Clinical Tract

Module on

Palliative Care

LEARNING OUTCOMES FOR ALL PARTICIPANTS

After completion of this module the learner should:

- Be able to describe what palliative care is.
- Understand the role of palliative care early in the course of HIV infection and in terminal disease.
- Know the role played by hospice and home based care and be able to refer patients to such facilities.
- Manage pain in the end stage of life.
- Manage other symptoms in the end stage of life.
- Understand the importance of the multidisciplinary team in offering psychosocial and spiritual support in addition to physical care.

1. PALLIATIVE CARE IN HIV/AIDS

What is palliative care?

Palliative care represents the holistic management of patients with incurable life-threatening disease, starting at the time of diagnosis and culminating in active relief of symptoms in the terminal phase of the illness. Palliative care does not imply a withdrawal or phasing out of medical management.

The palliative care needs of individual HIV patients vary during the course of the illness, which is characterised by acute severe illnesses interspersed by periods of relative wellness. Many patients with advanced HIV infection will use antiretroviral therapy (ART) successfully, during which time palliation of symptoms is less critical. Should ART not be an option or should it fail, the disease will advance and palliative care will play a greater role. In the final stages of the illness, only terminal palliative care is required.

The coexistence between disease-specific treatment and palliative care in incurable disease is demonstrated in Figure 1.

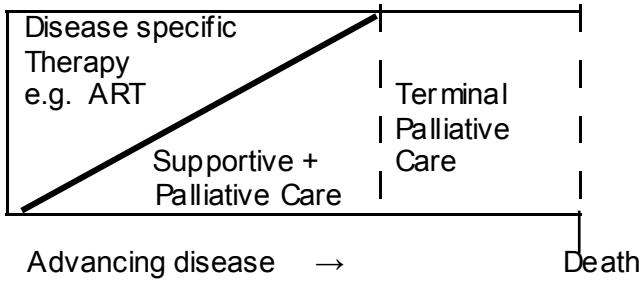

Figure 1.

Terminal palliative care usually brings about a change in the focus and direction of medical management.

The focus of care is on quality of life, rather than prolonging life. Quality of life implies minimal physical discomfort and a substantial level of psychological and social well-being. Requirements for an acceptable quality of life vary between patients and where possible the patient should be involved in all decisions regarding his/her care.

Other important characteristics of palliative care are:

- Thorough assessment and treatment of pain and other symptoms.
  The following can be used to palliate symptoms:
  - effective medication e.g. acyclovir for herpes ulcers
  - appropriate medical procedures e.g. tapping a pleural effusion
  - radiotherapy e.g. for troublesome tumour metastases
- Care is **patient** centred rather than disease centred.
- Holistic care- management of physiological, psychological, social and spiritual needs.
- The focus is on the patient and his/her family.
- Emphasis is given to the multidisciplinary approach.

When to institute terminal palliative care

The decision as to when a patient with advanced HIV disease should be managed with terminal palliative care is not always a clear cut or easy decision.

It requires sensitive clinical judgement and it is important that this decision is made in conjunction with the patient and/or family (where the patient is incapable of decision making).

The decision to institute terminal palliative care is made when disease specific therapy (e.g. ARV, invasive diagnostic tests) is unlikely to result in a sustained acceptable quality of life for the patient.

Figure 2 represents a state of advanced illness where disease specific therapy results in more hardship than benefit to the patient

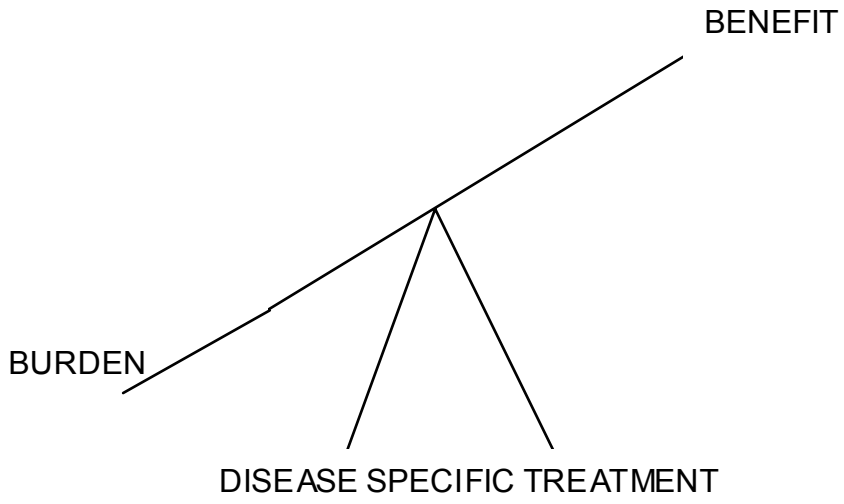

Figure 2

Terminal palliative care should be initiated when:

- The patient has an illness or complication that is irreversible and results in poor quality of life e.g. severe HIV associated dementia or *Mycobacterium avium complex (MAC) infection.*

  OR

- The patient has multiple severe complications resulting in poor quality of life

  AND

  ARV is not an option (due to unavailability, social problems or failure of ART)

  AND

  Objective severe immune suppression (CD_4 count 50 or less)

When a decision is made not to investigate a new infection or treat a non-responsive infection with additional antibiotics, the reasoning and basis for the decision should be documented in the patient notes.

Who will provide terminal palliative care?

All clinicians – whether private, hospital- or clinic-based can be involved in the provision of terminal palliative care.

Hospice programmes and **Home Based Care** networks offer specific palliative care services. All health care workers should be aware of the resources available for the care of HIV-infected patients in their area.

Hospice programmes offer mainly domiciliary care (at home) and most hospices have limited in-patient facilities for stabilisation of symptoms, respite care and advanced terminal care.

