

# Palliative Pain Care in Children and Adolescents



## International Association for the Study of Pain

---

Palliative care for people of all ages, including children, was recognized in 2014 as an integral component of universal health coverage, with a need to increase access given the benefit of such care [1] and can be argued to be a human right [2]. There are an estimated 21 million children globally with non-communicable and communicable diseases, such as HIV, MDR- and XDR-tuberculosis that could benefit from palliative care; 98% live in LMIC's [3]. Eight million children are estimated to require specialized CPC [3]. Estimated prevalence rates of the need for CPC in children aged 0 to 19 years range from 20 per 10,000 in the United Kingdom (high income country) to almost 120 per 10,000 children in Zimbabwe (low income country) [3]. The prevalence of life-limiting conditions appears to be rising based on improved survival [4] with higher rates in more deprived populations [5]. CPC covers a wide range of illnesses with non-cancer causes constituting around 80% of cases; the majority of conditions are distinct from those seen in adult palliative care [3,4].

### Characteristics of pain

- Pain features prominently across the spectrum of conditions seen in CPC with 50% or greater reporting pain in both cancer and non-cancer groups [6,7,8,9,10,11].
- Pain and other symptoms are commonly interrelated, including fatigue and anxiety in children with cancer, and feeding intolerance and altered sleep in children with neurological conditions; this requires a wider focus and skill set than just managing pain [11,12,13].
- In CPC, the pain associated with cancer diagnoses requires rapid assessment and adjustment in pain management; in contrast children with neurological conditions often involves acute on chronic management over months to years [10,11].
- Acute, procedural and treatment-related pain are common in children with severe illnesses, many of whom are supported by CPC.
- Nociceptive pain is a common etiology of cancer pain, with peripheral or central neuropathic pain conditions a less common consideration.
- Pain in children with HIV includes sensory neuropathy as a frequent complication of the disease and some treatments [14].
- Central neuropathic pain and visceral hyperalgesia are possible sources of chronic pain in children with severe impairment of the central nervous system [15].

## Assessment

- The etiology of pain in CPC is often multifactorial making individualized assessment important; at times, proxy reporting from the child's carer is necessary.
- Assessment should be interdisciplinary, conducted by professionals trained in pediatrics, and with a family-centered care focus.
- Pain assessment tools are unidimensional and only play a small part in the multi-dimensional CPC evaluation.
- No one pain assessment tool is fit for purpose across all ages and stages of development [16].
- Reliable and well validated tools exist for all childhood groups, from the extreme premature infant and children who are unable to communicate, to the older adolescent [16,17].

## Management

- An interdisciplinary team is essential to deliver individualized, holistic pain management for the child and their family that integrates pharmacological and non-pharmacological strategies.
- Non-pharmacological strategies are available to manage pain in newborn infants [18].
- Good communication is essential with management strategies openly discussed and anxieties or misconceptions actively addressed.
- Assessment and management guidelines very applicable to CPC exist for:
  - Acute and procedural pain in children (Australian and New Zealand College of Anaesthetists) [17].
  - Persisting pain in children with medical illnesses including cancer (World Health Organization) [19].
  - Children with significant impairment of the central nervous system (American Academy of Pediatrics) [20].
- Any therapy commenced should be frequently monitored and modified, as appropriate, to maximize pain relief.
- Pain management is not always straightforward and specialist advice should be sought when initial, basic approaches are not effective.

## Medication

- Published evidence for medications in CPC are generally lacking with extrapolation often from studies in healthy adults or those suffering from cancer.
- Extrapolations should be done with caution as children and adults differ in anatomy, physiology and, more importantly, their cognitive responses to pain and analgesia; these differences are most pronounced in the neonatal period [18,21] and in children with neurological conditions [20].
- Opioids are a therapeutic mainstay in CPC, especially in children with a cancer diagnosis.
- Access to medications remains a barrier around the world, especially access to opioids [22,23] which has a negative impact on managing pain in CPC [24].

