
Clinical Topics

Care for patients with HIV infection and AIDS

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Patients with the acquired immune deficiency syndrome (AIDS) present only a few of the clinical problems that we have to deal with, and it is important to consider all of those with human immunodeficiency virus (HIV) infection as well as those with AIDS. There are 730 patients with AIDS but up to 60 000 people infected with HIV. Many of the people with HIV infection are well, asymptomatic, and unaware that they are infected, but others who have not yet developed AIDS have physical, psychological, social, and occupational problems that require as much care as in the case of patients with AIDS. Therefore we need to be concerned about a large number of people infected with a virus who will be making demands on every part of the health and social services, and the numbers will undoubtedly increase. New infections will occur and the public health education campaign will need to continue. The best we can hope for is a slowing down of the epidemic. None of us should consider that the problem of HIV infection and AIDS is unimportant and that it will go away because of the campaign and the possible magic bullet of a cure or vaccine. We can all hope for these things, but it would be a mistake to be lulled into inertia and complacency. HIV and AIDS represent the greatest public health problem faced by the United Kingdom and possibly the world in this century. All of us in the health service will be concerned with AIDS for the rest of our professional lives. We must start to get our act together now so that we can look back over our working lives with pride and say that we did as much as we could as well as we could.

I discuss here the effect of HIV and AIDS on the hospital service

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and raise some epidemiological and general questions that need to be answered to plan services, and then review different approaches that might be used to provide care in the community.

Effect on the hospital service

Patients with HIV and AIDS remain well for long periods. The median incubation period from infection to the development of AIDS has been estimated to be five years and may be longer, and once AIDS is diagnosed patients may live for several years. After a patient develops AIDS acute illnesses will necessitate admission to hospital. The natural course of AIDS shows that the patient recovers but at each supervening illness is a little weaker. The median survival varies with the manifestation of the disease and is roughly 31 months for patients in the United States with Kaposi's sarcoma and nine months for those with *Pneumocystis carinii* pneumonia. The figures in the United Kingdom are similar, with a median survival of 21.2 months for patients with Kaposi's sarcoma and 12.5 months for those with pneumocystis pneumonia.

Nearly 80% of the patients in the United Kingdom have been looked after in hospitals in the four Thames regions and particularly in St Mary's, St Stephen's, and the Middlesex. We saw our first case at the Middlesex in 1983 and by the end of 1986 had a total of 89 cases. We expect a further 104 new cases in 1987 and 252 in 1988, giving us cumulative totals of 193 and 445 by the end of 1987 and 1988, respectively. Our new 12 bedded ward will be overcrowded by the end of 1987, and by the end of 1988 the estimated average bed occupancy will be 35. If we could reduce the length of stay from the current 16.5 days to 11, which is the average in San Francisco, the estimated bed occupancy could be reduced from 15 to 10 in 1987 and from 35 to 22 in 1988. If for no other reason than a shortage of beds, we would wish to cut our patients' length of stay: undoubtedly, all of us and our patients would prefer that care took place out of hospital if possible and for as long as possible.

The cost of care for patients varies. Hardy *et al* reviewed the costs of 10 000 cases of AIDS in the United States and showed a lifetime

cost per case of \$140 000.¹ Other studies have shown lower figures. For example, Scitovsky *et al* found the lifetime cost for patients who died during 1984 in San Francisco General Hospital to be \$27 571; the mean length of stay was 11.7 days per admission, with patients spending roughly 35 days in hospital during their lifetime.² We estimated the lifetime costs of inpatient and outpatient care at the Middlesex Hospital for our first 30 patients to be a total of £6730.³ Both the San Francisco study and ours show that basing calculations on those who die tends disproportionately to select those with short survival times. It cannot be assumed, however, that costs of care rise proportionately to survival times. Requirements for care vary according to the stage of the illness and diagnostic category. Costs for inpatient care for those with Kaposi's sarcoma are lower over a defined time period, but in turn these patients have longer survival times. Eighty per cent of the hospital costs in most of these studies relate to charges for inpatient care and rooms, so that reducing the length of stay by developing community care or outpatient care could reduce the cost. I use the word "could" advisedly and discuss this below.

Epidemiological and general questions

Several epidemiological and general questions need to be acknowledged and discussed if we are going to plan services.