Home Based Care is provided by a network of inter-sectoral services (local authority, province, non-governmental organisations and community based organisations). These services offer holistic supportive care in the patients' homes by community caregivers (CCG's). These community caregivers may be formal (e.g. registered nurse) or informal (community-derived volunteers with several months training in basic AIDS care).

Home Based Care services should include:

- Counselling and information
- Symptom control
  - wound care
  - use of medication
  - home remedies
- General care
- Ambulation
- Direct Observed Treatment (DOT)
- Psychological and spiritual support (visiting, supporting, praying)
- Assessment of the patient's physical, psychological and social needs and arranging and networking with other support systems to meet these needs. (e.g. social worker to arrange social grants or future care of potentially orphaned children).

When referring patients to Hospice or Home Based Care:

- The transition from curative to terminal palliative care needs sensitive communication with the patient and family. Future care should take the patient/family's needs and expectations into consideration.
- The local hospice programme or Home Based Care network can be contacted by the health care worker or the patient/family.
- A referral form or letter should accompany the patient, with the diagnosis, CD_4 count (if available), confirmation that disease specific therapy (e.g. ARV) is no longer appropriate, current problems and treatment.
- It is important that the link between the referring institution and the patient/family is maintained to enable ongoing clinical evaluation and access to medication and medical supplies.
- Disclosing the diagnosis of HIV infection to the palliative care services is a sensitive issue and it is important to ascertain the patient and family's wishes in this regard. Should the clinician contact the relevant palliative care institution himself, permission to disclose the diagnosis must be obtained from

the patient. When completing a referral form, the patient should be made aware that the diagnosis appears on the referral form.

Patients or families who refuse to disclose the diagnosis can be counselled regarding the benefits of disclosure and the need for care-givers (within and outside of the family) to understand the medical condition of the patient. At the same time, they should be reassured that care will not be withheld, should they not comply.

- This is a useful time to discuss issues of advance directives, such as appointing a health care proxy and/or making a living will.
  A health care proxy is someone who knows and understands the patient's desires regarding quality of life issues that will affect the direction of terminal care.

  A living will demonstrates a patient's desire not to have life prolonged utilising invasive strategies once there is no longer any reasonable hope of an acceptable quality of life. At present in South Africa, this document cannot be used as a legal determinant of care, but is does help family and medical caregivers to understand the patient's wishes. It is especially useful in situations where various family members have conflicting opinions as to what care should be given to the patient.

2. HOLISTIC CARE OF THE TERMINALLY ILL HIV/AIDS PATIENT

Successful symptom management does not only involve specific treatment and medication, but also attention to other aspects of the person. Pain and other symptoms are subjective experiences, which are influenced by several factors besides a physical stimulus. Psychological issues such as fear or depression, social problems and spiritual matters can all affect the patient's perception of pain and other symptoms and therefore need to be addressed.

Important points when managing symptoms

- Health care workers should take the patient's symptom(s) seriously. Patients are reassured when their clinician acknowledges and explores their symptoms. This in itself may bring symptom relief.
- Health care workers need to take time to enquire about the patient's symptoms. Patients with HIV/AIDS are sometimes so accustomed to pain and discomfort that they do not volunteer information about their symptoms.
- A thorough history and examination is necessary to determine the likely cause of symptoms. This allows the use of the most appropriate available treatment for a symptom.
- Ongoing evaluation is essential for optimal symptom management.

Psychosocial and spiritual issues

Every HIV patient requiring palliative care has a unique personality, set of experiences, coping mechanisms and support system.

Common causes of psychological distress in patients with terminal illness include the following:

- A sense of loss
  - of physical attractiveness
  - of physical functions (healthy appetite, physical mobility)
  - of independence
  - of role in family and community
  - of employment and finance
- A sense of alienation from normality

These patients feel isolated from healthy family, friends and community members.

- Fear
  - of uncontrolled pain or other symptoms
  - of being a burden to family and others
  - of family member's suffering once they have died
  - of the process of dying
  - regarding dying and after-life issues
- Depression as a result of their physical condition and losses (present and anticipated)

Family dynamics and issues

Family members of terminally ill patients also have special needs regarding issues such as:

- Multiple losses
  - e.g. a breadwinner or finances
  - a normal life
  - future loss of a close relationship
- Fear
- Guilt regarding the limited care they are able to provide for their terminally ill family member
- Feelings of helplessness when symptoms are unrelieved
- exhaustion due to the heavy physical and emotional demands of caring
- role changes
- the dying person and the illness tend to dominate family life and other family needs are neglected

3. SUPPORTING TERMINALLY ILL HIV/AIDS PATIENTS AND THEIR FAMILIES

Psychological and spiritual needs

- Sensitive enquiry and empathic active listening is important.
  The following kind of questions can be used to give patients an opportunity to share what is going on in their minds:
  "How are you coping with your life right now?"
  or
  "What are your biggest concerns now?"
- Allow patients/family to express negative feelings. These can only be dealt with once they are verbalised and acknowledged.
- Spiritual care:
  All people are spiritual beings. *Spirituality can be defined as personal views and behaviour that express a sense of relatedness to something greater than self. It is a person's search for meaning through religion, God, naturalism, humanism or the arts.*

- Health care workers are not expected to generate solutions for all the issues patients express. Many issues have no clear answers and the task of caregivers is to show empathy, care and understanding while the patient finds his/her own meaning in their suffering. People cope with their suffering through finding meaning in it.
- Patients with clinical signs of depression may benefit from antidepressant medication.
- Some patients remain distressed in spite of support from their primary caregiver and counselling by a psychologist, social worker or trained counsellor may be of great help.

