Purchasing for Quality: the Providers' View

Purchasing care for people with HIV infection and AIDS

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Since 1982, 6798 cases of AIDS have been reported in the United Kingdom. The long asymptomatic phase of HIV infection often leads to delayed diagnosis so it may be several years before the full extent of the HIV epidemic becomes apparent. In the past two years cases of AIDS attributed to sexual intercourse between men rose 8%, cases attributed to sexual intercourse between men and women rose 23%, and those attributed to injecting drugs decreased 9%.¹

The pattern of care of patients with HIV infection is changing rapidly. Services initially customised for homosexual men are now coping with an increasing number of women, drug users (many from other countries in the European Community), and African refugees. A quality health service for those with HIV infection must therefore be flexible, easy to access, and yet well organised. The service should be able to deliver health care for all age groups of people from many ethnic backgrounds and offer support to the "worried well" and those in all stages of HIV infection and offer education and support to health professionals caring for these patients. Patients' needs will range from counselling to high technology medicine in a field where today's advance is tomorrow's prescription.

The need for HIV services varies considerably from region to region, and this variation will affect the services provided. Hospitals in areas where there are only few people with HIV infection will not be able to provide the comprehensive services available in major centres which look after several hundred patients with HIV infection. Although purchasing is a function a district health authority carries out on behalf of its residents, many people infected with HIV already "shop around" for their care. This is particularly evident in clinics linked to genitourinary medicine services, in which open access, confidentiality, and anonymity are emphasised.

Objectives of HIV care

The main objectives of HIV care are to offer readily accessible and highly confidential HIV testing to all and to offer a high standard of clinical care and support to all those with HIV infection.

The full extent of the HIV epidemic in the United Kingdom is unknown. But preventing infection is a high priority for every health

authority and must be a concern also for those looking after people with HIV infection. Prevention ranges from educating individuals to providing needles and syringes to intravenous drug users.

Organisation of care

People with HIV infection need the skills of health care workers from many different professions and it is essential that coordination and continuity of care is maximised.* There is an increasing trend for patients, particularly in the later stages of their disease, to be cared for at home. Careful liaison between the hospital and community based services is clearly important and the development of home care teams or task forces is one approach appreciated by many patients. In hospitals which look after a large number of patients infected with HIV there is the scope for the HIV team to have a broad multidisciplinary base. In those district hospitals which look after only a few patients the team may be smaller, perhaps including specialists in genitourinary medicine and respiratory medicine, but it remains important that there are adequate links with the community services and primary care.*

A model of care has developed where the views of individual patients have an important influence on the level of intervention they wish at any stage of their illness.* Such a service has therefore to be able to cater for seriously ill patients who require high technology intervention and to offer supportive or terminal care when appropriate. The service needs to be organised so that there is a seamless interaction between the inpatient and outpatient facilities provided by the hospital and all the other supportive networks throughout the community.

Outpatient care

HIV TESTING

HIV testing is an area where there may seem to be a difference between public health needs and those of the individual. Until recently, individuals without symptoms of HIV infection were seldom encouraged to determine their HIV status as there was little therapeutic advantage. But as evidence has emerged that earlier treatment is beneficial²

* Accepted good practice unsupported by published evidence.

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the diagnosis of HIV infection has important implications for future health.

The decision to have an HIV test is often difficult, and the input of specially trained counsellors has proved helpful.³ Many people prefer the anonymity of a genitourinary clinic or other specialist clinic to a general practitioner's health centre. Patients should feel assured that confidentiality will be maintained, and this applies as much to information held on computerised databases as to oral reports and paper records.

Before having an HIV antibody test patients should be given the opportunity to discuss the issues with a health adviser.* The aims of this "pretest counselling" are not to dissuade or to encourage the patient to be tested but rather to explain and discuss the implications and limitations of the test so that each patient can make an informed decision. Written consent should be obtained if possible and an appointment arranged to discuss the result in person. The result of the test should be given in a safe, controlled setting. Counselling after testing is essential, whatever the result.* For people found to be antibody negative it is a useful opportunity to promote safer sexual practices. Those who are antibody positive should be introduced to the framework of support that is available, and notification of partners and management can be introduced into the discussion. Follow up appointments for ongoing support can be arranged.

CARE OF PEOPLE WITH HIV INFECTION

For people with HIV infection who do not have symptoms an outpatient clinic should offer careful monitoring, access to counselling and other support, treatment facilities, and ready access to specialist services or inpatient care as needed. The development of day care; home care⁴; and, when appropriate, terminal care facilities have improved the quality of life for patients and enabled more rational use of inpatient facilities and allowed patients to spend less time in hospital and more time at home.

