

Chapter 10

Neuro-Psychiatric Problems***Overview***

With its ability to present in a myriad of different ways, HIV/AIDS has taken over from syphilis, diabetes, and tuberculosis (TB) as ‘the great pretender’ when it comes to clinical presentation. Neurological and psychiatric symptoms are very common in HIV/AIDS for a number of reasons.

- HIV is neurotrophic (attracted to the nervous system); as the virus takes its time exhausting the immune system, it slowly causes progressive damage to the nervous system. Initially such damage may reveal itself in subtle ways. Thus, the affected person may present with a common complaint such as a headache or with bizarre behaviour and unfamiliar neurological signs.
- Antiretroviral drugs (ARVs) may cause complications such as peripheral neuritis, especially when combined with TB treatment.
- Multiple losses — health, friends, family, respect, future — experienced by the person living with HIV/AIDS can cause psychological problems. For example, the economic hardship resulting from chronic ill health or the loneliness of rejection by one’s community can very easily lead to anxiety, despair, alienation, depression, and even suicide.

This chapter presents the common neurological problems and provides a practical approach to supportive and palliative care in dealing with these problems in sub-Saharan Africa.

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At a Glance

Issues in Neurological Assessment

Issues in Management of Neurological Disorders

Headaches

Painful Hands and Feet

Other Painful Conditions

Weakness

Seizures

Confusion/Delirium
Dementia

Depression

References

Neuro-Psychiatric Problems

Table of Contents

Overview	145
Issues in Neurological Assessment.....	147
Issues in the Management of Neurological Disorders	148
Headaches	149
Painful Hands and Feet	150
Other Painful Conditions	151
Herpes Zoster	
Mononeuritis Multiplex	
Weakness	151
Difficulty Walking	
Facial Weakness	
Hemiparesis	
Seizures.....	152
Confusion/Delirium, Dementia	153
Depression	154
References	154

Issues in Neurological Assessment

Clinical Staging

WHO Clinical Staging (See Chapter 3: Principles of Clinical Assessment) is useful in examining patients with neurological problems, especially where laboratory and testing facilities are limited or absent. Staging can give an idea of the person's disease progression.

However, there are challenges inherent in palliative assessment and management of HIV/AIDS. A daily dose of 'mental gymnastics' ensures sound, realistic, innovative, and compassionate thinking as we negotiate the minefield of the neuro-psychiatric problems facing the person with HIV/AIDS (see Chapter 3: Principles of Clinical Assessment).

Understanding Cultural Perspectives

Symptoms that do not respond to the usual remedies may be interpreted as being due to supernatural forces. For example, the burning feet of the peripheral neuropathy so common in advanced stages of HIV disease is notoriously difficult to relieve. Patients may interpret this condition as being caused by an evil person who has sprinkled poison on the pathway near the patient's home. Walking over this poison will cause the feet to burn and will be resistant to all forms of conventional treatment. It is only when a more powerful *muti* (a medicinal plant remedy) can be obtained that the power of the evil person is destroyed.

Some forms of mental disturbance may be interpreted in a similar way. The disturbance may be thought to be due to a call from the affected person's ancestors to become a traditional healer. A good strategy for someone who is unfamiliar with the local beliefs is to acknowledge this ignorance and to ask help from the affected person or family. See also Chapter 15: Traditional Medicine.

Diagnostic Testing

Serological testing for syphilis is one of the few tests worth doing routinely even when resources are limited. The prevalence of syphilis is similar to that of HIV in many areas. Syphilis cannot be diagnosed clinically during the long latent phase. Failure to treat may have very serious consequences in the immune-compromised person.

That said, as many different conditions may present with the same signs and symptoms, and as some conditions respond well to specific treatment, it is important to investigate as fully as possible.

If available, consider the following:

Lumbar puncture: One should have a low threshold for doing a lumbar puncture in the face of strange neurological signs.

Scan: With signs of an intracranial mass a CT scan may be helpful. Otherwise, empirical treatment is warranted (see empiric therapy under Management).