Family support

- Give adequate information regarding the patient's illness, likely course of the illness and practical ways the family can help in relieving symptoms.
- Talk to family members about themselves and how they are coping.
- Offer family members counselling support from professionals where needed.
- Facilitate home-based care and admission of patients to a hospice in-patient unit for respite care to give family members an opportunity to rest. Sometimes, even a few free hours for the caregiver to go out is useful.

Social needs

Financial support

Patients in need of financial support can be assisted in obtaining appropriate social grants. The following social grants presently available may be utilized in HIV/AIDS situations:

- Social Grants for Persons with a disability
  - Persons applying for these grants should be functionally impaired to the extent that they are unable to work.
  - Most HIV patients with a CD_4 count of less than 200 will qualify for this grant.
  - Patients on- and intending to use anti-retroviral therapy should be given temporary grants for 6 to 12 months.
  - R 740 per month
- Care-dependency grants
  - These are payable to parents, guardians or foster parents of a child (1-18 years) requiring full time care due to a severe mental or physical disability.
  - R 740 per month
- Child support grant
  - This is an amount of R130 per month payable to the primary caregiver of a child (even if the caregiver is not related to the child).
- Foster care grant
  - This is payable to foster parents of a child placed in their custody in terms of the Child Care Act.
  - R 530 per month

Last will and testament

A will does not only indicate what a dying person wishes to be done with his money and possessions once he has died, but it can be used to indicate the dying person's wishes regarding the children. A will can be written and signed by the patient and a witness. A person within the household should know about the will and where it is kept.

In the case of larger estates or complex issues regarding guardianship of children, it is prudent to get legal advice. Patients who cannot afford legal assistance can approach the Legal Aid Board in their region.

Guardianship of children

Where the dying patient is the last remaining adult in a nuclear family, it is advisable for the patient to plan or make arrangements for the guardianship of the children.
This should be done in writing and a social worker should witness and write a report regarding the patient's wishes for the children. Should any dispute be anticipated, it would be helpful to involve a lawyer in recording the patient's wishes.

- In most cases, a member of the extended family is willing to adopt or foster the child or children. It is preferable to keep siblings together in one family rather than spread them between various family members.
- Where there is no suitable or willing family member, other persons may apply to adopt or foster the children. The process of adoption and foster care is managed by a court of law and the social worker plays an active part in assessing the suitability of the home.
- Where no guardian is forthcoming, children are institutionalised.

Practical arrangements following death

The death certificate of persons dying at home:

Where patients were managed by a family doctor or hospital doctor on a regular basis, the family can request a death certificate from these persons.
If the doctor does not get the opportunity to view the body, the family will need to make an affidavit to the police, confirming the person's death.

Where the patient is not known to a doctor, the police will send the body to the state mortuary, where a death certificate will be issued following a post mortem examination.

Transport of the body:

The funeral undertakers can arrange all transport. Families may be advised that transporting the body to another town is expensive and could cost several thousand rand depending on the distance. Families are permitted to make their own transport arrangements. Transporting bodies outside the borders of the RSA is done by air and is prohibitively expensive.

5. MANAGEMENT OF PAIN IN ADVANCED HIV

Common causes of pain in HIV

Neurological:	Peripheral neuropathy
	Post herpetic neuralgia
	Headache due to cryptococcal meningitis or intracranial mass lesions (e.g. lymphoma or toxoplasmosis)
Gastrointestinal:	Oral or oesophageal ulcers (aphthous, herpes or cytomegalovirus [CMV])
	Oral or oesophageal tumours (lymphoma or Kaposi's sarcoma)
	Acute necrotising gingivitis
	Cholangitis
	Pancreatitis
	Intestinal infection e.g. cryptosporidium
	Peritoneal infiltration and enlarged abdominal lymph nodes due to TB, Kaposi's sarcoma, lymphoma
	Anorectal ulcers e.g. Herpes simplex
Genital:	Ulcers (herpes simplex, chancroid)
Skin:	Herpes Zoster
	Kaposi's sarcoma especially if there is infiltration of regional lymph nodes
General:	Debilitation and immobility leading to muscle pain and pressure ulcers

Mechanisms of pain

- Nociceptive pain (caused by tissue injury)
    - Somatic (skin, bone, joint, muscle)
    - Visceral (internal organs)
- Neuropathic pain (caused by damage to the central or peripheral nervous system)
- Functional – colic (frequently due to obstruction of a hollow organ)

Nociceptive pain can be localised (often somatic) or diffuse (often visceral). It is sharp, dull, gnawing or throbbing. **Neuropathic pain** tends to produce a burning, tingling, or shooting sensation. It may be accompanied by allodynia which is pain produced by a minimal stimulus, such as light touch. Deciding on the probable dominant mechanism of pain helps in prescribing the most appropriate analgesia.

Pain Assessment

- Site and radiation
- Quality
- Intensity
- Timing
- Aggravating and relieving factors
- Associated symptoms
- Functional disability as a result of the pain

When assessing intensity of pain, various scales can be used e.g. a ten point scale where 0 is no pain and 10 is unbearable pain. Alternatively, a pain- faces scale can

be used. Since severity of pain often varies throughout the day, the pain intensity at its worst, at best and on average should be assessed.

