

# Palliative care in children with advanced HIV/Aids

R Chunda, V Lavy  
Department of Paediatrics, College of Medicine

Acquired Immuno-Deficiency Syndrome (AIDS) is a fatal disease with many curable manifestations, so the distinction between active, curative treatment and palliative treatment is blurred. The World Health Organisation (WHO) defines palliative care as: “...the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death, it provides relief from pain and other distressing symptoms. Palliative care integrates the psychological and spiritual aspects of care, offering a support system to help family cope during the patients' illness and their own bereavement”.<sup>1</sup> Much of the discussion below is based on this broad definition of palliative care.

Central to the philosophy in the WHO definition is the belief that everyone has a right to be treated and to die with dignity, and that the relief of pain – physical, emotional, spiritual, social – is a human right. Palliative care combines the professionalism of an inter-disciplinary team which includes the patient and family. It can be provided in hospitals (hospices in some countries), out-patient clinics and the community when patients are living at home. An integral part of this care is enabling and supporting caregivers to work through their own emotions and grief.

In many developing countries, Malawi included, the existing health infrastructures are inadequate to provide in-hospital care for AIDS patients, and thus there is great pressure on hospital personnel to discharge AIDS patients quickly, with little or no treatment. To cope with this crisis, many nations have encouraged 'Home-Based Care' (HBC) for persons with advanced HIV/AIDS disease. Through this, follow-up in the community can be provided after hospital care. The AIDS Support Organisation (TASO) in Uganda has established day-care centers that provide medical treatment, counseling and food supplements for AIDS patients, plus a limited programme of home care.

Unfortunately in many countries like Malawi, home and community-based care programs are weak and provide few services. Links to local health centers and hospitals are poor and HBC volunteers have little or no access to any drugs for palliative care. Diagnosis of tuberculosis and other opportunistic infections is often ignored. Training of HBC volunteers often over-emphasizes 'counseling' and does not provide them with practical skills in home nursing. Lack of food for patients and their children is a serious problem.<sup>2</sup> All in all, best palliative care practices should contain the following elements:

## 1. MEDICAL ELEMENTS

### Pain Control

Pain may be related to the disease itself or associated infections, or the procedures the child frequently has to undergo during diagnosis and treatment. The underlying principles in pain control are:

- Give analgesia by mouth, where possible since intramuscular or intravenous is painful
- Give analgesia regularly so that the child does not have to experience the recurrence of severe pain in order to get

the next dose of analgesia.

### (a) Analgesic Ladder

Following the analgesic ladder, the following drugs can be used:

#### Step 1

Paracetamol  
NSAIDs eg Ibuprofen

#### Step 2

##### Weak opioids

For example Codeine: given orally every 6 hrs; it may be combined with non-opioids to achieve additive analgesia. It is usually used with laxatives as it may cause constipation. Step 2 drugs have a “therapeutic ceiling,” which means that once the maximum dose is being given, there will be no increase in analgesic effect by increasing the dose further. If a step 2 drug is not controlling the pain, move up the ladder to a step 3 drug instead.

#### Step 3

##### Strong opioids

- Morphine (oral tablet or solution) every 4 hrs
- Slow release morphine (MST) given 12hrly

### Adjuvant treatments for pain

These include amitriptyline and phenytoin for neuropathic pain, diazepam for muscle spasm and steroids for raised intracranial pressure and liver capsule pain.

### (b) Management of other Symptoms

Common symptoms include fever, cough, diarrhoea, anorexia, sore mouth, nausea, vomiting and shortness of breath. Below are some brief points on the management of some of these symptoms:

#### Loss of appetite, nausea & vomiting

Loss of appetite in a terminal illness is difficult to treat. Carers should be encouraged to continue providing meals and try the following:

- Small feeds given frequently especially in the morning when the child's appetite may be better.
- Give cool foods rather than hot foods.

If there is distressing nausea and vomiting metoclopramide (1-2mg/kg) every 8 hrs is given as required. Dehydration should be treated by oral rehydration as appropriate. If there is persistent diarrhoea not responsive to standard antibiotics, loperamide should be considered.

#### Care for the mouth

Oral candidiasis is very common amongst children with HIV/AIDS. Treating with GV paint or anti-fungal drugs is effective and can bring marked improvement in feeding and well-being.

Aphthous ulcers can be improved by applying crushed prednisolone directly onto the ulcer.