SIZE OF PROBLEM IN FUTURE

The first question is: What is the size of the problem going to be in the future? Accurate models and projections are required to plan services and predict the potential costs. We have looked at this from the narrow perspective of a hospital based service and projected future bed use. We have attempted to estimate the future bed use by patients with AIDS by using the prevalent rather than incident cases of AIDS.⁴ Assuming that a patient with AIDS spends about one day in hospital a week from the time of the diagnosis and that a total of 2338 patients will be alive by the end of 1988,⁵ we estimate an average national need of 334 beds by then. Most of these beds would be in inner London, where the number of beds is currently being reduced, and it may be necessary to alter or slow down this policy to deal with the workload and avoid denying other patients treatment in a reasonable time. The annual cost of these beds for patients with AIDS in a London National Health Service teaching hospital would be roughly £15.5m. Such a calculation is limited because it does not cost community care and the changes in hospital costs that would ensue if patients stayed in hospital for shorter periods and is hostage to the uncertainties of further changes in the scale of the epidemic. It is vital that we do not plan in a vacuum. We need to develop good epidemiological and mathematical models that will allow us to predict what will occur for the rest of this century. We need to take into account changes that may occur in lifestyle and risk taking behaviour and the possibilities of an increase of cases in the heterosexual and drug abusing population and build into such models how different strategies might alter the size of the epidemic. If we do not grapple with this first question we will not be able to plan services and models of care.

NATURAL COURSE OF HIV INFECTION

The second question is related to the first and concerns the natural course of the progression of HIV infection and the range of cases. We believe that up to 35% of people who are infected with HIV will develop AIDS. This has changed since the early days and will continue to change. The worst outlook would be that all those who are infected developed AIDS, which would have a profound impact on health services. The range of infection with HIV is wide, from well, asymptomatic people who make few demands on services to those with chronic infection shown by persistent generalised lymphadenopathy, chronic skin and other infections, and the AIDS related complex and through to full blown AIDS, all of whom

make heavier demands. We need an accurate assessment of the proportions in each group at any one point and how quickly they move from one group to another, if they do. We do not have this in the United Kingdom, and the data from America are sketchy. The San Francisco cohort of homosexual men, however, indicates that there were 9.4 symptomatic seropositive patients for every case of AIDS as well as many more undiagnosed symptomatic seropositive patients, more of whom may be diagnosed as HIV testing becomes more widely available.⁶ We are quantifying this range of infection in the Bloomsbury area of London, but it must be done widely, and such information is needed for planning services. There are many developments that might affect the size of the problem and also alter the natural course—for example, the introduction of zidovudine (Retrovir) and other drugs. Will these increase or decrease the cost of care? (The estimated annual cost of maintenance treatment for suitable patients is £6600 a person.) Apart from the large drug bill, patients may live longer and make more demands on services; on the other hand, it may be possible to care for them for longer periods out of hospital.

ARE AIDS AND HIV INFECTION SPECIAL?

The third question is whether HIV and AIDS are special and different from other medical problems. It might be argued that apart from the considerable anxiety and hysteria surrounding the infection, which can be dealt with, there is no requirement for special facilities. The NHS and local authority and community services should be able to cope with patients whatever their diagnosis. Are we not good at making these different services work together regardless of AIDS? We need to ask whether a discussion like this and an injection of extra resources into AIDS should be allowed without also examining what is wrong with delivery of care, particularly in the community, for other client groups. Do current management arrangements allow efficient and optimal care to be given to patients by general practitioners and local authority and community services, or should a better process be adopted?

In relation to the question of the special nature of AIDS it is important to be aware of the possible backlash. There are groups in the health service who believe that their problems have been ignored and that AIDS is attracting too much money and publicity. This backlash could be attenuated to some extent if we examined how to make services for community and terminal care work more efficiently so that all client groups, regardless of condition, would benefit. If such an examination came up with the right answers there would be no need for us to think about AIDS as a separate issue as the services would work as they would do for all other patients.

SAVING MONEY?

The fourth question that we and the Secretary of State for Health need to examine is whether we are trying to save money by cutting down expensive hospital care or whether we are going to place any savings into community services. There is a danger in assuming that we can recreate a San Francisco model in the United Kingdom. The Shanti Project, which provides community support and housing, and the Hospice Program, which provides community care, had a total expenditure of \$1 688 000 in 1984-5.⁷ Local government provides substantial support to these, but private donations are the second largest source of funding. In addition, these organisations rely heavily on donated labour. The economic value of donated labour to the Shanti Project and Hospice Program was \$830 000 in 1984-5. In the United States, which has no health service, there are strong incentives to get out of hospital quickly, and if it was not for the voluntary sector the patient would receive little or no care. This is why the Shanti Project evolved. It cannot be assumed, however, that community services will be largely underwritten by voluntary donations and donated labour in the United Kingdom. Will the savings from a reduction in the number of bed days bring with it a shift of resources from hospital to the community? The precedent of shifting people with mental handicap and mental health problems

into the community without a shift in resources does not augur well for AIDS. Those who are concerned with care will need to be vigilant and sensitive in seeing that appropriate funding is made available for such community services.

