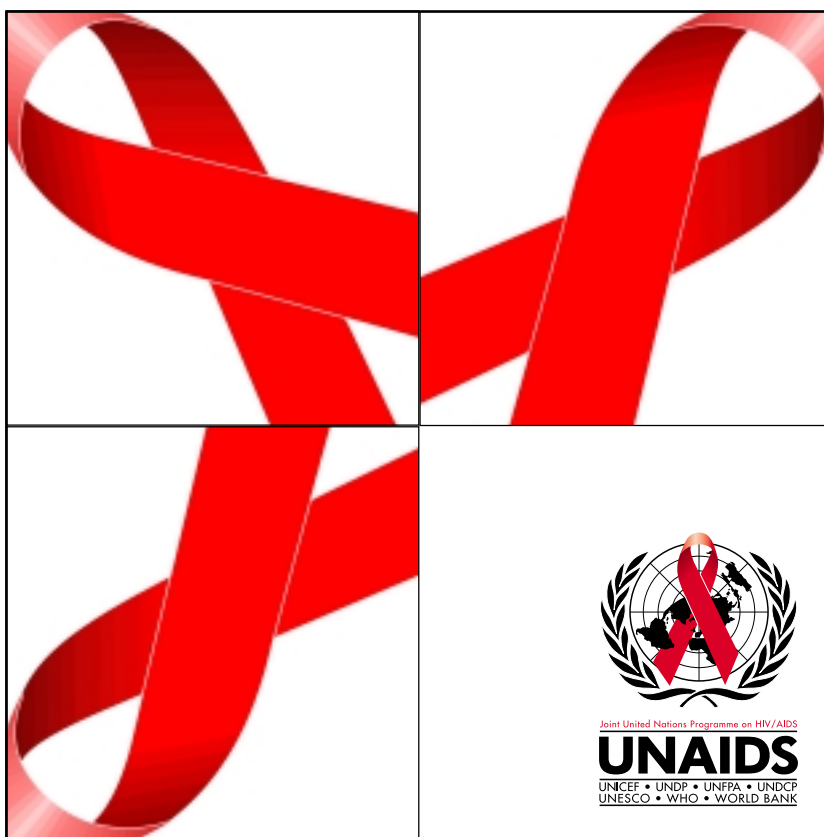


AIDS: Palliative Care



UNAIDS
Technical update

October 2000

UNAIDS Best Practice Collection

At a Glance

Palliative care aims to achieve the best quality of life for patients (and their families) suffering from life-threatening and incurable illness, including HIV/AIDS. Crucial elements are the relief of all pain—physical, psychological, spiritual and social and enabling and supporting caregivers to work through their own emotions and grief.

Palliative care has relieved the intense, broad suffering of people living with HIV/AIDS but the latter brings a number of challenges to its philosophy and practice including:

- The complex disease process with its unpredictable course and wide range of complications, which means that palliative care has to balance acute treatment with the control of chronic symptoms;
- Complex treatments which can overstretch health services;
- The stigmatization and discrimination faced by most people living with HIV/AIDS;
- Complex family issues, such as infection of both partners;
- Role reversal in families, such as young children looking after their parents;
- Burdens on health care workers.

A wide range of palliative care is needed for people living with HIV/AIDS, including:

- Pain relief;
- Treatment of other symptoms such as nausea, weakness and fatigue;
- Psychological support for psychological problems;
- Spiritual support and help with preparation for death;
- Support for families and carers—help with nursing, infection control and psychological support.

To ensure that effective palliative care is provided for all people living with HIV/AIDS, governments must tackle the misconceptions that palliative care is only for people approaching death. They also need to:

- improve the training of health and community workers, and general health education, including tackling stigmatization;
- make good palliative care widely available in hospital, hospices and in the community for people living at home;
- provide access to the necessary drugs;
- provide support for carers, counsellors and health care workers;
- recognize the special needs of children.

UNAIDS Best Practice materials

The Joint United Nations Programme on HIV/AIDS (UNAIDS) publishes materials on subjects of relevance to HIV infection and AIDS, the causes and consequences of the epidemic, and best practices in AIDS prevention, care and support. A Best Practice Collection on any one subject typically includes a short publication for journalists and community leaders (Point of View); a technical summary of the issues, challenges and solutions (Technical Update); case studies from around the world (Best Practice Case Studies); a set of presentation graphics; and a listing of Key Materials (reports, articles, books, audiovisuals, etc.) on the subject. These documents are updated as necessary.

Technical Updates and Points of View are published in English, French, Russian and Spanish. Single copies of Best Practice materials are available free from UNAIDS Information Centres. To find the closest one, visit the UNAIDS website (<http://www.unaids.org>), contact UNAIDS by e-mail (unaids@unaids.org), or telephone (+41 22 791 4651), or write to the UNAIDS Information Centre, 20 Avenue Appia, 1211 Geneva 27, Switzerland.

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UNAIDS, Geneva WC 503

What is palliative care?

Palliative care is a philosophy of care which combines a range of therapies with the aim of achieving the best quality of life for patients (and their families) who are suffering from life-threatening and ultimately incurable illness. Central to this philosophy is the belief that everyone has a right to be treated, and to die, with dignity, and that the relief of pain – physical, emotional, spiritual, and social is a human right and essential to this process.

This philosophy of care developed out of the treatment of patients dying in hospital, usually from cancer. It led to the establishment of the hospice movement, and palliative care is now provided for patients living with many life-threatening diseases, including HIV/AIDS.

Palliative care ideally combines the professionalism of an interdisciplinary team, including the patient and family. It is provided in hospitals, hospices and the community when patients are living at home. This care should be available throughout a patient's illness and during the period of bereavement. An integral part of palliative care is providing the opportunity and support for caregivers to work through their own emotions and grief, which inevitably arise from their work.

