We thank Mrs Eileen Cartoon for her collaboration in preparing the final version of the manuscript.

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(Accepted 12 April 1995)

Strategies for dealing with problems associated with use of services for HIV infection and AIDS out of region: views of providers and users

Adrian Coyle, Sheena McGrellis

Abstract

Objectives—To identify reasons why people with HIV infection and AIDS living within the former South West Thames Regional Health Authority use HIV and AIDS services outside the region, and to identify strategies for dealing with the problems associated with such use.

Design—Qualitative study consisting of interviews with individual subjects and focus groups.

Setting—Providers of services for patients with HIV infection and AIDS in South West Thames, central London, and Brighton. Users of such services resident in South West Thames.

Subjects—Thirty four South West Thames residents with HIV infection and AIDS who use or used services outside the former region; and 70 providers of services within and beyond South West Thames.

Results—Principal reasons for use of services out of the region were accessibility (15) and negative appraisals of local services (14). Three main strategies for dealing with the problems of such use were suggested by providers. These entailed introducing users of services outside the region to services in their locality (16); sharing the responsibility for care between providers in specialist centres and in the person's locality (10); and involving the person's general practitioner in their care (12). These strategies were deemed acceptable by 29, 30, and 20 service users respectively.

Conclusion—The reasons underlying use of services for patients with HIV infection and AIDS

outside the region offer suggestions for developing services in areas with a high incidence of such use. The suggestions advanced by service providers offer an acceptable framework for dealing with the problems.

Introduction

About two thirds of people with AIDS who live in the area covered by the former South West Thames Regional Health Authority were first reported to the Communicable Disease Surveillance Centre by clinicians outside the region.¹ It seems that people with HIV infection and AIDS resident in this area tend to travel to "centres of excellence" for HIV and AIDS care (chiefly in central London) for services. This leads to certain problems. As the patient's condition deteriorates he or she may no longer be able to travel and may seek treatment from services in their area of residence.² The transition to using local services may, however, prove difficult for a person with AIDS who may have become accustomed to receiving coordinated, specialist services at centres of excellence outside the region and who may perceive local services as inferior. Furthermore, in delivering services to patients who have transferred from other centres late in the course of their illness, local providers of services may be treating patients who are already very ill and with whom they have not had the opportunity of establishing a therapeutic relationship over time.

We studied the reasons for use of HIV and AIDS services outside the region among residents with HIV

Department of Nursing and Midwifery, University of Surrey, Guildford, Surrey GU2 5XH
Adrian Coyle, lecturer in psychology
Sheena McGrellis, research officer

Correspondence to:
Dr Coyle.

BMJ 1995;310:1636-8

infection and AIDS in South West Thames (outside the region was defined in terms of the regional boundaries before the 1994 reorganisation) and explored what practical steps might be taken to facilitate their transition to using services in their locality.

Subjects and methods

We recruited 34 people with HIV infection and AIDS who lived in the area covered by the former South West Thames region and who used or had used HIV and AIDS services outside this area. Methods of recruitment entailed advertising in testing and treatment centres across and beyond South West Thames; advertising in the gay press; and liaising with voluntary organisations. Thirty one men and three women were recruited with a mean (SD) age of 34.4 (7.7) years. Twenty nine were white, four black, and one Asian. Most (26) had contracted HIV through unprotected homosexual intercourse. Semistructured interviews were conducted with service users during which they were asked to identify why they had chosen to use services outside the region. They were then invited to evaluate various suggestions for overcoming problems associated with such use.

Fifty two providers of health services for patients with HIV infection and AIDS were interviewed, 34 from centres within South West Thames and 18 from central London and Brighton. A further 18 providers of services from South West Thames took part in three interviews with focus groups. Table I shows the occupational groups of the providers. As there are

TABLE I—Occupational groups of providers of services to patients with HIV infection or AIDS

Occupational group	No of providers
Consultants in genitourinary medicine	15
Health advisers	15
HIV/AIDS community nurse specialists/liaison nurses	9
HIV/AIDS voluntary organisation representatives	8
District HIV prevention coordinators and other managerial district HIV/AIDS officers	7
Staff nurses	7
Nursing sisters/charge nurses	6
HIV/AIDS local authority representatives	3

difficulties in quantifying opinions expressed by individual people within focus groups,³ each interview was regarded as one respondent unit, giving a total of 55 providers. These participants were asked to suggest strategies for overcoming or preventing the problems associated with use of HIV and AIDS services outside the region.

