minister of Health. The past few years have seen significant developments in both cancer and palliative care in Uganda, and this was evident in the presentations, and the way that provision has changed and improved since the first cancer and palliative care conference in 2017. Emphasis on UHC, along with the support of government and other stakeholders, is important in the ongoing development of cancer and palliative care services in Uganda.

<https://pubmed.ncbi.nlm.nih.gov/31921347/>

Ebelhar, J., Allen, K., DeGroot, N., Wasilewski-Masker, K. and Brock, K. E. (2020). "Defining palliative opportunities in pediatric patients with bone and soft tissue sarcomas." *Pediatr Blood Cancer*, 10.1002/pbc.28363: e28363.

**BACKGROUND:** Pediatric patients with sarcomas experience significant morbidity and compromised quality of life throughout their course. These times could be viewed as opportunities for increased subspecialty palliative care (PC). Systematically defining opportunities for additional PC support has not occurred in pediatric oncology. The frequency, timing, and associated factors for palliative opportunities in pediatric patients with sarcomas are unknown. **METHODS:** A priori, nine palliative opportunities were defined (disease progression or relapse, admission for symptoms, social concerns or end-of-life, intensive care or bone marrow transplant admission, phase 1 trial or hospice enrollment, do-not-resuscitate status). A single-center retrospective review was conducted on patients aged 0-18 years with bone/soft tissue sarcomas who died from January 1, 2012 to November 30, 2017. Demographic, disease, and treatment data were collected. Descriptive statistics were performed. Opportunities were evaluated over quartiles from diagnosis to death. **RESULTS:** Patients (n = 60) had a mean of nine (SD = 4) palliative opportunities with the majority occurring in the last quartile of the disease course. Number and type of opportunities did not differ by demographics or diagnosis. Eighteen patients (30%) received PC consultation a median of 2.2 months (interquartile range [IQR] 11.5) prior to death. Consultation was unrelated to diagnosis or total opportunities. **CONCLUSIONS:** Patients with sarcomas incur repeated events warranting subspecialty PC, which increase toward the end-of-life. Increased PC utilization may help decrease suffering and bolster family coping during these episodes. Additional work should further refine if opportunities differ across cancers, and how to incorporate this framework into clinical oncology care to prevent missed opportunities for PC.

<https://pubmed.ncbi.nlm.nih.gov/32706495/>

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://pubmed.ncbi.nlm.nih.gov/31149941/>

**Ellis, K. and Lindley, L. C. (2020). "A Virtual Children's Hospice in Response to COVID-19: The Scottish Experience." *J Pain Symptom Manage* 60(2): e40-e43.**

This case report describes a pediatric hospice provider in Scotland and their experience implementing a telehospice program in response to COVID-19. Children's Hospices Across Scotland (CHAS) is the only provider of pediatric hospice care in the entire of Scotland, and we describe their experience offering pediatric telehospice. CHAS had strategically planned to implement a telehospice program, but COVID-19 accelerated the process. The organization evaluated its pediatric clinical and wrap-around hospice services and rapidly migrated them to a virtual environment. They creatively added new services to meet the unique needs of the entire family, who were caring for a child at end of life during COVID-19. CHAS's experience highlights the planning and implementing processes of telehospice with key lessons learned, while acknowledging the challenges inherent in using technology to deliver hospice care.

<https://pubmed.ncbi.nlm.nih.gov/32416232/>

**Falke, M. and Rubarth, L. B. (2020). "Implementation of a Perinatal Hospice Program." *Adv Neonatal Care* 20(3): 223-228.**

**BACKGROUND:** In 2017, the Nebraska Unicameral passed legislative bill 506, which required physicians to inform patients carrying fetuses diagnosed with a life-limiting anomaly of the option to enroll in a comprehensive perinatal hospice program. The bill also required the Department of Health & Human Services to provide information about statewide hospice programs. Families enrolled in hospice programs are better prepared for the birth and death of their child. This large academic medical center was listed on the registry but did not have a formal perinatal hospice program. **PURPOSE:** Implementation of a comprehensive perinatal hospice program. **METHODS:** The program was designed and implemented, beginning with the formation of an interdisciplinary team. Guidelines were developed for program referral, care conferences, team communication, and family follow-up. The team was educated. Electronic record documentation and order set were implemented. A data collection process was developed to track referrals and critical data points. **RESULTS:** The perinatal hospice program has been accepting referrals but has not had any qualifying referrals. **IMPLICATIONS FOR PRACTICE:** The development of an evidence-based guideline for referral that can improve referral consistency. While trisomy 13 and 18 diagnosis was historically considered life-limiting, these families now have the option of full intervention and transfer for specialists. **IMPLICATIONS FOR RESEARCH:** Future research will include collecting data from patients who could have benefited from hospice, including infants who were born 20 to 22 weeks, or for maternal reasons. Future research will evaluate the experience after bereavement, the hospice team's experience, and the effectiveness of the referral process.

<https://pubmed.ncbi.nlm.nih.gov/32384325/>

**Fortney, C. A. (2020). "Neonatal Palliative, End of Life, and Hospice Care Across Multiple Settings." *Adv Neonatal Care* 20(2): 101-102.**

<https://pubmed.ncbi.nlm.nih.gov/32221134/>

Friedel, M., Gilson, A., Bouckenaere, D., Brichard, B., Fonteyne, C., Wojcik, T., De Clercq, E., Guillet, A., Mahboub, A., Lahaye, M. and Aujoulat, I. (2019). "Access to paediatric palliative care in children and adolescents with complex chronic conditions: a retrospective hospital-based study in Brussels, Belgium." BMJ Paediatr Open 3(1): e000547.

**BACKGROUND:** Paediatric complex chronic conditions (CCCs) are life-limiting conditions requiring paediatric palliative care, which, in Belgium, is provided through paediatric liaison teams (PLTs). Like the number of children and adolescents with these conditions in Belgium, their referral to PLTs is unknown. **OBJECTIVES:** The aim of the study was to identify, over a 5-year period (2010-2014), the number of children and adolescents (0-19 years) living with a CCC, and also their referral to PLTs. **METHODS:** International Classification of Disease codes (ICD-9) corresponding to a CCC, as described by Feudtner et al, and national registration numbers were extracted from the databases of all hospitals (n=8) and PLTs (n=2) based in the Brussels region. Aggregated data and pseudonymised national registration number were transmitted to the research team by a Trusted Third Party (eHealth). Ages and diagnostic categories were calculated using descriptive statistics. **RESULTS:** Over 5 years (2010-2014) in the Brussels region, a total of 22 721 children/adolescents aged 0-19 years were diagnosed with a CCC. Of this number, 22 533 were identified through hospital registries and 572 through PLT registries. By comparing the registries, we found that of the 22 533 children/adolescents admitted to hospital, only 384 (1.7%) were also referred to a PLT. **CONCLUSION:** In Belgium, there may be too few referrals of children and adolescents with CCC to PLTs that ensure continuity of care.  
<https://pubmed.ncbi.nlm.nih.gov/31646199/>

Garcia, X., Frazier, E., Kane, J., Jones, A., Brown, C., Bryant, T. and Prophan, P. (2020). "Pediatric Cardiac Critical Care Transport and Palliative Care: A Case Series." Am J Hosp Palliat Care, 10.1177/1049909120928280: 1049909120928280.

**OBJECTIVE:** To present our center's experience with terminal extubation in 3 palliative critical care home transports from the Pediatric Cardiac Intensive Unit. **DESIGN:** All cases were identified from our Cardiovascular intensive care unit ( CVICU). Patients were terminally ill children with no other surgical or medical option who were transported home between 2014 and 2018, for terminal extubation and end-of-life care according to their families' wishes. **INTERVENTIONS:** The patients were 7, 9 months, and 19 years; and they had very complex and chronic conditions. The families were approached by the CVICU staff during multidisciplinary meetings, where goals of care were established. Parental expectations were clarified, and palliative care team was involved, as well as home hospice was arranged pre-transfer. The transfer process was discussed and all the needs were established. All patients had unstable medical conditions, with needs for transport for withdrawal of life support and death at home. Each case needed a highly trained team to support life while in transport. The need of these patients required coordination with home palliative care services, as well as community resources due to difficulty to get in their homes. **CONCLUSIONS:** Transportation of pediatric cardiac critical care patients for terminal extubation at home

is a relatively infrequent practice. It is a feasible alternative for families seeking out of the hospital end-of-life care for their critically ill and technology dependent children. Our single-center experience supports the need for development of formal programs for end-of-life critical care transports.