Carers work hard to remain sensitive to patients' personal, cultural and religious values, beliefs and practices, and to ensure effective communication with patients, their families and others involved in their care.

Palliative care for people with HIV/AIDS

Experience shows that palliative care can relieve the intense,

broad suffering of people living with HIV/AIDS. However, HIV/AIDS has challenged the ideas of palliative care because of its specific dimensions:

■ **The complex disease process.**

The course of HIV/AIDS is highly variable and unpredictable, with a wide range of potential complications, rates of progression, and survival. Some patients remain free of serious symptoms for a long time; others experience alternating periods of increasing dependency with episodes of acute illness, or suffer frequent non-life threatening complications throughout their infection. So palliative care for HIV/AIDS is – unlike that for other illnesses – a balance between acute treatment and attending to the control of chronic symptoms and conditions. Patients also vary in their emotional response to the infection; this again complicates the planning and delivery of palliative care.

■ **Complex treatments.**

A wide range of treatments for HIV/AIDS patients is now available. Antiretroviral drugs (ARV) have been shown to be highly effective in controlling the progress of HIV disease, but their high cost means they are not readily available to most patients in developing countries. Patients may experience many treatable opportunistic infections and other symptoms, which puts stress on health delivery systems as well as creating compliance problems when the treatments produce unpleasant side-effects. As HIV/AIDS patients are living longer, they may become more dependent on health care workers, and this can create psychologi-

cal problems for both patients and carers.

■ **Stigmatization and discrimination.**

People living with HIV/AIDS face a very specific set of psychosocial problems. Many patients have to live with stigmatization and discrimination, even in high-prevalence countries where HIV affects nearly every member of the population. People are reluctant to be open about their HIV status, thus increasing their feeling of isolation, and carers may be wary of disclosing the positive status of a sick relative. In communities where HIV is less common, people with HIV are often from marginalized or minority groups, such as drug users, men who have sex with men, or sex workers. They may have less well established support networks, and face added discrimination if they are suspected of being seropositive.

■ **Complex family issues.**

HIV/AIDS has a major effect on families, especially in areas of high prevalence and where most patients are young and economically active. Both partners in a relationship may be infected. Or often the partner of someone with HIV may be unsure if he or she is infected, and thus the illness of one partner raises worries about infection in the other as well as anger with the infected partner. If a child is infected, the mother, and often the father, will usually be infected. Siblings may also be infected. Financial problems increase as the breadwinner becomes ill and children will often not be able to continue, or even start, schooling.

Background

■ Role reversal in families.

HIV care often involves older people looking after their younger, previously productive children, without the financial contribution from those children. This has resulted in harsh economic and social consequences. When people become unwell with HIV disease, and are unable to continue working to support their family, they may return to their parents to be cared for during the last stages of their illness. Old people are being left to care for their grandchildren. In other homes, children have become the main carer for their parents or their sick siblings. Child carers need special emotional and practical support.

■ The burden on health care workers.

Caregivers working with HIV/AIDS patients face causes of stress unique to this condition. So many patients are young and health workers caring for people with late-stage HIV disease face the death of all their patients. Eventually, workers may become withdrawn and fatigued by multiple losses and the complex care needs of patients. In developing countries, these stresses are exacerbated by the lack of resources, in turn creating feelings of hopelessness because workers feel they have so little to offer patients in terms of treatment. In palliative care, the mental health of health care workers is vital if they are to remain empathic and effective in the direction and delivery of care.

The range of care needed for the patient

Treatment of symptoms

PREVALENCE OF SYMPTOMS: Multi-centre French National Study (314 people) ¹

Symptom	Prevalence
Pain.....	52%
Tiredness.....	50%
Anxiety.....	40%
Sleep disturbance.....	37%
Mouth sore.....	33%
Sadness.....	32%
Weight loss.....	31%
Nausea.....	28%
Fever.....	27%
Cough.....	27%
Depression.....	24%
Diarrhoea.....	24%
Skin problem.....	24%
Pruritus.....	23%
Respiratory problem.....	22%
Vomiting.....	20%

¹ Larue F, Brasseur L, Musseault P, Demeulemeester R, Bonifassi L, Bez G. Pain and symptoms during HIV disease. A French national study. *J Palliative Care* 1994; 10(2):95

The medical management of people with AIDS is a balance between acute treatment and trying to control symptoms. Most people living with HIV/AIDS suffer from many symptoms, including pain. These symptoms can occur at the same time, can affect one or more body system(s)/function(s) and can lead to other symptoms, including anxiety and depression. As people reach the end of their illness, it may be inappropriate to continue investigations and treatments that will have little long-term benefit and merely add to the distress of the patient. However, some of the HIV associated illnesses and opportunistic infections (OIs) are easy to treat – for example, tuberculosis—and should be treated. Early and accurate

diagnosis of OIs is important at any stage of HIV disease. Wherever possible, the person with HIV should decide about his/her treatment and be informed of the options; educating the patient is an essential tenet of palliative care. He/she should be helped to understand the limits of any treatment, and its outcome.

1. Pain

Pain relief is paramount for people living with HIV/AIDS. Pain is what the patient says hurts. It is always subjective, never what others, such as caregivers, think it ought to be. Every patient should be helped to lead as pain-free a life as possible. Health workers should not withhold pain relief because they worry that a

patient will become addicted to pain killers. Pain medication should be reviewed frequently and increased when necessary. Pain should be controlled in a way that keeps the patient as alert and active as possible.

Pain relief should begin with a straightforward explanation of the causes of pain. Many pains are best treated with a combination of drug and non-drug measures.

Unlike cancer, pain for AIDS patients is not permanent, but temporary and associated with infections. So if the infections are treated energetically, the pain reduces and less pain control is needed. But there is often more than one source of pain and each needs to be diagnosed and treated.

It is important to remember that emotional pain, the fear of dying, for example, or the pain of guilt, the meaninglessness of life, can be as real and hurt just as much as physiologically inspired pain. The psychological and spiritual suffering of AIDS patients can be unusually severe.

