

Routine care of people with HIV infection and AIDS: should interested general practitioners take the lead?

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SUMMARY

People with HIV and AIDS in the developed world are living longer and healthier lives following the introduction of highly active antiretroviral therapy. The medical management of stable HIV infection could eventually fit into the more normal pattern of chronic disease management in the United Kingdom (UK).

Routine monitoring of many chronic conditions is generally regarded as primary care business in partnership with secondary care. The latter service should be reserved for what it does best: periodic review, in-depth assessment, major changes in medication, management of complex or refractory cases, and inpatient care.

We look at some of the issues and the arguments for and against any change from the current position in the UK, where almost all HIV infection is managed medically by specialist clinics in secondary and tertiary care.

Keywords: AIDS; HIV; chronic disease management.

Introduction

WORLDWIDE the prevalence of HIV infection continues to increase inexorably. Since the mid-1990s, the United Kingdom (UK) has experienced a significant decrease in the numbers of people reaching an AIDS-defining disease. As a result, the number of people with diagnosed HIV infection requiring care is rising¹ though there is great geographical variation throughout the UK (Table 1).

Genitourinary medicine (GUM), with its primary care-oriented open-access reputation for non-discriminatory competence in sexual matters, confidentiality, and specialist staffing, was the main resource at the start of the HIV epidemic. Certain client groups; for example, gay men, perceived general practitioners (GPs) to be prejudiced and ignorant of their lifestyles as well as their condition — and many still do.^{2,3,21,22} However, GUM was never designed to encompass the whole range of primary care services. In high prevalence areas (London, Edinburgh, and some other large cities) multidisciplinary teams came together to offer a wide range of primary and secondary care services, to some extent mirroring those already provided by GPs.⁴

Thus, up to now GPs and their staff have been unable to acquire sufficient relevant experience because of structural and behavioural factors which have been described elsewhere.⁵

This mutual withdrawal of patient and GP from each other will, if sustained, soon have a more serious consequence; the inability and, thus, unwillingness of GPs and primary care teams to take on the general surveillance, identification, and routine monitoring of people with HIV infection. Should this happen to any greater extent than allied tasks, such as prevention,⁶ including antenatal testing⁷ and sexual health promotion,⁸ may well fall by the wayside. This latter need has been highlighted recently with the finding that high-risk behaviour among gay men in London is increasing, perhaps because the immediate and overwhelming fear of AIDS-related deaths have (thankfully) been removed.^{9,10}

Furthermore, current treatments with highly active anti-retroviral therapy are reducing the numbers of people progressing to AIDS or death, raising the possibility of some patients remaining more or less well for many years.¹¹ While the long-term effects of these treatments have yet to be elucidated, it is time to view these significant interventions with cautious optimism. One result of this success is the opportunity to radically alter how patients affected by HIV are cared for, both in hospitals and in the community.

Thus, if many such patients achieve this stability of their condition, how necessary is it to continue to attend a specialist secondary care provider for routine monitoring and prescribing of therapy? Traditionally this is precisely where

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Submitted: 25 January 2000; Editor's response: 11 May 2000; final acceptance: 5 January 2001.

© *British Journal of General Practice*, 2001, 51, 399-403.

GPs and primary health care teams (PHCTs) excel; the routine monitoring and treatment of patients with a chronic and treatable condition and sharing care with hospitals for more complex cases or modifying aspects of a particular patient's condition.^{12,13} There are obvious analogues with other chronic conditions; for example, diabetes, arthritis or even antenatal care.¹⁴

The pattern of HIV and AIDS in the UK

Overall, the number of people in the UK with diagnosed HIV infection requiring care is rising.^{1,6} However, the demographic pattern of HIV infection is changing, with a relative increase in the proportion of new infections through heterosexual transmission. In 1999, transmission via this route had overtaken that through homosexual intercourse, though this was mainly confined to people acquiring the infection abroad and usually from high-risk areas.¹ However, approximately a thousand new infections per year in gay men still occur — with up to two-thirds of these occurring in London.