Prognosis

Patients who have spent more than 50% of the day time in bed over the past month have an average life expectancy of less than one month (see Table 3.1: Palliative Performance Scale in Chapter 3).

Box 10.1

Mental 'Landmines' in HIV/AIDS Care

The mental 'landmines' facing health professionals in the context of the overwhelming AIDS epidemic include:

Over-diagnosing AIDS as the cause of everything: This may lead to the overlooking of alternative and potentially treatable conditions in their early stages.

The danger of 'therapeutic nihilism': The narrow fixation on cure overlooks the rich diversity of care.

The danger of technology: Those in well-equipped facilities will be tempted to throw technology at the problem, while those in resource-limited areas may feel that they cannot practice good medicine without it.

Issues in the Management of Neurological Disorders

Addressing Psychosocial Issues

Patients with neuropsychiatric disorders present a great challenge to everyone involved. Strange behaviour or the need for constant care, added to the stigma of AIDS, can be an overwhelming prospect to families. Adopting a team approach to care is a good strategy to facilitate optimal care in such difficult circumstances. The team should include the patient, the family, members of the community, and all the relevant care providers, including traditional healers and spiritual leaders if desired by the family.

The aims of management are:

- Relief of suffering
- Promoting the best quality of life possible
- Rehabilitation where feasible

Interventions include:

Counselling: Provide supportive counselling and negotiate culturally appropriate solutions (see Chapter 14: Communicating With Patients and their Families).

Community support: Deal with spiritual and emotional issues. The extended family, local support groups and churches can play a vital role here (see Chapter 16: Spiritual and Cultural Care and Chapter 20: Care and Support for the Carers).

Advocacy: Consider the implications of the person's condition for his or her ability to continue to work (see Chapter 24: Financial and Legal Issues). In addition, there have been unfortunate incidences of patients with dementia or delirium being thrown out of their homes or of being locked up in a small shed. It may be possible to prevent such unfortunate events by reducing fear and by supporting the family. Occasionally legal steps may be necessary to prevent discrimination and abuse.

Essential Drug Supply

It is obvious that appropriate treatment requires the availability of essential drugs at facilities accessible to the patient. Unfortunately drug supply at the primary care level is a major problem in sub-Saharan Africa, especially in rural areas. The limited and erratic supply of essential drugs not only causes much suffering but it also frustrates and demoralises the professional staff. This is a significant contributing factor in the decision by many professionals to leave such areas. (See Chapter 35: Role of Government and Chapter 36: Drug Policy)

Empiric Medical Therapy

Empiric therapy is a practical approach in resource-limited settings. Lack of access to laboratory or sophisticated diagnostic facilities may make it difficult to arrive at a specific diagnosis. An empirical trial of treatment is justified for conditions that are common and treatable, such as toxoplasmosis in the case of a person who presents with focal neurological signs. Other conditions that may be treatable include cryptococcal meningitis, syphilis, or tuberculosis.

Palliative Medical Therapy

Effective relief of pain may be difficult, especially when there is severe neuropathic pain. However, significant relief can be achieved using tricyclic antidepressants (such as amitriptyline) and/or anticonvulsant drugs (such as phenytoin or carbamazepine, depending on availability) in combination with opioid analgesics.

Haloperidol with or without a benzodiazepine (such as lorazepam) is usually effective and safe in controlling agitated behaviour. (Thioridazine can be used if haloperidol is not available but may cause arrhythmias or hypotension.)

After careful consideration of all the pros and cons, steroids (such as dexamethasone) may give dramatic relief to pain due to pressure on sensitive structures.

See sections below on specific conditions as well as Chapter 4: Pain Management.

Deciding When to Stop ART

In patients on ART with continued deterioration or evidence of permanent brain damage, it is appropriate to stop the drugs and concentrate on symptom relief.

ART should also be withdrawn if there is a severe drug reaction such as an acute toxic neuropathy (see Chapter 12: Integration of Palliative Care with Antiretroviral Therapy).

