

# Palliative Pain Care in Children and Adolescents

International Association for the Study of Pain



Palliative care, including for children, was recognized as a human right in 2014 [1]. 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 [2]. Eight million children are estimated to require specialized CPC [2]. Prevalence rates for 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) [2]. The prevalence of life-limiting conditions appears to be rising [3]. 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<sup>4-9</sup> but is consistently more frequent in children with cancer [7].
- Pain and other symptoms are commonly interrelated especially in children with neurological conditions; this requires a wider focus and skill set than just managing pain [9,10,11].
- In CPC the pain associated with cancer diagnoses requires rapid assessment and adjustment in pain management; in contrast children with neurological conditions involves chronic management over months to years [8,9].
- Acute, procedural and treatment-related pain are common in children supported by CPC
- Pain in children with HIV includes sensory neuropathy as a frequent complication of the disease and some treatments [12].
- Central neuropathic pain is a possible source of pain in children with severe impairment of the central nervous system [13].

## 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.



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- No one pain assessment tool is fit for purpose across all ages and stages of development [14].
- 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 who can use typical adult tools [15].

## 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.
- Good communication is essential with management strategies openly discussed and anxieties or misconceptions actively addressed.
- 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.
- Assessment and management guidelines for cancer pain [16] and persisting pain in medical conditions [17] seen in CPC has been well detailed by the WHO.
- Assessment and management guidelines for managing pain in children with significant impairment of the central nervous system are available in a report published by the American Academy of Pediatrics [18].

## Medication

- Access to medications remains a barrier around the world especially access to opioids [19,20].
- Opioids are a therapeutic mainstay in CPC, especially in children with a cancer diagnosis.
- Multiple barriers to opioid access continue to impact negatively on managing pain in CPC [21].
- 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; this is most evident in the neonatal period [22,23].

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