

## Chapter 13

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

Antiretroviral therapy (ART) has not been freely available to date in sub-Saharan Africa, and, as a consequence, many people with AIDS have needlessly died. Sub-Saharan Africa is just entering an era of ART and hopes not to duplicate the mistakes made in developed countries — including becoming ‘curative’ or over-optimistic about the eventual outcome of HIV infection. A high mortality rate is still expected, since a large proportion of those infected already have AIDS, and current guidelines recommend commencing ART when people have either or both CD4 counts <200 or AIDS-defining conditions (see Chapter 12: Integration of Palliative Care with ART). The introduction of ART will not reduce the need for good palliative care throughout the spectrum of caring for a person with HIV, including end-of-life care.

Negotiating end-of-life care often involves intense work in a short time for palliative care providers, who may need to act as advocates for their patients. The patient may not have told the family of the HIV diagnosis, or the family may be unwilling to care for a person dying of AIDS in their home even though the patient is desperate to go home. It may not always be possible to negotiate a peaceful, comfortable death at home, where the patient is surrounded by loved ones and is well cared for. Respect for the wishes of the patient and the family is critical in providing high quality end-of-life care.

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***At a Glance***

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Risk Versus Benefit of Treatment

Preparing Patients and Families for Imminent Death

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Suggested Resources

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## Recognising Signs of Imminent Death

One of the difficulties in caring for patients with AIDS is knowing when the end is really the end. The 'Lazarus' phenomenon is well described by hospices that have admitted patients for terminal care, only to have them walk out weeks later once they have recovered from an opportunistic infection or received adequate nutrition. But it is important that health care workers be able to recognise the terminal phase because all patients with HIV/AIDS will eventually reach the end of their lives. Familiarity with this phase is important:

### For The Patient and Relatives

- Prepares them so the patient may die in comfort and peace
- Helps to avoid panic-stricken calls for an ambulance, often only to have the patient die in the ambulance or another vehicle, on the way to hospital
- Lets them make plans, discuss advance directives, wills, and other legal paperwork

### For Health Care Professionals

- Lets them alter the goals of treatment
- Guides decisions about making appropriate changes to treatment and care regimens
- Increases their ability to provide support and explanations to the patient and family

The signs and symptoms associated with decreased survival time include:

- Such AIDS-defining conditions as malignancies or progressive multi-focal leucoencephalopathy
- Poor performance status, with >50% of the day spent in bed
- End-stage organ failure and anoxia
- Decreased response to ART, or the development of viral resistance
- Wasting and loss of >30% lean body mass, and serum albumin <30g/L
- CD4 count <200/mm<sup>3</sup>

Whilst these factors are indicative of decreased survival, they could be misleading in that actual survival time may vary from days to weeks, months or even a year or more. Some very practical signs of imminent death include:

- Decreased social interaction, withdrawal from the caregiver, family, and health care team
- Decreased consciousness, increased sleep, confused speech or actions, or coma
- Increased discomfort, general aches and pains from being mostly bedridden and very thin
- Reduced interest in and intake of food and drink
- Decreased urinary and GIT output
- Changes in breathing, which may become irregular, stop and start, or become noisy ('death rattle')
- Changes in circulation manifested in cold and grey or blue/purple hands, feet, nose, and ears

### Risk Versus Benefit of Treatment

The most appropriate end-of-life care and treatment must be negotiated with the patient and family. Once it becomes obvious that death is inevitable and imminent, the primary aim of any treatment must be to improve the patient's quality of life. This concept may be explored in the context of the following:

**Treatment of opportunistic infections (OI)** is a thorny issue. By the time patients with AIDS reach the end of their lives, they and their families may have experienced several 'false alarms', caused by opportunistic infections. They might argue that treating an OI previously allowed the patient to 'arise from a death bed', and could do so again.

**Nutrition and hydration** are very emotive issues and cause most of the disagreements between health care workers (HCWs) and relatives. It is important to try to foster understanding by carefully explaining the processes that are occurring, and the fact that artificial rehydration in this phase of life could be harmful.

**Aggressive medical interventions**, such as intravenous infusions, cardio-pulmonary resuscitation, intubation, and ventilation, are mostly inaccessible in sub-Saharan Africa. However, denial can motivate the patient or family to continue to seek aggressive treatment. Specific considerations:

**Second and third-line ART:** For patients on ART where the HIV infection has become resistant to the first regimen of ART, second or third line options are explored. There is a time, however, when such treatment becomes futile. Patients, but more often families, resist cessation of ART. Open, honest communication explaining the shift in treatment aims might be helpful.

**Chemotherapy or radiotherapy** might have a place earlier in the disease trajectory as curative or palliative measures, but are no longer appropriate at this point.