In addition, new infections with HIV continue to be added to the population and, as a consequence, the number of people living with HIV infection rose by 30% between 1995 and 1998.¹ Members of known risk groups continue to seroconvert despite multiple prevention campaigns. Estimates from anonymous unlinked HIV testing suggest that between 30% and 50% of all individuals remain clinically undiagnosed; that is their HIV infection is known neither to them nor to their medical practitioners.¹ Lastly, among injecting drug users, there is evidence that sharing equipment is on the increase — there was a reported doubling of the practice in the years 1997 to 1998, with obvious implications for HIV infection and other blood-borne infections, including hepatitis B and C.

To summarise, despite the low prevalence of HIV in the UK, HIV transmission still continues and, importantly, those individuals with HIV are too often missing out on proven interventions simply because they are not being identified.

The arguments for care in the community

It is widely accepted that primary care forms the core of the National Health Service in the UK. Family doctors traditionally provide general medical services to patients who are registered with a named practitioner. These services are accessible, local, flexible, and available, as well as being 'free' at the point of delivery.¹³

In inner cities especially, increasing numbers of heterosexual men and women from Africa or Asia, asylum seekers, and women detected through antenatal screening, may continue to use generic services such as their GP and primary health care team, as some of the evidence testifies.¹⁵⁻¹⁷

The GUM service is not always familiar to these various groups and, additionally, the service may be more stigmatising than using ordinary, more frontline community services.¹⁸

The potential transfer of chronic disease management into the community is in line with the continuing pressure for a 'primary care-led NHS' and the emergence of primary care groups (PCGs) as responsible for commissioning local services.^{6,19}

Of course, general practice as is currently practised does

not have to provide these services. Another model worth exploring is the separate contracting for such services, perhaps by 'interested GPs'; personal medical service pilots may be an example of this.²⁰ These units, invariably staffed by salaried medical and nursing personnel, have emerged in a variety of settings and one of their priorities is to ensure good access for people from vulnerable groups, including individuals with HIV infection and AIDS.

The arguments against care in the community

A major shift of HIV/AIDS care towards the community has many challenges. It is easy to overlook the fact that the clinical knowledge base in HIV and AIDS has occurred at a pace never before experienced and much of this comes down to a systematic approach to clinical scientific research being conducted on, and with, patients in large hospital settings. Thus, for some units, if there is a large-scale transfer of patients to the community, this would inevitably impact on loss of centralised 'data' — with implications for research and funding.

Another factor is that diffusing routine patient care into an inexperienced primary care sector may threaten existing levels of expertise among secondary care specialists themselves. However, it may have a contrasting benefit of freeing up secondary care to spend more time dealing with the increasingly complex decisions about initiation and alteration of evolving therapeutics and management of advanced disease.

Just how many GPs are keen, motivated, and competent to do this type of work?

While earlier studies pointed to GPs' relative lack of involvement in the care of patients with HIV infection^{21,22} — highlighting several underlying reasons for this — there has been some undoubted improvement lately, both in high and low prevalence areas.²³ Furthermore, while there are some practitioners already undertaking this work it will be a challenge to encourage others, especially in the inner cities where workloads are already high. Whether the new PCGs — composed of GPs, nurses, and lay members — can respond to these specific and local issues is unknown at present.¹⁹

It must be stated that some patients will not want their GP involved in their HIV/AIDS care, despite attempts to make the service mutually beneficial and accessible from all sides.²⁴ From a patient perspective, it is vital that 'confidentiality' and 'non-discrimination' are not simply lip-service phrases. One of three major barriers highlighted by parents of children with HIV infection accessing primary care services in the London area has been their concern regarding confidentiality.²⁵

Lastly, and unfortunately, there is still an ongoing debate regarding the problem of personal medical reports supplied by GPs to insurance and lending companies.²⁶ Although these debates have involved the General Medical Council, the British Medical Association, various patient groups, and the insurance industry, very few realise how much of a barrier this is to patients. People affected by HIV also want to know that all the staff, from receptionist through to clinicians, have some understanding of issues related to HIV and AIDS.²⁶

How could GP care work?

