

Palliative care in advanced HIV



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Although antiretrovirals are the most effective palliation for HIV, they are frequently not available and another approach is necessary.

HIV/AIDS is a disease almost exclusively affecting younger people, both in the productive and reproductive times of their lives. Antiretroviral treatment does not cure HIV/AIDS, but effectively alters it from a terminal to a chronic disease. As such, ART is the most effective palliation for HIV/AIDS so far. Given that antiretroviral therapy is neither freely available nor affordable for most of the more than 90% of infected people living in sub-Saharan Africa, HIV is a terminal disease. This makes it a life-altering diagnosis, impacting on the biomedical, psychosocial and spiritual well-being of the patient. The response to dealing with this disease should be equally holistic, not just at the end of life, but from the very time of diagnosis. Patient care from the time of diagnosis should be multidisciplinary, involving a diversity of practitioners. This approach is applicable from diagnosis to death, with close collaboration between acute and palliative physicians. This model of care should be encouraged because the natural course of untreated HIV/AIDS is characterised by a progressive deterioration of the underlying immune system, punctuated by consequent opportunistic infections and cancers. Progress of the disease is also influenced by the patient's pre-morbid immune status, previous disease, nutrition, lifestyle and social status.

FEATURES OF PALLIATIVE CARE IN AIDS

Distinguishing characteristics of end-of-life care in AIDS include:

- the youth of the infected person, resulting in more aggressive curative treatment being pursued far later in the course of the disease

- multisystem disorders with variable presentation, curable components within a progressively fatal disease, compounding uncertainty and creating indistinct boundaries between cure and palliation
- a higher proportion of extremely emotive issues surrounding sexuality, reproduction, guilt, loss of vitality, loss of productivity and death.

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BIOMEDICAL MARKERS DETERMINING THE TERMINAL PHASE

Clinical markers:

- cachexia
- presence of AIDS-defining diagnoses, especially where there is no access to HAART, or active specific treatment with a good possibility of cure or guaranteed access to prophylaxis, e.g. central nervous system (CNS) lymphoma, disseminated Kaposi's sarcoma (KS), cytomegalovirus (CMV) viraemia
- low rating on the Karnofsky Performance Scale (Table I).

Laboratory markers:

- CD4 < 50 cells/ μ l or absolute lymphocyte < $0.75 \times 10^9/l$
- high viral load.

The following are poor prognostic factors in individual opportunistic infections, e.g. in cryptococcal meningitis:

- age < 35 years

Table 1. Karnofsky Performance Status Scale

Definition	Percentage	Criteria
Able to carry out normal activity and work, no special care needed	100%	Normal, no complaints, no evidence of disease
	90%	Able to carry on normal activity, minor signs or symptoms of disease
	80%	Normal activity with effort, some signs or symptoms of disease
Unable to work but able to live at home and care for most personal needs Assistance needed to varying degrees	70%	Cares for self but unable to carry on normal activity or to do active work
	60%	Requires occasional assistance but is able to care for most needs
	50%	Requires considerable assistance and frequent medical care
Unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly	40%	Disabled, requires special and assistance
	40%	Severely disabled, hospitalisation is indicated, although death not imminent
	30%	Severely disabled, hospitalisation is indicated, although death not imminent
	20%	Very sick, hospitalisation necessary, active supportive treatment necessary
	10%	Moribund, fatal processes progressing rapidly
	0	Dead

- CSF — high opening pressure, low cell count, high antigen titre, low glucose
- hyponatraemia
- abnormal CT scan of the brain
- extracranial evidence of cryptococcosis, e.g. in the lung.

Approximate survival rates for opportunistic infections/cancers are dependent on availability, affordability and accessibility of HAART and adjuvant active treatment:

- any AIDS-defining illness — up to 2 years expected survival
- KS, pneumocystic pneumonia and other opportunistic infections — median survival of 7 months
- AIDS-related cancers — median survival of 4 months
- severe dementia — median survival 2 months
- untreated cryptococcal meningitis — between 19 and 54 days.

PRACTICAL MANAGEMENT OF AIDS PATIENTS

This entails the formulation of structured individualised care plans for each patient and their family, drawn up by the multidisciplinary team in conjunction with the patient and family or caregivers.