<https://pubmed.ncbi.nlm.nih.gov/32462881/>

**Garten, L., von der Hude, K., Strahleck, T. and Kronen, T. (2020). "Extending the Concept of Advance Care Planning to the Perinatal Period." *Klin Padiatr* 232(5): 249-256.**

Easier access to prenatal diagnostic procedures led to its widespread use as a screening measure. Hence, today it is more common for life-limiting illnesses to be diagnosed during fetal life. The concept of Advance Care Planning (ACP) provides a framework for caregivers, families and their multidisciplinary teams to anticipate and plan ahead for potential future medical decisions so that the affected children are reliably treated according to their parents' individual values and wishes. In the perinatal context, ACP also has the potential to tackle the needs of unborn or newborn children with life-limiting illnesses and their families better, avoid unnecessary and burdensome measures and focus upon goals that are valuable and meaningful to both child and family.

<https://pubmed.ncbi.nlm.nih.gov/32542620/>

**Grossoehme, D. H., Humphrey, L., Friebert, S., Ding, L., Yang, G., Allmendinger-Goertz, K., Fryda, Z., Fosselman, D. and Thienprayoon, R. (2020). "Patterns of Hospice and Home-Based Palliative Care in Children: An Ohio Pediatric Palliative Care and End-of Life Network Study." *J Padiatr*, 10.1016/j.jpeds.2020.04.004.**

**OBJECTIVE:** To describe the demographic and clinical characteristics of a cohort of patients referred to pediatric hospice and home-based palliative care (HBPC) programs across Ohio in 2016. **STUDY DESIGN:** Retrospective cohort study of patients referred to hospice/HBPC from 3 pediatric palliative care programs in Ohio in 2016. Demographic and clinical data were extracted from the medical record and analyzed with descriptive statistics. **RESULTS:** There were 209 patients referred: 49 (24%) to hospice and 160 (77%) to HBPC. The most common diagnoses were genetic/chromosomal syndromes (23%), neurologic or neurodegenerative conditions (23%), and cancer (21%). Durable medical equipment use was frequent (85%), with gastrostomy or jejunostomy tubes (22%) the most common. Most patients (64%) retained full-code resuscitation status. Fifty-seven patients (27%) died before July 1, 2018: 37 in hospice (18% of the overall cohort, 65% of decedents) and 20 in HBPC (10% of the overall cohort, 35% of decedents). Sixty-seven percent of hospice and 40% of HBPC patients died at home. **CONCLUSIONS:** Pediatric hospice and HBPC programs serve a diverse cohort of patients. Patients referred to pediatric HBPC programs commonly die and are likely to die at home despite not being enrolled in hospice care. The high proportion of decedent HBPC patients indicates that the notion of hospice vs palliative care may present a false dichotomy in many children with life-limiting conditions. Reimbursement models for HBPC should reflect the clinical similarity to hospice in the care of children with life-limiting illnesses.

<https://pubmed.ncbi.nlm.nih.gov/32532649/>

Grossoehme, D. H., Mark, M. S., Lane, B., Rednour, A. and Thienprayoon, R. (2020). "Compassionate Design: Utilizing Design Thinking to Preserve Sanctity, Dignity, and Personhood When Children Die." *Pediatr Qual Saf* 5(4): e317.

**INTRODUCTION:** Greater than 70% of children who die in our institution annually die in an intensive care unit (ICU) setting. Family privacy, visitation policies, and an inability to perform religious rituals in the ICU are barriers to provide children with culturally competent, family-centered care when a child dies. The goal of this project was to profoundly understand family and staff experiences surrounding pediatric death in our institution to identify unique opportunities to design improved, novel delivery models of pediatric end of life (EOL) care. **METHODS:** This project utilized a structured process model based on the Vogel and Cagan's 4-phase integrated new product development process model. The 4 phases are identifying, understanding, conceptualizing, and realizing. We utilized an adaptation of this process model that relies on human-centered and design thinking methodologies in 3 phases: research, ideation, and refinement of a process or product opportunity. **RESULTS:** There were 2 primary results of this project: 5 process and opportunity areas to improve the EOL experience across the hospital, and a set of criteria and considerations for a dedicated EOL space. **DISCUSSION:** Sometimes, the best outcome we can provide for a child and their family is a peaceful, dignified death. This project utilized human-centered design to create improved process outcomes and to design a dedicated EOL space for children who die in the hospital. Offering grieving families quiet, private time with their child in a beautiful, dignified, peaceful location enables the beginning of improved bereavement outcomes for the family and staff.

<https://pubmed.ncbi.nlm.nih.gov/32766491/>

Hein, K., Knochel, K., Zaimovic, V., Reimann, D., Monz, A., Heitkamp, N., Borasio, G. D. and Führer, M. (2020). "Identifying key elements for paediatric advance care planning with parents, healthcare providers and stakeholders: A qualitative study." *Palliat Med* 34(3): 300-308.

**BACKGROUND:** Although international guidelines recommend discussions about goals of care and treatment options for children with severe and life-limiting conditions, there are still few structured models of paediatric advance care planning. **AIM:** The study aimed at identifying key components of paediatric advance care planning through direct discussions with all involved parties. **DESIGN:** The study had a qualitative design with a participatory approach. Participants constituted an advisory board and took part in two transdisciplinary workshops. Data were collected in discussion and dialogue groups and analysed using content analysis. **SETTING/PARTICIPANTS:** We included bereaved parents, health care providers and stakeholders of care networks. **RESULTS:** Key elements were discussions, documentation, implementation, timing and participation of children and adolescents. Parents engage in discussions with facilitators and persons of trust to reach a decision. Documentation constitutes the focus of professionals, who endorse brief recommendations for procedures in case of emergencies, supplemented by larger advance directives. Implementation hindrances include emotional barriers of stakeholders, disagreements between parents and professionals and difficulties with emergency services. Discussion timing should take into account parental readiness. The intervention should be repeated at regular intervals, considering emerging needs and increasing awareness of families over time. Involving children and adolescents in

advance care planning remains a challenge. **CONCLUSION:** A paediatric advance care planning intervention should take into account potential pitfalls and barriers including issues related to timing, potential conflicts between parents and professionals, ambiguity towards written advance directives, the role of non-medical carers for paediatric advance care planning implementation, the need to involve the child and the necessity of an iterative process.

<https://pubmed.ncbi.nlm.nih.gov/31985331/>

**Holmen, H., Riiser, K. and Winger, A. (2020). "Home-Based Pediatric Palliative Care and Electronic Health: Systematic Mixed Methods Review." J Med Internet Res 22(2): e16248.**

**BACKGROUND:** Children and families in pediatric palliative care depend on close contact with health care personnel, and electronic health (eHealth) is suggested to support care at home by facilitating their remote interactions. **OBJECTIVE:** This study aimed to identify and review the use of eHealth to communicate and support home-based pediatric palliative care and appraise the methodological quality of the published research. **METHODS:** We conducted a convergent, systematic mixed methods review and searched Medical Literature Analysis and Retrieval System Online (Medline), EMBASE, PsycINFO, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, and Scopus for eligible papers. Studies evaluating 2-way communication technology for palliative care for children aged  $\leq 18$  years and applying quantitative, qualitative, or mixed methods from 2012 to 2018 were eligible for inclusion. Quantitative and qualitative studies were equally valued during the search, screening, extraction, and analysis. Quantitative data were transformed into qualitative data and analyzed using a thematic analysis. Overall, 2 independent researchers methodologically appraised all included studies. **RESULTS:** We identified 1277 citations. Only 7 papers were eligible for review. Evaluating eHealth interventions in pediatric palliative care poses specific methodological and ethical challenges. eHealth to facilitate remote pediatric palliative care was acknowledged both as an intrusion and as a support at home. Reluctance toward eHealth was mainly identified among professionals. **CONCLUSIONS:** The strengths of the conclusions are limited by the studies' methodological challenges. Despite the limitless possibilities held by new technologies, research on eHealth in home-based pediatric palliative care is scarce. The affected children and families appeared to hold positive attitudes toward eHealth, although their views were less apparent compared with those of the professionals. **TRIAL REGISTRATION:** PROSPERO CRD42018119051.

