



FACT SHEET No. 9

Palliative Pain Care in Children and Adolescents

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].



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- 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]



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which has a negative impact on managing pain in CPC [24].

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