The multidisciplinary care team

The core of the team comprises:

- physicians to manage biomedical issues — acute care physicians for active treatment of intercurrent infection e.g. IV amphotericin B on an in-patient basis for patients with confirmed cryptococcal meningitis; palliative care physicians to provide symptom control, e.g. analgesia and serial lumbar puncture to relieve the headaches of cryptococcal meningitis
- social worker or psychologist to manage psychosocial issues and

adjustment to change, e.g. loss of income and subsequent financial problems, assistance in completing unfinished business, e.g. making a will, bereavement counselling for patient and family

- nurses for case management, to communicate with the physician with regard to home care issues, monitor compliance and side-effects of treatments, educate caregivers about specific interventions to address biomedical problems that may arise in the home setting.

Adjuvant members may include:

- home care aides to assist with activities of daily living, e.g. bathing, to provide company, and to call for assistance when needed
- rehabilitation specialists to assist with specialised approaches to reducing discomfort and increasing independence, e.g. modifications to the home for non-ambu-

- splints to rest acutely inflamed joints
- spiritual carers — to address issues specific to the spirituality of each patient (this must be embarked upon after discussion with and approval by the patient)
- volunteers to provide companionship, arrange transportation etc.

THE PATIENT CARE MANAGEMENT PLAN

This plan must be tailored for each patient and take into account the community of origin with its local practices, customs and culture. The nursing component of the multidisciplinary team should facilitate strong liaison between the specialised hospital team and the home and hospice or palliative care teams. The plan must address biomedical, psychosocial, spiritual and cultural issues. Important steps in the management plan include:

- assessment — collection of data, both subjective (statements from patient and caregivers) and objective (detailed history, observation, examination and investigations); it includes a psychosocial and spiritual assessment
- problem identification or diagnoses
- planning — setting priorities, e.g. immediate care for overwhelming biomedical symptoms before addressing longstanding social problems; establishing short-, medium- and long-term goals of treatment, and documented interventions on how to achieve those goals, preferably with time frames
- evaluation — an ongoing process of assessment, to identify and address shortfalls and achievements of the initial assessment.

CLINICAL CARE IN THE TERMINAL PHASE

Symptoms in the terminal phase may be due to:

- HIV itself, e.g. AIDS dementia, HIV enteropathy, HIV neuropathy
- the treatment, e.g. peripheral neuropathy secondary to INH (used in TB prophylaxis) or secondary to the nucleoside analogues didanosine or stavudine
- debility, e.g. odynophagia with oropharyngeal candida, anxiety (with/without somatic symptoms) secondary to fears about mortality
- concomitant illness, e.g. dyspnoea from pre-existing asthma.

Evaluation – an ongoing process of assessment, to identify and address shortfalls and achievements of the initial assessment.

The assessment includes a full history and relevant examination and investigation. Many terminal patients are inappropriately subjected to aggressive invasive procedures. Thus any symptom needs to be fully assessed, keeping in mind the following:

- premorbid performance status of the patient
- access to effective treatment
- benefit v. possible side-effects of treatment
- problems with withdrawing trials of treatment
- possible drug interactions between new and existing drugs.

Treatment will be defined by the cause of the symptom. Consider the following approach:

- modification of the underlying disease process, e.g. HAART, nerve blocks for difficult neuropathic pain
- specific drug therapy for reversible causes, e.g. antifungals

for oesophageal candida plus systemic analgesics for the odynophagia plus antacids for associated dyspepsia

- symptom control drug therapy for symptoms secondary to irreversible causes, e.g. long-term loperamide for diarrhoea secondary to HIV enteropathy
- non-drug therapy, e.g. relaxation techniques for anxiety, specific psychotherapy
- alternative therapies, e.g. acupuncture for peripheral neuropathy, music therapy as an adjuvant for pain control
- modification of the environment, e.g. wheelchairs for non-ambulant patients, splints etc.

While it is impossible to address control of all the possible symptoms in AIDS in this article, some of the more common possibilities are covered.

PAIN

Pain is common in AIDS and the prevalence increases as the disease progresses. While the principle of assessing the cause of the pain must be applied, it can be used in conjunction with the WHO stepped care strategy for pain management (Fig. 1 and Table II).