<https://tinyurl.com/rtsw5ky>

<https://pubmed.ncbi.nlm.nih.gov/32130127/>

**Jarvis, S., Parslow, R. C., Hewitt, C., Mitchell, S. and Fraser, L. K. (2020). "GPs' role in caring for children and young people with life-limiting conditions: a retrospective cohort study." Br J Gen Pract 70(693): e221-e229.**

**BACKGROUND:** GPs are rarely actively involved in healthcare provision for children and young people (CYP) with life-limiting conditions (LLCs). This raises problems when these children develop minor illness or require management of other chronic diseases. **AIM:** To investigate the association between GP attendance patterns and hospital urgent and emergency care use. **DESIGN AND SETTING:** Retrospective cohort study

using a primary care data source (Clinical Practice Research Datalink) in England. The cohort numbered 19 888. METHOD: CYP aged 0-25 years with an LLC were identified using Read codes (primary care) or International Classification of Diseases 10 (th) Revision (ICD-10) codes (secondary care). Emergency inpatient admissions and accident and emergency (A&E) attendances were separately analysed using multivariable, two-level random intercept negative binomial models with key variables of consistency and regularity of GP attendances. RESULTS: Face-to-face GP surgery consultations reduced, from a mean of 7.12 per person year in 2000 to 4.43 in 2015. Those consulting the GP less regularly had 15% (95% confidence interval [CI] = 10% to 20%) more emergency admissions and 5% more A&E visits (95% CI = 1% to 10%) than those with more regular consultations. CYP who had greater consistency of GP seen had 10% (95% CI = 6% to 14%) fewer A&E attendances but no significant difference in emergency inpatient admissions than those with lower consistency. CONCLUSION: There is an association between GP attendance patterns and use of urgent secondary care for CYP with LLCs, with less regular GP attendance associated with higher urgent secondary healthcare use. This is an important area for further investigation and warrants the attention of policymakers and GPs, as the number of CYP with LLCs living in the community rises.

<https://pubmed.ncbi.nlm.nih.gov/32041769/>

**Jensen, H. I., Halvorsen, K., Jerpseth, H., Fridh, I. and Lind, R. (2020). "Practice Recommendations for End-of-Life Care in the Intensive Care Unit." Crit Care Nurse 40(3): 14-22.**

TOPIC: A substantial number of patients die in the intensive care unit, so high-quality end-of-life care is an important part of intensive care unit work. However, end-of-life care varies because of lack of knowledge of best practices. CLINICAL RELEVANCE: Research shows that high-quality end-of-life care is possible in an intensive care unit. This article encourages nurses to be imaginative and take an individual approach to provide the best possible end-of-life care for patients and their family members. PURPOSE OF PAPER: To provide recommendations for high-quality end-of-life care for patients and family members. CONTENT COVERED: This article touches on the following domains: end-of-life decision-making, place to die, patient comfort, family presence in the intensive care unit, visiting children, family needs, preparing the family, staff presence, when the patient dies, after-death care of the family, and caring for staff.

<https://pubmed.ncbi.nlm.nih.gov/32476029/>

**Jersak, T., Gustin, J. and Humphrey, L. (2019). "Challenges of the Transition: A Case of Noncompliance in an Adult with Congenital Heart Disease." J Palliat Med 22(12): 1621-1623.**

There are more adults than children living with congenital heart disease (CHD) due to improvements in surgical and medical CHD management today. In 2011, though, fewer than 30% of adult CHD patients were following up with specialized providers. An ineffective transition from pediatric to adult-focused medical care can result in lapses in CHD medical care, patient noncompliance, and increased risk of late complications. Early involvement of a palliative care team offers development of autonomy, identification of potential barriers to care, and support for patient and family that may improve transition success and quality of life in CHD patients.

<https://pubmed.ncbi.nlm.nih.gov/31090489/>

Johnston, E. E., Martinez, I., Currie, E., Brock, K. E. and Wolfe, J. (2020). "Hospital or Home? Where Should Children Die and How Do We Make That a Reality?" J Pain Symptom Manage 60(1): 106-115.

CONTEXT: Most of the 20,000 U.S. children dying of serious illnesses annually die in the hospital. It is unknown if this hospital death predominance reflects family wishes or systemic issues such as lack of hospice access. Hence, we need to better understand location of death preferences for children and their families. OBJECTIVE: To better understand location of death preferences in North America, we reviewed the literature to examine the evidence for and against home death in seriously ill children (0-18 years). METHODS: We searched English articles in PubMed, PsycINFO, and Embase published during 2000-2018 for articles related to parental, child/adolescent, and provider preference for death location and articles that correlated death location with bereavement or quality of life outcomes. RESULTS: The search results (n = 877 articles and n = 58 abstracts of interest) were reviewed, and 34 relevant articles were identified. Parent, child, and provider preferences, bereavement outcomes, and associated factors all point to some preference for home death. These findings should be interpreted with several caveats: 1) many studies are small and prone to selection bias, 2) not all families prefer home death and some that do are not able to achieve home death due to inadequate home support, 3) studies of bereavement outcomes are lacking. CONCLUSION: Adequate resources are needed to ensure children can die in their chosen location-be that home, hospital, or free-standing hospice. This review highlights research areas needed to better understand death location preference and programs and policies that will support home death for those that desire it.

<https://pubmed.ncbi.nlm.nih.gov/31887402/>

Kain, V. J. and Chin, S. D. (2020). "Conceptually Redefining Neonatal Palliative Care." Adv Neonatal Care 20(3): 187-195.

BACKGROUND: First defined in 2002 by Catlin and Carter, neonatal palliative care (NPC) is a relatively new model of care in neonatal pediatrics, first appearing in the medical literature in the early 1980s. PURPOSE: The purpose of this article is to suggest a conceptual definition of NPC that encompasses all the essential concepts as a way of moving NPC forward by having a consistent approach. METHODS: Following a review of the NPC literature, a thematic analysis as a method for identifying, analyzing, and interpreting patterns of meaning in the definitions ("themes") within the literature was undertaken. FINDINGS: The major themes identified included philosophies of care, support, culture and spirituality, the team, and clinical management. IMPLICATIONS FOR RESEARCH: At the heart of NPC is the primacy of maintaining quality of life, while providing ethical and humane care that supports a "good death." The extensive elements presented in this article are considered essential to a comprehensive and conceptual definition of NPC proposed here.

<https://pubmed.ncbi.nlm.nih.gov/32384328/>

Kaufman, B. D. and Cohen, H. J. (2019). "Palliative care in pediatric heart failure and transplantation." Curr Opin Pediatr 31(5): 611-616.

**PURPOSE OF REVIEW:** Advanced heart failure in children is characterized by dynamic clinical trajectories, uncertainty of prognosis, and intermittent need for difficult decision-making, often related to novel therapeutic interventions with uncertain impact on quality of life. This review will examine the current role of palliative care to support this unique population. **RECENT FINDINGS:** Pediatric heart failure patients commonly die in ICUs with high burden of invasive therapies together with end of life care needs. In addition, several studies advocate for integration of palliative care early in disease trajectory, not only focused on end of life care. Many advocate for the core tenets of palliative care (symptom management, communication of prognosis, and advanced care planning) to be provided by the primary cardiology team, with consultation by pediatric palliative care specialists. There is also a consensus that palliative care training should be incorporated into pediatric advanced heart disease training programs. **SUMMARY:** Palliative care is an important component of pediatric heart failure care. Research and quality improvement efforts are needed to determine the most effective palliative care interventions for children with advanced heart disease. Provision of palliative care is an essential component of training for pediatric heart failure and transplant specialists. <https://pubmed.ncbi.nlm.nih.gov/31335747/>

**Kerr, H., Price, J. and O'Halloran, P. (2020). "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* 189(1): 33-42.**

