

Palliative care for children: pain is inevitable, suffering is optional

Why do we allow children to suffer from pain if it is possible to control it in almost all cases? Hanneke Brits and Joan Marston explore why this is so

Status of children's palliative care

Palliative care for children has been slow to develop in Africa. Few countries have established programmes, and South Africa is presently the only country with a national network of services. A recent mapping of children's palliative care by the International Children's Palliative Care Network shows the present situation (see Figure 1 below).

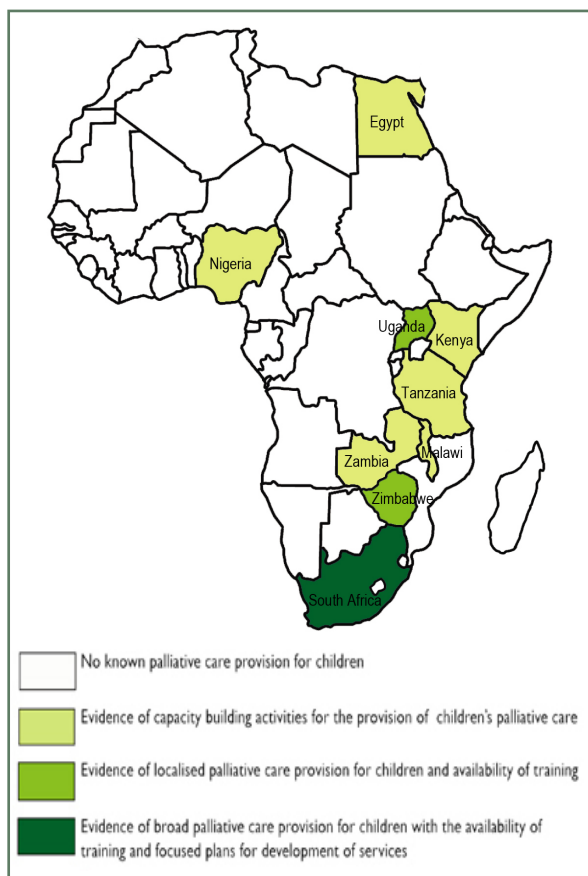


Figure 1 Status of children's palliative care in Africa

Defining palliative care for children and young people

(see www.who.int/cancer/palliative/definition/en)

Palliative care for children is defined as:

- an active and total approach to care of the child's body, mind and spirit;
- beginning from the time of diagnosis of a life-threatening, life-limiting, or chronic condition;

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- requiring a multi-disciplinary approach to meet the physical, emotional, social, spiritual, developmental, and cultural needs of the child and family;
- including the management of pain and distressing symptoms, and care through death and bereavement;
- focusing on the enhancement of quality of life and relief of suffering;
- including support for the family and continuing into the bereavement period;
- being provided in the child's home and in healthcare institutions.

Children requiring palliative care

Children with life-limiting or life-threatening conditions including cancer, HIV, tuberculosis, severe malnutrition, malaria, severe disabilities, genetic and metabolic conditions, birth anoxia, organ failure, neuro-degenerative conditions, and many other conditions. The UK palliative care charity ACT (Association for Children's Palliative Care) has identified four categories of conditions in children requiring palliative care (see www.act.org.uk).

In Africa we consider bereavement as a fifth category (see The Baobab Paediatric Palliative Care website www.baobabppc.co.za).

Symptom burden of children

Children with HIV, cancer, severe malnutrition, and other conditions requiring palliative care very often experience mouth ulcers and fungal infections, which can be very painful and prevent them from eating properly. Poor feeding contributes to malnutrition and decreased immunity. Abdominal pain can be due to colitis, enlarged lymph nodes due to tuberculosis, or lymphoma, as well as diarrhoea as a side-effect of medication or from HIV disease. Procedural pain can be minimised with proper planning and timely topical or systemic analgesics. Peripheral neuropathy, as a side-effect of different drugs also contributes to the pain burden in children. Other distressing symptoms include shortness of breath, nausea and vomiting, and skin infections.

Pain

Pain is inevitable, suffering is optional. Why do we allow children to suffer from pain if it is possible to control pain in almost all cases? Possible answers include:

- children are not assessed and diagnosed with pain as they seldom complain of pain;
- the correct pain medication and dosage is not prescribed;
- pain is not re-assessed and treatment adjusted as



Children should not suffer. Palliative care services can be integrated into existing services

- necessary;
- medications such as morphine may not be available;
- healthcare professionals do not have the knowledge and skills to treat paediatric pain.

Pain assessment

Assessment should always include pain of the body, the mind, and the spirit. Pain can be considered as the fifth vital sign and should be assessed whenever vital

signs are taken. For children unable to communicate the FLACC pain assessment scale is most appropriate. The FLACC scale assesses: (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability. For more information visit <http://bcmartin.yolasite.com/resources/FLACCSCALE.pdf> (see Table 1). When assessing pain in verbal children older than 3 years, the Wong Baker FACES scale, which was validated in Africa, a simple numerical scale, or the Revised Faces Scale, may be used – see <http://www.geriu.org/uploads/painDVD/AdditionalMaterials/Wong-BakerPainScale.pdf>.

Pain management

Before prescribing pain medication the following should be taken into consideration:

- What non-pharmacological treatment can be used?
- Does my medication match the type of pain?
- Is the dosage interval correct?
- What administration route is most appropriate?