Pain is common in AIDS and the prevalence increases as the disease progresses.

Attempts to identify the cause of the pain should not delay the use of analgesia. The sensitivity of the specific pain to different analgesics, e.g. opioids and NSAIDs, should be kept in mind when prescribing. Different pains should be documented, with each being given a severity rating. Serial assessments

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to ascertain response to treatment should be carried out regularly. Treatment failure should lead to re-assessment, to determine if the original diagnosis was correct, if the appropriate analgesic was chosen, if the dosing amounts and frequency are optimal, if adherence is good, and if the pain is not controlled because exacerbating psychological elements, e.g. insomnia, have not been addressed. The use of co-analgesics for specific pain management is recommended, e.g. amitriptyline 10 - 75 mg po nocte for the pain of peripheral neuropathy or anxiolytics, e.g. lorazepam, for pain exacerbated by anxiety.

SKIN CONDITIONS

Common skin conditions include xeroderma, seborrhoeic dermatitis, folliculitis, herpes zoster, and generalised pruriginous dermatitis. Specific treatment of these conditions has been addressed in other articles, but the palliative approach to pruritis bears mention. This approach is in conjunction with specific treatment dependent on the cause.

- Try to avoid the use of electric blankets or sitting too close to the heater.
- Apply principles of moist wound healing to open skin lesions, e.g. moist compresses, saline dressings, paraffin gauze.
- Add UEA or non-perfumed bath oil to the bath water, and avoid commercial soaps.
- Moisturise the skin with emollients (UEA or aqueous cream) after the bath.
- Cucumber used topically is a good home remedy.
- Use weak corticosteroids in menthol or UEA topically
- Oral antihistamines or short-course steroids can be tried.

Pre-emptive measures to maintain a well-moisturised, intact skin are still the best approach. For thin patients prone to developing pres-

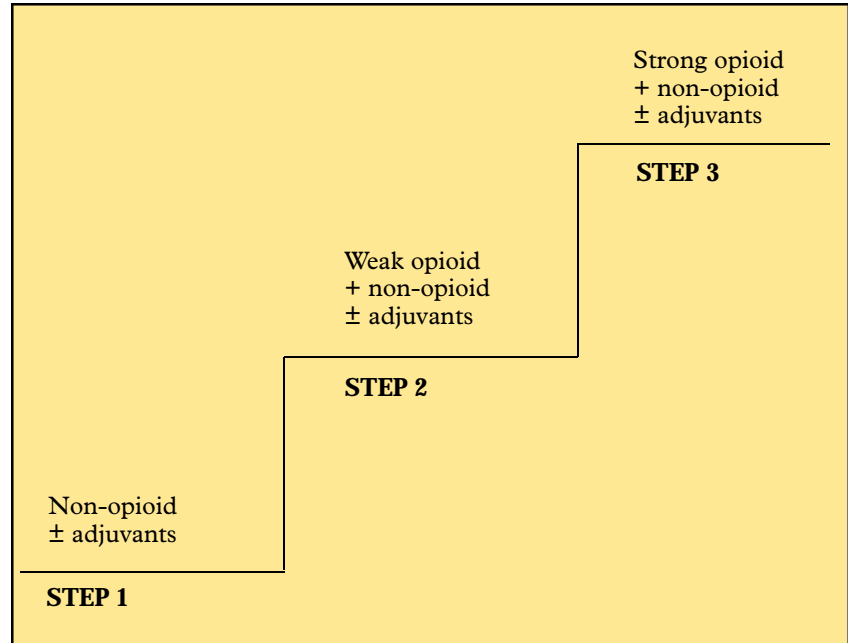


Fig. 1. World Health Organisation 3-step analgesic ladder.

Table II. Adjuvant drugs for analgesic ladder

Control of adverse effects	Secondary analgesics
Laxative Antiemetic	Corticosteroid Antidepressant Anticonvulsant NSAID
Psychotropic medication	
Night sedative Anxiolytic Antidepressant	

sure sores, regular turning (every 2 hours), and light skin massage are essential. Special mattresses or pressure prevention devices are an option.