**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://pubmed.ncbi.nlm.nih.gov/31273561/>

**Kerr, H., Widger, K., Cullen-Dean, G., Price, J. and O'Halloran, P. (2020). ""Transition from children's to adult services for adolescents/young adults with life-limiting conditions: developing realist programme theory through an international comparison". *BMC Palliat Care* 19(1): 115.**

**BACKGROUND:** Managing transition of adolescents/young adults with life-limiting conditions from children's to adult services has become a global health and social care issue. Suboptimal transitions from children's to adult services can lead to measurable adverse outcomes. Interventions are emerging but there is little theory to guide service developments aimed at improving transition. The Transition to Adult Services for Young Adults with Life-limiting conditions (TAYSL study) included development of the TASYL Transition Theory, which describes eight interventions which can help prepare services and adolescents/young adults with life-limiting conditions for a successful transition. We aimed to assess the usefulness of the TASYL Transition Theory in a Canadian context to identify interventions, mechanisms and contextual factors associated with a successful transition from children's to adult services for adolescents/young adults; and to discover new theoretical elements that might modify the TASYL Theory. **METHODS:** A cross-sectional survey focused on organisational approaches to transition was distributed to three organisations providing services to adolescents with life-limiting conditions in Toronto, Canada. This data was mapped to the TASYL Transition Theory to identify corresponding and new theoretical elements. **RESULTS:** Invitations were sent to 411 potentially eligible health care professionals with 56 responses from across the three participating sites. The results validated three of the eight interventions: early start to the transition process; developing adolescent/young adult autonomy; and the role of parents/carers; with partial support for the remaining five. One new intervention was identified: effective communication between healthcare professionals and the adolescent/young adult and their parents/carers. There was also support for contextual factors including those related to staff knowledge and attitudes, and a lack of time to provide transition services centred on the adolescent/young adult. Some mechanisms were supported, including the adolescent/young adult gaining confidence in relationships with service providers and in decision-making. **CONCLUSIONS:** The Transition Theory travelled well between Ireland and Toronto, indicating its potential to guide both service development and research in different contexts. Future research could include studies with adult service providers; qualitative work to further explicate mechanisms and contextual factors; and use the theory prospectively to develop and test new or modified interventions to improve transition.

<https://pubmed.ncbi.nlm.nih.gov/32731863/>

**Leske, V., Guerdile, M. J., Gonzalez, A., Testoni, F. and Aguerre, V. (2020). "Feasibility of a pediatric long-term Home Ventilation Program in Argentina: 11 years' experience." *Pediatr Pulmonol* 55(3): 780-787.**

**BACKGROUND:** Pediatric home ventilation (HV) has increased worldwide. A Home Ventilation Program (HVP) was started in the Pulmonary Department of the "Hospital de Pediatría Prof. Dr. J. P. Garrahan," Argentina, in 2007. This is the largest Argentine national pediatric tertiary care referral center. Limited studies on pediatric HV from Latin American countries have been published. **OBJECTIVE:** This study describes and analyzes the cohort of children admitted to the HVP during an 11 years period. **METHODS:** Longitudinal study. **POPULATION:** all patients (pts) admitted to the HVP between 2007 and 2018. We analyzed demographic and clinical variables, sleep study results, ventilation setting, and start manner collected in a prospective data base. **RESULTS:** A total of 244 pts were admitted. Median age at ventilation start was 9.41 (3.47-14.08) years, 84% of pts had health insurance. The most frequent underlying

diseases were neuromuscular disease (43%) and genetic syndromes (23%). Home-hospital distance was 100-500 km in 16% of cases and greater than 500 km in 34%. Seventy percent of pts had sleep studies before ventilation initiation. Ventilation was started in our general pediatric ward in 83.6%. Noninvasive ventilation was used in 86.1%. The actual number of pts still on follow up is 133 of 244 (54.5%), 16.8% dropped out, 16.4% were transitioned to adult care, 5.32% resolved their sleep-disordered breathing, and 5.32% died. CONCLUSIONS: The HVP admitted pts from all the country. Ventilation was started on the basis of clinical and objective sleep measures. This long-term experience underlines the feasibility of a HVP in an emergent country.

<https://pubmed.ncbi.nlm.nih.gov/31977167/>

**Lewis, F. M., Loggers, E. T., Phillips, F., Palacios, R., Tercyak, K. P., Griffith, K. A., Shands, M. E., Zahlis, E. H., Alzawad, Z. and Almulla, H. A. (2020). "Enhancing Connections-Palliative Care: A Quasi-Experimental Pilot Feasibility Study of a Cancer Parenting Program." *J Palliat Med* 23(2): 211-219.**

Background: In 2018, >75,000 children were newly affected by the diagnosis of advanced cancer in a parent. Unfortunately, few programs exist to help parents and their children manage the impact of advanced disease together as a family. The Enhancing Connections-Palliative Care (EC-PC) parenting program was developed in response to this gap. Objective: (1) Assess the feasibility of the EC-PC parenting program (recruitment, enrollment, and retention); (2) test the short-term impact of the program on changes in parent and child outcomes; and (3) explore the relationship between parents' physical and psychological symptoms with program outcomes. Design: Quasi-experimental two-group design employing both within- and between-subjects analyses to examine change over time and change relative to historical controls. Parents participated in five telephone-delivered and fully manualized behavioral intervention sessions at two-week intervals, delivered by trained nurses. Behavioral assessments were obtained at baseline and at three months on parents' depressed mood, anxiety, parenting skills, parenting self-efficacy, and symptom distress as well as children's behavioral-emotional adjustment (internalizing, externalizing, and anxiety/depression). Subjects: Parents diagnosed with advanced or metastatic cancer and receiving noncurative treatment were eligible for the trial provided they had one or more children aged 5-17 living at home, were able to read, write, and speak English, and were not enrolled in a hospice program. Results: Of those enrolled, 62% completed all intervention sessions and post-intervention assessments. Within-group analyses showed significant improvements in parents' self-efficacy in helping their children manage pressures from the parent's cancer; parents' skills to elicit children's cancer-related concerns; and parents' skills to help their children cope with the cancer. Between-group analyses revealed comparable improvements with historical controls on parents' anxiety, depressed mood, self-efficacy, parenting skills, and children's behavioral-emotional adjustment. Conclusion: The EC-PC parenting program shows promise in significantly improving parents' skills and confidence in supporting their child about the cancer. Further testing of the program is warranted.

<https://pubmed.ncbi.nlm.nih.gov/31613703/>

Listermar, K. H., Sormunen, T. and Rådestad, I. (2020). "Perinatal palliative care after a stillbirth-Midwives' experiences of using Cubitus baby." *Women Birth* 33(2): 161-164.

**BACKGROUND:** Usually, parents remain at the hospital for two or three days after a stillbirth in Sweden, and the routine until recently has been to place the baby in a refrigerator during the night. A device, the Cubitus Baby, a specially designed cot with cooling blocks, was implemented in all 47 delivery wards during 2013 and 2014. **AIM:** To investigate the midwives' experiences of using the device when supporting parents after the stillbirth. **METHOD:** Questionnaires were completed by midwives, and a single open-ended question was analysed using content analysis. **FINDINGS:** 154 midwives responded. Four categories were identified, with two subgroups in each category: Feelings of dignity (Satisfactory feelings in working with grief; Design and function), Caring cooling (The cooling function; A cold baby), Time for farewell (Time together; Time to make your own choice) and Satisfying feelings for the parents (The parents and Cubitus Baby; The possibility for bonding). **CONCLUSIONS:** The midwives found that this practice provided a more dignified and worthwhile form of care. There is no need to separate the stillborn baby from the parents during their stay at the hospital. In modern perinatal palliative care, it is not justifiable to place a stillborn baby in a refrigerator.  
<https://pubmed.ncbi.nlm.nih.gov/31202583/>

Lotstein, D. S. (2020). "Concurrent Care Is Not Enough: More Hospice Reforms Are Needed for Children with Serious Illness." *J Pediatr*, 10.1016/j.jpeds.2020.05.012.

Mahoney, D. P., Brook, I., Fossa, M. and Kang, T. (2020). "Attempting to Define Clinical Productivity Metrics among Pediatric Palliative Care Services at Academic Children's Hospitals." *J Palliat Med* 23(3): 397-400.

