Pain Relief for Children: A Global Issue

An ICPCN briefing paper

ICPCN
July 2012
Website: www.icpcn.org.uk

The ICPCN is a Registered Charity in England and Wales No: 1143712 and a Registered Company in England and Wales No: 767 172

The International Children’s Palliative Care Network

The International Children’s Palliative Care Network (ICPCN) was established in 2005 and is the only international organization bringing together individuals and organizations involved in the development and provision of palliative care for babies, children and young people. Present membership is from 81 countries. The vision of the ICPCN is a world where all life-limited children have access to palliative care services. The objectives of the ICPCN are Advocacy; Education and Research; Information- sharing and Networking; and Sustainability.

Pain Relief

In 1998 the World Health Organisation (WHO) published a global guide to the management of pain in Children [REF]. In 2005 the International Narcotics Control Board and WHO were invited to examine the feasibility of a possible assistance mechanism that would facilitate the adequate treatment of pain using opioid analgesics.

In 2007, WHO acknowledged that in many countries pain management is poorly addressed and it estimated that over 80% of the world’s population is inadequately treated for moderate to severe pain, although opioid analgesics continue to be the mainstay for the relief of moderate to severe pain. The priority objective of the framework proposes an assistance programme that would facilitate access to opioid analgesics for the adequate treatment of pain. Access to “essential drugs, as defined by the WHO Action Programme on Essential Drugs” is part of the minimum core content of the right to health.

The Access to Controlled Medications Programme identified the development of treatment guidelines that cover the treatment of all types of pain as one of the core areas of focus for improving access to opioid analgesics. Such guidelines are interesting both for health-care professionals and policy-makers. They are also important in improving access to controlled medicines for determining when those opioid medicines and when non-opioid medicines are preferred.
In May 2012 WHO launched new guidelines *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses*.
http://www.who.int/medicines/areas/quality_safety/guide_perspainchild/en/index.html

The overall objectives of the guidelines are:

- to provide evidence-based recommendations on pain treatment, including opioid analgesics, non-opioid analgesics and adjuvant medicines
- to improve the management of pain in children, that is, neonates, infants and children aged 0-10 years experiencing persisting pain related to medical diseases.

They can also be applied to adolescents as the majority of the evidence retrieved and appraised refers to studies in populations comprising patients from 0 to 18 years.

Correct use of analgesic medicines will relieve pain in most children with persisting pain due to medical illness and relies on the following key concepts:

- using a two-step strategy
- dosing at regular intervals
- using the appropriate route of administration
- adapting treatment to the individual child

The Guidelines recommend:

- A " 2 Step" approach to the management of persisting pain in children
- Exclusion of Step 2 of the existing WHO Pain Ladder
- Use of a low dose of a strong opioid rather than a weak opioid

The Millennium Development Goals were adopted by 189 world leaders from rich and poor countries, as part of the Millennium Declaration which was signed in 2000. The health of women and children play a role in **all** MDGs, but especially in relation to pain relief within:

MDG 1: eradicate extreme poverty and hunger: Charging people less for health services reduces poverty and makes families and children more willing to seek care.

MDG 6: combat HIV/AIDS, malaria and other diseases: Many women and children die needlessly from diseases that we have the tools to prevent and treat. In Africa, reductions in maternal and childhood mortality have been achieved by effectively treating HIV/AIDS, preventing mother-to-child transmission of HIV and preventing and treating malaria. Hain et al (2010)[1] have compiled a list of 574 ICD10 diagnoses that have been judged by professionals working in paediatric palliative care to be life-limiting. In 2011 respondents to an ICPCN online survey, the following diagnoses were identified as the most common seen in children cared for in palliative care services:

1. Malignancies
2. Non-malignant
    - Cardiac
    - Neurological
    - Metabolic/ Neurodegenerative
    - Chromosomal/ Syndrome
    - Respiratory
    - Genetic blood diseases
    - Other e.g. HIV, renal failure etc

MDG8: develop a global partnership for development: Global partnership and the sufficient and effective provision of aid and financing are essential. In addition, collaboration with pharmaceutical companies and the private sector must continue to provide access to affordable, essential drugs as well as to bring the benefits of new technologies and knowledge to those who need them most. Approximately 20 million children worldwide are believed to be in need of palliative care services.