Physical pain can lead to anxiety and/or depression, which in turn can lower a person's pain threshold. If there is a conspiracy of silence in the family concerning the patient's disease, he or she may feel even more isolated and this can lead to more pain and fears about the pain worsening. The problem of uncontrolled pain can create anger from the patient and the family, and anger and/or feelings of inadequacy among carers.

Very anxious or depressed patients may need an appropriate psychotropic drug in addition to analgesia, otherwise the pain may remain intractable. Psychotropic drugs, however, are not analgesics and should not be

used instead of analgesics.

A relatively inexpensive yet effective method of pain relief exists for the majority of people with pain. The keys to this method are:

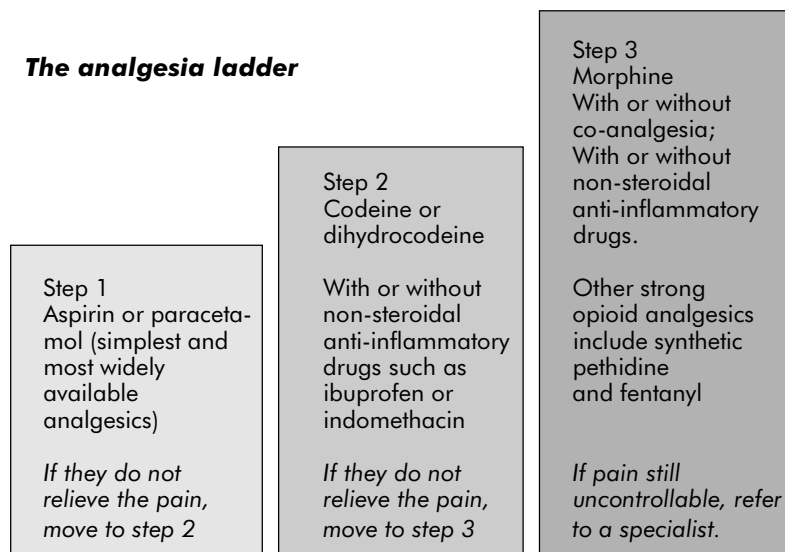
- **"By mouth"**. If possible analgesia should be given by mouth.
- **"By the clock"**. Analgesics should be given at fixed time intervals. The dose should be titrated against the patient's pain and the next dose should be given before the previous one has fully worn off. In this way, it is possible to relieve pain continuously.

Recently, pain guidelines have recognized that pain suffered by people with HIV disease is very like that of cancer pain. For this reason, carers should rapidly advance to step 3 medications. When opiate analgesia is given, nausea and constipation commonly occur and it will be necessary to treat these at the same time.

2. Diarrhoea and constipation

Initial management should include the diagnosis and treatment of underlying infection. If no cause can be found and there is no blood in the stools or

The analgesia ladder



Adapted from Cancer pain relief, second edition, WHO, 1996 and Douleurs sans frontières, 1998

- **"By the ladder"**. The sequential use of analgesic drugs is shown in the figure:
- **"For the individual"**. The choice and dosages of analgesics will vary widely from individual to individual and must be tailored accordingly. Keeping a pain score is useful for adjusting the dose of pain medications.

constant fever, diarrhoea should be treated with oral agents such as loperamide (up to 16 mg per day in divided doses) or codeine (15–60 mg every 4 hours). People with diarrhoea should take plenty of fluids or use oral rehydration solutions to avoid dehydration. If the person has diarrhoea immediately after eating, the initial problem could be lactose intolerance or pancreatic

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insufficiency. A review of the diet and an attempt to temporarily eliminate milk products or fat may be helpful. A stool with the consistency of thick soup may be caused by the mechanical obstruction by a hard stool or a tumour, and might be treated with an enema rather than something to decrease motility.

Constipation may result from prolonged bed rest, profound cachexia (weakness through considerable weight loss), a poor diet, or opioid use. Treatment includes dietary advice, increased fluid intake and the use of stool softeners and laxatives.

3. Nausea, vomiting, anorexia and weight loss

Nausea and vomiting can be caused by drug therapy, central nervous system infections or space occupying lesions, gastro-intestinal infections, or blockage of the gastric outlet or proximal duodenum by intra-abdominal tumours (most commonly a lymphoma or Kaposi's sarcoma).

Prochlorperazine (5–10 mg 2–3 times daily) is useful for mild nausea. Metoclopramide (10 mg every 4–8 hours) or ginger is useful for nausea caused by gastro-intestinal disturbance.

However, it may cause neurological side effects in people who are cachexic. It should not be used in intestinal obstruction. When nausea is caused by central nervous system disorders, low doses of antidopaminergic drugs such as haloperidol may be useful.

If oral and oesophageal infection is present, antifungal treatment may improve dysphagia (problems with, or painful, swallowing) considerably.

Summary of treatment for oral and oesophageal infections

Gingivitis	oral hygiene metronidazole 400 mg twice daily for 5 days. betadine mouth wash
Oral candidiasis	topical or systemic antifungals (e.g. nystatin oral suspension 2–4 times daily, miconazole oral gel (2–4 times daily) or amphotericin lozenges (10 mg 2–4 times daily)
Oesophageal candidiasis or severe oral candidiasis	systemic antifungals (e.g. ketoconazole 200 mg twice a day for 10–14 days) or fluconazole 200 mg for 3 days
Mouth ulcers	1% gentian violet prednisolone 10 mg daily for 5 days

Nutritional support with multivitamin and micronutrient supplementation may be useful, with, if possible, advice from a dietician. Making meals smaller, more appetizing and more frequent may improve dietary intake.

People with advanced HIV infection may have profound weight loss with loss of muscle bulk: the so-called "wasting syndrome". Although dietary advice, antiemetics, appetite stimulants, treatment of diarrhoea, and anabolic steroids may be of some benefit, this usually has a poor prognosis.

