ABC of palliative care

HIV infection and AIDS

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When AIDS first emerged as a clinical problem, some 15 years ago, many patients died early from acute illnesses such as pneumocystis carinii pneumonia. Cumulative experience and increased awareness have led to the use of prophylaxis, earlier diagnosis, and more effective treatments for HIV itself and the many complications of HIV infection and AIDS. As a result, patients with AIDS now have improved survival but are more likely to experience months or years of increasing dependency, punctuated by episodes of acute illness.

Currently, the clinical picture is changing through the use of new combinations of antiretroviral drugs, which improve patients' wellbeing and delay disease progression. They are not, however, a cure. Three drugs are usually used in combination, resulting in problems with drug interactions and compliance.

During the later stages of the disease many patients prefer to remain at home whenever possible, relying on the support of community services. Hospices are then used when residential respite care is needed. In addition, many patients have also been choosing to die at home or in a hospice rather than in hospital. This has meant that increasing numbers of people who are not specialists in HIV infection are needing to become familiar with managing HIV infection, especially in advanced or terminal cases.

Some people with AIDS are very well informed about the illness and may also have experience of caring for partners and friends with AIDS. They can be a valuable source of knowledge for the health workers looking after them. Others are less well informed or are too bewildered and frightened to express their needs clearly. The complexity of the issues involved means that open discussion with patients is needed in order to help establish their medical and personal priorities, and to allow agreement to be reached in balancing realistic therapeutic goals and quality of life.

Natural course of HIV infection

HIV infection has a variable and unpredictable course, with a wide range of potential complications, rates of progression, and survival. Some patients remain free of serious symptoms and complications until they have reached an advanced stage of immunosuppression, while others suffer debilitating malaise and fatigue or frequent non-life threatening complications throughout their infection. Many seem to come to terms with their situation at an early stage, but some find themselves living with daily uncertainty and fear, which may continue for many years. Many also experience a drawn out series of crises relating to emotional, psychological, social, economic, and physical milestones.

People with AIDS are not necessarily ill all of the time and may remain fit and working long after their AIDS defining diagnosis. It is, however, an aging illness, and, as it progresses, patients become increasingly debilitated and dependent on others, ultimately requiring intensive practical support and nursing care. Like elderly people, they may also experience multiple loss through death of peers and family, cognitive impairment, degrees of dementia, reduced mobility, and incontinence. Cachexia and malnourishment are psychologically distressing and increase the risk of developing

Cases of AIDS and HIV infection in the United Kingdom*

	Total No of cases		People living with AIDS†
	HIV infection	AIDS	
To end of March 1992	17 494	5782	2152
To end of March 1997	29 107	14 075	2594

*As reported to the Public Health Laboratory Service since 1984

†Calculated by subtracting notified deaths from notified cases

Combination antiretroviral therapy

- Responsible for decreased death rates, progression to AIDS, inpatient admissions
- Dramatic physical and medical improvement in patients with apparently end stage AIDS
- May help to control previously uncontrollable opportunistic infections and AIDS related symptoms
- Benefits may be time limited, and therapeutic failure is increasingly common
- Complex drug interactions, toxicities, and intolerance
- Requires specialist management

Specific issues in palliative care of AIDS patients

Medical

- Multiple infections
- Chronic suppressive therapy
- Increased risk of adverse drug reactions
- Continued prophylaxis
- Multiple medications

Psychosocial

- Young patients (usually)
- Marginalised or minority groups
- Partners and carers often infected
- Family members often infected
- Often well informed
- Stigmatised
- Confidentiality
- Infected peer networks
- Multiple bereavements
- Fears of "contagion"

Average time from HIV seroconversion to developing AIDS is 8-10 years

Average survival after developing AIDS is 18-30 months

(These times are approximate with considerable variability)

Radiograph of pulmonary Kaposi's sarcoma. Average prognosis is 3-9 months

bedsores. Death is usually due to multiple causes, including chronic incurable systemic infections, malignancies, neurological disease, wasting and malnutrition, and multisystem failure.

Multidisciplinary and shared care

Most people who are infected with HIV obtain their care from a specialist hospital clinic. These clinics usually provide a safe environment and a variety of services, such as access to specialised drugs, walk-in and day care facilities, counselling, complementary treatments, peer support, and advice about services and benefits.