When the cost of the drugs is causing severe economic hardship to the whole family, withdrawing them is also appropriate.

Headaches

Assessment

Headaches are common in HIV/AIDS. While they are usually not an indication of serious pathology in the general community, extra care needs to be taken with the person who is HIV-positive who complains of headache. The following aetiologies should be considered:

Migraine and muscular contraction

headaches: Signs include a stable, long standing pattern, no change in behaviour, mood, or cognitive function, and no signs of infection.

Drug-induced headaches: One specific drug may be zidovudine (AZT).

Sinusitis: Signs include a recent upper respiratory infection and tenderness over the sinuses.

Meningitis: Cryptococcal and tuberculous meningitis are common in patients with HIV/AIDS in Africa, but other bacteria as well as viruses may be the cause. Suspect meningitis if there are signs of infection and the headache is of recent onset, severe, and persistent. Other signs indicative of meningitis that may be present are:

- A change in behaviour, mood, or cognitive function
- Photophobia
- Unexplained projectile vomiting without nausea
- Neck stiffness (may not always be present)

Space-occupying lesion (cerebral lymphoma or toxoplasmosis): Suspect if there is:

- Neurological sign of an intracranial mass
- A history of recent convulsions
- A reduced level of consciousness

Management

Treating Reversible Causes

If drug-induced, stop the offending drug.

Treat cryptococcal meningitis with fluconazole, or, if severe and available, amphotericin B followed by fluconazole.

Treat meningeal TB with standard 4-drug antituberculous therapy.

Treat toxoplasmosis with co-trimoxazole (sulphamethoxazole + trimethoprim) or clindamycin and pyrimethamine.

Non-Pharmacologic Symptom Management

Measures such as being in a quiet, dark room, having a cool cloth over the eyes, and having the neck massaged may be helpful. See Chapter 4: Pain Management for other interventions.

Pharmacologic Symptom Management

See Chapter 4: Pain Management.

Painful Hands and Feet

Assessment

Peripheral neuropathy is a very common problem in HIV disease that may be caused by opportunistic infections, HIV itself, or ARVs. Alcohol use and vitamin deficiencies may exacerbate the neuropathy.

Distal Sensory Polyneuropathy (DSP):

Symptoms include burning, aching, and painful numbness of the extremities. Often worse at night, it is aggravated by innocuous stimuli such as the weight of the sheets or by wearing shoes. A high proportion of patients with advanced AIDS have severe symptoms.

Acute Toxic Neuropathy (ATN): Same symptoms as DSP. Damage caused by certain ARVs (ddC, d4T, and ddI – dideoxynucleoside NRTIs). Symptoms may occur 1 week to 6 months after starting treatment.

Diffuse Infiltrative Lymphocytosis Syndrome

(DILS): Signs and symptoms include:

- Painful hands and feet
- Bilateral parotid swelling
- Dry mouth and eyes (Sicca syndrome)
- Lymphadenopathy
- Splenomegaly
- Interstitial pneumonia

Management

Treating Reversible Causes

If a drug is suspected, stop or change the drug.

Non-Pharmacologic Symptom Management

Advise patients with these symptoms not to use alcohol (Wilson, 2002).

Pharmacologic Symptom Management

See section on managing neuropathic pain in Chapter 4: Pain Management.

Give thiamine 100 mg daily.

For patients on isoniazid,

give pyridoxine 50 mg daily (Wilson, 2002).

Other Painful Conditions

Assessment

Herpes zoster (shingles) is common even early in the course of HIV disease. It can be severe when the immune system is very depressed, including:

- Multi-dermatome involvement
- Delayed healing
- Post herpetic neuralgia
- Ramsey-Hunt Syndrome — severe earache

Mononeuritis multiplex (MM) presents with pain followed by asymmetrical patchy sensory and motor loss. In early HIV disease it is due to an auto-immune reaction or vasculitis and in late-stage HIV it is due to CMV infection.