Analgesic medication

Analgesic medication for chronic pain should be given:

- by mouth (whenever possible)
- by the clock i.e. regularly and not only as needed
- by the ladder i.e. World Health Organisation (WHO) Analgesic Ladder

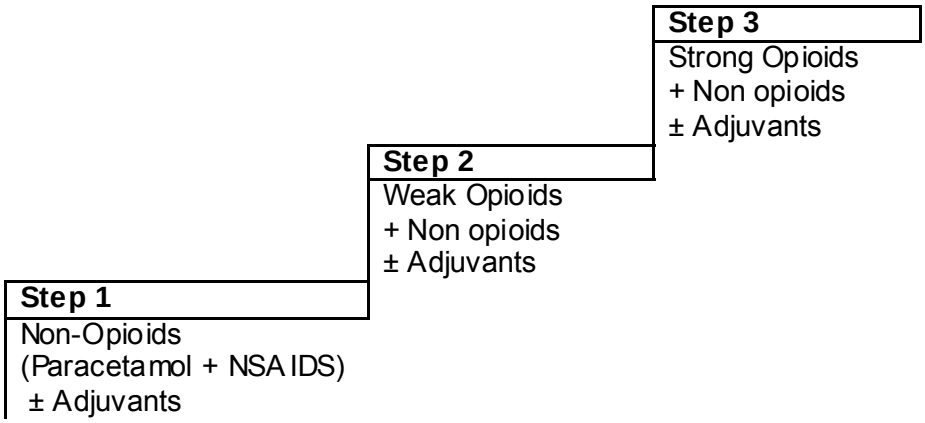

Figure 3 WHO 3 STEP ANALGESIC LADDER

(Recommended doses are for adults – see Standard Treatment Guidelines and Essential Drugs List for paediatric doses)
(Examples of well-known trade names have been included for convenience)

Paracetamol

Used for its analgesic and antipyretic properties.
Regular dosing offers effective analgesia for mild to moderate pain.
Useful when used in combination with NSAIDS.

NSAIDS

These have an analgesic, anti-inflammatory and antipyretic action.
Useful for bone, joint and pleuritic chest pain.
Be aware of potential adverse effects:

- Peptic ulceration and gastrointestinal bleeding
- Can precipitate impaired renal function if used in dehydrated patients

Ibuprofen (Brufen®) is probably the safest, but also the least effective NSAID
Diclofenac (Voltaren®) and naproxen (Naprosyn®) are effective with a good side effect profile (not on EDL)
Indomethacin (Indocid®) is more potent, but also more toxic and should therefore be reserved for patients not responding to less potent NSAIDS.

Weak Opioids

(a) Codeine

It is usually used in combination with a non-opioid such as:
Paracetamol 1g + codeine phosphate 30-60mg 4-6 hourly (EDL)
When using combination analgesics (not on EDL), choose an agent containing an effective dose of codeine such as:
Empacod® (Each tablet contains paracetamol 500mg and codeine 20mg)

(b) Dihydrocodeine (DF-118®) (not on EDL)
When used orally, it has similar potency to codeine
The usual dose is 30-60mg 4-6 hourly

(c) Dextropropoxyphene (not on EDL)
An example is Doloxene®
It is also used in combination analgesics (together with a non-opioid)
An example is Synap Forte® which contains paracetamol 500mg and dextropropoxyphene 50mg
Potency is two thirds that of codeine

(d) Tramadol (Tramal®) (not on EDL)
More potent than codeine
The usual dose is 50-100 mg 4-6 hourly
Slow release tablets can also be used 100mg 12 hourly.
Can be used orally, IM, IV or SC

All opioids can cause significant constipation.

Strong Opioids

a) Morphine

- Morphine is versatile and effective.

- Common side effects are:
  -Drowsiness
  -Nausea and vomiting
  -Constipation

Respiratory depression is rarely a problem if the initial dose is low and gradually increased). Tolerance develops to most side effects except constipation.

Opioid-induced nausea and vomiting can be treated with haloperidol (Serenace®) or metoclopramide (Maxolon®). See treatment of nausea and vomiting for drug doses.
Always prescribe laxatives together with morphine (adjust for patients with frequent diarrhoea). See management of constipation for details regarding medication.

Morphine metabolites tend to accumulate and cause toxicity in patients with renal failure. Symptoms of toxicity include severe sedation, myoclonus and hyperalgesia (increased pain). This often occurs in pre-terminal patients and requires a reduction in the morphine dose.

Morphine Preparations

Oral: **Morphine oral solution** (4 hourly)
Morphine controlled release tablets (12 hourly)
(MST continus®)
(The total daily morphine dose remains the same for both preparations)

Injectable: **Morphine sulphate** (usually given by continuous subcutaneous infusion using a syringe driver)

When changing from oral morphine to injectable morphine, the dose of injectable morphine sulphate is approximately 50% of the oral dose.

Morphine oral solution is relatively cheap, offers effective, rapid pain control and is easy to titrate the dose up or down due to its short half life.

Controlled release morphine tablets are more expensive than the morphine solution, however offer a more convenient dosing schedule and measuring or spilling is not an issue, especially in debilitated patients.
The following strength tablets are available: 10mg, 30mg, 60mg and 100mg. (Only the 10mg and 30mg tablets are available on the EDL)

- The following starting doses for oral morphine can be used:

The usual starting dose	10mg 4 hourly
Opioid naive patients	5mg 4 hourly
Elderly and frail patients	2,5mg 4 hourly

  Should the patient experience significant pain between doses, an extra dose equivalent to the 4 hourly dose can be given.

  The dose can be increased by approximately 50% every few days (or sooner in severe pain) until the pain is controlled or intolerable undesirable effects occur.

  There is no maximum dose. The dose of morphine is titrated against the pain, however most patients' pain is controlled on 200mg oral morphine daily.

- Morphine oral solution is bitter and may be flavoured with fruit juice.

Example of morphine use

Isobel has advanced AIDS. She was discharged from hospital a month ago following an episode of pneumonia. She has ongoing severe diarrhoea. Since her discharge, she has been bedridden due to weakness and pain in her feet. She has a large and very painful pressure ulcer over the sacrum. She seldom sleeps for more than an hour at a time and the family can no longer cope with her constant cries for help. She has now been admitted to the hospice for symptom control.