4. Cough and shortness of breath

In developing and many middle-income countries, tuberculosis (TB) is commonly associated with HIV infection. As TB can occur at any stage during HIV infection, it should always be actively sought for and treated in people with HIV disease. Any cough that persists for longer than three weeks after treatment with a standard antibiotic should be thoroughly investigated for TB (including by chest X-ray where available because many patients with HIV-associated TB have negative

sputum smears). Other causes of cough that should be considered are *Pneumocystis carinii* pneumonia (PCP) and bacterial and fungal pneumonias. Non-infectious causes of cough include pulmonary Kaposi's sarcoma, lymphoma and interstitial pneumonitis.

As well as treating the underlying infections, use should be made of antitussive agents (cough suppressants).

Morphine or codeine can also be used to decrease the sense of breathlessness. People who are very short of breath despite treatment may find breathing easier if they are sitting upright. Physiotherapy is usually helpful to clear secretions and improve air-entry.

Benzodiazepines should be used to relieve the associated anxiety. During a patient's last days of life, scopolamine 0.3–0.6 mg subcutaneously every 4–8 hours or glycopyrrolate 0.1–0.4 mg intramuscularly every 4–6 hours will be useful in reducing the quantity of secretions when the person is too weak to cough.

Oxygen may prolong death rather than improve quality of life, and may not be appropriate.

It is important in such cases to provide support and information for those people at the bedside, particularly if this laboured breathing is perceived as distressing to the patient.

5. Malaise, weakness and fatigue

Fatigue, lack of energy and malaise are common symptoms reported by people with HIV disease. Fatigue is reported as being a distressing symptom by 40-50% of people with advanced HIV disease. There are often many reasons for fatigue, but it may be associated with:

- anaemia
- direct HIV effects on the central nervous and neuromuscular systems
- malnutrition and "wasting" syndrome
- secondary infections and tumours
- adverse effects from drug therapy
- chronic pain
- insomnia
- depression.

Where possible, any underlying problem should be treated. Often no specific cause is found but physiotherapy and rehabilitative exercise may be helpful. Changes in work and household duties may enable people with fatigue to cope better and have an improved quality of life.

6. Fever

Fever is often the sign of secondary infections, and every effort should be made to find and treat the underlying cause. For symptomatic treatment, paracetamol (500-1000 mg every 4-6 hours) or aspirin (600 mg every 4 hours) is usually effective. Paracetamol and aspirin can be alternated every 2

hours if necessary. Ensuring adequate fluid intake is important and sponging the person with a wet towel can also bring some relief.

7. Skin problems

About 90% of people with HIV have skin problems. It is important to recognize the underlying cause, as some of these are treatable with cheap and simple medicines. Successful treatment will improve a person's quality of life because skin problems often cause emotional

distress and the avoidance of social interaction. Some people fear stigma or rejection if their lesions are unsightly and may need counselling and reassurance. Scabies is often atypical and should always be considered if significant itching pruritus is present, regardless of the nature of the rash. This will often require at least three courses of treatment as well as antipruritic agents such as antihistamines and/or topical steroids after the treatment is washed off. Opioids may be needed to treat severe itching.

Common skin problems associated with HIV disease	
Skin problem	First-line treatment
Bacterial infections (boils, abscesses etc.) violet	Antibiotic treatment (e.g. erythromycin or flucloxacillin) and topical gentian violet Abscesses should be drained, cleaned and dressed before antibiotic treatment
Fungal infections tinea corporis, folliculitis, candidiasis	Topical antifungals if mild, systemic antifungals in severe cases
Viral infections herpes simplex herpes zoster molluscum contagiosum papillomavirus (warts)	Early herpes zoster can be treated with aciclovir 800 mg 5 times daily (if available) or topical gentian violet and most importantly pain relief. If warts/molluscum are uncomfortable they can be treated with topical podophyllin or a silver nitrate stick.
Scabies	Topical treatment with lindane, benzyl benzoate or permethrin (treat contacts as well).
Pressure sores	Prevent by keeping skin clean and dry and turning a bed-bound person every 2-4 hours. Treat by cleaning with salt solution (should taste no more salty than tears) daily and covering with a clean dressing.
Wounds or ulcers	Clean with salt solution and keep covered with a clean dressing. Infected wounds can be treated with antibiotics: smell and infection can be controlled by metronidazole powder or gel.
Drug-induced eruptions	Supportive care with oral antihistamines and 1% hydrocortisone cream.

Background

8. Brain impairment

HIV associated brain impairment (often called HIV dementia) is an important illness of advanced HIV disease. Up to 15% of people with advanced HIV disease will develop some degree of brain impairment and a further 15–20% may develop some degree of motor or cognitive impairment. HIV associated brain impairment is characterised by abnormalities in motor and cognitive function consisting of psychomotor slowing with behavioural disturbance. Early symptoms include apathy, poor concentration, mood swings and memory disturbance. Later symptoms may include disinhibited behaviour, agitation and poor sleep. Global dementia, paralysis and incontinence can occur in the final stages. It is important to differentiate mild brain impairment from a depressive illness, as the latter is treatable with antidepressants.

Antiretroviral drugs are helpful in treating HIV dementia. Where these are not available, the outlook is poor, as the brain impairment is irreversible and progressive. At the early stages, counselling may be helpful. Environmental clues to improve memory such as family pictures calendars and clocks may be useful. Most importantly, family members and friends should receive support and counselling so that they understand the illness and are aware of the prognosis. Delirium or agitation of late-stage dementia may respond to neuroleptic drugs, such as haloperidol (1–5 mg 6–8 hourly) or chlorpromazine (25–50 mg 6–8 hourly). Low doses should be used initially because of the increased risk of extrapyramidal side effects in people with HIV-related brain impairment. For brain impaired

patients who live on their own, day-to-day activities can be a major problem, especially as some people may have few physical symptoms or problems but still need 24-hour supervised care. Hospices or palliative care units, if available, may be required to give medium-term care. If these are not available, regular support and supervision from a home care team is important to support the carer and patient.