**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://pubmed.ncbi.nlm.nih.gov/31403351/>

Martínez Lorenzo, R., González Piñeiro, Y. and Gayoso Couce, M. (2020). "[Experience with paediatric palliative care in a district hospital]." *An Pediatr (Barc)* 93(1): 69-70.

<https://pubmed.ncbi.nlm.nih.gov/32057711/>

McLaughlin, S. N., Song, M. K., Hertzberg, V. and Piazza, A. J. (2020). "Use of Palliative Care Consultation Services for Infants With Life-Threatening Conditions in a Metropolitan Hospital." *Adv Neonatal Care* 20(2): 136-141.

BACKGROUND: Palliative care is becoming an important component for infants with life-limiting or life-threatening conditions and their families. Yet palliative care practices appear to be inconsistent and sporadically used for infants. PURPOSE: The purpose of this study was to describe the use of an established pediatric palliative care team for seriously ill infants in a metropolitan hospital. METHODS: This was a retrospective medical record review. FINDINGS: The population included 64 infants who were admitted to a level IV neonatal intensive care unit (NICU) and then died during hospitalization between January 2015 and December 2016. Most infants died in an ICU (n = 63, 95%), and only 20 infants (31%) received palliative care consultation. Most common reasons for consultation were care coordination, defining goals of care and end-of-life planning, and symptom management. IMPLICATIONS FOR PRACTICE: Palliative care consultation at this institution did not change the course of end-of-life care. Interventions provided by the ICU team to infants surrounding end of life were similar to those in infants receiving palliative care services from the specialists. Our findings may be useful for developing guidelines regarding how to best utilize palliative care services for infants with life-threatening conditions who are admitted to an ICU. IMPLICATIONS FOR RESEARCH: These findings support continued research in neonatal palliative care, more specifically the impact of palliative care guidelines and algorithms.

<https://pubmed.ncbi.nlm.nih.gov/32224820/>

Menon, A. P., Mok, Y. H., Loh, L. E. and Lee, J. H. (2020). "Pediatric Palliative Transport in Critically Ill Children: A Single Center's Experience and Parents' Perspectives." *J Pediatr Intensive Care* 9(2): 99-105.

The transfer of critically ill children from intensive care units (ICUs) to their homes for palliation is seldom described. We report our 10-year pediatric palliative transport experience and conducted a survey to gain parents' perspectives of their child's transport experience. Over the study period, eight patients were transported from our pediatric ICU to their homes or hospice facilities. There were no intratransport adverse events. Parents who participated in the survey responded positively to the transport experience. The availability of a dedicated critical care transport service allowed for palliative transfers to be performed safely. Facilitating transport to allow withdrawal of life support at home is an acceptable option to families as part of holistic end-of-life care.

<https://pubmed.ncbi.nlm.nih.gov/32351763/>

Miller, E. G., Weaver, M. S., Ragsdale, L., Hills, T., Humphrey, L., Williams, C. S. P., Morvant, A., Pitts, B., Waldman, E., Lotstein, D., Linebarger, J., Feudtner, C.

and Klick, J. C. (2020). "Lessons Learned: Identifying Items Felt to Be Critical to Leading a Pediatric Palliative Care Program in the Current Era of Program Development." *J Palliat Med*, 10.1089/jpm.2020.0205.

Background: The experience of starting and growing a pediatric palliative care program (PPCP) has changed over the last 10 years as rapid increases of patient volume have amplified challenges related to staffing, funding, standards of practice, team resilience, moral injury, and burnout. These challenges have stretched new directors' leadership skills, yet, guidance in the literature on identifying and managing these challenges is limited. Methods: A convenience sample of 15 PPCP directors who assumed their duties within the last 10 years were first asked the following open-ended question: What do you wish you had known before starting or taking over leadership of a PPCP? Responses were grouped into themes based on similarity of content. Participants then ranked these themes based on importance, and an online discussion further elucidated the top ten themes. Results: Thirteen directors responded (86.7%; 69% female). The median age of their current-state PPCP was 5.1 years (range: 0.3-9.3), and the median number of covered pediatric-specific hospital beds was 283 (range: 170-630). Their responses generated 51 distinct items, grouped into 17 themes. Themes ranked as most important included "Learn how to manage, not just lead," "Negotiate everything before you sign anything," and "Balance patient volume with scope of practice." Conclusion: These themes regarding challenges and opportunities PPCP directors encountered in the current era of program growth can be used as a guide for program development, a self-assessment tool for program directors, a needs-assessment for program leadership, and a blueprint for educational offerings for PPCP directors. <https://pubmed.ncbi.nlm.nih.gov/32552386/>

Mitchell, S., Bennett, K., Morris, A., Slowther, A. M., Coad, J. and Dale, J. (2020). "Achieving beneficial outcomes for children with life-limiting and life-threatening conditions receiving palliative care and their families: A realist review." *Palliat Med* 34(3): 387-402.

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://pubmed.ncbi.nlm.nih.gov/31431129/>

Mulligan, S., Guerin, S., McKiernan, A., Brown, A., Hartnett, M., Gray, D. and Kiernan, G. (2019). "The core features and outcomes of a specialised camp programme for children with life-limiting conditions and their families: A qualitative multi-perspective approach." *J Child Health Care*, 10.1177/1367493519875593: 1367493519875593.

Previous research has reported that the families of children with enduring and life-limiting health conditions are at risk of negative psychosocial effects. Adjunct to medical interventions, specialist camp programmes have been developed to promote familial adjustment. However, limited research has been carried out in this area. The aim of this study was to describe the core features and outcomes of a specialised camp programme for children with life-limiting conditions (LLC) and their family. Semi-structured interviews were conducted with four professionals, three volunteers involved in facilitating the programme and two mothers representing families that attended the programme. Multiple perspectives were sought to gain a detailed understanding of the programme and outcomes. Data were analysed through an inductive thematic approach. There was considerable overlap among participant groups on the core features and outcomes of the programme. Thematically, core features are described in terms of familial togetherness, peer interaction, safety and positive experiences. Noted outcomes include lasting memories, continued peer relations for parents and siblings and enhancement of relationships between family members and professionals. Findings suggest that specialised camp programmes may provide families of children with LLC with positive experiences that support adjustment, although further research is required.

<https://pubmed.ncbi.nlm.nih.gov/31594387/>

National Guideline, C. (2019). Evidence review: Optimal transition and facilitating discharge: End of life care for adults: service delivery: Evidence review M. London, National Institute for Health and Care Excellence (UK)  
Copyright © NICE 2019.

Optimal transition between care settings for an adult who is approaching the end of their life is critical to providing the best standards of care and to meet the wishes and needs of the person set out in advance care plans. The consequences of a person dying in a setting which is inappropriate or not their preferred place of care can have considerable impact upon them and their carers, family and friends. The carers, family and friends' distress at the death may be exacerbated by the knowledge that it did not happen as the person who died wished. SMOOTH TRANSITIONS: Transition is a purposeful, planned process that addresses the medical, social and psychological needs of a person as they move from one system/place to another. Throughout this guideline many transition points have been identified, for example from one service provider to another, from one setting to another from one age group to another and

from one life style to another. There appear to be no studies which are universally applicable to all transitions. Studies have included transitions between teams for example within a hospital or from hospital to home. Usually systems have been developed locally to meet identified problems with transitions, for example the use of a form or computer template, patient held records similar to those used in ante natal care. Probably the group where transition has been studied most is the transfer from children's to young persons or adult services and most of this work has been undertaken in cancer service and for those with learning difficulties. Another area where work has been undertaken is in the discharge of people from hospital to home and the copying letters to patients is an initiative, which has its roots in this area. There appear to be some principles, which can help to make these transitions smoother. These include effective methods of communication, verbal, written, and electronic, between all those involved. It is most effective if the person who is being transferred and their relatives, carers and those important to them are all included. However there does not appear to be one factor that overwhelmingly contributes to a smooth discharge but a number of things which taken in combination makes transitions smoother. RAPID DISCHARGE: For patients who require rapid discharge to their preferred place of death (usually their home from hospital) there is a need for a clear process that allows for the timely initiation of resources with which to facilitate this care planning. This may or may not necessitate rapid access to specialist palliative care. It is dependent on the patient's wishes being known to health care professional and relatives usually in the form of an Advanced Care Plan (ACP) and Do Not Resuscitate (DNR) orders and the ability of local system processes to enable the prompt implementation of support services once the patient has arrived at their preferred place of death. As with all rapid discharges what underpins them is effective communication with all parties and clear, concise documentation that allows for a smooth transition of care. With an ever-increasing pressure on services provided by health care providers, there is a widespread recognition that effective discharge planning from the time of admission is essential to enable a patient centred pathway, which is both safe and effective. The rapid discharge of patients is multi-factorial being dependent on realistic estimated day of discharge, senior decision making, effective communication, liaison with other health care partners, the families and most importantly the patient themselves. Much has been written in the literature regarding discharge, which has accumulated in national programmes such as the 'SAFER' bundle and most recently the 'End PJ paralysis' campaign both of which have seen improvements in improving the discharge process for patients.