The easiest and most effective non-pharmacological measure is distraction, where the attention of the child is guided away from the site of pain and focused on something that the child enjoys, e.g. looking at pictures in books, blowing bubbles, or singing.

Dosage interval should correspond with the half-life of the drug in order to keep the patient pain free, e.g. morphine solution should be prescribed every 4 hours.

Although most medication can be prescribed using different routes the oral route works rapidly and causes less discomfort for children and should be used whenever possible. Neonates may require reduced dosages.

Re-assessment

Pain should be re-assessed and treatment adjusted if the child is still in pain before the next dosage of medication is given. Combine different drugs if necessary, e.g. paracetamol and ibuprofen; and use adjuvant drugs as required, e.g. morphine plus amitriptyline.

Respiratory symptoms and shortness of breath

The worst death must be the inability to breathe freely.

Type of pain	Drug	Dosage
Mild pain	Paracetamol	10–15 mg/kg q4–6h po
Severe pain	Morphine	0.2 mg/kg q4h po
Muscle or inflammatory pain	Ibuprofen	10 mg/kg q8h po
Abdominal colic	Hyoscine bromide	5–10 mg q8h po
Raised intracranial pressure and swelling	Dexamethasone or prednisone	4 mg once daily po 1–2 mg/kg daily po
Peripheral neuropathy	Amitriptyline	0.2 mg/kg/day and titrate to 2 mg/kg if needed
Spasticity	Baclofen Diazepam	5 mg q8h po (max 20mg q8h for children) 1–2.5 mg q8h po
Procedural pain (local)	EMLA	1g/10 cm ² – 1 hour before procedure
Procedural pain (sedation)	Diazepam	1–2 mg – ½ to 1 hour before procedure
Procedural pain (babies)	Sucrose 20%	Put on pacifier or give 1 ml po
Oral <i>Candida</i> infections	Nystatin	0.5–1 ml q6h po. Wipe away plaques with NaHCO ₃ solution before application

Table 1 Pain medication for different types of pain (EMLA, entecic mixture of local anaesthetics; po, per os)



What works? Keeping a history of treatment can help when symptoms recur

Unfortunately many of the terminal conditions in children cause difficulty in breathing. It is, therefore, important to use all means available to address dyspnoea. Most important is to put the patient in a comfortable position, usually sitting up, and never leave the child alone. Ensure adequate ventilation in the room by opening windows or using fans. Speak to the patient and address all fears. Treat the cause of distress with appropriate drugs, e.g. co-trimoxazole for *Pneumocystis pneumonia* (PCP), furosemide for heart failure. Morphine is excellent to calm the patient, open the airways and decrease awareness of breathlessness. Start with 0.2 mg/kg q4h orally and increase if necessary. Do what you can with what is available, stay calm and be present.

Providing palliative care for Africa's children

In a continent where access to healthcare is often limited, and palliative care services for children are few, the most effective way to reach children is to integrate children's palliative care into existing services for children – hospitals, clinics, and community organisations such as hospice programmes – and to build



Apparently happy. But are all needs addressed?

competence through integrating children's palliative care training into the undergraduate and post-graduate courses of all healthcare professionals. A project to develop Beacon Centres for Children's Palliative Care, in Uganda, Tanzania, and South Africa is increasing the number of skilled practitioners through education and clinical experience.

The few specialised children's palliative care programmes have led the way in highlighting that life-limited children are not little adults, but have specific developmental, psychological, spiritual, and clinical needs that must be addressed.

Further information

- Amery J. *Children's Palliative Care in Africa*. Oxford, UK: Oxford University Press, 2009.
- Zeichner SL, Read JS. *Handbook of Paediatric HIV Care*. Cambridge, UK: Cambridge University, 2006.
- ACT website. www.act.org.uk.
- ICPCN website. www.icpcn.org.uk.
- The textbook *Children's Palliative Care in Africa* may be downloaded free of charge from the ICPCN website.
- Baobab Virtual Resource Centre. www.baobabppc.co.za.
- World Health Organisation. www.who.int/cancer/palliative/definition/en. St Nicholas Children's Hospice for Godfrey's story.

Godfrey's story

Godfrey was 11 years old, HIV positive, and orphaned by AIDS, when he was admitted into a palliative care partnership between a hospital department of family medicine and a children's hospice. When admitted to hospital, he was diagnosed with pulmonary TB and right-heart failure. Transferred to a children's palliative care unit, he completed TB treatment and started on ARVs (3TC, d4T and EFV). He had a CD4 count of 78, viral load of 170000 copies/ml. An intelligent child, he expressed his emotions through art. He enjoyed a close relationship with the doctor and the chaplain, who visited him daily. He was encouraged to attend school each day for short periods of time. He did well on treatment and went to his family for the holidays. His family stopped his ART, and he was re-diagnosed with TB. Godfrey requested to go to the hospital, demanded to see 'his' doctor and to be admitted to the palliative care unit. He was also diagnosed with PCP (*Pneumocystis carinii pneumonia*) and became oxygen dependent. The multi-disciplinary team ensured that his physical, spiritual, and emotional needs were met and limited schooling and art helped meet his developmental needs. Godfrey developed arthritis and received effective pain management. He contracted chicken pox which led to his death, a death he predicted through a drawing. He was able to discuss his fears with the chaplain and died peacefully in the palliative care unit. Bereavement support was provided to his family, the staff, other children, and his school.