Many patients do not have a general practitioner and are often reluctant to register with one. Even if they are registered they may still not disclose their HIV status. The reasons for this include their concerns over confidentiality, the fear of discrimination, and the risk of rejection because of the belief of potential financial costs to the practice of looking after a patient with AIDS. This means that general practitioners often become involved with AIDS patients only at a late stage in their disease. It is important to encourage patients to register early with a general practitioner in whom they can build trust so that the transition to shared care can be made as smoothly as possible.

It is often feasible to reduce the need for patients with end stage disease to attend hospital by providing care in their homes and using local hospices and services when appropriate. Medical conditions, and thus the required treatments, change frequently in these patients, so good communication between the many agencies involved is essential. This is facilitated by patient held record cards (including updated details of medication) and direct communication by telephone and fax (with care to ensure confidentiality). Named key workers help to coordinate patients' care and also act as patients' advocates if required.

For patients with advanced disease, prior discussion about advance directives, desired levels of medical intervention in the event of clinical deterioration, and preferred place of death can help to prevent unnecessary hospital visits and inappropriate hospital admissions. Contingency plans need to be made so that patients and carers are clear which agencies should be called in an emergency.

Medical management

Medical management of patients with AIDS is a balance between acute treatment and attempting to control chronic symptoms and conditions. As patients approach the end stage of the illness, they may decline certain investigations and treatments if these seem unlikely to be of much long term benefit.

New symptoms, however, may still warrant invasive investigations because atypical presentations and extensive differential diagnoses can make easily treatable conditions unrecognisable—for example, endoscopy should be considered when investigating retrosternal pain and nausea not responding to antifungal treatment. There are also some distressing symptoms that can be controlled effectively only by specific treatment of the underlying condition (such as perianal infection with herpes simplex virus and oro-oesophageal candida).

While the underlying cause of pain and other symptoms in AIDS is often susceptible to specific treatment, symptomatic treatment should not be delayed. The principles of pain management should follow those outlined in the first article of this series.

Community provision of care for AIDS patients

Individuals

- Informal carers
- General practitioners
- District nurses (general)
- Specialist HIV nurses
- Palliative care nurses
- Community psychiatric nurses
- Social worker
- "Buddies" (volunteers)
- Community care assistants (including 24 hour cover)
- Community occupational therapists
- Spiritual advisers

Organisations

- Social services
- General hospices
- Specialist HIV hospices
- Local support groups

Contacts for details of services available

- *National AIDS Manual*
Published yearly
Telephone (0171) 627 3200
- National AIDS Helpline
Telephone 0800 567123

Common symptoms in AIDS

Causes	Management
Cough Sinus disease with postnasal drip, bacterial chest infection, pneumocystis carinii pneumonia, pulmonary Kaposi's sarcoma, tuberculosis	Sputum for diagnosis, treat specific conditions when appropriate, consider decongestants
Diarrhoea <i>Treatable</i> —Salmonella, giardia, campylobacter, clostridium difficile, cytomegalovirus <i>Unresponsive</i> —Cryptosporidium, microsporidium, and "pathogen negative" diarrhoea	Stool samples may be appropriate, specific antibacterial treatment Symptomatic control can be difficult, subcutaneous diamorphine or octreotide may be tried
Anorexia, nausea, vomiting Candida, malignancy (early satiety, acute abdomen), drugs, constipation	Review candida treatment, re-evaluate medication, consider antiemetics, dietary advice
Pruritus Dry skin, drug reactions, scabies, folliculitis	Emollients, antipruritics, anti-scabies treatment, topical corticosteroids
Malaise, weakness, pyrexia May be no detectable cause, drug reactions	Investigate, consider corticosteroids

Common causes of pain in AIDS

Oropharyngeal—Candida, herpes viruses (herpes simplex virus, cytomegalovirus, varicella zoster virus), aphthous-type ulcers, malignancy, gingivitis, tooth abscesses
Retrosternal—Oesophageal candida, infection with cytomegalovirus or herpes simplex virus, giant oesophageal ulcers, reflux oesophagitis, pneumocystis carinii pneumonia
Headache—Toxoplasmosis, cryptococcal meningitis, cerebral lymphoma
Abdominal—Diarrhoea with or without infection, AIDS related sclerosing cholangitis, malignancy (such as Kaposi's sarcoma, lymphoma), drugs (such as clarithromycin), constipation
Perianal and perineal—Herpes simplex virus (very common, needs high index of suspicion), candida, excoriation of skin due to diarrhoea

Patients entering the terminal phases of disease are often receiving several drugs because many symptoms and conditions need continued prophylaxis or chronic suppressive treatment. Uncontrolled cytomegalovirus retinitis, for example, can cause blindness, so usually needs to be actively managed until death. Systemic infection with mycobacterium avium complex, may cause general malaise with fevers, anaemia, and debilitating fatigue. In this situation specific treatment of the infection, which usually involves two or three drugs, may be appropriate, or use of corticosteroids for further palliation of symptoms may be considered.