Counselling and social support

Psychological problems

People living with HIV/AIDS frequently experience emotional and psychiatric problems. But their quality of life can be considerably improved when health workers, family members and carers understand these problems, and support the patient experiencing them.

Depression is common. If mild and clearly associated with factors in the patient's life, it may be helped by counselling alone. If it does not respond quickly to psychological support, or symptoms are severe, treatment with antidepressant drugs should be started promptly. Tricyclic antidepressants (such as amitriptyline, imipramine or trimipramine) will usually be the first line therapy. In physically ill patients, antidepressant drugs should be started slowly, to minimize side-effects (such as dry mouth, sedation and postural hypotension). Once the depression improves, antidepressants should be continued for a further 4–6 months to avoid relapse. When antidepressants are stopped the dose should be reduced gradually, monitoring for signs of relapse.

People living with HIV/AIDS may consider suicide. This may result

from depression or be a rational choice. Such tendencies can usually be helped with emotional support from health care workers, including the reassurance that these feelings of hopelessness are common with any chronic illness and tend to be short-lived. Some people with advanced disease, with severe symptoms, or those who have also watched family and loved ones die from HIV disease, state that they wish to end their lives. Family and spiritual support as well as counselling may be particularly important in these circumstances.

Anxiety is also a common symptom in people with advanced HIV infection, expressed in physical as well as psychological symptoms. Tachycardia, palpitations, shortness of breath and panic attacks may occur. Emotional support and behavioural interventions such as relaxation therapy are the first line of management. Benzodiazepines (such as diazepam 2 mg 6–8 hourly as required) may be helpful for short-term severe anxiety, and beta-blockers (e.g. propranolol 10 mg 4–6 hourly as required) may be used for palpitations.

Forms of psychological support

1. VCT (voluntary counselling and testing)

In many developing countries a diagnosis of HIV infection or AIDS is made by a health care worker when the patient already has advanced HIV infection. If HIV testing is available it should confirm the diagnosis. Whether HIV testing is carried out or not, it is important to share the presumed or confirmed diagnosis with the patient. Carers and families often believe that it is kinder to shield the patient from

the diagnosis of HIV infection and that talking about HIV will make him/her more depressed. However, most people with symptomatic HIV infection will have given it much thought and sharing their worries and fears can be of great comfort. They may wish to discuss whether they should disclose their HIV status to other family members and friends, if they have not already done so. Carers can listen, be non-judgmental and offer love and support, especially if the patient feels isolated or fears rejection.

2. Spiritual support

Even if they have not been actively involved with a church or religious group, many people find great comfort from priests or other spiritual leaders during chronic illness. Others, however, may feel pressurized into talking about spiritual issues by loved ones, when they would prefer not to. Carers should acknowledge the patient's spiritual needs, or lack of them, and arrange for support and visits from a priest, pastor or other spiritual person, when appropriate.

3. Preparing for death

It is often believed that it is not appropriate to talk about the fact that someone is going to die, and that mentioning death will in some way hasten it. However, for those who wish to discuss death, open discussion, ideally from early diagnosis, can help dying persons to feel that their concerns are heard, that their wishes are followed, and that they are not alone. Sometimes it is easier for patients to express their feelings and concerns with a counsellor rather than their family, especially initially. Support groups can provide great comfort and relief; many patients are helped by talking to other people who are terminally ill.

Most people want to know that they will be remembered.

Encouraging friends and family to share stories or memories of the individual's life makes the person feel loved and cared for.

People who are nearing death are frequently afraid of dying in great pain. Health workers should be able to reassure patients that pain relief will be carried out up to the point of death. Another great worry is what will happen to patients' dependants after they die. Where possible, plans should be made for dependants and partners. Although it can be distressing to discuss these issues, making plans can reduce anxiety. Making a will can prevent family conflict and ensure that partners and children are not left destitute. This is particularly important where "property grabbing"¹ is common.

Practical issues to be discussed before death

- custody of children
- family support
- making a will
- funeral costs
- future school fees.

Emotional issues to be discussed before death

- resolve old quarrels
- tell patient and family members or friends that they are loved
- share hopes for the future, especially for children who are left behind
- say goodbye to carers and providers.

Support for families and carers

For family members, partners and friends, looking after someone with HIV infection can be very daunting. In high-prevalence areas carers may be looking after several family members who are sick with HIV infection. Carers need technical assistance with nursing and infection control, and emotional support. They need educating in the limits and outcomes of particular treatments, and advice and support so as to avoid burnout.

1. Nursing

Nursing people with late-stage HIV can be time consuming and tiring. If the patient is not fully mobile or bed bound he/she will need constant attention, such as:

- turning to prevent bedsores
- helping to the toilet or latrine, or to use a bed pan
- washing and keeping cool by sponging with a damp towel
- if the patient is incontinent of urine or faeces, washing both patient and bedclothes
- preparing food and drinks and helping to feed the patient
- providing company when the patient is feeling lonely, anxious or scared
- helping with drug taking
- cleaning and dressing sores and ulcers.

Many of these nursing tasks will be new to the family or community carer. They will therefore need help and support from a nurse, or knowledgeable health worker, who can explain about drug taking schedules and simple nursing techniques, such as how to dress ulcers. This will

¹ "Property grabbing" occurs in some countries in sub-Saharan Africa. It is the practice of relatives of the deceased to seize his/her property at death. This often results in women and orphans being left destitute following a death.

Background

give them confidence and make them feel less isolated. Written or illustrated material explaining drug taking schedules can be useful as these may be complicated, and some medicines have adverse effects, drug interactions or must be taken with particular foods.