Children's Palliative Care

The goal of palliative care is the relief of suffering and the improvement of quality of life. ICPCN believes that babies, children and young people with life-threatening, life-limiting and chronic diseases or conditions have the right to receive palliative care for the relief of their suffering and enhancement of quality of life. Countries would need to put the following in place

- education specifically for palliative care for children
- relevant policies
- systems to provide care at primary, secondary and tertiary levels

---

[1] Hain et al (2010), Directory of life-limiting diagnoses in children, based on ICD10codes, Unpublished work on behalf of ACT

- equitable access to pain-relieving and other palliative medicines, including opioids.
- Adequate funding

Many medications are unavailable in paediatric formulations and prescribers are often untrained in the use of pain medications, especially opioids, in children. Most adults have an inherent belief that children should not die and therefore ignore the needs of these children.
While we believe that the primary focus of health care must be cure and the promotion of health, in reality, health care services for children with chronic conditions are often inadequate to meet the multiple and complex needs of these children and their families. Another sad reality is that children in developing countries often present at health services too late for cure. Added to this, there are still many childhood diseases and conditions which are, by their nature, incurable.

Children suffer physical pain, distressing symptoms and emotional and spiritual pain, but are often unable to express this due to their age, lack of verbal skills or disability. Few health care professionals are trained and skilled at evaluating children's pain and suffering, and therefore this is left unrecognised, ignored and untreated. Acknowledgement and support for spiritual pain and conflict; and the impact of culture and language, is mostly ignored in children. Children and families also have specific communications requirements due to the very nature of surrogate decision making. Children who live to young adulthood need transitional support for them to transfer from children's to adult palliative care, when this is their wish. Children dying in pain and suffering leave families and health care workers with complex emotions and feelings of guilt and inadequacy.

Call to Action

The International Children's Palliative Care Network believes that children have the right to have their total pain managed effectively by informed and competent practitioners.

ICPCN encourages members to consider how to raise awareness of children's palliative care within their own countries and use this awareness to encourage governments and international agencies address the need for countries to provide palliative care services for babies, children and young people as an essential element of the child's right to health, for children with chronic, life-threatening or life-limiting conditions. This includes neonates and children with disabilities.
Action might include:

- Working together with other agencies and professionals to develop health plans which include plans for the development of palliative care for babies, children and young people.
- Working with others to strengthen health systems to improve pain management in children
- Building equitable approaches to health to ensure that vulnerable babies, children and young people can access medical expertise and drugs, the essential medicines for children, including opioids and other pain-relieving medications, be available and in paediatric formulations
- Working together to advocate for pain relief to be available to all children
- Ensuring that children have access to a universal package of guaranteed benefits, including pain management.
- Access to appropriate ready-to-eat foods to prevent and treat malnutrition.
- Planning and delivering integrated care and access to health promotion to help prevent and treat diseases such as diarrhoea, HIV/AIDS, malaria, tuberculosis, and non-communicable diseases.

- Strengthening health care systems to deliver integrated, high-quality services. They should extend the reach of existing services, especially at the community level and to the underserved, and manage scarce resources more effectively.
- Building workforce capacity to deliver integrated care by developing strategies to train, retain and deploy health workers e.g. palliative care for children, including pain management, should be included in the undergraduate and postgraduate trainings of all health care professionals
- Reviewing existing prescribing processes to explore whether changing these can improve access to medication
- Developing coordinated research and innovation to increase efficiency and provide high quality care.
- Considering how to utilise the Millennium Development Goals to support advocacy work in relation to access to pain relief.