Approaches to care in the community

Patients with HIV infection and AIDS spend most of their time out of hospital in the community. Admission to hospital is required only when an acute clinical illness supervenes. Unfortunately, it is occasionally difficult to discharge patients home for convalescence as general practitioners and domiciliary and social services sometimes cannot look after them. As the number of cases increases it will be essential for the community services to be able and willing to cope. The problems encountered so far are probably due to anxiety and lack of funding and training. I can see no virtue in hectoring those who work in primary and community care for not looking after patients or not being as willing to do so as some of us would wish. We will carry all the professions with us only if we try to identify with their concerns and anxieties. This is a new disease, and people are frightened. Those of us who are more sure of our ground should not waste our breath on alienating others but use it to educate them and answer their fears. Community services will work only if primed by an extensive educational programme towards those whom we expect to do the work.

What we are all working towards is keeping patients out of hospital. What sort of models can we develop to do this for most of the time? It is helpful to look at care in relation to disease progression as requirements will change with this (table). Take, for example, a person who is positive for HIV antibody but well. This person should be seen regularly, at the very least once every three to six months, to see that he or she is not having any medical, social, or psychological problems. This care can be provided equally well in general practice or in an outpatient department of genitourinary medicine or another specialty. Once the patient develops symptoms due, for example, to persistent generalised lymphadenopathy or the AIDS related complex, he or she can still be looked after in the same way. Short term admission to hospital may occasionally be required for specialised procedures and investigations.

The transition from antibody positivity to AIDS may be heralded by an acute opportunistic infection or tumour. This first episode warrants admission to hospital as the diagnosis of AIDS depends on an accurate clinical and laboratory diagnosis. The diagnosis of Kaposi's sarcoma, however, can be made in an outpatient department. Once the patient is fit enough to convalesce this can be done under the supervision of the general practitioner or a day care centre, which could be in the community or in a hospital. If treatment, even intravenous treatment, needs to continue this can be done in the home by means of a Hickman line. Failing this the patient could be seen in a day care centre in a hospital.

If a subsequent acute infection occurs this can be managed in different ways, but, unlike with the first episode, it is not necessary for the patient to be in hospital—for example, the general practi-

tioner and practice team can manage many of the problems, or the patient can be managed by the hospital team in a day care centre, or a hospital based home care team can go into the patient's home and facilitate investigation and treatment by the general practitioner.

Some patients are ill and unable to live at home but are not ill enough to be in hospital or a hospice for terminal care. I suggest that a network of hostels should be provided to care for such patients. These will need to be staffed by caring people who have access to medical help if required. Local authorities should be encouraged and funded to provide such facilities.

Finally, facilities for terminal care are required. It is well known that it is difficult to find places for patients with AIDS in existing hospices. There is a national shortage of such places for patients with all kinds of illnesses. I do not think that it is necessary to set up terminal care homes specifically for patients with AIDS. Planning future requirements for terminal care should not be done under the assumption that all patients with AIDS die in the same way. Some of our patients die by slowly going downhill and would be suitable for such terminal care facilities, but others die in hospital as a result of acute or complicated infections. We have looked at the first 33 patients with AIDS whom we treated at the Middlesex from diagnosis until they died. These 33 had a total of 99 admissions and occupied in total 1630 bed days at an average length of stay per admission of 16.5 days. Only seven of the patients died at home. Of the 26 who died under our care in hospital, 12 did so while undergoing active treatment and the remaining 14 did so from general debility. A total of 448 bed days were used essentially for palliative care—that is, 27% of all the bed days from diagnosis to death. Thus an appreciable proportion of our acute beds are used for terminal care, but even though it might be argued that at least some of those who die with chronic disease could be managed in the community, some of those who die during an active episode will die in hospital.

An examination of hospice facilities in the United Kingdom is required so that more places for patients with all kinds of illnesses can be found. Then, it is hoped, patients with AIDS will also be looked after with sympathy and will be able to retain their dignity throughout their terminal illness without feeling shunned by society. A complementary approach is to develop "terminal home care teams" in areas that treat many patients with AIDS to enable those who wish it to die with dignity at home. This works successfully in Bloomsbury for patients with terminal malignancy, and we hope to develop a home care team or AIDS support team based in hospital that would intervene at different points in the course of the disease, not just at the end. This team would have a broad brief of providing the link between community, hospital, and hospice care. It would function as an adviser or facilitator, and the final clinical responsibility would lie with the general practitioner or hospital physician. It would provide services that would include preadmission assessment in the home, organising discharge from hospital to home, providing a graded level of services to patients living outside Bloomsbury, and offering a 24 hour on call service for patients and families and advice about symptoms for general practitioners and district nurses. Teams might also provide diag-

Care for the patient with HIV/AIDS

Progress of infection	Facility						
	Community			Hospital			
	General practice/ district nurses, etc	Hostels	Hospice	Day care centre	Outpatient clinic	Inpatient	Home care team
HIV:							
Asymptomatic/well	+					+	
Symptomatic (persistent generalised lymphadenopathy, AIDS related complex, etc)	+						(+)
AIDS:							
Acute infection (first) or tumour							
Convalescence	+			+	+		(+)
Subsequent acute infections/other problems	+			+			+
Not suitable for home or terminal care		+					
Terminal care	+		+			+/-	+