Current investigations and treatments

If GPs and PHCTs are to consider involvement with patients' disease management, they will need to become more conversant with the indicators of immune damage and viral replication currently measured in hospital clinics.

Special interest GPs need experience of the natural history of the condition, including its many complications, as well as opportunistic infections and tumours. In addition, common problem-solving skills are required for interpretation of the commonly-used investigations and the medications in common use.²⁷ This type of education needs to commence with the basic clinical method of interviewing and examining a patient, as in any other branch of medicine.

Among the investigations, the CD4 lymphocyte count and the trend in its percentage of the total lymphocyte count will often be the most useful. This is because one of the key questions to ask about a patient with an acute or sub-acute problem is 'to what extent is their immune system functioning?' The current thinking is that the CD4 count, and its proportion of the total lymphocyte count, provide a reasonable estimate of this. The viral load is a measure of viral replication; the higher the load, the faster will be the patient's disease progression. For patients already on therapy, a rising viral load is an indicator of developing resistance and of the need to consider a change in the combination of drugs.²⁷

Thus, a well patient who is already stable on a particular combination, with a stable or rising CD4 count and percentage, together with undetectable viral load and absence of clinical or laboratory markers of adverse drug effect, could remain under three-monthly supervision and treatment in well-trained and experienced primary care.

Development of signal symptoms or signs, or deterioration in the patient's laboratory or clinical markers suggesting the need for changes to medication, would trigger early re-referral to secondary care, or at a minimum, an urgent request for a specialist telephone advice. Could this model work?

One or two of the partners in a progressive, modern, interested group practice may have more training in, and empathy for, patients with HIV infection. A similar model of care, at varying levels of GP involvement, is being actively pursued in some European countries where some family physicians currently prescribe combination therapies.²⁸

In a different context — for example, diabetes care — it is often the case that, in a middle-sized practice, one or two GPs take an active interest in the care of these patients. This involves the usual monitoring procedures, follow-up, treatment of complications, and referral if and when necessary.

Some patients with HIV infection will continue to suffer with HIV-related illnesses as their immune function deteriorates and some will die through lack of adherence to medication (allowing resistance to develop), poor drug bio-availability, or through lack of sustained therapeutic activity against their particular strains of HIV.

Cost implications

The current costs of a year's prescription of triple combina-

tion therapy for HIV lies in the order of £12 000.²⁹ However, there is some debate about overall costs, since combination therapy has so far proved so successful that morbidity and mortality has decreased significantly.³⁰

If primary care prescribing for HIV were to become more widely established then transfer of funds to the community will necessarily follow and new arrangements would need to reflect this. Initially, the extra cost could be built into GP prescribing budgets in the same way as it is for expensive medications for other chronic conditions (e.g. chronic renal failure or infertility). The cost implications might include investigation, monitoring, and a likely increase in referral to the multidisciplinary services available within primary care itself.^{27,31} At present however, each of these disciplines is usually represented in the secondary care teams and, in a similar way to the lack of skills among GPs, their primary care colleagues may not be sufficiently skilled to take on this specialised work. Perhaps the shared-care model could eventually operate successfully in these areas too? The increase in GP and PHCT workload, however, measured in sheer numbers of patients attending for monitoring, is likely to be low even in willing practices with willing patients. However, current workload in primary care is already excessive, particularly in the very areas where HIV is most prevalent, and there may well be pressure for this additional activity to be paid for separately, as a 'non-core' service. There is now a precedent for this, in that methadone prescribing for people can now be remunerated separately as an item-for-service.^{32, 33} In the original study this extra remuneration was dependent on specific educational requirements which the practitioners had to fulfil prior to payment.