GASTROINTESTINAL SYMPTOMS

Abdominal cramps with or without diarrhoea should be assessed for cause, but can be palliated with antispasmodics, e.g. hyoscine butylbromide 10 mg 8 hourly. Nausea and vomiting should be treated in part by treating the underlying cause. In HIV common causes include:

- GI infection
- GI irritation — due to toxins or drugs

- raised intracranial pressure, e.g. cryptococcal meningitis, CNS lymphoma or toxoplasmosis
- unknown reasons.

For GI causes maxolon 10 mg 6 - 8 hourly po or haloperidol 2.5 mg stat with 0.5 - 5 mg po nocte is useful as a first line. Raised intracranial pressure may respond to serial therapeutic lumbar puncture for cryptococcal meningitis. The procedure is precisely as for the diagnostic procedure, removing up to 10 ml of CSF at a time, until normal CSF pressure is obtained.

Drug therapy for raised intracranial pressure will often include the addition of dexamethasone 4 - 8 mg po daily to the first-line antiemetic. Cyclizine is a good broad-spectrum

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antiemetic that acts on the vomiting centre in the brain, and controls most vomiting irrespective of the cause. Often vomiting may need to be controlled by a combination of antiemetics, in which case the mode of action of the chosen combinations should be carefully researched to avoid antagonistic drug interactions, e.g combining buscopan with maxolon (both use the cholinergic pathway).

Route of administration is of prime importance in the patient with significant emesis, as this may preclude the use of the oral route. Rectal, subcutaneous, intravenous and intramuscular routes can be considered, guided by patient preference and expected duration of treatment.

Cyclizine is a good broad-spectrum antiemetic that acts on the vomiting centre in the brain, and controls most vomiting irrespective of the cause.

Diarrhoea may be acute, subacute or chronic and stool microscopy and culture is vital to ascertain the cause. If no pathogen is isolated and diarrhoea persists for more than 5 days, a trial of Bactrim 2 bd plus Flagyl 200 mg tds for 7 days is warranted. For chronic prolonged or intermittent recurring diarrhoea *Mycobacterium avium*, *M. tuberculosis*, CMV and even KS are possible candidates. While the level of investigation depends on patient preference and performance status, as well as institutional protocols and budgetary constraints, symptomatic control of diarrhoea is possible. The following

choices are available:

- diphenoxylate, most useful in acute diarrhoea due to short half-life, 10 mg po stat, with 5 mg 6 - 8 hourly thereafter
- loperamide, useful for acute and chronic diarrhoea, 8 mg po stat, with 4 mg after each loose stool (acute) or 4 - 8 mg daily in divided doses (chronic diarrhoea); maximum doses of 16 - 32 mg/24 h can be used
- codeine phosphate 30 mg qid
- morphine po or subcutaneously can be used as it acts both centrally and peripherally, whereas loperamide is peripheral only.

Note that diphenoxylate and loperamide are more convenient, being in tablet form. Loperamide is also three times more potent than diphenoxylate, and fifty times more potent than codeine.

CONFUSION

This is a common presentation with the CNS complications of HIV. It is useful to differentiate acute delirium from the more chronic dementia. Delirium usually implies a reversible, treatable cause and must be investigated appropriately. Fear, anxiety and decreased level of consciousness are often major factors, with episodes of lucidity. Dementia is characterised, in the later stages, by a calm, non-aggressive patient, who has difficulty retaining information. Both may exhibit problems with memory, concentration, orientation, hallucinations and delusions. It is not unusual for an acute delirium to compound a chronic dementia.

A full assessment to ascertain reversible causes and to treat appropriately is prudent, but often in the terminal phase the cause is multifactorial. Alcohol withdrawal, hyperstimulation from external stimuli, e.g. creases in sheets, dehydration and psychological factors such as anxiety are important pre-

cipitating and causative factors.

Full explanation to the family, and the patient (if there are episodes of lucidity) is vital. Non-drug measures include treating the patient with dignity, avoiding restraints, re-orientating the patient, use of a night light, avoiding changing the position of the patient's bed, establishing set routines for meals and ablutions, and having a small number of familiar staff or a close family member involved in care.