Interviews were mostly audiotaped and transcribed. Data were subjected to thematic analysis of content. Procedures for maximising the reliability of qualitative research were implemented.⁴

Results

Table II gives the reasons for use of HIV and AIDS services outside the region cited by more than 10% of users.

TABLE II—Reasons for using HIV/AIDS services outside the region cited by more than 10% of service users

Reason	No of users
Accessible from workplace	15
Negative appraisals of local services	14
Skill of staff	10
Recommended by peers/partners	10
Previously attended there for genitourinary medicine services	8
Recommended by a doctor	6
Concerns about confidentiality within local services	4

When we asked service providers to suggest strategies for dealing with problems associated with such use, 33 spoke of the need to establish links between patients with HIV infection or AIDS or the centre outside the region where they were being treated and key providers of services for patients with HIV infection and AIDS in their locality. Three main linkage options were outlined. Sixteen providers thought that staff at centres outside the region should introduce local services to patients at an early stage and discuss with them the advantages and disadvantages of transferring their care. Patients could then make an informed decision about their arrangements.

While the interviews with service providers were in progress, provisional findings were presented to service users, who were asked to comment on their acceptability. It was suggested to users that staff in centres outside the region could arrange for them to visit their local clinic or centre. The patient could talk to local staff about what services were available and about whether care should be transferred there. This suggestion was considered acceptable by 29 users and unacceptable by five, chiefly because of concerns about the quality of local services and the difficulty of establishing trusting relationships with a new set of service providers.

The second linkage option, advocated by 10 providers, entailed centres outside the region and providers of local services sharing the care of people with HIV infection and AIDS who choose to use services outside the region. The feature common to all the proposals of shared care was that patients should attend the centre outside the region for treatment for serious complaints or for drug trials, or both, and should receive routine care from providers in their locality. This suggestion proved acceptable to 30 users—sometimes with certain provisos—and unacceptable to four. Reservations centred on the quality of local services, the complexity of arrangements for shared care, and a perceived lack of skill in care among local providers, especially general practitioners.

The third strategy, cited by 12 providers, advocated involving general practitioners. Two suggested that general practitioners may need support in this. It was suggested to service users that they could transfer responsibility for their care to their general practitioners, who would be supported by staff in the centre outside the region that they had been attending. Twenty found this suggestion acceptable and 13 unacceptable, chiefly because of fears about general practitioners' lack of skill in caring for patients with HIV infection and AIDS and perceived negative attitudes towards people with HIV infection and AIDS and a lack of confidentiality in surgeries.

Discussion

Although the sample of service providers was sizeable (in qualitative research terms) and varied, the sample of service users was relatively small and homogeneous. This may have been due to the specificity of the criteria for participation and the likelihood that the population from which this sample was drawn was small. It does mean, however, that the information from service users can be interpreted only as offering tentative insights into the issues rather than generalisable comments.

Few of the factors identified as prompting use of services outside the region could not be dealt with by service development. For example, the most commonly cited factor was that services outside the region (presumably based in London) were easily accessible from participants' places of work. It might be possible to encourage these people to use services in their locality if these were equally accessible. As other HIV

Key messages

- Various problems in provision of services can arise when a person with HIV infection or AIDS travels long distances for HIV and AIDS services
- The main reasons for use of HIV and AIDS services outside the region identified by a sample of South Thames (West) residents with HIV infection or AIDS were service accessibility and negative appraisals of local services
- To overcome the problems of such use service providers advocated encouraging people with HIV infection or AIDS to transfer their care wholly or partly to their local area
- Strategies for transferring and sharing care were rated as broadly acceptable—with certain provisos—by service users

and AIDS research has noted, accessibility could be increased by making services available in the evenings or on Saturdays, or both.⁵