(+) Indicates an option but not the primary one.

nostic services in the community when necessary. Thus they could start investigations in the home, take specimens, and advise on treatment if required by the general practitioner, the objective being to avoid admission to hospital. The team would "hand hold" but not take over the practitioner's role and care. The relationship between the general practitioner and hospital team will need to be nurtured and be built on trust. The team could do joint visits with the general practitioner and act as a catalyst as well as facilitator. Finally, the team would help to educate and train other support teams and community workers and provide liaison with existing voluntary organisations and social services locally. The team would have two nurses who had had hospice training, a social worker to act as community liaison officer, a secretary at the hospital, and a full time doctor. Finally, we would have a research worker with the team who could evaluate the project.

Conclusions

There are many ways to look after patients with varying degrees of HIV infection and AIDS. AIDS will be with us for a long time. This should allow us to develop a series of models that can be evaluated, such as normal care as carried out at present; more aggressive home care facilitated by doctors and nurses who would troubleshoot and be prepared to institute more aggressive care so that patients are treated early; and day care either in the community or in the hospital. Different models of terminal care might also be assessed. Such evaluation would require different parameters that incorporated clinical outcome and an examination of the patients' attitudes and those of their families, general practitioners, domiciliary nurses, and home help staff. Finally, the social and

economic costs of different kinds of care need to be studied to help us realise the most efficacious, acceptable, and cheapest form of care.

The community projects in San Francisco are impressive. The NHS and local authorities in the United Kingdom offer the same infrastructure of community services as now exist in San Francisco—they just need to be made to work. This is a challenge for all of us. We will all undoubtedly respond to that challenge and will be able to look back and know that we tried and showed the same commitment and dedication to this problem as we do to all others that we face each day. None of us should adopt a rigid and uncaring stance towards patients with HIV infection and AIDS that would mean looking back at our professional lives with a feeling of shame rather than one of endeavour and achievement.

References

- 1 Hardy AM, Rauch K, Echenberg D, Morgan WM, Curran JW. The economic impact of the first 10 000 cases of acquired immunodeficiency syndrome in the United States. *JAMA* 1986;255:209-11.
- 2 Scitovsky AA, Cline M, Lee PR. Medical care costs of patients with AIDS in San Francisco. *JAMA* 1986;256:3103-6.
- 3 Johnson AM, Adler MW, Crown JM. The acquired immune deficiency syndrome and epidemic of infection with human immunodeficiency virus: costs of care and prevention in an inner London district. *Br Med J* 1986;293:489-92.
- 4 Johnson AM. Economic aspects of care and prevention of HIV infection and AIDS. *Proceedings of European Commission workshop on statistical analysis and mathematical modelling of AIDS*. Oxford: Oxford University Press (in press).
- 5 Tillett HE, McEvoy M. Reassessment of predicted numbers of AIDS cases in the UK. *Lancet* 1986;ii:1104.
- 6 Jaffe HW, Darrow WM, Echenberg DF, et al. The acquired immunodeficiency syndrome in a cohort of homosexual men. *Ann Intern Med* 1985;103:210-4.
- 7 Arno PS. The nonprofit sector's response to the AIDS epidemic: community based services in San Francisco. *Am J Public Health* 1986;76:1325-30.

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Lesson of the Week

Extrapyramidal disturbances caused by inappropriate prescribing

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Despite the long known extrapyramidal side effects of even the weak dopamine receptor blocking agents^{1,2} such drugs are frequently prescribed inappropriately.³ Acute dystonic reactions, drug induced parkinsonism, and akathisia usually resolve quickly when the offending drug is withdrawn. The tardive dyskinesias, however, including orofacial dyskinesia, may take years to resolve and some may be permanent.⁴ There is no effective symptomatic treatment for these. Medicolegal action in which the original reason for the prescription is questioned is remarkably rare in Britain. We wish to emphasise the distress caused to patients by frequent abuse of this class of drug.

The long term use of phenothiazines, butyrophenones, and metoclopramide for dizziness, nausea, and night sedation is inappropriate and must be avoided to prevent extrapyramidal reactions. Compound preparations that contain a phenothiazine have little or no place in present day treatment

Case Reports

Case 1—An elderly woman had seen her family doctor to complain of non-vertiginous dizziness. In retrospect it was clear that this was a problem of anxiety and agoraphobia. Prochlorperazine 5 mg three times a day had been prescribed and she had been on the medication for 18 months when she developed a tremor, her gait slowed, and she became clumsy with her hands. On examination a moderately severe parkinsonian syndrome was evident. The prochlorperazine was stopped and when seen four months later she had

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