<https://pubmed.ncbi.nlm.nih.gov/32614547/>

Niinomi, K., Soejima, M., Hiraga, K., Kodama, S., Okazaki, S. and Nakao, S. (2020). "Effectiveness of a Volunteer Training Program on the Learning Support of Children in Hospice Palliative Care." *Am J Hosp Palliat Care* 37(2): 100-107.

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://pubmed.ncbi.nlm.nih.gov/31272189/>

**Paul, S., Cree, V. E. and Murray, S. A. (2019). "Integrating palliative care into the community: the role of hospices and schools." *BMJ Support Palliat Care* 9(4): e31.**

OBJECTIVES: Palliative care services have, up to now, paid insufficient attention to social aspects of dying and bereavement and this has affected how patients and their families experience end of life and bereavement within their communities. New public health approaches to palliative care offer a different way forward by seeking to develop communities that support death and bereavement. Such approaches are now a priority for the majority of hospices in the UK and work with schools has been identified as a key area of work. Practice that engages schools and children on issues concerning end-of-life care is, however, underdeveloped and under documented. This research explored the role of hospices in working with schools to promote education and support around end-of-life and bereavement experiences. METHODS: Action research was used to explore the potential for hospices to work with schools and engage participants in change processes. The research was conducted in 1 hospice and 2 primary schools in Scotland. Participants included children, parents and school and hospice staff. RESULTS: Seven innovations were identified that were found to be useful for the school curriculum and the relationship between hospices, school communities and wider society. A model for integrated practice between hospices and schools is suggested. CONCLUSIONS: This research adds to knowledge about how hospices might engage in community engagement activities that encourage school staff to develop greater openness and support around end-of-life and bereavement care for their children. This will require a rethinking of normal hospice services to also participate in community capacity building.

<https://pubmed.ncbi.nlm.nih.gov/27515864/>

**Podda, M., Schiavello, E., Visconti, G., Clerici, C. A., Armiraglio, M., Casiraghi, G., Ambroset, S., Grossi, A., Rizzi, B., Lonati, G. and Massimino, M. (2020). "Customised paediatric palliative care: Integrating oncological and palliative care priorities." *Acta Paediatr*, 10.1111/apa.15415.**

AIM: To describe the experience involving the early introduction of palliative care (PC) in oncological patients treated within the paediatric oncology unit of the Istituto Nazionale Tumori of Milan and compare this cohort with a cohort of patients resident in the same

area treated before the introduction of early palliative care. **METHODS:** A virtual team was assembled in 2015. The PC providers operate outside the hospital. Conference calls were scheduled to discuss patients' problems. This sample was compared with the clinical records of patients residing in the same area who died between 2009 and 2014. **RESULTS:** Between January 2015 and April 2019, 41 patients residing in the Milan area mainly with CNS tumours or sarcomas were referred to the team. Comparing the results with the previous cohort, there was a rise in the number of patients dying at home or in a hospice and the duration of PC increased over time. From 2015, none of the patients died in an intensive care unit. **CONCLUSION:** Patients managed by the virtual team were able to continue their cancer treatments, take part in Phase I trials and receive PC. All patients with a poor prognosis should have PC at an early stage.

<https://pubmed.ncbi.nlm.nih.gov/32544257/>

**Quinn, M., Weiss, A. B. and Crist, J. D. (2020). "Early for Everyone: Reconceptualizing Palliative Care in the Neonatal Intensive Care Unit." Adv Neonatal Care 20(2): 109-117.**

**BACKGROUND:** Palliative care (PC) in the neonatal intensive care unit (NICU) is often provided exclusively to infants expected to die. Standards of care support providing PC early after diagnosis with any condition likely to impact quality of life. **PURPOSE:** To determine the state of early PC practice across populations to derive elements of early PC applicable to neonates and their families and demonstrate their application in practice. **SEARCH STRATEGY:** Multiple literature searches were conducted from 2016 to 2019. Common keywords used were: palliative care; early PC; end of life, neonate; NICU; perinatal PC; pediatric PC; family-centered care; advanced care planning; palliative care consultant; and shared decision-making. **FINDINGS:** Early PC is an emerging practice in adult, pediatric, and perinatal populations that has been shown to be helpful for and recommended by families. Three key elements of early PC in the NICU are shared decision-making, care planning, and coping with distress. A hypothetical case of a 24-week infant is presented to illustrate how findings may be applied. Evidence supports expansion of neonatal PC to include infants and families without terminal diagnoses and initiation earlier in care. **IMPLICATIONS FOR PRACTICE:** Involving parents more fully in care planning activities and decision-making and providing structured support for them to cope with distress despite their child's prognosis are essential to early PC. **IMPLICATIONS FOR RESEARCH:** As early PC is incorporated into practice, strategies should be evaluated for feasibility and efficacy to improve parental and neonatal outcomes. Researchers should consider engaging NICU parent stakeholders in leading early PC program development and research.

<https://pubmed.ncbi.nlm.nih.gov/31990696/>

**Ramelet, A. S., Bergstraesser, E., Grandjean, C., Dorsaz, A., Fahrni-Nater, P., Cignacco, E. and Zimmerman, K. (2020). "Comparison of End-of-Life Care Practices Between Children With Complex Chronic Conditions and Neonates Dying in an ICU Versus Non-ICUs: A Substudy of the Pediatric End-of-Life CARE Needs in Switzerland (PELICAN) Project." Pediatr Crit Care Med 21(5): e236-e246.**

**OBJECTIVES:** To describe and compare characteristics of care provided at the end of life for children with chronic complex conditions and neonates who died in an ICU with

those who died outside an ICU. DESIGN: Substudy of a nation-wide retrospective chart review. SETTING: Thirteen hospitals, including 14 pediatric and neonatal ICUs, two long-term institutions, and 10 community-based organizations in the three language regions of Switzerland. PATIENTS: One hundred forty-nine children (0-18 yr) who died in the years 2011 or 2012. Causes of death were related to cardiac, neurologic, oncological, or neonatal conditions. INTERVENTIONS: None. MEASUREMENTS AND MAIN RESULTS: Demographic and clinical characteristics, therapeutic procedures, circumstances of death, and patterns of decisional processes were extracted from the medical charts. Ninety-three (62%) neonates (median age, 4 d) and children (median age, 23 mo) died in ICU, and 56 (38%) with a median age of 63 months outside ICU. Generally, ICU patients had more therapeutic and invasive procedures, compared with non-ICU patients. Changes in treatment plan in the last 4 weeks of life, such as do-not-resuscitate orders occurred in 40% of ICU patients and 25% of non-ICU patients ( $p < 0.001$ ). In the ICU, when decision to withdraw life-sustaining treatment was made, time to death in children and newborns was 4:25 and 3:00, respectively. In institutions where it was available, involvement of specialized pediatric palliative care services was recorded in 15 ICU patients (43%) and in 18 non-ICU patients (78%) ( $p = 0.008$ ). CONCLUSIONS: This nation-wide study demonstrated that patients with a complex chronic condition who die in ICU, compared with those who die outside ICU, are characterized by fast changing care situations, including when to withdraw life-sustaining treatment. This highlights the importance of early effective communication and shared decision making among clinicians and families.