The common theme in strategies suggested by service providers for overcoming or preventing problems with use of services outside the region entailed encouraging the person to transfer their care partly or wholly from such a centre to their locality. At least 85% of service users found two of these strategies acceptable. Even the third, focusing on general practitioners becoming involved in care, was acceptable to over 60%. Potentially, a skilled and knowledgeable general practitioner is well placed to respond quickly to any symptoms experienced by a person with HIV infection or AIDS and either to offer reassurance or to arrange speedy and appropriate treatment. Service users in this and other research, however, expressed reservations about involving general practitioners in their care.⁶⁻⁸

In terms of how these reservations might be over-

come the suggestion that general practitioners should be offered support in caring for people with HIV infection and AIDS has been successfully implemented in Hammersmith and Ealing in North Thames. There the provision of specialist advice and support to general practitioners has been adopted as part of a model of shared care and has been positively evaluated by general practitioners and patients.⁹ It has also been suggested that general practitioner facilitators may have a liaison role in supporting general practitioners who are inexperienced in the care of patients with HIV or AIDS.¹⁰ With modifications to suit local conditions all the suggestions advanced by service providers offer a framework acceptable to service users for dealing with the problems associated with patients with HIV or AIDS using services outside their own region.

This study was funded by the former South West Thames Regional Health Authority. We acknowledge the support and assistance of the former South West Thames HIV Team (Derek Bodell, Stephen Jones, and Debbie Renyard).

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(Accepted 24 March 1995)

WORDS TO THE WISE

Yoked together

Zygoma and *zygote* clearly share an etymological ancestor; both derive from the Greek *zygon*, a yoke. The zygomatic arch is, perhaps, a little yoke shaped, while the zygote derives its name from the harnessing together of two gametes to perform a common task. *Zygon* gives us other fine and interesting words: *zeugma* is a rhetorical device in which a single word is used to do double duty in a sentence, often for comic effect—"She left in a cab and floods of tears"—while the splendid Scrabble winner *syzygy* is an astronomical term indicating the alignment of two planets with the sun.

The yoke is an ancient technological innovation, apparently known to that tribe of Asian pastoralists who spoke the original proto-Indo-European tongue from which so many of our modern languages derive. Their word for the device has been reconstructed as sounding something like *yeugom*, and from this has come Greek *zygon*, Latin *jugum*, Sanskrit *yugam*, and our own English *yoke*.

From the Sanskrit root comes *yoga*, union: in this case the union achieved with the supreme spirit by means of contemplation. Latin, too, has spawned words connected with the idea of union or united action. We refer to the *conjugal* rights of married couples and the *conjugate* gaze of properly functioning eyes. The *jugular* veins, on the other hand, derive their name by way of Latin *jugulum*, the throat; the place where a yoke may rest. In fact, a yoke across the throat is an undesirable thing. Early Bronze Age horse yokes were strapped around the unfortunate

animals' necks and vigorous pulling was ruled out by the strangulatory effects of the harness. The *carotid* arteries get their name from Greek *karoun*, to stupefy, because of the effects of such compression.

Yoke gave its name to a peculiarly British letter of the alphabet, which no longer exists. It was called *yogh*, it resembled an italic "3," and it flourished between the 12th and 16th centuries. It was used to indicate the sound "y"—or a fricative "gh," which is now absent from English but common in Spanish. It began its descent into obscurity with the advent of printing, when the *yogh* character was often difficult to obtain, because it was not available on imported European continental presses. Many English printers began to replace it with "y" or "gh." At almost the same time the English palate seems to have become incapable of voicing a hard "gh," and the sound soon disappeared from spoken English, leaving the modern pronunciation of *light* and *night* as a puzzle for foreigners. Scots retained a milder, unvoiced pronunciation for a while, giving us the famous line about a *braw bricht moonlicht nicht*. Scottish printers had another approach to the missing *yogh*. Because the letter resembled an ornate italic "z" they occasionally inserted a "z" to take its place, so that troublesome Scottish names like Dalziel and Menzies (pronounced Dayell and Mengis) are actually little bits of alphabetic archaeology, testifying to the existence of the now defunct *yogh*.—GRANT HUTCHISON is a consultant anaesthetist in Dundee