Bringing favourite familiar items from home to the bedside of a hospitalised patient also helps.

Drug choices are guided by the presence of hallucinations, where an antipsychotic may be needed, and by the need for sedation.

Choices include:

- largactil and etomine where deep sedation is required in a patient who is actively hallucinating; hypotension and arrhythmias can be problematic with largactil
- lorazepam 0.5 - 2 mg tds
- diazepam 2 mg 1 - 3 times daily
- midazolam 10 - 60 mg/24 h is a useful sedative in the non-hallucinating patient.

Doses must be titrated according to need, starting at the lowest dose and titrating up rapidly if required. Initial studies in AIDS patients show that extrapyramidal side-effects with haloperidol are more likely.

PSYCHOSOCIAL, SPIRITUAL AND CULTURAL ASPECTS OF TERMINAL CARE

Bereavement care for the patient and family assists in creating an environment conducive to a good death. A family meeting involving relevant family members, with or without the patient, allows for the transfer of information, education of the family on the patient's con-

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dition and for support on a practical and emotional level. These discussions should take into account the religion and culture of the people involved, with the health care workers taking care not to impose their own customs on the patient and family.

The core multidisciplinary team of the doctor, nurse and counsellor (social worker or psychologist) is a good combination to host this meeting. Adequate time and an appropriate venue should be ensured.

CARING FOR THE CARERS

Caring for terminally ill patients, especially young patients, can be a physically, psychologically and emotionally exhausting task.

Health care workers need to feel confident and comfortable with this challenge, as personal fears and anxieties surrounding mortality are often conveyed to the patient. Formal and informal sessions with a skilled therapist to debrief health care workers are highly recommended, as are group discussion and structured breaks.

CONCLUSION

AIDS has provided a challenge to the medical fraternity at large, calling for closer collaboration between curative and palliative care. It demands that curative medicine adopts a higher level of care, and that palliative medicine adopt a reasonable measure of cure.

FURTHER READING

- Bekker LG. Palliative care. In: *The Foundation for Professional Development Manual 2001*, Chapter 10. FDP: Johannesburg.
- Evian C. *The Care of People who are in Pain, Discomfort or Dying*. Primary Aids Care, 3rd ed. pp. 281-299.
- Galasso D. Guidelines for developing multidisciplinary treatment plans. *Hospital and Community Psychiatry* 1987; **38**(4): 394-397.
- Jennings AL, George R. Palliative care of HIV disease and AIDS. *Progress in Palliative Care* 1996; **4**: 44-47.
- Sanne I, Dalakas E, Smego RA. Treatment of HIV-associated cryptococcal meningitis: prognostic factors and clinical outcome. *CME* 2000; **18**: 315-320.

IN A NUTSHELL

The natural course of untreated HIV/AIDS is characterised by a progressive deterioration of the underlying immune system, punctuated by consequent opportunistic infections and cancers.

ART is the most effective palliation for HIV/AIDS so far.

Patient care from the time of diagnosis should be multidisciplinary.

Palliative care in AIDS is characterised by a higher proportion of extremely emotive issues surrounding sexuality, reproduction, guilt, loss of vitality, loss of productivity and death.

Practical management of AIDS patients entails the formulation of

individualised care plans for each patient and their families, drawn up by the multidisciplinary team in conjunction with the patient and family or caregivers.

Symptoms in the terminal phase may be due to the HIV itself, treatment of HIV or opportunistic infections, associated debility or concomitant illness.

Clinical care involves a detailed assessment to ascertain cause, followed by treatment of reversible causes, drug and non-drug palliation of chronic symptoms, and re-evaluation to assess response.

Psychosocial care is facilitated by a family meeting involving relevant family members, with or without the patient, which allows for the transfer of information, education of the family

on the patient's condition and for support on a practical and emotional level.

Caring for terminally ill patients, especially young patients, can be a physically, psychologically and emotionally exhausting task, with which health care workers need to feel confident and comfortable, as personal fears and anxieties surrounding mortality are often conveyed to the patient.

AIDS has provided a challenge to the medical fraternity at large, calling for closer collaboration between curative and palliative care, demanding that curative medicine adopts a higher level of care, and that palliative medicine adopt a reasonable measure of cure.