Coping with HIV related brain impairment could be particularly difficult and distressing for friends and relatives, especially when the patient behaves aggressively or without normal inhibitions. Health care workers need to take time to explain what is happening when cognitive and behavioural problems develop, and to support carers in this situation.

2. Infection control

There are many myths about HIV and its transmission. Carers often worry about being infected themselves with HIV by the person they are looking after. Health workers should help carers explore these anxieties and, whilst giving them practical information on how to avoid infection, reassure them that the risk of catching HIV whilst caring for someone is minimal.

Carers should be aware of and understand the following:

- The risk of HIV infection to carers and household contacts is *extremely low*.
- There is no risk from casual household contact such as sharing eating utensils, and gloves do not need to be worn when touching and lifting someone with HIV.
- Gloves, when available, should be worn for cleaning wounds and clearing up blood or body fluids. When gloves are not available, covering the hands with plastic bags is a helpful alternative.

- Spillage of blood, faeces, urine or vomit should be cleaned up using household bleach.
- Cutlery, bed linen, etc. should be washed with normal washing products.

3. Psychological support

When carers, such as partners or children, are uncertain about their own HIV status, health workers can help them address their worries and offer a referral to voluntary counselling and testing (VCT).

Other problems, such as a shift in family dynamics when the elderly parent or young child becomes the carer, can make carers feel isolated. They may be reluctant to talk about these issues for fear of being judged as inadequate. Health workers can try to reassure them that their concerns are normal, or put them in touch with other carers. Sharing their experiences, for example, through support groups, can be very helpful to both parties.

The need to offer counselling to partners and families following the death of a family member or friend is often overlooked, particularly in developing countries. Bereavement counselling can help the bereaved person to discuss and reflect on the changes brought about by loss, to mourn appropriately and to look to the future. Partners and parents of a child who dies may have unresolved fears about HIV infection for themselves, or other family members, and can be helped to come to decisions about HIV testing.

The process of grieving may last many months or even years. However, for some people a single counselling session may be sufficient to clarify their thoughts and feelings, and to reassure them that they are coping as best

they can under the circumstances. This is particularly true for people who have other emotional supports, such as family, friends and church or other spiritual support. Other people may need several sessions. Some people never completely come to terms with a loss, particularly that of a child.

In high-prevalence developing countries, grieving may be made worse by multiple losses of friends and relatives through HIV infection. People who have recently suffered multiple losses may be afraid that they are 'going crazy' or losing their mind. Reassurance that such feelings are a normal part of grieving is important. Some traditional beliefs and practices may be helpful, but others, such as "property grabbing", may add to difficulties.

4. Helping the carers to care

Carers may become exhausted if they have been looking after a sick person for a long time, or if they have had many other friends or family members die recently. If they are tired or distressed, they cannot give their sick relative or friend the care they need. If respite care is available, it may be appropriate for the patient to spend short times there. If this is not available, other family members, friend or volunteers can be encouraged to share the care so that the main carer can get adequate rest. Health workers should reassure carers that they are bound to be tired and give them 'permission' to 'have a break' or take more rest.

Day respite care for children with symptomatic HIV disease may be offered. This not only gives respite to the children, but also to the carers who are often themselves sick or elderly.

Structured home-based care programmes, where available,

can provide good support for carers as well as patients. Health workers can share the burden of care, as well as providing treatment, advice and support. They also encourage acceptance of HIV/AIDS patients by communities, and help dispel myths and stigmatization.

Many patients first seek help and support from traditional or complementary medical practitioners. These practitioners may offer symptomatic treatment with herbal or other remedies, or pain relief through therapies such as acupuncture. Patients and carers may also be offered counselling and support. Health workers should discuss treatment and care plans with other practitioners involved in a patient's care, and should ensure that any complementary therapy is useful and not too costly. They can protect patients and carers from exploitation by unscrupulous charlatans.

Challenges:

Perceptions and recognition of palliative care

Palliative care has developed considerably since its early days when most patients treated were terminally ill and approaching death. But still many people living with HIV/AIDS shy away from the notion of palliative care because they link it with death and many of them don't want to admit they are dying. Policy-makers, planners and health workers have to tackle this misconception in order to ensure patients with HIV/AIDS receive palliative care.

Many developing and middle-income countries have limited health resources, including drug budgets, and palliative care,

particularly medicines used for symptomatic relief, is not always seen as a priority. Governments must appreciate that for humanitarian reasons alone, palliative care—reducing the pain and suffering of those who are chronically ill or dying—should be a priority.

Although HIV has added enormously to the health care burden in many of the poorest countries, many of the drugs and services which can benefit people with HIV are readily available, listed as WHO/UNAIDS essential drugs, and are cheap. If, however, additional resources are not provided to care for the increasing numbers of people with HIV, and to train carers and health workers, many people will die in pain, isolation and distress, and their carers, including many orphaned children, will be left feeling unsupported and helpless.

In some low-prevalence countries, people living with HIV/AIDS are even more isolated because HIV is perceived as a problem of marginalized groups such as injecting drug users, refugees and men who have sex with men. Health services need to structure health care and support to meet the needs of these particular groups, including tackling their isolation and stigmatization.

There are other sound development reasons for ensuring that people living with HIV/AIDS receive treatment to ensure a decent quality of life. Many people who are ill with HIV are intermittently ill and with access to appropriate medicines they have much to contribute to their families and communities. As people with HIV are often young adults, many have young children who need their parents to be with them for as long as possible.

In order to provide effective palliative care, governments and planners may need to transform health services through improved training, by making care available in a wide range of settings and by ensuring a sustained supply of appropriate drugs and medicines.

Organizing training

Even in settings where HIV is a major health problem, most communication about HIV infection has dealt with HIV transmission and prevention, with little emphasis on how to care for people with HIV. Nor do the majority of health professionals know how to holistically assess and control pain.