Isobel requires immediate pain control.

Morphine oral solution, which is short acting and easy to titrate will be the most appropriate analgesic to achieve fast and effective analgesia.
Since Isobel has not used any opioid agents up until this point, the starting dose will be 5mg 4 hourly.
Should she experience break through pain between doses, an extra dose of 5mg can be given.
If the pain is not controlled, the dose can be increased to 10mg 4 hourly the following day. The number of extra doses for break through pain can give an indication of how much extra morphine is required. Subsequent dose

increases may be as follows: 15mg 4 hourly, then 20mg 4 hourly, then to 30mg 4 hourly etc.

Once the effective dose of oral morphine has been established, she can be switched to controlled release morphine. If she is now receiving 20 mg morphine solution 4 hourly, her total daily morphine dose is 120mg. She will therefore require 60mg of controlled release morphine 12 hourly.

If vomiting is a problem, halve the oral morphine dose and give the morphine subcutaneously until the vomiting improves.

b) Fentanyl (Durogesic®) (not on EDL)
For chronic pain, this is available only in a transdermal patch, which allows controlled release of fentanyl over 72 hours.
It is useful for patients who are unable to swallow as a result of severe oropharyngeal pain or neurological lesions, or where the oral route is not appropriate due to vomiting.
It is very expensive.

Pethidine – a strong opioid – is not suitable for treatment of chronic pain due to excitatory nervous system side effects. It is also only available as a parenteral medication.

Adjuvant medication

These agents augment the analgesic effect of opioids and non-opioids and as such have an opioid sparing effect. They may be used at any level of the analgesic ladder.

Commonly-used adjuvants:

- Tricyclic antidepressants e.g. amitriptyline
  - These are used as non-specific multi-purpose analgesics. They are especially useful in neuropathic pain such as peripheral neuropathy or post-herpetic neuralgia.
  - Initial dose 10-25mg at night, increasing weekly to 50-75mg daily. An effect may be experienced within days. Later analgesic effects peak over a two to four week period.
- Anticonvulsants such as carbamazepine or sodium valproate.
  - These are used in neuropathic pain, especially stabbing type neuropathic pain.
  - Dosages used for pain are similar to those used to prevent seizures.
  - Carbamazepine 200mg daily increasing to 600mg daily in divided doses.
  - Sodium valproate controlled release tablets 300mg 2 x daily.
- Corticosteroids
  - These are useful for headaches due to space occupying lesions in the brain.
  - Dexamethasone 16mg daily until a response is achieved, then slowly taper to minimal effective dose.
  - (Dexamethasone 1mg is equivalent to Prednisolone 7mg).
- Capsaicin
  - This is used as a topical analgesic (apply the cream 4x/day for several weeks) and is particularly useful in the treatment of neuropathic pain.
  - Preparations containing capsaicin are available in health shops.

Other analgesic techniques

- Physical interventions
  Bed rest
  Exercise programmes
  Application of hot or cold packs to painful areas.
  Massage
  Application of ultrasound or transcutaneous electrical nerve stimulation (TENS)

- Psychological interventions
  Relaxation techniques
  Distraction
  Hypnosis

- Nerve blocks where available

5. PALLIATIVE MANAGEMENT OF OTHER SYMPTOMS IN HIV PATIENTS

Oral problems

Oral infections, opportunistic cancers and xerostomia (dry mouth) are the most common causes of oral discomfort and pain in terminally ill HIV patients.

Oral Candida

Decreased cell mediated immunity, mucosal trauma secondary to a dry mouth and the use of broad-spectrum antibiotics all contribute towards the high incidence of oral candida. Oral candida may be asymptomatic, but in some patients it can cause pain and/or altered taste sensation, both of which may interfere with eating and drinking.

Management

- Prophylaxis: Good oral and dental hygiene help to prevent oral candida infection.
- Treatment is discussed in the module on opportunistic infections.

Oral Herpes simplex and Aphthous Ulcers

These ulcers can be difficult to distinguish from one another and sometimes a trial of treatment may be the only way to differentiate between the two. Aphthous ulcers are painful, mucosal ulcers with a red margin. Herpes simplex lesions usually start as small vesicles which break down to form multiple lip and intra-oral ulcerations. These ulcers are shallow and irregular in shape.

Management

- Analgesics – use the WHO analgesic ladder. The degree of pain and ulceration will determine the level of analgesia required.
- Herpes simplex ulcers:
  - Gentian violet 3 x daily painted onto the ulcer
  - Acyclovir (Zovirax®) 400mg 3 x daily PO (on EDL)
- Aphthous ulcers:

- Topical steroids
    - Prednisolone 5mg tablet directly applied to ulcer
    - Prednisolone 5mg tablet dissolved in 15ml water and used as a mouth wash 3 x daily
    - triamcinolone in carboxymethylcellulose base (Kenalog in Orabase®) applied to the ulcer 3 x daily
- Benzydamine (Andolex®) mouth wash as required
- Systemic steroids – Prednisolone 0,5mg/kg/day for 5 days PO

Oral Kaposi's Sarcoma and Lymphoma

Both of these opportunistic malignancies may present as discrete swellings in the mouth. This may result in discomfort, severe pain, dysphagia, difficulty with chewing or speech impairment.

Management

Treatment depends on the size and extent of the malignancy and the general condition of the patient. Modalities can include:

- Surgery
- Radiotherapy
- Chemotherapy
- Analgesia
- Oral hygiene

In most cases surgery, radiotherapy or chemotherapy provide palliation and not cure of the malignancy. Frequently, analgesia is the only available treatment and must be given in sufficient doses, since the pain can be considerable.

Good oral hygiene (brushing of teeth, mouth washes) help prevent secondary infection of these tumours.