If there is a foul smell or discharge in the mouth, topical metronidazole is very effective. A mouthwash can be made up using iv metronidazole solution mixed with

orange squash (metronidazole is very bitter.) In the absence of iv solution, crushed tablets can be used instead.

### (c) Anti-Retroviral Therapy

ARVs have now been introduced in the management of HIV/AIDS patients in Malawi. For children with HIV/AIDS, ARVs are available only at selected hospitals in the country because of the need for specialist care and follow-up. It is thus appropriate for children with HIV/AIDS who meet the WHO criteria to start ARVs to be referred to the specialized ARV Clinics. Nonetheless palliative care for these patients should continue alongside ARV therapy, so effective ways of coordinating and combining services are needed.

## 2. PSYCHOLOGICAL SUPPORT

This involves empathy with the patients and their guardians. Ideally, health care providers should have time to listen to and explore anxieties and questions and to provide information and counseling, or refer appropriately.

## 3. SOCIAL SUPPORT

The family should be encouraged to share the burden of care. Participation of well-known or well-connected individuals (like aunts, uncles, grandparents etc) is helpful. "*A problem shared is a problem halved.*" Encouraging the mother to share her problem with a friend or someone within the family would greatly help her in terms of social support.

## 4. SPIRITUAL ELEMENTS

The child and the mother/guardian should be encouraged to consult their spiritual leaders for spiritual encouragement and guidance during this difficult time in their lives

## 5. ADVOCACY

Education about palliative care for people in authority, health workers and the general public may reduce the stigma and hopelessness attached to HIV/AIDS.

## CRITICAL COMPONENTS IN END OF LIFE CARE FOR CHILDREN WITH HIV/AIDS

It is essential for the clinician to build and foster a caring, supportive and empathetic relationship with the child and family. Children need to know what is happening to them, which raises the difficult issue of disclosure of diagnosis. In accordance with the United Nations Convention on Rights of Children<sup>1</sup>, children should be informed in an age appropriate manner regarding their illness, its treatment and consequences. During this period of time they need to be supported and loved, and participate in decision making commensurate with their age and understanding. For the most part, it is desirable for children to know they are dying and to be given the opportunity to discuss their fears with their loved ones. Likewise, families and loved ones of a dying child also need to be informed and supported so that they can be active participants in decisions regarding end of life care for their child. In most cases this may be difficult considering our Malawian culture of secrecy on issues of death and dying; however it is necessary to treat each individual case separately. The physician needs to maintain a physical presence that is compassionate, and recognizes the need to relieve pain and suffering. The guiding ethical principles of palliative care include: autonomy, beneficence, non-maleficence, compassion and justice.

Thus, the family and child are full partners with the health care team in management decisions, the child's best interests are paramount, caring is provided in an atmosphere of kindness and access to appropriate palliative care is good.

It is important to note that benefits of palliative care for HIV children should not just be reserved for end of life care. It should be continuous from the time the child becomes infected through the course of the disease and death of the child. As the disease progresses, there is a gradual shift from restorative care to palliative care for the child and the family. Sometimes the issue of medical futility in continuing restorative care is raised by either family or health care worker. At this point a discussion with the family of the medical status and prognosis needs to be initiated including age appropriate discussion of death and dying with the child. The discussion of the dying process should include both signs and symptoms of impending death, as well as assurance to the family of continuing support. When end stage disease is evident, HBC is an appropriate option to be considered, if available.

## MEETING OUR OBLIGATION TO CARE AND RELIEVE SUFFERING

Due to shortage of health care staff in Malawi, it is difficult to provide the care for individual children with advanced HIV/AIDS as stipulated in this article. I would like to finish this article with some words of encouragement to all health care workers looking after children with advanced HIV/AIDS. A number of religious traditions and philosophies provide the historical imperative for the obligation to care and relieve suffering of others

The first principle of Buddha is to "Look deeply into the nature of suffering to see the cause of suffering and the way out" From the sayings of Prophet Mohammed we learn, "for every good deed there is a reward – but for taking care of a person in need, the reward is God Himself"

The New Testament tells us that Christ was a carpenter but throughout His ministry He was a healer: "Let the little children come to me" (Mark 10:14) – was his call, not just to hold a beautiful child, but to heal and comfort the leper, "the 20 yr old prostitute with HIV infection, the 40 year old businessman with AIDS" etc.

In providing care to those with chronic life threatening diseases, always remember that, **no act of kindness, no matter how small, is ever wasted.** Sometimes in life, the little things we do become our most important accomplishments.

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