Management

Pharmacologic Symptom Management

See section on managing neuropathic pain in Chapter 4: Pain Management. For herpes zoster, see also Chapter 9: Skin and Wound Care.

Weakness

Assessment

Several HIV-related conditions cause weakness, including difficulty walking or paralysis.

Guillain-Barré syndrome or acute inflammatory demyelinating polyneuropathy (AIDP): Often occurs early in the course of HIV disease and is thought to be caused by either an auto-immune reaction or vasculitis. Signs and symptoms include:

- Sudden onset, progressive ascending weakness of legs
- Minimal sensory signs and symptoms
- In severe cases, respiratory paralysis

Chronic inflammatory demyelinating neuropathy: This is a chronic form of AIDP that occurs later in the course of the disease. Marked by:

- Patchy weakness and numbness
- Diminished reflexes

Progressive polyradiculopathy (PP): This occurs in the very advanced stage of HIV (CD4 count <50). CMV infection is the most common cause, but others include syphilis, herpes simplex, herpes zoster, toxoplasmosis, and TB. Signs and symptoms include:

- Low backache and radicular pain for a few days
- Weakness and sensory loss progresses to complete paraplegia
- Urinary incontinence or retention

Facial weakness or Bell's palsy: This occurs in all stages of HIV disease.

Hemiparesis: Paralysis, suggestive of a stroke, especially in a young adult, can be caused by:

- Cerebral toxoplasmosis (focal signs)
- Neurosyphilis
- Cerebral lymphoma
- Progressive multifocal leukoencephalopathy (PML)

Management

Treating Reversible Causes

Treat infections such as syphilis and TB according to national guidelines.

Treat the person with focal neurological signs empirically for toxoplasmosis with co-trimoxazole.

Non-Pharmacologic Symptom Management

Provide supportive care for loss of function. If the patient has become dependent, teach the caregivers basic nursing care, including skin care and the prevention of contractures (how to position patient and put all joints through a full range of motion).

See Chapter 17: Loss, Grief, and Bereavement and Chapter 20: Care and Support for the Carers.

Pharmacologic Symptom Management

Chronic inflammatory demyelinating neuropathy is responsive to steroids, but AIDP is not.

See section on managing neuropathic pain in Chapter 4: Pain Management.

Seizures

Assessment

Seizures can be caused by:

- Infections: meningitis, encephalitis, or cerebral toxoplasmosis
- Tumours: cerebral lymphoma
- Metabolic disorders: hypoglycaemia, hypoxia, electrolyte imbalances
- Drugs can lower the anticonvulsant threshold or increase the risk if withdrawn suddenly: neuroleptics, opioids, benzodiazepines

The features, which vary according to the cause, may involve myoclonic jerking, focal motor seizures, or generalised seizures.

Management

Treating Reversible Causes

Identify and treat the underlying disorder if possible.

Non-Pharmacologic Symptom Management

If patient is actively convulsing, maintain airway and protect from injury.

Teach caregivers how to observe for seizures and to provide care if the patient has one in the future.

Pharmacologic symptom management

Manage the seizure with standard anticonvulsants. If the patient is on ART, valproic acid is the drug of choice (Wilson, 2002).

Confusion/Delirium, Dementia

Assessment

Confusion, delirium, or dementia may be due to infections, tumours, metabolic disturbances, substance abuse, or the withdrawal of alcohol, as well as certain drugs such as morphine, INH, rifampicin, and ketoconazole. An important initial step in assessing the cause is to conduct a thorough medication review.

Dementia: HIV-associated dementia occurs in about 20% of patients. The patient or the family may complain about changes in mental ability or poor memory. Initially these may be subtle and difficult to detect. The person may also exhibit:

- Strange behaviour with apathy or agitation
- Gradually progressive mental slowing, apathy, and withdrawal
- Clumsiness, weakness, and incontinence

Delirium: Occasionally a patient may present with agitation and delirium or psychotic features requiring appropriate sedation once treatable conditions have been excluded.