Xerostomia (Dry mouth)

This is a common cause of discomfort in terminally ill patients and predisposes to infections like candida.

Management

- Attend to any reversible causes:
    - drug side effects (opioids, anti-emetics and tricyclic antidepressants)
    - dehydration
    - mouth breathing
- Good oral hygiene improves comfort.
- Chewing stimulates production of saliva:
    - offer the patient appetising foods that require chewing, where appropriate
    - sugar-free chewing gum
- Increase fluid intake where possible
- Frequent sips of water and sucking ice chips or frozen lollies
- Saliva substitutes containing methylcellulose or artificial saliva with a mucin base can be used (not on EDL).

Oral and Dental Hygiene

This is important to improve comfort and to avoid oral infections in terminally ill patients.

The following routine can be followed:

- Patients with teeth
  - Twice daily brushing of teeth with a soft toothbrush and toothpaste.
  - The mouth is rinsed with water or in patients who are unable to cooperate, a foam stick (or similar material) is used to wipe the mouth.
- Patients with dentures:
  - Dentures may be removed and cleaned with soap or toothpaste twice daily.
  - Meanwhile the mouth is rinsed with an antiseptic mouthwash.
  - Dentures should be removed and soaked overnight in an appropriate solution.
- A coated mouth may be treated by chewing fresh pineapple, rinsing with sodium bicarbonate solution or dissolving effervescent vitamin C on the tongue.
- Petroleum gel (Vaseline®) should be applied frequently to the lips.

Oesophageal Symptoms

Similar lesions to those affecting the oral cavity can occur in the oesophagus. These include:

- Oesophageal candida
- Ulcers (aphthous, herpes simplex and cytomegalovirus)
- Malignancies (kaposi's sarcoma and lymphoma)

These may result in painful swallowing and retrosternal pain. Patients with these symptoms and oral candida may be treated empirically for oesophageal candida. Failure to respond to systemic fluconazole (Diflucan®) may require endoscopic examination for a diagnosis.

Management

Treatment of specific infections is discussed in the module on opportunistic infections.
Antacids (used after meals) and mucosal coating agents such as sucralfate (Ulsanic®) (used before meals) may give symptomatic relief.

Constipation

Constipation is often the result of opioid medication.

Management

- Vegetables, fresh and stewed fruit (especially prunes) and oats porridge can be included in the diet where appropriate.
- Medication
  Stimulant laxatives are frequently combined with stool softeners.
  - Stimulant Laxatives:

- Sennosides 2 tablets at night, may be increased to 4 tablets at night in severe constipation (EDL)

o Stool softeners

Osmotic laxatives are the most appropriate stool softeners in opioid induced constipation. Of the following osmotic laxatives, lactulose has the lowest insidence of side effects:

- Lactulose (Duphulac®) 15-30 ml daily (EDL)
- Liquid Paraffin 15-25ml daily (EDL)
- Magnesium hydroxide (Milk of Magnesia®) 25ml daily

o Rectal agents

These are required when constipation does not respond to oral agents

The following may be used:

- Glycerine suppositories (the suppository should make contact with the rectal mucosa)
- Large volume sodium phosphate enemas
- Warm olive oil enema followed by a warm water enema

- Occasionally, digital removal of stools is required. This is best done in a facility where parenteral sedation or analgesia can be given during the procedure.

Chronic Diarrhoea

In HIV/AIDS, chronic diarrhoea is very common and may result from:

- an idiopathic HIV enteropathy
- various infective causes (including cryptosporidium, giardia)
- overflow diarrhoea secondary to faecal impaction

Management

- Where appropriate, infective causes should be sought and treated. Where facilities are available, three stool specimens should be sent to the laboratory and the following tests requested: microscopy, culture and sensitivity and special coccidial stains Frequently, however, no cause can be found or the diarrhoea does not respond to specific treatment.
- Diet:
  Caffeine and dairy products tend to aggravate diarrhoea, while foods such as bananas, rice and apple juice are binding.
- Oral rehydration solution:
  1 litre boiled water, 8 teaspoons of sugar and half a teaspoon of salt.
  See module on nutrition for specific details on how to use it.
- Medication:
  - o Codeine phosphate 30-60mg 4 x daily (EDL)
  - o Loperamide (Imodium®) This is an opioid with local activity in the gut lumen.
    - 2mg tablets
    - Used 2 x daily or more frequently where necessary
    - Total daily dose is 4-16mg daily
  - o Morphine

If strong opioids are required for analgesia, morphine may be used to treat diarrhoea and pain simultaneously.

- Morphine 30mg daily in divided doses is used initially and titrated up by 25-50% each day.

Nausea and Vomiting

Some causes of nausea and vomiting in terminally ill HIV patients include:

- Drugs (e.g. opioids)
- Biochemical disturbances such as renal and liver failure
- Gastric stasis e.g. secondary to an enlarged liver
- Intestinal infection e.g. cryptosporidium
- Subacute intestinal obstruction due to mass lesions e.g. kaposi's sarcoma or lymphoma
- Pharyngeal irritation by tenacious sputum or candida infection
- Raised intra cranial pressure due to cryptococcal meningitis, toxoplasmosis, brain abscess or lymphoma

Management

- Diet
    - Avoid fatty or spicy foods
    - Small, frequent meals
- Use of mentholated solutions applied topically under the nose can help to eliminate unpleasant odours.
- Chewing thinly sliced ginger root or drinking peppermint tea maybe helpful.
- Many patients find relief with reflexology and massage of appropriate pressure points.
- Attention should be given to maintenance of hydration (orally or parenterally as appropriate)
- Medication:

It is important to try to ascertain the **cause** of the nausea and vomiting in order to choose the most appropriate agent.

