



Position paper on pain relief in children and young adults

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| Purpose | Raise awareness for the need to treat pain effectively in children |
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| Summary | This paper explains the need for effective treatment of pain to relieve suffering in children, adolescents and young adults |
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Introduction

The International Children's Palliative Care Network (ICPCN) is a network of individuals and organisation working in children's palliative care worldwide. The vision of ICPCN is to live in a world where children's palliative care is acknowledged and respected as a unique service, and every child and young person with a life-limiting or life-threatening condition and their families can receive the best quality of life and care regardless of which country they live in. We believe that the total needs of life limited and life threatened children should be met to encompass physical, emotional, spiritual and developmental aspects of care. To achieve this, children's palliative care must be acknowledged as a unique and specialist service.

ICPCN aims to:

- Assist services across the world to develop and meet the total care and support needs of life-limited children and their families.
- Advocate for and raise awareness of children's palliative care and the specific needs of life-limited or life-threatened children and their families.
- Campaign for the global development of children's palliative care services.
- Increase the international evidence base for children's palliative care.

Pain relief in palliative care

Pain in children remains a major public health concern in all parts of the world. It is a highly prevalent symptom in children's palliative care and ICPCN believes that babies, children, adolescents and young adults with life-threatening and life-limiting conditions have the right to good quality palliative care and pain relief to relieve suffering and enhance quality of life. Pain is the most prevalent symptom, experienced by 80% of children with cancer; 67% of children with non-malignant diseases; and 55% of children with HIV/AIDS. Yet the need for pain relief has been largely ignored, even for the most vulnerable populations, including children with terminal illnesses and those living in humanitarian crises. This is despite the fact that palliative care and pain relief are essential elements of universal health coverage (UHC). According to the Lancet Commission on palliative care and UHC 2017, every year nearly 2.5 million children die needing palliative care and pain relief and more than 98% of these children are from developing countries.

Pain is often under recognised or unrecognised and even ignored or denied by health care professionals [1] despite good evidence showing children, of any age, can feel pain. Furthermore, pain when recognised is often inadequately treated. The reasons for this include:

- Children express pain differently to adults particularly children who are not verbal such as premature and term babies, infants and severely disabled children;
- Training and education of health care professionals in the evaluation and treatment of pain in children is poor;
- Many, if not the majority, of health care professionals are not competent or lack confidence in prescribing analgesic medication for children, especially opioids;
- Opioids are under used due to unfounded fears, myths and misconceptions especially in regards to adverse effects and addiction;
- Acknowledgement and support of spiritual pain and emotional conflict is mostly ignored in children as is the impact of culture and language.

In response the World Health Organization (WHO) published a global guide, *Cancer Pain Relief and Palliative Care in Children* [2] in 1998. The 1998 guidelines were founded on the consensus opinion of experts and were to be, explicitly, companioned by the earlier WHO publication, *Cancer Pain Relief* [3]. The close approximation of the children's strategy to those for adults, reliance on expert opinion and the heavy focus on pharmacological management was contentious. After fourteen years the WHO launched updated recommendations in the *WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses* [1] to address some of the expressed disapproval. The overall objectives of the 2012 guidelines were to provide evidence-based recommendations to improve the pharmacological management of persisting pain related to medical diseases in neonates, infants and children. Predictably, the new guidelines exposed inadequacies with research in pain management in children's palliative care because of the emerging nature of the speciality [5].

To ensure relief of pain in most children the guidelines emphasised the correct use of analgesic medication and re-iterated previous WHO concepts:

- Dosing at regular intervals ("by the clock")
- Using the appropriate route of administration ("by the mouth")
- Adapting treatment to the individual child ("by the individual")

The principle of prescribing analgesia according to recorded pain intensity ("by the ladder") was modified from the three-step approach to a two-step strategy by removing the use of weak opioids like codeine and replacing this with starting a low dose of strong opioids such as morphine.

Why is good pain control important?

- Children dying and suffering in pain is unacceptable.
- Children dying and suffering in pain places a significant and lasting emotional burden on their families and health care professionals.
- Untreated acute pain is responsible for considerable morbidity and, even mortality.
- Untreated acute pain can lead to persistent pain syndromes.
- Untreated acute pain can influence pain pathways affecting the rest of the child's life.
- Untreated pain can lead to lifelong psychological disturbances.

What is required?

In May 2014, the World Health Assembly resolution called for member states to:

- Develop, strengthen and implement palliative care policies.
- Support palliative care initiatives including education and training, quality improvements and availability of medicines essential for the provision of palliative care.
- Ensure access to essential medicines.
- Foster partnerships between government and civil society to increase access to palliative care.

To ensure the best possible palliative care for children, pain must be well managed. This requires countries to place emphasis on:

- Integrating palliative care and pain management for children into their national health care system(s).
- Integrating palliative care and pain relief into UHC.
- Developing relevant policies on palliative care and pain management for children.
- Providing palliative care and pain management at the primary, secondary and tertiary level of health care.
- Training and educating health care professionals in the proper assessment and management of pain in children.
- Ensuring equitable access to palliative medicines and analgesics including opioids. According to the Lancet Commission, the cost of opioid analgesics for children in low income countries, at best international prices, is just over 1 million USD per year, which is only 63 cents per child in need.

Conclusion

In order to realise goal 3 of the Sustainable Development Goals, palliative care and pain relief must be acknowledged as core elements of UHC. Pain in children is real and should not go untreated. Even in resource limited countries, palliative care can be made accessible to those who need it by using the Essential Package proposed by the Lancet Commission which includes medicines, equipment and human resources which are affordable even in LMICs.

References

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