Most of the assessment tools commonly used in palliative care have been developed for use in cancer or in patients with senile dementia. Educational and language barriers as well as an inability to read and write in English also undermine the validity of such tools.

Management

Treating Reversible Causes

If a drug is suspected, stop or change the drug.

Non-Pharmacologic Symptom Management

See earlier section, Issues in Management of Neuropsychiatric Disorders.

Pharmacologic Symptom Management

Sedation for delirium: Although severe agitation is not common in advanced AIDS, delirium may occur suddenly, quite often at night. While most delirious patients require little if any sedation, occasionally such a patient may become very restless and even aggressive. A restless aggressive patient is very disruptive and may even be dangerous to the caregivers, other patients, or the nursing staff.

If reversible conditions have been excluded, appropriate sedation should be used. There is no place for physical restraints in such patients.

- Begin with haloperidol 2.5–5 mg PO or SC every 20–30 minutes (2.5–20 mg/24 hours). Gradually titrate the dose until the patient is calm. (High doses are only appropriate when a patient is very restless and where the estimated life expectancy is short.) Note: A less expensive alternative, thioridazine 25–50 mg nocté, is used in some countries; however, it is not recommended owing to the high risk of ventricular arrhythmias. In most countries it is licenced for specialist use only with ECG screening and electrolyte measurement before treatment, after each dose increase, and at 6-month intervals.

With a severely aggressive or violent patient, add lorazepam 1–2 mg SC or IV or another suitable benzodiazepine (such as clonazepam), repeating until the patient is adequately sedated.

In the mildly restless patient, reassurance to the patient and family, asking them to have a calm presence around the patient, and answering his/her fears is often sufficient. If required give lorazepam sublingually. If necessary the tablet can be dissolved in a little water. Alternatively small doses of diazepam 2 mg may work.

If available, and if all else fails,

give phenobarbital 200 mg SC 6 hourly.

Depression

Assessment

Depression is common at all stages of HIV disease and can include sadness, fears, insomnia, and thoughts of suicide. Appropriate treatment will not only help to prevent suicide and relieve the suffering of the depressed person, but will also improve compliance with other medications. Guilt, unresolved conflicts, and concerns about the care of dependent children may cause great distress. Sensitive probing may reveal concerns that can be addressed. See Chapter 14: Communicating with Patients and Their Families.

It may be very difficult to differentiate between depression and the 'normal' response to dying. In both situations there may be loss of interest in the outside activities, reduced libido, difficulty in concentrating, poor appetite, and poor sleeping pattern. The presence of suicidal ideation and inappropriate guilt may help to differentiate the two. With limited access to ARVs in sub-Saharan Africa, most people understand the inevitable grim outcome of AIDS. Many cope by using denial and desperately seeking some 'miracle' cure.

Management

Non-Pharmacologic Symptom Management

Concentrate on good palliation of symptoms while exploring and addressing the person's concerns. This may enable many to come to terms with dying. Spiritual support from an appropriate person or religious group is a vital aspect of good care.

AIDS affects the whole family and, especially where there have been multiple deaths, ongoing support and counselling may be needed.

Some forms of mental disturbance may be interpreted as being due to supernatural forces. A careful explanation of the reasons for the strange behaviour will help the family to understand the need for effective medical treatment.

See the chapters in Part III: Psychosocial/Spiritual and Traditional Care for much more on interventions to support patients having emotional difficulties related to AIDS.

Pharmacologic Symptom Management

Because anti-depressant drugs take several weeks to be effective, they should be tried for at least 2 weeks and preferably 4 weeks.

If available:

Psychostimulants, such as methylphenidate 2.5–5 mg in the morning and at lunchtime, give a faster response, often within 24 hours. The dose may be gradually increased to 20 mg if necessary.

References

Wilson D, Naidoo S, Bekker LG, Cotton M, Maartens G, eds. 2002. *Handbook of HIV Medicine*. Cape Town SA: Oxford University Press Southern Africa.