Use a suitable route. Oral medication is not appropriate in established vomiting.

- Metoclopramide (Maxolon®) This is a prokinetic agent and also has a central action in the chemoreceptor trigger zone. (EDL)
  10-20mg 6 hourly PO, SC or IV. 40-100mg/24h can be used in a syringe driver
  This is a useful agent in most patients with nausea and vomiting. It is the first choice with gastric stasis or ileus
- Haloperidol (Serenace®) This is a butyrophenone acting principally in the chemoreceptor trigger zone. (EDL)
  1,5mg-5mg daily or twice daily in divided doses PO or SC
  It is especially useful for drug induced nausea (e.g. opioids) or biochemical disturbances
- Prochlorperazine (Stemetil®) This is a phenothiazine acting primarily in the chemoreceptor trigger zone. (not on EDL)
  5-10mg 8 hourly PO
  12,5mg 8 hourly IM
  25mg rectal suppository

Suppositories are useful in severe vomiting where injectable route is not available.

- Cyclizine (Valoid®) This antihistamine acts primarily in the vomiting centre (not on EDL)
  50mg 8 hourly PO, SC or PR
  50mg tablet
  50mg ampoule
  100mg suppository

This is a good choice for nausea related to raised intracranial pressure, vestibular causes and peritoneal and intestinal irritation.

- Odansetron (Zofran®) and Granisetron (Kytril®) These are serotonin receptor antagonists) (not on primary EDL)
  These are very effective especially in chemotherapy induced nausea, but also in other settings.
  Very expensive, therefore not used as a first line agent in non-chemotherapy settings.
- Dexamethasone (Decadron®) This is a corticosteroid.
  4-16mg daily PO or SC
  This is used, in the lower dose range, for non-specific nausea and vomiting, not responding to standard therapy. In the upper dose range, it is helpful in relieving nausea due to space occupying brain lesions.

Several patients with nausea and vomiting may require more than one agent for symptom control.

Chronic cough

- Specific treatment of infections where appropriate
- Various cough syrups (expectorants, mucolytic agents and bronchodilators) may be used depending on the cause and nature of the cough
- Codeine phosphate, starting at 10mg 6 hourly and increasing to 60mg 6 hourly is a useful antitussive in a dry cough
- Other opium derivatives such as dextromorphan (Benylin DM®), noscapine or pholcodine can be used to suppress a dry cough.

Dyspnoea

- Patients who are short of breath need sufficient support and reassurance that the discomfort of dyspnoea can be successfully managed with medication.
- All reversible causes should be sought and treated e.g. bronchodilators for bronchospasm or tapping a large pleural effusion or ascites.
  Look out for pulmonary edema as a cause of dyspnoea.
- Patients should be allowed to choose a position that allows them maximum comfort e.g. sleeping upright in a comfortable chair.
- Facial cooling by a fan or an open window may relieve dyspnoea.
- Distraction and massage can be helpful.
- When available, intermittent oxygen using nasal catheters gives symptomatic relief.
- Medication:
  - Morphine solution 5-10mg 4 hourly
    If the patient is already using morphine for pain, the dose can be increased by 25-50% in order to relieve the dyspnoea.
  - Benzodiazepines such as lorazepam (Ativan®) or diazepam (Valium®) may be used as second line agents.

Both these drugs have an effect on the respiratory centre in the medulla, allowing it to tolerate higher levels of carbon dioxide without being aware of the sensation of dyspnoea.

Skin ulcers

Infective, malignant and pressure ulcers

- Pressure point care involves regular turning of the patient, positioning using pillows for support and lying on a sheepskin.
- These ulcers can be very painful, therefore adequate analgesia should be given.
- Ulcers should be cleaned daily with saline, chlorhexidine or betadine solution. The following basic dressings may be used:
  - Gauze soaked with 50% liquid paraffin and 50% bactericidal solution
  - Metronidazole 400mg tablets (crushed) x 10 and aqueous cream 500 grams (as an alternative to metronidazole gel) is very useful for offensive ulcers and cavities.

Genital ulcers

See module on STI's for causes and specific treatment of these ulcers.
Herpes simplex infection can cause extensive ulceration.

Management

- *Disease specific treatment*
- *Analgesia*
- *Sucralfate suspension used as a topical application helps to relieve discomfort.*

Delirium, Confusion and Restlessness

More than 50% of pre-terminal AIDS patients experience delirium.

It is important to recognise a patient with delirium and not mistake it for emotional anguish (e.g. anger or anxiety), psychiatric illness or dementia. Some useful distinguishing features of delirium are:

- sudden onset
- fluctuating level of consciousness (patient may be drowsy or poorly responsive at times, interspersed with intervals of alertness).

Although the cause of delirium in terminally ill patients is not always clear or treatable, reversible causes should be actively searched for and treated where appropriate.

Common treatable causes of delirium are:

- Infection (cystitis or pneumonia)
- Urinary retention or faecal impaction
- Drugs (high doses of corticosteroids or accumulation of morphine metabolites in patients with poor renal function).
- Alcohol withdrawal.

Management

- Ensure the safety of the patient e.g. nurse the patient on a mattress on the floor.
- Nurse the patient in an uncluttered environment.

- A familiar person should stay with the patient for as much of the day as possible.
- Medication:

  Haloperidol 1,5mg – 20mg daily PO or SC
  (This brings relief to the disordered thinking and hallucinations of the patient).
  Patients with AIDS are particularly sensitive to the extrapyramidal side effects of haloperidol, therefore a low initial dose should be used.
  Phenothiazines such as chlorpromazine (Largactil®) can also be used, although these agents have more side effects than haloperidol.
  Benzodiazepines may be added, e.g. lorazepam (Ativan®) 1mg PO or SC as necessary.
  (These reduce agitation) It is important not to sedate delirious patients with benzodiazepines alone, without using haloperidol.