**Surgery** falls into the same category as above, and has no place in end-of-life care.

### Preparing Patients and Families for Imminent Death

Unfortunately it may become necessary to assist patients and their families in addressing an imminent death soon after meeting them because of late referral for palliative services. The communication is further complicated by the fact that even at the end of life there may still be issues of denial or secrecy regarding HIV/AIDS. It is helpful to concentrate on the inevitable fact of imminent death rather than dwelling on the cause of death. However, overcoming the taboo around talking about death can still be challenging (see Chapter 14: Communicating With Patients and Their Families).

#### *Set Reasonable Goals with the Patient and Family*

Although the patient or family may still deny or be ignorant of the HIV/AIDS diagnosis, they tend to shift their focus from dealing with the fact of HIV/AIDS, to dealing with imminent death. This is a time of repeated, intense, and emotional conversations with the patient and family. Often the HCWs will be expected repeatedly to interpret and discuss the patient's clinical signs and symptoms. It is imperative to maintain hope and to have realistic goals. It is helpful when discussing the patient's condition for staff to express their hopes, saying, for example, 'We hope to reduce the vomiting today with...', or 'We hope that the pain will be under control now that we are using suppositories rather than the tablets'.

***Negotiate the Place of End-of-Life Care with the Patient and Family***

Often patients express the wish to die at home, under difficult circumstances. There might be a mattress on the floor and no running water, making the caregiver's task daunting. But this place is home for the patient, and where she or he feels most comfortable. In other cases the patient might be afraid to go home because there is no formal health care, preferring to stay in hospital, or, where available, an inpatient hospice. The family might resist this, partly because of the prohibitively expensive cost of transporting a body for burial at 'home'. Other families may not yet have accepted the inevitability of the patient's imminent death and may rush the dying patient to hospital in a last-ditch attempt to appear to have 'done all they could'. Involving community-based carers and hospice staff is still complicated by fear due to the stigma of HIV/AIDS. Relatives might be reluctant to accept a home visit, in case the neighbours identify them as having someone with AIDS at home. These concerns should be brought into the open, so that a care plan can be agreed upon. One or more family conferences might be a way to accomplish this (see Chapter 14).

***Encourage and Empower the Carer***

Helping family caregivers to remain actively involved in the patient's care can empower them. Specific measures they can take to make the patient comfortable are listed in Table 13.1. Protecting family members who care for dying patients from exposure to HIV infection can be difficult when the HCW does not have consent to divulge the HIV diagnosis. With so many AIDS-related deaths, children often head households and care for ill adults and other children. In both these instances, some pointed questions about the different roles in the family and how family members are coping could highlight a need for intervention. Involving care partners in the community, including spiritual leaders, traditional healers, or church communities, may be helpful, but again must be negotiated because of the stigma of HIV/AIDS.

**Table 13.1: Care Suggestions for the Family When Death is Imminent**

Changes	Care Suggestion
Decreased social interaction	<ul style="list-style-type: none"> <li>• Encourage the family to remain in the same room and not leave the patient alone, explaining the calming effect of a human presence. (Suggest that children do their homework in the room.)</li> </ul>
Decreased consciousness	<ul style="list-style-type: none"> <li>• Encourage the family to talk to and touch the patient.</li> <li>• Skin care and pressure relief become crucial at this point.</li> </ul>
Increased discomfort, general aches and pains of being bedridden and very thin	<ul style="list-style-type: none"> <li>• Continue analgesics even if the patient is comatose or can no longer swallow.</li> <li>• Use alternative routes of administration if appropriate.</li> <li>• Reduce the dose if there is an increased risk of side effects (such as myoclonic jerks) which may be treated with any benzodiazepine.</li> </ul>
Reduced interest in and intake of food and drink	<ul style="list-style-type: none"> <li>• Explain the natural physiological process to the family.</li> <li>• Discourage force feeding and allow family to offer sips of water or chips of ice hourly to keep the mouth moist.</li> <li>• If the family requests to admit the patient to hospital for intravenous fluids, explain the consequences.</li> </ul>
Decreased urinary and GIT output	<ul style="list-style-type: none"> <li>• Reassure the family that the patient is not uncomfortable.</li> <li>• Address possible incontinence and the need for extra careful skin care.</li> <li>• Repeat information about measures to protect the carer against body fluids.</li> </ul>
Changes in breathing (irregular, stopping and starting, or noisy—the 'death rattle')	<ul style="list-style-type: none"> <li>• Explain what is happening and reassure the family.</li> <li>• Keep the mouth moist, especially if the patient is mouth breathing.</li> <li>• Consider using hyoscine butylbromide by various routes to reduce secretions.</li> </ul>
Changes in circulation (cold and grey or blue/purple hands, feet, nose and ears)	<ul style="list-style-type: none"> <li>• Explain that death is near.</li> <li>• Encourage the family to stay with the patient.</li> <li>• Suggest that they say goodbye each time they leave the room in the event the patient dies before they return (provided they wish to be present).</li> </ul>

### ***Include the Work of Anticipatory Grief***

Anticipatory grief, which occurs before a person dies, is often a neglected element of an end-of-life-care-plan, because whilst all people find it difficult to talk about death, for some there may be a powerful taboo. Creating memory boxes for younger children, writing letters to older ones, and having a photograph taken are practical ways of saying goodbye. Ideally this work should have been started long before, since often by this time the patient is frail and tired or confused. If there was no prior opportunity to do so, there still might be time for legal paperwork, such as wills or guardianships of children. The patient and family could be encouraged to talk, forgive, express their feelings of loss and love, remember, and say goodbye.