Palliative care training should be provided for health care workers in hospitals and in the community, for teachers, religious and community leaders; they in turn can teach community health workers, community volunteers and families caring for people living with HIV/AIDS.

General HIV education in the community can be very beneficial in reducing stigma, by helping to change negative attitudes towards people with HIV and their families, and giving factual information about caring for people living with HIV/AIDS.

Making good palliative care services available

In areas of high HIV prevalence the number of people with symptomatic disease requiring medical and psychological support increases as the epidemic matures. For example, in Zambia, which has a population of about 8.5 million, one in five adults are infected and an estimated 90 000 become unwell with HIV each year. In some hospitals in sub-Saharan Africa, 50–70% of adult medical beds

Challenges

are occupied by people with HIV-related illnesses. This has put an impossible burden on already very over-stretched and under-funded health services. Wards and outpatient clinics become overcrowded and medical staff feel demoralized and impotent as they have little treatment to offer. In response to this crisis, two main approaches have been taken in developing countries. First, alternatives to traditional inpatient and outpatient hospital services were sought. Secondly, there has been a development and expansion of services, including home care services, provided by nongovernmental organizations (NGOs).

1. Home care

Many successful models of home care have been developed in different settings. Those that are community-based, rather than developed as outreach from hospitals, tend to be cheaper to run and provide a wider coverage. Using volunteers has not only been successful in keeping costs lower, but has also enabled communities to work together in supporting each other, raising awareness and promoting tolerance and acceptance.

2. Residential hospice care

Residential hospices have been set up in many industrialized countries to help care for people with terminal HIV disease. Hospice care is particularly helpful for people who live alone or who have poor symptom control or symptoms that are difficult to manage, such as those associated with severe brain impairment. Hospice care is also useful for providing respite care, when carers need a break or when patients are being stabilized on new drug regimes. In developing countries there are a few examples of hospices, often run by religious groups. In high-

HIV-prevalence developing countries, inpatient hospice care is too expensive to provide for the large numbers of people requiring palliative or terminal care.

3. Day centres

In some countries day care facilities for people living with HIV/AIDS may be available. These enable patients to remain at home whilst allowing carers time off during the day. Patients can receive palliative care at the day centre, counselling and emotional support, cooked meals, services for their children and, in some cases, schemes for income-generation.

Each of the models of care has advantages and disadvantages and patients may benefit from different care at different stages in their illness.

4. Access to analgesics and palliative care drugs

There are often strict legal controls on analgesics such as codeine and other opiates. Because of fears about their misuse, in many countries they can only be prescribed by doctors. In settings where the majority of palliative care is delivered by nursing staff or community carers, and there are few doctors, access to analgesics can be problematic. A balance is needed between increasing access to adequate pain relief for people with HIV and the careful supervision and record keeping of prescription of opiate analgesics.

In some settings cannabis has been found to be helpful in symptom control (particularly for the relief of nausea and improvement of appetite) for people with HIV. However, their use is often restricted by strict legislation. Some PLHA groups argue for these drugs to be made more widely available.

5. Providing support for carers, counsellors and health care workers

Health services need to address the specific causes of stress for people who care for HIV/AIDS patients. Support groups for carers enable them to share their particular anxieties and concerns, such as coping with multiple deaths or coming to terms with the person's sexual orientation. Caring for people with HIV at the end of their life is emotionally draining and can be depressing. To avoid burnout adequate support for carers, counsellors and health care workers should be available.

In many cultures, parents find it difficult to discuss painful issues with their children. As a result, children are unprepared for the death of their parents, unable to protect themselves from HIV infection in the future and often unable to trust adults. Children with HIV or whose parents or siblings have HIV disease may need culture and age-specific counselling and their parents or carers need support and guidance in talking to children about sensitive and distressing issues.

6. The special needs of children with HIV

Most children with HIV disease in developing countries have little access to medical care, and palliative care or rehabilitation is seldom offered. Assumptions such as 'because the child does not verbalize his or her problems he/she has none', or that 'addressing issues around death and dying will cause more harm than good' are now being challenged. The importance of communicating with children and involving them in decision-making is now being recognised by parents and health workers.

What is currently being done to overcome these challenges?

Examples of current projects initiatives in palliative care.

The Catholic Diocese in Ndola, Zambia

In the late 1980s Zambia developed the new strategy of "home based" care to cope with the increasing number of people with symptomatic HIV disease. This strategy was not confined to medical treatment and nursing care, but took a more comprehensive approach to the needs of individuals, families and communities. However, many of the early projects had limited coverage and were relatively expensive to operate. In 1991 the Catholic Diocese in Ndola, in the Zambian copperbelt, established a comprehensive home care programme for people with HIV disease, which aimed to provide much higher coverage at less expense. The key to its success is the role of the 500 volunteers who offer counselling, social and emotional support, and basic medical and nursing care for people with HIV disease and their families. They also provide links between the local health centres and the community, allowing people with HIV to receive care in their homes rather than as inpatients. HIV education to the communities has helped to change attitudes to PLHA increasing acceptance and tolerance and reducing stigma.

The AIDS Support Organisation (TASO), Uganda

TASO in Uganda was founded in 1987 as a self-help support group, and it is an example of what can be done when people living with HIV/AIDS and their families identify their own needs and spearhead the process of defining the nature of services to meet those needs. TASO began by offering counselling and

outpatient clinical care of opportunistic infections to people living with or affected by HIV/AIDS. Soon it became evident that when TASO clients became bed-bound, they were often not receiving good-quality care due to stigma in homes and communities, and the lack of care skills in the homes. TASO started a campaign of AIDS awareness aimed at changing attitudes in communities. At the same time TASO began training and supervision programmes for families and community members in basic home care. People living with or affected by HIV became the driving force of this campaign, sharing their personal experience and advocating "positive living". Family level income-generation activities were started and linked to church and other community-based organizations. TASO also runs training programmes for counsellors, community carers and community-owned resource persons.