Meeting the medical needs of the people with HIV infection requires input from many diverse hospital services, including reliable diagnostic and laboratory facilities for routine investigations as well as for more specialised tests such as CD4 lymphocyte counts (CD4 cells are T helper lymphocytes affected by infection with HIV which fall in number as the condition progresses), with specialist back up from other teams.

AIDS develops in about half of people within 10 years after infection with HIV.⁵ People with AIDS are now surviving longer,⁶ probably as a result of a combination of improving medical services, use of anti-retroviral agents, and use of primary and secondary prophylaxis against opportunistic infections.

During the early asymptomatic phase of HIV infection patients should be seen every three to four months for clinical checks and for estimation of the CD4 lymphocyte count, as this seems to be one of the few surrogate

markers that may help in determining prognosis.⁷ One purpose of this regular follow up and assessment is to decide whether and when to introduce antiretroviral treatment or prophylaxis against opportunistic infection, or both.

In early disease zidovudine has been shown to delay the progression to AIDS² and may also improve survival.⁸ Cost benefit analysis of zidovudine treatment supported antiretroviral intervention in patients with symptoms and in those with asymptomatic infection but deterioration according to surrogate markers.^{9 10} In the early experience of the use of zidovudine the doses recommended were associated with anaemia and many people taking the drug needed frequent blood transfusions. However, now that lower doses have been shown to be effective the demand for blood transfusions has been reduced to less than 1% of those taking zidovudine. But there remains the need for regular blood counts and, when necessary, adjustments in treatment.

The risk of infection with *Pneumocystis carinii* pneumonia is greatly increased if the CD4 lymphocyte count falls to less than 200/ml,¹¹ and most doctors would recommend primary prophylaxis at this stage. The best chemoprophylactic regimen for this infection has not been established yet. Regimens include thrice weekly co-trimoxazole, dapsone/pyrimethamine, and Fansidar, and all have been shown to be cost effective.¹² Nebulised pentamidine, strongly supported by many American physicians, is the least cost effective regimen, and the occurrence of extrapulmonary pneumocystis infection¹³ has limited its use. However, intolerance of the first line oral agents is common, and nebulised pentamidine may be the only suitable regimen for some patients.

Living with HIV infection can be very stressful and ready access to psychology services is particularly helpful for patients.¹⁴ Liaison with support groups may also be important at an early stage. For patients who use drugs careful liaison with drug dependency services is required*; in Edinburgh, for example, methadone maintenance regimens are available from the infectious diseases clinic.¹⁵ With increasing numbers of infected women and children issues surrounding the care of families with HIV infection need to be addressed. The best model for family care has not yet been established, and centres are reviewing the optimum approach for combined paediatric and adult services. Ready access to family planning and antenatal services is clearly important.

FACILITIES FOR OUTPATIENT CARE

Useful, investigative services (in addition to routine facilities) include:

- CD4 lymphocyte counts – useful in monitoring patients without symptoms and assessing their need for prophylaxis against

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opportunistic infection and for antiretroviral treatment

- Testing pulmonary function – useful for early diagnosis of *P carinii* pneumonia
- Endoscopy – bronchoscopy, endoscopy of upper and lower gastrointestinal tract, etc.
- Standard radiological services with access to computed tomographic scanning.

Useful specialist services (in addition to standard hospital services) include:

- Ophthalmology – suspected retinitis caused by cytomegalovirus needs urgent confirmation and instigation of treatment to avoid blindness. Severe cases may require retinal surgery
- Oncology – access to radiotherapy and chemotherapy for lymphomas and Kaposi's sarcoma
- Psychiatric and psychological support
- Surgery – many "minor" procedures are required, including examination under anaesthesia and placement of tunnelled central venous catheters
- Drug and alcohol dependency services
- Obstetric and gynaecological services, including family planning services and ready access to colposcopy
- Nutritional assessment and advice.

LIAISON WITH GENERAL PRACTITIONERS

The extent of involvement of general practitioners (GPs) in the care of people with HIV varies greatly. Many patients are reluctant to consider GP involvement as they fear breaches of confidentiality within primary health care centres.¹⁶ Currently, many patients attending HIV clinics do not involve their GPs in their care. Clearly, a specialist service cannot replace a general practitioner and deprives the patient of primary health care and a valuable, integrated approach to their problems.