It is important to prepare the family for the event of death and what actions are to occur afterwards. In some areas resources are scarce and most deaths occur at home, amongst people who have faced death before. This may not always be true, and relatives may be facing death for the first time, unsure of their responsibilities. If the patient has died in hospital, staff must be sensitive about different cultural and religious customs in handling the body. A longer discussion of this topic can be found in Chapter 16: Spiritual and Cultural Care.

## Symptom Management

As death nears, symptom management continues to be essential (see other chapters for specific interventions), but the focus may shift and practices may differ from what was appropriate earlier in the disease process. Generally, it is important to:

- Revisit all prescribed treatments and review them with new goals appropriate for end-of-life-care.
- Simplify.
- Discontinue treatment for concurrent conditions — such as diabetes, hypertension, or high cholesterol — which are superfluous at this stage and often do not contribute to the patient's comfort.
- Continue medication — such as anticonvulsants — that, if stopped, may cause distress to the family, if not the patient.
- Adjust dosages of pain medication and adjuvants as needed due to reduced circulation and organ function and increasing side effects.
- Use alternative routes to administer medication once the patient can no longer swallow.
- Continue nutritional support, but respect the patient's wishes. Because families are often disturbed when attempts to provide nutrition are discontinued, it is wise to offer sips of water, chips of ice, or even just to moisten the mouth and lips with a damp cloth.
- For dyspnoea, fan the face; give morphine (see Chapter 6: Respiratory Symptoms).
- For respiratory panic attacks, provide reassurance and encourage breathing exercises; give diazepam 2.5 to 5 mg.
- For 'death rattle', reposition the person in bed, reassure the family. To dry secretions, give hyoscine butylbromide 20 mg 4 hourly.
- For nausea and vomiting, give antiemetics SC (see Chapter 7: Gastrointestinal Symptoms).
- For delirium, review drugs (see Chapter 10: Neuro-Psychiatric Problems). Consider haloperidol. For agitated delirium, consider haloperidol, with diazepam 5 mg PR 4 to 6 hourly for sedation.
- For 'terminal restlessness', treat the physical cause (e.g., full bladder, pain). Encourage the presence of family member. Consider sedation.
- For convulsions, give diazepam 5–10 mg PR stat (repeat if required to max of 30 mg).
- For haemorrhage (e.g., haematemesis), sedate (see Chapter 6: Respiratory Symptoms).
- For urinary retention or incontinence, if possible, catheterize the patient.

## Recognising Death

If the patient is dying at home, HCWs should describe to the family what to expect. Once death occurs the clinical signs will include:

- No heartbeat nor pulse
- No breathing
- Fixed pupils, eyelids may be open or closed
- Waxed skin colour and darkened extremities
- Drop in body temperature
- Relaxed muscles and sphincters (incontinence may occur)

When the patient dies, encourage the family to take their time at the bedside to say goodbye. Some might want a minister, rabbi, or imam to attend to them and the body; others may wish to quietly take their leave. It is important to remember that the body remains infectious for about a week after death, and universal precautions should be applied to all bodies regardless of diagnosis.

Death certificates and insurance reports are the next trauma that the family must face. Because the right of confidentiality remains intact even after death, the HCW is often trapped in the conflict between truth-telling and respecting confidentiality. As far as death notifications are concerned, patients with AIDS die from a variety of immediate causes, such as pneumonia, tuberculosis, or Kaposi's sarcoma, and these may be cited as the cause of death rather than AIDS. If the patient had insurance, completing insurance certificates is trickier since the forms ask direct questions about HIV tests and AIDS. It is a good idea not to send forms directly to an insurance company, but to alert the family to the facts written on the form, and allow them to decide whether or not to submit it.

Mourning cannot be fully discussed in this chapter, but is important enough to be mentioned. (For a fuller discussion of mourning, see Chapter 17: Loss, Grief, and Bereavement.) Families losing loved ones to AIDS are at risk for complicated bereavement because of many factors:

- Multiple losses, including loss of one family member after another, leaving no time to grieve
- Carers who are ill themselves
- Loss of parents and of bread winners, leaving families with few resources or support
- Stigma and shame in dying of AIDS

### Suggested Resources

The EPEC Project: Education on Palliative and End-of-Life Care. 1999. *Participant's Handbook: Module 12: Last Hours of Living*. Princeton, NJ: The Robert Wood Johnson Foundation. Available at <http://epec.net/EPEC/webpages/index.cfm>. Accessed 11/04.

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