<https://pubmed.ncbi.nlm.nih.gov/32091504/>

**Ribbers, S., Wager, J., Hartenstein-Pinter, A., Zernikow, B. and Reuther, M. (2020). "Core outcome domains of pediatric palliative care for children with severe neurological impairment and their families: A qualitative interview study." *Palliat Med* 34(3): 309-318.**

BACKGROUND: The interest in outcome measurement in pediatric palliative care is rising. To date, the majority of studies investigating relevant outcomes of pediatric palliative care focus on children with cancer. Insight is lacking, however, about relevant outcome domains for children with severe neurological impairment and their families. AIM: The aim of this study was to identify meaningful outcome domains of pediatric palliative care for children with severe neurological impairment and their families. DESIGN: A qualitative research design following a constructivist research paradigm was employed. Guided interviews were conducted with parents of children with life-limiting conditions and severe neurological impairment and professional caregivers. The data were analyzed using qualitative content analysis. SETTING: Overall, 10 cooperating pediatric palliative care institutions across Germany (outpatient and inpatient settings) aided in the recruitment of eligible parents and professional caregivers. A total of 11 interviews with 14 parents and 17 interviews with 20 professional caregivers were conducted. RESULTS: Six core outcome domains of pediatric palliative care for children with severe neurological impairment and their families were identified, namely (1) symptom control, (2) respite and support, (3) normalcy, (4) security, (5) empowerment, and (6) coping with the disease, each consisting of 1 to 13 individual aspects. CONCLUSION: As for other diagnostic groups, symptom control is a relevant outcome domain for children with severe neurological impairment. However, other outcome domains which focus on the whole family and take into account the long

disease trajectory, such as respite and support, security, empowerment, and coping with the disease, are also crucial.

<https://pubmed.ncbi.nlm.nih.gov/31680627/>

**Rost, M., De Clercq, E., Rakic, M., Wangmo, T. and Elger, B. (2020). "Barriers to Palliative Care in Pediatric Oncology in Switzerland: A Focus Group Study." *J Pediatr Oncol Nurs* 37(1): 35-45.**

**Introduction:** For children with cancer, early integration of pediatric palliative care in conjunction with curative treatments is recommended. In Switzerland, pediatric palliative care is mostly provided by an interdisciplinary primary oncology team that is mainly composed of nurses. However, only a small fraction of children receive pediatric palliative care and only a minority of them in a timely manner. The main aim was to identify barriers to the provision of pediatric palliative care in Swiss pediatric oncology. **Method:** This qualitative study consisted of five focus groups. In total, 29 pediatric oncology providers participated (13 nurses, 11 physicians, 4 psycho-oncologists, 1 social worker). Data were analyzed employing applied thematic analysis. **Results:** Analysis revealed eleven barriers: lack of financial resources, lack of prejob education regarding pediatric palliative care, lack of awareness in politics and policy making, absence of a well-established nationwide bridging care system, insufficient psychosocial and professional supervision for staff, understaffing, inadequate infrastructure of hospitals, asymmetry of factual and emotional knowledge between parents and providers, cultural aspects, irrational parental hopes, and "the unspoken." **Discussion:** Awareness should be raised for pediatric palliative care (in particular in demarcation from palliative care in adults) among politics and policy makers which could lead to increased financial resources that, in turn, could be used to improve bridging care, hospital's infrastructure, and team support. More flexibility for care determining factors is needed, for example, with respect to convening team meetings, short-termed staffing, and reimbursement at the interface between inpatient and outpatient services.

<https://pubmed.ncbi.nlm.nih.gov/31478463/>

**Rothschild, C. B. and Derrington, S. F. (2020). "Palliative care for pediatric intensive care patients and families." *Curr Opin Pediatr* 32(3): 428-435.**

**PURPOSE OF REVIEW:** Children with medical or surgical critical illness or injury require skillful attention to physical, emotional, psychological, and spiritual needs, whereas their families need support and guidance in facing life-threatening or life-changing events and gut-wrenching decisions. This article reviews current evidence and best practices for integrating palliative care into the pediatric intensive care unit (PICU), with a focus on surgical patients. **RECENT FINDINGS:** Palliative care is best integrated in a tiered approach, with primary palliative care provided by the PICU and surgical providers for all patients and families, including basic symptom management, high-quality communication, and end-of-life care. Secondary and tertiary levels of care involve unit or team-based 'champions' with additional expertise, and subspecialty palliative care teams, respectively. PICU and surgical providers should be able to provide primary palliative care, to identify patients and families for whom a palliative care consult would be helpful, and should be comfortable introducing the concept of palliative care to families. **SUMMARY:** This review provides a framework and tools to enable PICU and

surgical providers to integrate palliative care best practices into patient and family care. <https://pubmed.ncbi.nlm.nih.gov/32374580/>

Schleien, C., Pryce, P. and Fidler, G. (2019). "Falling Short: Lack of Equality in End-of-Life Care for Children." *Pediatr Crit Care Med* 20(9): 897-898. <https://pubmed.ncbi.nlm.nih.gov/31483385/>

Snaman, J., McCarthy, S., Wiener, L. and Wolfe, J. (2020). "Pediatric Palliative Care in Oncology." *J Clin Oncol* 38(9): 954-962.

Pediatric palliative care aims to alleviate suffering and improve the quality of life of children with serious disease and increase support for their parents and other family members. Integration of palliative care into the routine care of children, adolescents, and young adults with cancer has resulted in improved outcomes in patients and their families. The field of pediatric palliative oncology-encompassing primary palliative care provided by the multidisciplinary oncology team as well as subspecialty palliative care provided by the palliative care team for more complex cases-is unique from palliative care in adults given its focus on care of the child and the larger family. In this review, we focus on advancements in the specific domains within pediatric palliative oncology care including family-centered communication, assessment and management of physical symptoms and distress, psychosocial concerns, and spiritual considerations of the patient, parents, and siblings.

<https://pubmed.ncbi.nlm.nih.gov/32023163/>

Taylor, J., Booth, A., Beresford, B., Phillips, B., Wright, K. and Fraser, L. (2020). "Specialist paediatric palliative care for children and young people with cancer: A mixed-methods systematic review." *Palliat Med* 34(6): 731-775.

BACKGROUND: Specialist paediatric palliative care services are promoted as an important component of palliative care provision, but there is uncertainty about their role for children with cancer. AIM: To examine the impact of specialist paediatric palliative care for children and young people with cancer and explore factors affecting access. DESIGN: A mixed-methods systematic review and narrative synthesis (PROSPERO Registration No. CRD42017064874). DATA SOURCES: Database (CINAHL, Cochrane Database of Systematic Reviews, Embase, MEDLINE, PsycINFO) searches (2000-2019) identified primary studies of any design exploring the impact of and/or factors affecting access to specialist paediatric palliative care. Study quality was assessed using The Mixed Methods Appraisal Tool. RESULTS: An evidence base of mainly low- and moderate-quality studies (n = 42) shows that accessing specialist paediatric palliative care is associated with less intensive care at the end of life, more advance care planning and fewer in-hospital deaths. Current evidence cannot tell us whether these services improve children's symptom burden or quality of life. Nine studies reporting provider or family views identified uncertainties about what specialist paediatric palliative care offers, concerns about involving a new team, association of palliative care with end of life and indecision about when to introduce palliative care as important barriers to access. There was evidence that children with haematological malignancies are less likely to access these services. CONCLUSION: Current evidence suggests that children and young people with cancer receiving specialist palliative care

are cared for differently. However, little is understood about children's views, and research is needed to determine whether specialist input improves quality of life.  
<https://pubmed.ncbi.nlm.nih.gov/32362212/>

**Tatterton, M. J. (2019). "Approaches to community-based palliative care provision by children's hospices in the UK." *Nurs Child Young People* 31(5): 42-48.**

The number of children in the UK with life-limiting conditions and the demand for home-based palliative care is increasing. Children's hospices remain a dominant provider of palliative care. This study aimed to determine the approaches taken by children's hospices across the UK in meeting the planned and unplanned health needs of children and their families who receive palliative care at home. In addition, the survey aimed to identify the professional composition of community teams and the number of children and families supported by each service. An internet-based questionnaire survey was sent to all children's hospices in the UK, comprising ten questions exploring the size of the team, geographical areas covered, workforce composition, services offered and approaches to managing unplanned, out of hours care. Responses were received from 14 (26%) of the hospices. A total of 1,618 children and their families were being cared for by these hospices, of whom 825 received care at home. Registered nurses constituted the greatest proportion of staff and were employed by all teams. Care provided at home was broadly split into two categories: planned short breaks and responsive palliative nursing. The latter comprised advance care planning, anticipatory prescribing and active symptom control. Out of hours care was usually offered in the form of telephone support. Models of community-based care are evolving to include nurses practising at specialist and advanced levels, allowing more children with increasingly complex conditions to be cared for at home.  
<https://pubmed.ncbi.nlm.nih.gov/31486600/>