Many GPs are keen to look after patients with AIDS and at this hospital, for example, a trial shared care scheme (Graham *et al.* General practitioner shared care scheme for HIV patients, abstract 038, third European conference on clinical aspects and treatment of HIV infection, Paris 1992) has been established to encourage two way communication between the hospital and primary health care services. But it may be difficult to preserve confidentiality and anonymity for patients living in small, closely-knit communities. Additionally, free prescriptions at genitourinary medicine clinics and concern about the impact of HIV related costs on GP budgets do not encourage GP involvement for either doctor or patient.

LIAISON WITH OTHER SERVICES

It is important for the hospital to have strong links with the various support groups and to be aware of their services. With failing health many people run into financial problems so access to appropriate advice is helpful.

Strong links with the psychology department are essential.* Alterations in lifestyle; changes in body image; and problems with sexuality, families, and relationships add

to patients' distress, and psychologists can help patients to create coping strategies.

HOME CARE TEAM

The home care team, consisting of nurses, an occupational therapist, and often a general practitioner, can act as a very important link between the hospital and community based services.* The emphasis is on coping with the practicalities of living with ill health and on support for those who are dying. Many intravenous treatments which previously required administration as an inpatient procedure can now be given at home via semipermanent central venous catheters inserted in hospital. The move towards more community bed care for those requiring an inpatient facility without the need for technological intervention is likely to continue.

Inpatient care

Patients require inpatient care for the management of more serious opportunistic infections and other complications related to HIV and for surgical and other procedures which require the technological support and expertise of the hospital. Urgent admission is often required, which demands on beds can make difficult at times. Isolation facilities are needed for only a few specific conditions such as cases in which sputum positive pulmonary tuberculosis is suspected¹⁷; and side rooms are preferable for patients with severe diarrhoea¹⁸ or severe disfigurement. Generous support from many charitable organisations have enabled many units to offer comfortable facilities which often contrast sharply with those in the rest of the hospital.¹⁹

The complement of nursing staff should be appropriate for the care of people who may need a large amount of both physical and psychological support. In hospitals looking after many people with HIV infection the ward staffing structure should include a specialist ward manager supporting enough first level primary associate nurses of D and E grade.* Psychiatric problems are common, and there should be easy access to psychiatric facilities.²⁰ Similarly, the incidence of suicide is high,²¹ and disturbed, ill patients require adequate levels of nursing staff.

Endoscopy facilities and necessary radiological back up such as computed tomographic scanning and endoscopic retrograde cholecystopancreatography (ERCP) are needed for both inpatients and outpatients. But these services will be used for both HIV positive and HIV negative people, and it is therefore essential that safe practices are followed in terms of disinfecting endoscopes and that appropriate protective clothing is available for the staff carrying out the procedures.

Patients with HIV will need access to surgical intervention for many reasons. The

* Accepted good practice unsupported by published evidence.

recent introduction of an increasing number of surgical procedures which can be performed laparoscopically has proved particularly useful for these patients as it reduces the time to wound healing and the risk of infection to the surgeon.

Specific conditions

P. CARINII PNEUMONIA

The use of primary and secondary prophylaxis against *P. carinii* pneumonia has considerably reduced mortality from this opportunistic infection, but patients are still affected. In patients taking such prophylaxis diagnosis of the infection may be delayed because it is considered less likely and the clinical pattern of infection is different.

Access to respiratory and cytology services for diagnostic bronchoalveolar lavage is necessary for confirming the diagnosis. Patients with mild cases of pneumonia can be investigated and treated in the outpatient facility. However, other patients, particularly those with HIV infection presenting as *P. carinii* pneumonia, may have a more severe infection, possibly leading to respiratory failure. They need hospital care with intravenous antibiotics, oxygen therapy, and adjunctive treatment with steroids.

Earlier studies suggested that ventilatory support in managing severe pneumonia was not beneficial.²² However, with increased survival of patients with AIDS and use of steroids as adjunctive treatment,²³ it is now appropriate to consider ventilatory support and more recent studies support its use.^{24 25} Intensive care units need to be prepared to admit patients with HIV infection.

TOXOPLASMA INFECTION

Reactivation of toxoplasma infection classically causes intracerebral abscesses and can present with symptoms and signs of space occupying lesions. Computed tomographic scanning facilities are required for diagnosis. The value of facilities for brain biopsy has yet to be established. The differential diagnoses of toxoplasmosis include lymphoma and progressive multifocal leukoencephalopathy. In most units patients with signs and changes on computed tomography compatible with toxoplasma infection are treated empirically with antitoxoplasmosis treatment. It has often been argued that toxoplasmosis is virtually the only treatable condition in this setting and that brain biopsy is redundant even if the patient fails to respond to treatment. However, some cases of cerebral lymphoma do respond to radiotherapy.²⁶

The relapse rate of toxoplasmosis is high and secondary prophylaxis should be advised.

