



International Children’s Palliative Care Network (ICPCN) Position Paper on Palliative Care and Children Living with HIV and AIDS

Purpose	Policy statement
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Summary	The purpose of this statement is to highlight issues relating to the need and provision of palliative care for children living with HIV and AIDS and what countries need to do to meet those needs.
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Introduction

The International Children’s Palliative Care Network (ICPCN) is a network of all 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.

What is children’s palliative care?

The World Health Organization (WHO) defines palliative care for children as a special, albeit closely related field to adult palliative care which includes:

- The active, total care of the child’s body, mind and spirit, and also involves giving support to the family.

- It begins when the illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's own homes.ⁱ

The trajectory of children's palliative careⁱⁱ



Children and HIV

With effective interventions the risk of vertical transmission can be reduced to 2%. However, such interventions are still not widely accessible, particularly in resource limited countries where the burden of HIV is highest. Without preventing mother to child transmission of HIV, transmission can range from 15% to be as high as 45%.ⁱⁱⁱ It is therefore not surprising that even in 2016, 160 000 children were infected with HIV, most of them living in sub-Saharan Africa. In the same year, 2.1 million children were living with HIV globally but only 43% had access to the life-saving antiretroviral therapy.^{iv} Access to ART is affected by various factors including the distances between home and health care centres, stigma, difficulty in administering treatment ART to children, insufficient paediatric formulations, lack of training and support for carers and health care workers in the provision of HIV services for children.^v Without treatment half of all infected children will die by the age of 2 years and the majority will die by the age of five years.^{vi} Adolescents (15 – 19 years) are the most affected group with one infected every two minutes and AIDS being the leading cause of death among them worldwide especially in Africa. The AIDS pandemic has resulted in 13.4 million orphans.^{vii} Some of these orphans have lost siblings, thus suffering multiple losses. Without timely intervention and support, they are therefore likely to experience unresolved anger, anxiety and depression.

Pain in the context of HIV

Antiretrovirals (ART) have brought about significant improvement to the health of people living with HIV but many, including children, continue to experience pain due to the following factors:

- The effects of specific opportunistic infections e.g. pneumonia, meningitis, herpes zoster, mouth ulcers, etc.
- The effects of HIV itself or the body's immune response to it e.g. peripheral neuropathy, cardiomyopathy, myelopathy, etc.

- Repeated painful procedures e.g. venesection, lumbar puncture, tube feeding, etc.
- Side effects of medications used to treat the disease e.g. nausea and vomiting, diarrhoea, skin rashes, etc.
- Psychosocial stressors e.g. emotional pain due to living with a chronic illness, long periods of hospitalisation, clinical depression, etc. ^{viii}

It is important to note that pain is often not adequately treated in children because:

- Some children are unable to describe their pain 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 pain is left unrecognised, ignored and untreated.
- Many health professionals lack competence in prescribing opioids for children.
- Opiophobia, which is a fear of using opioids for pain management due to persistent myths related to its use and the possibility of addiction.
- A lack of acknowledgement and support for spiritual pain and conflict, and the impact of culture and language, which is largely ignored in children.

Role of palliative care in children with HIV

It is a misconception that palliative care is only care that is provided at the end of life. End-of life care is only one component of palliative care which begins at diagnosis, continues throughout the duration of the illness and is applicable even during treatments aimed at cure. It is not a substitution for HIV treatment but part of holistic care and should be given alongside such treatment. Palliative care includes proper management of moderate to severe pain using effective analgesics, such as morphine, which is an effective, versatile and inexpensive analgesic. The "WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses" is a good tool to use for effective pain management. Distressing symptoms such as dyspnoea, wasting, adverse effects of drugs and other debilitating symptoms, should also be properly managed. The World Health Organization has compiled a list of basic medicines necessary for use in children's palliative for symptom management.

Important areas often overlooked in children with HIV and their families, including siblings, are their emotional, spiritual, cultural and educational needs. A multidisciplinary care team consisting of, for example, a doctor, nurse, social worker, therapist, educator and spiritual leader provides holistic care resulting in enhanced quality of life for the child and family. When death is inevitable, planning for end-of-life should take place well in advance if possible, to ensure a dignified death through the drawing up of an Advanced Care Plan (ACP). Bereavement care for all members of the family should be provided at the time of death and afterwards, for as long as it is necessary.

Key Points in Children's Palliative Care

- It provides comfort in the form of pain relief and the management of unpleasant symptoms.
- It relieves suffering and addresses the needs of the child and family.
- It requires an interdisciplinary team who have specific skills and experience.
- It can run concurrently with curative treatment
- It is applicable from diagnosis and continues into bereavement.
- It provides supportive, physical, psycho-social and spiritual care which includes members of the child's family.

Integration of palliative care into HIV care programmes for children.

1. FHI 360 has developed a toolkit to help HIV programmes integrate palliative care into their services. ***Integrating palliative care into HIV services: A practical tool for implementers***. This toolkit:
 - Reviews the many benefits of integration for the patient and health system.
 - Presents key issues to consider when planning for integration.
 - Offers clear, succinct ways to initiate and sustain integration.
 - Provides clinical and organisations with tools to guide integration.It is available at: www.fhi360.org/en/Publications/index.htm^{ix}
2. In 2012 the WHO developed pain treatment guidelines for the proper management of physical pain in children. ***WHO guidelines for the pharmacological treatment of persisting pain in children with medical illnesses***. This document is available at: www.who.int

Recommendations

Children's palliative care is a basic human right for all children living with life threatening and life limiting illnesses including HIV/AIDS. General comments No.15 (2013) Article 24 paragraph 1 of the Convention on the Rights of the Child, states that "*Children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services. At the primary level, these services must be available in sufficient quantity and quality, functional, within the physical and financial reach of all sections of the child population, and acceptable to all*".^x

To fulfil the right of making palliative care accessible to all children who need it, in line with the World Health Assembly Palliative Care Resolution (WHA 67.19) governments should:

1. Integrate children's palliative care into all health care services for children.
2. Include children's palliative care in relevant health, welfare and educational policies.
3. Ensure training for health care workers in children's palliative care and development of mentor programmes to support these professionals in their work settings.
4. Ensure equitable access to pain-relieving and other palliative medicines, including opioids.

ⁱ World Health Organization. 2002

ⁱⁱ International Children's Palliative Care Network. Children's Palliative Care in South Africa. The facts: Why should children suffer? 2010

ⁱⁱⁱ who.int/hiv/topics/paediatrics/hiv-padiatric-infopage/en/

^{iv} Fact Sheet. World AIDS Day. 2017. UNAIDS

^v Children and HIV. Fact Sheet. UNAIDS.2016

^{vi} UNAIDS .Joint United Nations Programme on HIV/AIDS. 2012

^{vii} <https://www.unicef.org/wp-content/uploads/2016/12/HIV-and-AIDS-2016-Seventh-Stocktaking-Report.pdf>

^{viii} Amery J. Children's Palliative Care in Africa. Oxford University Press. 2009

^{ix} Fact Sheet. Palliative Care and HIV. UK Consortium on AIDS and International Development. February //2013

^x United Nations. Convention on the Rights of the Child. General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health(art)