

Chapter 32

End-of-Life Care of Children***Overview***

The overwhelming number of children orphaned as a result of HIV/AIDS in sub-Saharan Africa has tended to overshadow the increasing number of children who themselves have AIDS.

Care of children in the end stages of AIDS often takes place in the home, as hospitals and other formal health care institutions increasingly are caring only for children with acute conditions. They often do not have the capacity to care for these children anyway.

There are few children's hospice or palliative care programmes and little training on the care of a child dying of AIDS available in Africa, although programmes have been operating in Uganda since 1999 and in South Africa since 1998. Support in the communities rests increasingly on the shoulders of community caregivers, who work with great compassion but often with little knowledge and skill in the field of paediatric palliative care, and often without professional supervision (see Chapter 38: Training, Mentorship, and Supervision).

Important issues during the final stage of the child's life include promoting the best possible quality of life for the child, supporting the family, and ensuring that the child receives skilled and compassionate care that effectively relieves pain and other symptoms (see Chapter 13: End-of-Life Care). All care interventions should aim to support the child physically, emotionally, spiritually, and socially. Palliative care for the child should always be appropriate to the needs of each child and be culturally acceptable.

Authors

Joan Mary Marston

Ruth Sims

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Promoting quality of life and dignity in dying for the child with AIDS involves:

- A caring adult to provide love and security
- The presence of family and/or friends for support
- Simple comfort measures to relieve pain and other distressing symptoms
- Access to medication for the relief of suffering and open communication will do much

Involving the Family and Community

There can be few more painful experiences than watching the dying and death of your child. Families need to be supported with compassion, practical help, counselling, education, and a caring presence throughout the child's illness and into the bereavement period. In Africa, trained and untrained community caregivers are often their only form of support.

It is important to assess the family's support structures before the death and to prepare these people to help the family at the time of death and in the bereavement period (see Chapter 29: Psychosocial and Spiritual Care; Chapter 30: Loss, Grief, and Bereavement in Children; and Chapter 31: Family and Community Support).

The family has often suffered multiple losses and does not have the emotional energy required to support the dying child. Support may come from the community, faith-based organisations, non-governmental organisations, and friends. Where the child is likely to die at home, families need to be prepared for the dying process, and be given the name and contact details of who to contact once death has occurred.

The belief that 'every child is my child' and that it takes a village to help a child grow is still found in many rural areas. Whatever the home circumstances it remains essential to have the family, and child, take part in important decision making as they have knowledge and insights that the care team do not. Respect for cultural differences must be part of all care planning. Many children are seen by traditional healers as well as medical doctors, and their treatments should also be respected.

Effective end-of-life care can be provided through community-based home care — despite the fact that the home environment may be less than ideal for children living in extreme poverty — if there is a caring adult, basic comfort, access to medication to relieve suffering, and a support system for the child and family. When these conditions are not available, residential care is preferable if possible, in a hospital, children's home, a hospice, or a shelter.

Recognising the Child Is Approaching the End of Life

Health care workers (HCW) often have difficulty admitting that a child is nearing the end of life and that no further curative treatment is indicated. At this stage, good palliative care can help the HCW and the family realize that they are providing the best possible care for the child (see Chapter 14: Communicating with Patients and their Families).

Identifying when the end of life is approaching may be difficult in a child with AIDS who is not on antiretroviral therapy (ART) as the weakness and disability may be due to poor nutrition and untreated opportunistic infections, including tuberculosis. In these cases, the child's health may be dramatically improved with good nutrition, vitamin supplementation, and effective treatment of infections. Active treatment of infections and improvement of nutritional status can take the child from 'dying' to relative health in a very short period of time. Children recover more quickly than adults, and the 'Lazarus effect' is frequently seen after the implementation of simple interventions.

When the child is truly nearing the end of life, however, an increase in clinical symptoms indicates disease progression (see Chapter 13: End-of-Life Care). If laboratory facilities are available, an increase in the viral load and a decline in the CD4 count can also be used to indicate that the condition is worsening.

When the family has accepted that the child is approaching the end of life, pain and symptom management and good holistic care become the focus of care (see Table 32.1). However, children should be encouraged to continue with their usual activities as far as possible, including education and play. Good control of pain and other distressing symptoms may be difficult in the homecare setting in countries that lack ready access to morphine and other palliative care drugs.

Treatment by traditional healers can be very effective in controlling some symptoms, and the use of complementary therapies such as massage and reflexology, have been shown to be effective (and low-cost) in relieving some painful conditions or emotional distress (see Chapter 15: Traditional Medicine and Chapter 18: Complementary Care). However, it is not advised to abandon prescribed medicines or to rely exclusively on traditional healers' remedies, which should not be viewed as replacements for 'Western' medication.