**Taylor, N., Liang, Y. F. and Tinnion, R. (2020). "Neonatal palliative care: a practical checklist approach." *BMJ Support Palliat Care* 10(2): 191-195.**

**OBJECTIVES:** Following publication of detailed national neonatal palliative care guidance, practical regional guidance, in the form of multidisciplinary 'checklists', was implemented aiming to improve the quality of neonatal palliative care. **METHODS:** Case note audit was used to examine the quality of locally delivered neonatal palliative care before and after regional guidance implementation. **RESULTS:** 27 patients were allocated to the 'before' cohort and 10 to the 'after' cohort. Introduction of the checklists was apparently associated with improvements in domains of pain relief and comfort care, monitoring, fluids and nutrition, completion of diagnostics, treatment ceiling decisions, resuscitation status and discussion with parents. Other support for parents was poorly adhered to. **CONCLUSION:** Regional guidance improved some aspects of palliative care delivery though other areas remained suboptimal. Other strategies, for example, consultation with paediatric palliative care services, need to be considered to further improve the quality of palliative care delivered to babies with life-limiting illnesses.  
<https://pubmed.ncbi.nlm.nih.gov/30224406/>

Verhagen, A. A. E. (2020). "Addressing fragmentation in paediatric palliative care." *Acta Paediatr* 109(3): 620.  
<https://pubmed.ncbi.nlm.nih.gov/31560802/>

Weaver, M. S., Neumann, M. L., Navaneethan, H., Robinson, J. E. and Hinds, P. S. (2020). "Human Touch via Touchscreen: Rural Nurses' Experiential Perspectives on Telehealth Use in Pediatric Hospice Care." *J Pain Symptom Manage*, 10.1016/j.jpainsymman.2020.06.003.

CONTEXT: Telemedicine has the potential to extend care reach and access to home-based hospice services for children. Few studies have explored nurse perspectives regarding this communication modality for rural pediatric cohorts. OBJECTIVES: The objective of this qualitative study was to learn from the experiences of rural hospice nurses caring for children at the end of life using telehealth modalities to inform palliative communication. METHODS: Voice-recorded qualitative interviews with rural hospice nurse telehealth users inquiring on nurse experiences with telehealth. Semantic content analysis was used. RESULTS: About 15 hospice nurses representing nine rural hospice agencies were interviewed. Nurses participated in an average of eight telehealth visits in the three months prior. Nurses were female with a mean age of 38 years and an average of seven years of hospice nursing experience. Five themes about telehealth emerged: accessible support, participant inclusion, timely communication, informed and trusted planning, and familiarity fostered. Each theme had both benefits and cautions associated as well as telehealth suggestions. Nurses recommended individualizing communication, pacing content, fostering human connection, and developing relationships even with technology use. CONCLUSION: The experiences of nurses who use telehealth in their care for children receiving end-of-life care in rural regions may enable palliative care teams to understand both the benefits and challenges of telehealth use. Nurse insights on telehealth may help palliative care teams better honor the communication needs of patients and families while striving to improve care access.

<https://pubmed.ncbi.nlm.nih.gov/32525081/>

Weaver, M. S., Robinson, J. E., Shostrom, V. K. and Hinds, P. S. (2020). "Telehealth Acceptability for Children, Family, and Adult Hospice Nurses When Integrating the Pediatric Palliative Inpatient Provider during Sequential Rural Home Hospice Visits." *J Palliat Med* 23(5): 641-649.

Background: Children in rural geographies are not universally able to access pediatric-trained palliative or hospice providers. Objective: Determine whether telehealth inclusion of a familiar pediatric palliative care provider during the first two home-based hospice visits was acceptable to children, families, and adult-trained home hospice nurses in rural settings. Design: Case series. Setting: Home hospice in rural Midwest. Participants: Patients <18 years of age enrolling in home hospice for end-of-life care. Measurements: The acceptability of telehealth inclusion of a hospital-based pediatric palliative care provider in home hospice visits to the family caregiver and home hospice nurse was measured using the Technology Acceptance Model Questionnaires with the inclusion of the child perspective when possible. Results: Fifteen patients mean age of seven years enrolled. Family caregiver included 11 mothers (73%), 2 grandmothers (13%), and 2 fathers (13%). Fifteen nurses from nine hospice agencies participated.

Twelve families (80%) included additional relatives by telehealth modality. Home distance averaged 172 miles with mean eight hours saved by accessing telehealth encounter. Visit content was primarily caregiver support, quality of life, goals of care, symptom management, and medication review. Telehealth acceptability improved between time points and was higher in family caregivers (4.3-4.9 on 5-point scale;  $p = 0.001$ ) than hospice nurses (3.2-3.8 on 5-point scale;  $p = 0.05$ ). All children able to self-report stated a "like" for telehealth, citing six reasons such as "being remembered" and "medical knowledge and care planning." Conclusions: Pediatric palliative telehealth visits partnered with in-person hospice nurse offer acceptable access to services, while extending support.

<https://pubmed.ncbi.nlm.nih.gov/31808722/>

Weingarten, K., Macapagal, F. and Parker, D. (2020). "Virtual Reality: Endless Potential in Pediatric Palliative Care: A Case Report." J Palliat Med 23(1): 147-149.

Pediatric palliative care deals with the physical, psychosocial, and spiritual concerns of patients and their families. And to do this, clinicians must use all the tools at their disposal, including pharmacological and nonpharmacological modalities. Virtual reality is quickly becoming a useful tool in many areas of medicine, including surgical planning, simulation training, rehabilitation, and pain prevention and treatment. Recently it has been used in the adult palliative care population, for symptom management, and memory and legacy creation. We present a case report for, what we believe to be, the first time in the pediatric palliative care population.

<https://pubmed.ncbi.nlm.nih.gov/31170022/>

Ziegler, T. R. and Kuebelbeck, A. (2020). "Close to Home: Perinatal Palliative Care in a Community Hospital." Adv Neonatal Care 20(3): 196-203.

**BACKGROUND:** Advances in prenatal testing and diagnosis have resulted in more parents learning during pregnancy that their child may die before or shortly after birth. These advances in testing and diagnosis have also resulted in more parents choosing, despite the diagnosis, to continue their pregnancies and pursue a palliative approach to their infant's short life. Perinatal hospice and palliative care is a growing model of care developed in response to these parents' previously unmet needs. A seldom-discussed opportunity to provide this care exists in outlying community hospitals, which are ideally placed to provide care close to home for families who have chosen comfort measures and time with their child. **PURPOSE:** This article reviews the definition and utility of perinatal palliative care, the population it serves, attempts to support a rationale for development of community-based programs, and describes one community hospital's experience with perinatal palliative care in their community. **METHODS/SEARCH STRATEGY:** This article describes the development and processes of a perinatal palliative care program at a community hospital in Fredericksburg, Virginia. **IMPLICATIONS FOR PRACTICE:** Perinatal palliative care can be developed with the assistance of already existing training materials, resources, and staff. While the cohort of patients may be small, implementing perinatal palliative care in a community setting may result in wider availability of this care and more accessible options for these families. **IMPLICATIONS FOR RESEARCH:** Research possibilities include developing a template for creating a perinatal palliative care program at community hospitals that could be replicated elsewhere; assessing parental satisfaction and quality indicators of

perinatal palliative care at community hospitals and at referral hospitals; and assessing outcomes in various settings.

<https://pubmed.ncbi.nlm.nih.gov/32384326/>



**Together for Short Lives**

New Bond House, Bond Street, Bristol, BS2 9AG

T: 0117 989 7820

E: [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)

**[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)**

Registered charity in England and Wales (1144022) and Scotland (SC044139) and a company limited by guarantee (7783702).