Drug treatments should be reviewed regularly so that clinical problems are controlled with a minimum of polypharmacy. Patients with AIDS and clinical or subclinical dementia can be susceptible to cognitive impairment with various drugs—sedatives, anxiolytics, strong opioids, and antidepressants.

Management of nutritional and dietary intake is also important for both medical and psychological reasons. In the final stages of AIDS, combination antiretroviral treatment may be helpful, but it is less effective than earlier in the disease and decisions about continuation should be taken with the patient.

Wasting is common in AIDS and can cause pain, bed sores, and psychological distress

Common conditions in AIDS that require active management until death

	Presentation and symptoms	Treatment
Cytomegalovirus retinitis	Potential blindness, scotomas	Intravenous ganciclovir, foscarnet (needs indwelling catheter such as PortaCath or Hickman line); oral ganciclovir may be appropriate in some cases. These drugs are expensive and must be prescribed by hospital doctor
Candidiasis	<i>Oropharyngeal or oesophageal</i> —Painful oropharynx, retrosternal pain, dysphagia, anorexia, nausea and vomiting. Even mild oral candidiasis can be symptomatic and associated with oesophageal candida	Fluconazole or itraconazole (may need up to four times recommended dose as resistance common in advanced AIDS). Intravenous amphotericin (intermittent treatment may be needed in resistant cases)
Herpes simplex virus	<i>Oropharyngeal or anogenital</i> —Pain, paraesthesia, ulcers. Patients may complain of “piles” or bleeding from rectum	Aciclovir for acute episode (may need maintenance and up to four times recommended dose)
Mycobacterium avium complex	Fevers, night sweats, malaise, fatigue, anorexia, weight loss, diarrhoea, anaemia; symptoms may occur singly or in combination	Combination therapy (such as rifabutin, clarithromycin, and ethambutol) may give good palliation of symptoms. Single drug for short periods if compliance or polypharmacy a problem
Kaposi's sarcoma	<i>Pulmonary</i> —Cough, dry or productive and may be paroxysms; progressive breathlessness; haemoptysis; effusions <i>Cutaneous, lymphatic, or other viscera</i> —Local symptoms such as lymphadenopathy, oedema, loss of function, breakdown or necrosis of skin, pain, possible severe disfigurement and distortion of tissues	Symptomatic control (such as anxiolytics, opioids, oxygen). Chemotherapy and radiotherapy of limited value. Poor prognosis Variable natural course (minor or considerable morbidity). Chemotherapy and radiotherapy may help palliation of problems. Corticosteroids can help oedema but may exacerbate infections
AIDS dementia complex	Variable neurological presentations, including dementia and psychiatric illness	Difficult and distressing to manage, requiring multidisciplinary approach. Combination therapy, which must include high dose zidovudine, is worth trying
Pneumocystis carinii pneumonia	Dry cough, possibly paroxysmal and distressing; chest pain; breathlessness; fevers; sweats; malaise; anorexia	Prophylaxis (primary or secondary) usually continued (co-trimoxazole, dapsone, pentamidine)
Co-infection with hepatitis B or C	Usually incidental finding with liver function tests	Poor response to treatment. Complicates prescribing of hepatotoxic drugs

Social and cultural issues

Many of those affected by HIV infection and AIDS belong to marginalised or stigmatised minority groups. Management of psychosocial problems may come to dominate the provision of palliative and terminal care. Carers also need adequate support, as many of them may be infected and facing, or already living with, AIDS themselves. Financial help (including advice on benefits, disability allowances, and other support) should be discussed and reviewed regularly.