Table 32.1: Management of Common Symptoms at the End-of-Life

| Symptom | Causes | Management |
|-------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| For detailed symptom management in children, see chapter 27: Management of Clinical Conditions. | | |
| Pain | Neuropathy, infections, malignancies, wounds | Provide distraction. See Chapter 29 for play therapy and other psychosocial means of distraction. Give back rubs and massage, reposition. Give pain medication according to WHO Pain Ladder. See Chapter 4: Pain Management. |
| Nausea and vomiting | Drugs, gastrointestinal infections, fever | Small frequent feeds, fluids between meals. Offer cold foods. Feed before giving medications. Avoid sweet, fatty, salty, or spicy foods. See Chapter 7: Gastrointestinal Symptoms. |
| Sore mouth | Herpes simplex, aphthous ulcers, thrush, gingivitis | Keep mouth clean: use soft cloth or gauze and clean water mixed with a little salt. Give clear water after each feed. Avoid acidic drinks (e.g., orange juice) and hot food. Give sour milk or porridge, soft and mashed. Cold food may help (yoghurt, ice cream, ice cubes if available). See Chapter 8: Mouth Care |
| Chronic diarrhoea | Infections, malabsorption, malignancies, drugs | Rehydration. Diet modification (e.g., give yoghurt rather than milk). Oral morphine can alleviate intractable diarrhoea. If available, micronutrient supplements. See Chapter 7: Gastrointestinal Symptoms. |
| Persistent cough | Infections, LIP, bronchiectasis | Low-dose morphine. If available, chest physiotherapy and nebulized air. See Chapter 6: Respiratory Symptoms. |
| Severe dermatitis | Infections and infestations, hypersensitivity reactions, malignancies | Keep nails short to minimise trauma and secondary infection from scratching. Apply emollients, antihistamines, antiseptics, topical steroids. See Chapter 9: Skin and Wound Care. |
| Convulsions | Infections and infestations, encephalopathy, malignancies, metabolic disorders | Give anticonvulsants, dextrose, steroids. If available, give mannitol. See Chapter 10: Neuro-psychiatric Problems. |
| Wounds | Infections, pressure, malnutrition | Dress wounds. Apply honey on clean wounds. Apply metronidazole powder to control odour. See Chapter 9: Skin and Wound Care. |

Source: Adapted from ANECCA Handbook, 2004.

Telling the Truth to the Child

Many times parents or guardians have a very difficult time disclosing to a child that she or he has an incurable condition and is dying. The parents' own fear of death may lead them to avoid telling the child the truth, but children often know intuitively that they are dying and need to speak of this to enable them to deal with their emotions (see Chapter 29: Psychosocial and Spiritual Care for issues of disclosure).

Many questions beg answers and their needs can only be served by the truth, told in a compassionate and age-appropriate manner. Children should be told the truth about their diagnosis and treatment, from the time of diagnosis, in a way that is appropriate to their age, understanding, and developmental stage. In some cases the parents' wish to 'protect' the child from the knowledge of the condition and approaching death may lead to a breakdown in communication, with the child not speaking of what she or he knows or suspects to 'protect' the parents, and the parents not telling the child the truth about his or her condition to 'protect' the child. This is called 'mutual pretence', a situation in which all parties know that the child is dying but act as though the child will live. Truth allows the child to become a full partner in the care, builds self-esteem, and establishes some form of control in a situation that often feels out of control.

The child who asks, 'Am I going to die?' has picked the best person to ask — a person she or he trusts and believes. An honest 'yes' and a time allowing the child to express fears and concerns open the door for further discussions. The parent or guardian should be responsible for disclosing this news to the child unless the HCW is asked to assist by, and in the presence of, the parent or guardian. In general, the child will trust the word of the parent or guardian.

To facilitate this disclosure, HCWs must know the wishes of the parent or guardian, what the child has been told by the parent/guardian, and what questions, if any, the child asks. This way if a child asks, 'Do I have AIDS?' the HCW will know whether to explore the question and refer the child back to the parent or guardian, if the child has not been told his or her status, or to respond with honesty and hope in an age-appropriate manner. Where a team are caring for a child, permission may be sought from the child after disclosure for shared confidentiality.

Box 32.1:

How Children Disclose Their Knowledge of Illness and Their Own Death

Children often sense that they are dying and communicate their knowledge of death in different ways. Caregivers need to be alert to verbal and non-verbal communication. They may tell stories related to someone or something dying; or ask for special prayers to be said for them or their loved ones.

Children may communicate their knowledge through art, and the colours they use often indicate their feelings. They typically choose increasingly dark and drab colours as they approach death. Children can be asked to tell a story about a picture with a child in it, into which they will usually intertwine their own story and inform the listener of their understanding of their illness and impending death.

Communication through play, often with dolls and/or puppets, allows children to enact their feelings (see Chapter 29: Psychosocial and Spiritual Care). They may use symbolic language and story-telling. Older children may even make plans for their own funeral and for the distribution of their belongings to family and friends after their death.

Ethical Decisions in End-of-Life Care for Children

Withholding or Withdrawing Therapies

In Africa's many poor economies, issues around the best use of limited resources affect decisions to provide treatment or not. Health departments spend an increasingly large percentage of their budgets on treating conditions associated with HIV/AIDS, often leading to cuts in their budgets for non-AIDS conditions such as cancers.

In the acute care setting, when it is perceived that 'nothing more can be done', all treatment is usually withdrawn — instead of initiating good, active palliative care. We need to capacitate colleagues in acute care through the development of palliative care to integrate palliative care early in the trajectory of the illness. In countries where patients must pay for medications themselves, and resources are insufficient, HCWs or families often must choose to evaluate the benefit of treatment in relation to life expectancy. They may feel it necessary to provide for the needs of the living rather than those who are going to die, a difficult but not callously made decision.

Decision Making

The family and, where possible, the child, should always be included and kept well informed in decisions around treatment. A child can make decisions related to his or her developmental stage and level of understanding.

- Even very small children can be involved in simple decision making, such as choosing between two pain medications or deciding what to eat and when.
- Financial implications often affect a decision taken by a family. For example, a child may be transported home when dying, despite discomfort and long distances, as it is more affordable for the family to transport the child whilst living than to transport the child's body home for the funeral.
- In areas where so many children have been orphaned, it may prove difficult to find the child's parent or legal guardian to make a decision. This may place an increased burden on the HCW, who must then make difficult decisions without the input of the child's family.

Disclosure and Sharing Information

Children have the right to expect their AIDS diagnosis to be kept confidential, especially as they are too vulnerable to defend that right themselves. In many cases, however, the diagnosis is impossible to keep confidential from donors or visitors from organizations that care for children with AIDS or orphaned because of AIDS. Confidentiality is vital to respect, however, within the community.

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Suggested Resources

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