## References

- [1] World Health Assembly, 67. Strengthening of palliative care as a component of comprehensive care throughout the life course. WHA67.19, 2014
- [2] Brennan F. Palliative care as an international human right. *J Pain Symptom Manage* 2007; 33(5):494-499
- [3] Connor SR, Downing J, Marston J. Estimating the global need for palliative care for children: A cross-sectional analysis. *J Pain Symptom Manage* 2017 Feb; 53(2):171-177. doi:10.1016/j.jpainsymman.2016.08.020. Epub 2016 Oct 17.
- [4] Fraser LK, Miller MM, Hain R, Norman P, Aldridge J, McKinney PA, Parslow RC. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics* 2012 Apr; 129(4):e923-e929. doi:10.1542/peds.2011-2846. Epub 2011 Nov 29.
- [5] Norman P, Fraser L. Prevalence of life-limiting conditions in children and young people in England: Time trends by area type. *Health Place* 2014; 26:171-179. Doi:10.1016/j.healthplace.2014.01.002.
- [6] Feudtner C, Kang TI, Hexem KR, Friedrichsdorf SJ, Osenga K, Siden H, Friebert SE, Hays RM, Dussel V, Wolfe J. Pediatric palliative care patients: A prospective multicentre cohort study. *Pediatrics* 2011 Jun; 127(6):1-8. doi:10.1542/peds.2010-3225. Epub 2011 May 9.
- [7] Drake R, Frost JJ, Collins JJ. The symptoms of dying children. *J Pain Symptom Manage* 2003 Jul; 26(1):594-603.
- [8] Gaughan DM, Hughes MD, Seage GR, Selwyn PA, Carey VJ, Gortmaker SL, Oleske JM. The prevalence of pain in pediatric human immunodeficiency virus/acquired immunodeficiency syndrome as reported by participants in the Pediatric Late Outcomes Study (PACTG 219). *Pediatrics* 2002; 109(6):1144-52
- [9] Goldman A, Hewitt M, Collins GS, Childs M, Hain R, United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses' Forum Palliative Care Working Group. Symptoms in children/young people with progressive malignant disease: United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses Forum survey. *Paediatrics* 2006 Jun; 117(6):e1179-86
- [10] Friedrichsdorf SJ, Postier AC, Andrews GS, Hamre KE, Steele R, Siden H. Pain reporting and analgesia management in 270 children with a progressive neurologic, metabolic or chromosomally based condition with impairment of the central nervous system: cross-sectional, baseline results from an observational, longitudinal study. *J Pain Res.* 2017 Jul 31; 10:1841-1852. doi: 10.2147/JPR.S138153. eCollection 2017.
- [11] Steele R, Siden H, Cadell S, Davies B, Andrews G, Feichtinger L, Singh M. Charting the territory: symptoms and functional assessment in children with progressive, non-curable conditions. *Arch Dis Child.* 2014 Aug; 99(8):754-62. doi: 10.1136/archdischild-2013-305246. Epub 2014 May 15.
- [12] Rasmussen LA, Grégoire MC. Challenging neurological symptoms in paediatric palliative care: An approach to symptom evaluation and management in children with neurological impairment. *Paediatr Child Health.* 2015 Apr; 20(3):159-65.
- [13] Hauer J. Feeding Intolerance in Children with Severe Impairment of the Central Nervous System: Treatment and Prevention. *Children (Basel).* 2017 Dec; 5(1). pii: E1. doi:10.3390/children5010001. Available at <https://www.mdpi.com/2227-9067/5/1/1>
- [14] IASP June 2010: Painful HIV-Associated Sensory Neuropathy. Available at [http://s3.amazonaws.com/rdcms-iasp/files/production/public/Content/ContentFolders/Publications2/PainClinicalUpdates/Archives/PCU\\_2010\\_June\\_2010-final\\_1390261293852\\_6.pdf](http://s3.amazonaws.com/rdcms-iasp/files/production/public/Content/ContentFolders/Publications2/PainClinicalUpdates/Archives/PCU_2010_June_2010-final_1390261293852_6.pdf)
- [15] IASP 2014-2015: Central Neuropathic Pain. Available at <http://s3.amazonaws.com/rdcms-iasp/files/production/public/AM/Images/GYAP/Central%20Neuropathic%20Pain%20no%20color.pdf>
- [16] von Baeyer CL, Spagrud LJ. Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. *Pain* 2007 Jan; 127(1-2):140-150
- [17] Schug SA, Palmer GM, Scott DA, Halliwell R, Trinca J; APM:SE Working Group of the Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine (2015), Acute Pain Management: Scientific Evidence (4th edition), ANZCA & FPM, Melbourne. Chapter 9: The Paediatric Patient: 409-514. Available at [http://fpm.anzca.edu.au/documents/apmse4\\_2015\\_final](http://fpm.anzca.edu.au/documents/apmse4_2015_final)
- [18] Mangat AK, Oei JL, Chen K, Quah-Smith I, Schmölzer GM. A review of non-pharmacological treatments for pain management in newborn infants. *Children (Basel)* 2018 Sep 20; 5(10). pii: E130. doi:10.3390/children5100130. Available at <https://www.mdpi.com/2227-9067/5/10/130>
- [19] World Health Organization. WHO guidelines on the pharmacological management of persisting pain in children with medical illnesses. Geneva: World Health Organization; 2012. Available at [http://apps.who.int/iris/bitstream/handle/10665/44540/9789241548120\\_Guidelines.pdf;jsessionid=304CE2F60106DEA29FD303747B86F40C?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/44540/9789241548120_Guidelines.pdf;jsessionid=304CE2F60106DEA29FD303747B86F40C?sequence=1)
- [20] Hauer J, Houtrow AJ, AAP Section on Hospice and Palliative Medicine, Council on Children with Disabilities. Pain assessment and treatment in children with significant impairment of the central nervous system. *Pediatrics* 2017 June; 139(6).