AIDS related problems with body image

- Wasting
- Severe facial dermatitis
- Permanent indwelling line
- Weakness and dependency
- Slowing of mental functions
- Loss of libido
- Premature greying and loss of hair
- Facial molluscum contagiosum
- Kaposi's sarcoma—common on face
- Progressive visual loss from retinitis
- Incontinence (especially faecal)

Patients and families may express concern about "AIDS" being written on the death certificate, and discussion of this issue can be helpful. Many doctors write a non-specific diagnosis on the main certificate and sign section B on the reverse side (this signifies to the registrar general that further information will be available later). Doctors should supply voluntary confidential notification of deaths to the Communicable Disease Surveillance Centre (CDSC).

Homosexual men may not have disclosed their sexual orientation, and families may not learn of their illness until it is advanced. Conflicts can arise between a patient's family and partner as to who is the main carer. Homosexual partnerships are not recognised legally in Britain, so patients should make an unambiguous will and specify their preferred "next of kin" or executor.

Immigrant groups—Most patients are from Africa, and in some immigrant communities the stigma of HIV infection is so severe that patients may avoid disclosing their HIV status to almost anyone. This can lead to reduced uptake of services that are identifiably HIV related (such as AIDS hospices and "AIDS wards"). Reassurance about confidentiality and the option of "discreet" services may be useful. Uncertain immigration status can cause great anxiety and can also prevent family members from entering Britain to visit or care for their dying relative.

Haemophiliacs—There are specific medical problems relating to haemophilia (including liver disease due to chronic infection with hepatitis B and C). More than one brother may be affected, and issues of parental guilt and multiple bereavement may arise.

Misusers of injected drugs—Management may be complicated by drug misuse. Ideally, patients should be managed in collaboration with a drug dependency unit, which should take primary responsibility for prescribing opioid maintenance therapy. Many doctors are reluctant to prescribe opioid analgesia to known drug misusers. A patient's pain should be properly assessed and, if necessary, the opioid dose adjusted in relation to the habitual opioid intake. An adequate dose to control pain will often abolish drug seeking behaviour.

Children and families—When both parents are sick, child care or fostering may be needed urgently. Care plans should be made well in advance for any children (whether infected or not) who are likely to be orphaned. Some infected parents fear that their children will be taken into care, and they may conceal their own diagnosis or deny the existence of their children to the authorities or health workers. Parents need help to discuss HIV, AIDS, and death with their children. Management of infected children needs collaboration with a specialist paediatric unit.

Conclusion

Looking after patients with AIDS can seem daunting. It affects young people who are often assertive and well informed, and there may be complex psychosocial issues. The variety of potential medical problems requires multiple medications (some needing an indwelling intravenous catheter) and diagnostic vigilance right up until the end.

Some people with AIDS never come to terms with their illness and impending death, although effective palliative care and management of their special needs can help to avoid unnecessary suffering and provide comfort for them and their bereaved families. It can also enable patients to take control at the end of their lives, allowing them to choose the place of death in the environment and company of their choice. Patients and their carers often display remarkable courage and fortitude, and, despite the inevitable tragedy, a satisfactory death can be a rewarding experience for those involved in their care.

Legal issues

- "Living wills," advance directives
 - "Next of kin," executors
 - Wills—Especially important when partner is not the legal spouse, as in homosexual relationships
 - Immigration status
 - Death certificates
 - Guardianship and provision for orphaned children
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Social and cultural issues

Homosexual men

- Sexual orientation may not have been disclosed to families
- Conflicts between patient's partner and family about caring roles and inheritance

Haemophiliacs

- Issues of parental guilt and blame for administering infected clotting factors
- Multiple loss within families

Misusers of injected drugs

- Problems of continuing drug misuse
- Non-conformist behaviour
- Chaotic lifestyles affecting compliance with treatment

Immigrant groups

- Isolation, especially from extended family
- Fear of stigmatisation within cultural community in Britain and for families in country of origin
- Issues of language and cross cultural communication—These can be avoided by using an agency that provides culturally appropriate advice and interpreters
- Past trauma in country of origin

Children and families

- More than one family member may be infected
 - Issues of child care and provision for orphans
 - Fear of social services "taking children away"
 - Care of a dying child
-

Control of infection

- Extremely low risk of infection to health workers and household contacts
 - HIV present in blood and bodily fluids—Gloves to be worn when risk of direct contact with these fluids
 - Main risk is direct parenteral inoculation of bodily fluids—Can be reduced by immediate use of antiretroviral drugs
 - No risk from casual household contact—Gloves not necessary for normal examination or contact
 - Spillages (blood, faeces, urine)—Use ordinary household bleach
 - Cutlery, linen, bath, etc—All can be cleaned with ordinary washing products
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