In a study that looked at the effects of a rigorous shared-care system involving primary and secondary care in west London, there was a 50% reduction in hospital workload but a subsequent rise in the work of the GP and associated health care team.³⁴

Extra remuneration for primary care development was announced three years ago to encourage the creation of Local Development Schemes. These are intended 'to improve the development and response of General Medical Services (GMS) by giving local GPs financial incentives beyond those set out in the Statement of Fees and Allowances: 'to help to address health inequalities and, particularly in areas of deprivation, to enhance the development of GMS above that currently provided'.³² While there is a danger that this would act as an incentive for GPs to take on work without adequate preparation and support, we think that this would be unlikely. It is far more likely that only interested GPs would undertake to see such patients and that a system of monitoring involving the use of informal guidelines could be beneficial for the participating GPs.

At a conference organised by the Royal College of General Practitioners and the Royal College of Physicians several years ago³⁵ the consensus was that an increase in both primary and secondary care workload would be an inevitable consequence of greater community involvement, especially in the short term. It is natural to assume that patients would want, and need, to have reviews in both settings. The frequency of both routine and urgent attendance at the hospital might well be expected to reduce gradually

over time as patient and primary care services familiarised themselves with each other.

Communication

Clear, fast, and confidential pathways for information sharing would need to be established through advanced, dedicated telephone lines with published hours of availability, e-mail or directly received faxes using encoded patient identities.³⁶

Where members of the primary care team are involved, such as community pharmacists, data monitoring will need to be an important facet of this new system. Crucially, confidentiality and non-discrimination policies, publicised to patients and regularly reviewed, have been shown to increase disclosure of HIV status to doctors in primary care.²⁶

Likely role of practice nurses and community pharmacy in routine HIV monitoring

Practice nurses and nurse practitioners, willing and properly trained, may well be able to play their part in the regular, long-term, and audited monitoring of such patients — more allied to a model seen in diabetes care.^{37,38} It is noteworthy, however, that proper evaluation of 'liaison nurses', characteristic of HIV/AIDS care in the larger cities, is still lacking.³⁹ Another use of the nurse practitioner would be for triage — some patients may prefer to confide their status to the practice nurse. Working alongside an interested and trained GP (called a 'specialist generalist') would be a prerequisite^{40,41} and the nurses would also need to receive regular education, support, and supervision by an appropriate clinician — one who straddles the primary care–secondary care interface.^{42,43} Specialised generalists appear in the Department of Health document outlining good practice for people mis-using or dependent on drugs.⁴⁴

The medications often used by patients are multiple and varied, with complex adverse reaction and interaction profiles.^{45,46} Some patients are often well-informed about their medication including the need for unrelenting adherence, potential interactions, and follow-up procedures. HIV-specialist pharmacists are being encouraged to play a more proactive role in the management of patients' conditions and symptoms.⁴⁷ However, infrequent dispensing, and inadequate conditions of privacy in most community pharmacists, could remain considerable obstacles to safe, confidential, and proactive dispensing in the community. One possible model could be the 'specialist' community pharmacist, such as already exists for particular conditions in a given locality; for example, the dispensing of oxygen or palliative care medications. The recent advent of specialist pharmacists who dispense the 'morning after pill' may be a prototype that is worth replicating, though audit and satisfaction indicators are needed. Alternatively, care could be shared by telephone between community and specialist hospital pharmacists, again a parallel to that proposed between GPs and secondary care physicians. Yet again, 'in-house' pharmacists are in development, leading to closer professional working between GP and pharmacist.⁴⁸

Conclusion

We began by seriously questioning whether all individuals or families with HIV require hospital-based care. The advantages of hospital care have been discussed alongside the disadvantages. Implicit in this is that care of patients with HIV infection could be more focused on the patient's home — in other words it could be primary care-based. We then explained how care in the community could work; it needs a network of willing and able GPs alongside first class hospital support — with access to up-to-date information — the like of which has only really been seen in time-limited research studies.³⁴

As may be imagined there are many potential pitfalls with obvious implications for continued research in HIV and AIDS, with the result that it may be tempting for all involved to want to continue the status quo. Nevertheless, with an increasingly primary care-led NHS, and the gradual reduction of social stigma⁴⁹ in HIV, a co-ordinated, purposive, respectful, and complementary alternative to total hospital care could emerge. This has the potential to combine the best of both primary and secondary care to the advantage of all in what could be the most appropriate approach to HIV care in the western world.

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