The Mildmay Mission Hospital, London, United Kingdom

Mildmay is a Christian foundation and was the first to set up inpatient and day palliative care services in Europe. It is funded mainly through contracts with the National Health Service together with by donations and grants. It is situated in central London and aims to care for people with HIV without regard to race, religion, culture or lifestyle.

People with HIV may be admitted for rehabilitation, respite or terminal care, or for support while changing drug regimens. The use of the hospice has changed since the use of ARVs became routine for people with HIV in the United Kingdom. Many more patients are now seen for rehabilitation or respite care than for terminal care. Associated

services include counselling, referral for hospital outpatient care such as gynaecology and dermatology, social support and support for children. Mildmay has a family care unit and a unit for people with brain impairment, with separate day care centres for children and adults. People who use the centre include men who have sex with men, injecting drug users, and people from Africa now living in London. Mildmay has found that close links with churches and religious groups in the community have helped to raise awareness about HIV and enabled people living with HIV/AIDS to obtain ongoing spiritual support once they are back in their homes.

The Mildmay Centre for AIDS palliative care and international study centre, Kampala, Uganda.

The Mildmay Centre in Uganda was developed as a joint project between the Ugandan Ministry of Health (AIDS control programme), the United Kingdom Department for International Development and Mildmay International, who have a contract to manage the centre for ten years. It was opened to patients in 1998.

The Mildmay Centre was designed to provide specialist outpatient palliative care and rehabilitation for people living with HIV/AIDS, and to serve as a demonstration model for cost-effective care in resource-limited settings. It also provides day and residential training programmes in all aspects of HIV care for health workers, volunteers and carers.

Responses

The emphasis is on rehabilitation and the promotion of independence wherever possible. It has a patient-focused team with support from:

- Medical and nursing staff
- Physiotherapists
- Occupational therapist
- Nutritionist
- Counsellors
- Spiritual care
- On-site laboratory services
- On-site pharmacy.

At the Mildmay Children's Centre in Kampala, children with HIV have free access to the same range of services as at the adult centre. The services are child-friendly, with therapeutic play and counselling. The aim is to meet not only their physical needs but also their emotional needs as many children seen are severely traumatized. Day respite care for orphans with advanced HIV disease is also provided.

Calmette Hospital, Cambodia

The Calmette hospital and a Phnom-Penh military hospital have implemented an innovative treatment and training programme to fight AIDS in the community through education, and to provide a comprehensive response to the medical and psychosocial care needs of the patients it serves. It is now estimated that 200 000 Cambodians are HIV-positive, of whom 30 000 have progressed to AIDS, with an impact that is also growing on military and police forces. Working with Doctors without Borders, the programme has developed a capacity to provide both care, including inpatient and outpatient services, and training for health care providers. As a result, trained physicians have established a pain clinic and provide pain management in these two

hospitals. The current project was based on the premise that a response is required which addresses medical and psychosocial needs simultaneously. Treatment focuses particular attention on pain management and responding to symptoms. Psychological and social supports are provided to infants who are orphans. Another primary objective of the project is to provide education and training for clinicians, pharmacists, and family members. Within communities, families and neighbourhoods receive health education and HIV prevention. The system of care has expanded to include ambulatory and home care for patients living with AIDS and cancer.

Sahara Michael's Care Home, India

Sahara Michael's Care Home, a nongovernmental organization in India, is pioneering a continuum of care that addresses aspects of HIV/AIDS care lacking in the health service, concentrating on areas that include treatment, training, human rights advocacy, and the development of networks and partnerships. The Care Home, a 16-bed facility, evolved in response to changing disease patterns for HIV/AIDS and the need for care giving of a greater intensity and longer periods. The programme has been serving areas of high need, in resource-constrained settings, since 1978. Funded by the Catholic Relief Organisation, the model of care initiated in 1997 for people living with HIV/AIDS is now being utilized by HIV/AIDS communities throughout India.

The model of care includes care giving, counselling, a nutrition programme, cost viable treatment strategies, crisis care, and training for self and family care provided by a team of

professionals and non-professionals. The professional team consists of a consulting physician and nurses. The care staff includes 17 men and women who perform a variety of tasks ranging from autoclaving, cooking and driving to hospital visits. In the next year, the team will be developing an outpatient department for HIV-positive people, counselling which embraces issues that go beyond HIV status, and a systematic training programme for the intricacies of HIV/AIDS care.

The Care Home has a spiritual undercurrent to its programmes and a team with a service-like devotion to care giving. This has fostered an acceptance of HIV/AIDS in local communities and encouraged people everywhere to offer materials and support.

The Positive and Living Squad (PALS) and Kara Counselling and Training Trust (KCTT), Zambia

KCTT and the PALS are closely linked Zambian NGOs, working to provide care and support services for people living with HIV/AIDS. The PALS are a group of people living openly with HIV. They organize a wide range of HIV prevention activities, but also have an important role in supporting other people with HIV when they become sick and families when a loved one dies. For people who are unwell with HIV, having support and understanding from someone who is also infected with HIV is often very helpful. It can lessen the feeling of isolation and help families to see that their problems are not unique. During the time of someone's last illness and death the PALS often provide practical and material help, including helping with funeral arrangements and helping make plans for dependants. The PALS

also have an important advocacy role and are active in fighting discrimination and promoting the rights of widows and dependants.

Among the activities provided by KCTT is a training programme for home care volunteers. Lay volunteers are taught about basic nursing and listening and counselling skills. KCTT also has a day centre where people with HIV can meet and learn skills from an income generation scheme, counselling services and close links with community based care teams. They also provide TB screening and preventive therapy for people with HIV and family counselling for families affected by HIV.

As palliative and supportive care needs are often overlooked, they must be emphasized in national strategic plans. There is also need for coordination with donors to ensure that palliative care is seen as a priority, and resource mobilization is essential to strengthen these efforts.

Selected Key Materials

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