LYMPHOMAS

Lymphomas and other HIV related malignancies are an increasingly frequent complication of HIV infection, possibly related to the generally improved survival of people with such infection, which prolongs their severely immunosuppressed state. For patients with lymphoma access to specialist

oncology services is required. These lymphomas are rapidly fatal without treatment, but the chemotherapeutic regimens are potentially toxic and will inevitably increase immunosuppression. However, current evidence suggests that it is worth while treating these patients,²⁷ although the optimum treatment has not yet been established.

CANDIDIASIS

Candidiasis is the commonest opportunistic infection in patients with HIV infection; the first manifestation of immunosuppression is often oral candidiasis. Topical antifungal regimens are rarely effective for long, and systemic treatment with antifungal agents such as ketoconazole or fluconazole is usually required. Although intermittent treatment may be sufficient initially, long term maintenance treatment is inevitably required, and this produces the problems of drug resistance and the need for treatment with some of the newer, expensive, azole drugs. Continuous treatment, should therefore be avoided for as long as possible.

CYTOMEGALOVIRUS INFECTION

Cytomegalovirus retinitis is another HIV related complication in which close liaison is required, between HIV physicians and ophthalmologists. Some centres now offer combined clinics as early diagnosis and treatment of the condition can save patients' sight. Reactivation is common, and specialist review is required. Treatment is given intravenously, and this is another instance where day care and home care facilities can be an adjunct to outpatient management. Despite best efforts some patients will develop severe visual impairment or blindness, and support from occupational therapists and psychologists should be readily available.

Staff training, safety, and support

Clear guidelines must be established and followed in order to limit the risk of transmission of HIV to staff. Such guidelines are not exclusive to the care of people known to be infected with HIV but will also apply to all patients. Most risks are related to invasive procedures, and it is therefore the duty of the hospital to ensure the availability of sufficient good quality gloves and protective gowns.²⁸ Some hospitals use Vacutainer systems for venepuncture to reduce the risk of needlestick injury. In all clinical settings there should be sufficient good quality disposal boxes for sharps, and these should be regularly removed and replaced. Several practices have been advocated to reduce the risk to surgeons; these include the use of visors, double gloving, blunt tipped needles, and staples for wound closure. As the risk groups for HIV and hepatitis B virus infections are similar all staff should have routine hepatitis B immunisation. When a needlestick injury occurs the incident should be reported, and all hospitals should have a policy document stating clearly the action to be taken in the event of such an

accident. The value of zidovudine prophylaxis in this setting has not been established²⁹ and although it may never be ascertained, procedures for action in the event of needlestick injury or other potentially hazardous event need to be drawn up in every unit.

Looking after patients with HIV can be stressful and demanding. Medical, nursing, and other health professionals may care for a patient for several years, and the final phases of the illness may be difficult for all those closely involved. There is concern about "burn out"³⁰ in staff looking after patients with HIV, and support or counselling services should be available for them.

Education

The role of a hospital in educating the public is often limited but every opportunity to inform about the prevention of HIV infection should be used. Ideally, such information should be available in public areas of the hospital. Patients attending the genitourinary medicine department can be educated about safer sexual practices and patients attending other departments should have the same ready access to HIV counselling and testing as is available in the specialist clinic.

HIV infection or AIDS and sexual health are among the main targets for action. Close liaison will be required between hospitals and health promotion units in order to achieve the targets set by the *Health of the Nation* white paper.³¹ Future doctors and nurses will also require knowledge of clinical management of HIV infection and it is important that this is included in the curriculum of every medical and nursing school.

Conclusions

Good quality care for patients with HIV includes a range of facilities, from support and counselling to knowledge and use of high technology and new clinical interventions. Thus a team of people from different professional backgrounds working closely and well together is required so that patients' needs can be assessed and patients can make choices about the care they receive. This paper describes only some of the aspects of care of people with HIV infection. In the next few years much of this is likely to change.

Keeping informed of new developments is part of a good quality service. Most patients want access to the best and latest treatments. Links with ongoing research programmes allow patients the opportunity to decide whether to participate in current clinical trials. Many patients with HIV are well informed and their care provides a challenge for those concerned.

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