© Copyright 2019 International Association for the Study of Pain. All rights reserved.

**IASP brings together scientists, clinicians, health-care providers, and policymakers to stimulate and support the study of pain and translate that knowledge into improved pain relief worldwide.**

pii: e20171002. doi: 10.1542/peds.2017-1002.

Available at <http://pediatrics.aappublications.org/content/139/6/e20171002>

[21] Hall RW, Anand KJ. Pain management in newborns. *Clin Perinatol*. 2014 Dec; 41(4):895-924. doi:10.1016/j.clp.2014.08.010. Epub 2014 Oct 7

[22] Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, Arreola-Ornelas H, Gómez-Dantés O, Rodriguez NM, Alleyne GAO, Connor SR, Hunter DJ, Lohman D, Radbruch L, Del Rocío Sáenz Madrigal M, Atun R, Foley KM, Frenk J, Jamison DT, Rajagopal MR; Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018 Apr 7; 391(10128):1391-1454. doi:10.1016/S0140-6736(17)32513-8. Epub 2017 Oct 12

[23] Downing J, Boucher S, Daniels A, Nkosi B. Paediatric palliative care in resource-poor countries. *Children (Basel)* 2018 Feb 19; 5(2). pii: E27. doi:10.3390/children5020027. Available at <https://www.mdpi.com/2227-9067/5/2/27>

[24] Namisango E, Allsop MJ, Powell RA, Friedrichsdorf SJ, Luyirika EBK, Kiyange F, et al. Investigation of the practices, legislation, supply chain, and regulation of opioids for clinical pain management in southern Africa: A multi-sectoral, cross-national, mixed methods study. *J Pain Symptom Manage* 2018 Mar; 55(3):851-863. doi:10.1016/j.jpainsymman.2017.11.010. Epub 2017 Nov 16

## AUTHORS

Ross Drake MBChB, FRACP, FChPM, FPPMANZCA  
Paediatric Palliative Care and Pain Medicine Specialist  
Clinical Lead Paediatric Palliative Care and Complex Pain Services  
Starship Children's Health  
Auckland District Health Board  
Auckland, New Zealand

Julie Hauer MD, FAAP  
Complex Care Service, Division of General Pediatrics  
Boston Children's Hospital  
Assistant Professor, Harvard Medical School  
Boston Massachusetts

### About the International Association for the Study of Pain®

IASP is the leading professional forum for science, practice, and education in the field of pain. [Membership is open to all professionals](#) involved in research, diagnosis, or treatment of pain. IASP has more than 7,000 members in 133 countries, 92 national chapters, and 24 Special Interest Groups.

**As part of the Global Year Against Pain in the Most Vulnerable, IASP offers a series of Fact Sheets that cover specific topics related to pain in vulnerable populations. These documents have been translated into multiple languages and are available for free download. Visit [www.iasp-pain.org/globalyear](http://www.iasp-pain.org/globalyear) for more information.**



© Copyright 2019 International Association for the Study of Pain. All rights reserved.

**IASP brings together scientists, clinicians, health-care providers, and policymakers to stimulate and support the study of pain and translate that knowledge into improved pain relief worldwide.**