The Imminently dying person

As a patient's condition deteriorates, his medication needs to be reviewed regularly. Unnecessary medications can be stopped.
The route of drug administration may need to be changed as the patient becomes less able to swallow. Certain medications can be given by a continuous subcutaneous infusion via a syringe driver. Where this is not available, the buccal, sublingual and rectal routes should be considered. e.g. slow release morphine tablets can be given rectally and morphine oral solution can be inserted into the buccal cavity in a patient lying on his side.

The following events are common in patients close to death:

- Loss of appetite
- Decreased thirst and oral fluid intake
- Decreased urine output
- Increasing weakness
- Neurological dysfunction which could include confusion, hallucinations, myoclonic jerks and coma
- Decreased circulatory perfusion causing peripheral cyanosis and cool extremities
- Noisy breathing as the pharyngeal muscles relax and secretions in the large airways cannot be coughed out.

It is important that these features of imminently dying persons are explained to the family. This helps to overcome anxiety of the family regarding the comfort of the patient.

The following situations occur frequently in imminently dying patients:

- In pre-terminal patients, secretions accumulate in the trachea and bronchial tree due to weakness and decreased level of consciousness. Movement of these secretions during breathing produces a sound known as the death rattle, which can be disturbing to those around the patient.
  Hyoscine butylbromide (Buscopan) 10-20mg 4 hourly SC or atropine 1mg 4 hourly SC minimises the production of secretions, but needs to be started early.

- Another common misperception is that the poor appetite and decreased food and fluid intake is causing the profound weakness and neurological disturbance.

  A frequent request from families of dying patients, who are no longer able to eat or drink, is that an intravenous infusion or nasogastric tube be used for feeding and hydrating the patient.

  Much work has been done regarding the use of artificial hydration in terminally ill patients. Artificial hydration includes the use of nasogastric tubes, intravenous infusions or subcutaneous infusions. The following points may be borne in mind when making decisions and discussing the use of artificial hydration with families of dying patients:

  1. The body adapts to fasting in a number of ways, in order to decrease fluid and energy requirements. This includes:
     -Decreased basal metabolic rate
     -Metabolism of stored fats for energy
     -Production of fluid endogenously during fat catabolism
     -Decreased renal urine output.

  2. Although research in this area is difficult, the evidence seems to suggest that artificial hydration in imminently dying patients neither influences survival nor symptom control.

  3. Use of artificial hydration may cause physical discomfort to the patient and acts as a barrier to communication and physical contact between the patient and family members.

  4. Ethically, the use of artificial fluids and nutrition is regarded as a medical treatment or intervention. Therefore its use, withholding or withdrawal is subject to the same considerations as any other medical intervention.

  Most palliative care institutions therefore do not advocate the use of artificial hydration in imminently dying patients, however each case needs to be considered on its own merits and the decision needs to be negotiated between the patient (where possible), family and medical caregivers.

Terminal delirium

Some patients experience delirium with severe restlessness in the last days of life. *This is often associated with multiple organ failure and is usually not reversible*.

The restlessness can be controlled using haloperidol 5mg PO or SC. This may be repeated after 30 minutes if necessary.

If the patient remains very restless, a further dose of haloperidol 10 mg may be used. The next step is to add a benzodiazepine such as lorazepam 1-2mg PO or SC or midazolam (Dormicum®) 10mg SC. Both the haloperidol and the benzodiazepines can be repeated 4 hourly as necessary or they are given continuously via a syringe driver.

6. DEATH AND BEREAVEMENT

Bereavement *is a situation where a person has lost someone to whom he/she was attached.*
Mourning *is the process of grieving that loss.*

A bereaved person experiences a number of phases and as with all traumatic experiences, he/she may fluctuate between phases. Knowledge of these phases is useful in understanding and predicting the normal range of behaviour found in bereaved persons.

Phases of mourning include:

- Numbness and disbelief
- A phase in which the person experiences waves of intense sadness, longing, guilt or anger
- Depression and despair
- Resolution and recovery – the bereaved person feels a sense of relief, regains energy and starts building a new life.

Several of the factors that place bereaved persons at particular risk of prolonged or difficult mourning commonly occur in HIV/AIDS situations. These include:

- Untimely death (person in prime of life)
- Death linked to stigma
- Multiple losses (frequently more than one family member has died or is ill)
- Prolonged period of caring for the deceased person
- Precarious social and/or financial situation of the bereaved person.

Health care workers need to recognise the complicated nature of bereavement in families affected by HIV and should make every effort to support these families.

Ways of assisting families and friends of dying HIV patients:

- Establish a caring and supportive relationship with the family during the terminal phase of the patient's illness.
- Counselling and informing the family
  - regarding the dying process
  - regarding immediate practical arrangements once the patient has died
  - where to find support during the bereavement.
- Families often need to see their doctor or health care worker within a day of the death to settle questions and issues surrounding the illness and death.
- Health care workers should attempt to visit the bereaved persons one to two weeks later to assess their physical and emotional well-being. This is a good opportunity to reassure bereaved persons that feelings and expressions of grief are normal and healthy.
- Bereaved persons will benefit from support during the first months following a loved one's death. This may be done by:
  - befriending (volunteers from community)
  - mutual help (other persons in the community who have experienced recent bereavement)
  - counsellors (usually linked to hospice or home based care groups)
- Those who with time persistently refuse to accept a loved one's death or who seem unaffected by the death may be experiencing pathological grief. Health care workers need to facilitate professional counselling for these persons.

Adequate palliative care is not only essential for patients with advanced HIV infection, but it is also a rewarding experience for care givers and one which advances much personal growth.

7. FURTHER READING

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