Attitudes towards and use of general practitioner services among homosexual men with HIV infection or AIDS

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SUMMARY. In a study of 263 homosexual men positive for the human immunodeficiency virus (HIV), it was found that 87% were registered with a general practitioner and of these, 55% said that the general practitioner knew their HIV status. Of the 104 men who had experienced symptoms, 39% had consulted the general practitioner for HIV-related advice. A total of 49% of those who were not registered used a specialist outpatient clinic for all their medical needs. Of those who were registered and whose general practitioner was aware of their HIV status but who did not consult their doctor, 72% used a specialist outpatient clinic. Reasons for not consulting the general practitioner included fears of breach of confidentiality and lack of confidence in the general practitioner's understanding of HIV. Fifteen per cent of the sample continued to see a general practitioner who was unaware of their HIV status, for non-HIV related advice.

The needs of patients must be taken into account when planning more integrated hospital and community care for those with HIV infection or the acquired immune deficiency syndrome (AIDS).

Keywords: patient choice of doctor; HIV; homosexuals; GP utilization; patient attitude; outpatient care.

Introduction

IN 1987 Adler postulated a possible integrated model of health care for those with the human immunodeficiency virus (HIV) or the acquired immune deficiency syndrome (AIDS).[1] Integrated care should be provided by existing services, with specialist advice at either district or regional level.[2,3] Emphasis should be placed on community rather than hospital based care, and outpatient services should be based in existing genitourinary clinics.[4] Indeed, Bebbington and Warren have argued that the particular needs of those with HIV and AIDS are best satisfied by a health service led model of community care, rather than social services, with the primary health care team and the general practitioner in a focal role.[5]

However, various studies looking at the attitudes of people with HIV infection or AIDS towards general practitioners have suggested that such calls for general practitioner involvement may meet with resistance from those who are HIV positive or have related illnesses. Although the majority of respondents in these studies were registered with a general practitioner,[6-8] only approximately half of the respondents said their general practitioners knew their diagnosis.[6,7] Where people were unwilling to register with or consult a general practitioner, most wanted their own care undertaken in the outpatient clinic.[6,8] This was despite an intellectual acceptance by half of these patients that general practitioners should take a greater part in the care of people with HIV infection or AIDS.[6]

Several reasons have been suggested for this reluctance to use general practice. Patients may not tell their general practitioners their diagnosis because they fear a negative reaction or outright rejection,[6] or are concerned about possible breaches of confidentiality.[6,8] Also, they may have little confidence in either the general practitioner's knowledge[6] or experience[6,8] of HIV-related conditions, and feel they have better care in the outpatient clinic.[8] In addition, general practitioners' reluctance to care for patients with HIV infection or AIDS has been given as a reason.[7] This may be because of a lack of confidence in dealing with HIV-related illness and fears about their own health.[9] Also the apparent eagerness of hospitals to retain the total care of these patients may serve to alienate the general practitioner.[7] Indeed, evidence suggests that general practitioners frequently require improved communication with the hospital.[10] From the general practitioner's point of view, it is difficult to provide primary care when the potential patients are reluctant to inform the general practitioner of their diagnosis.[7] These results, and others concerning general practitioners' knowledge of[11] and attitudes towards HIV[12] and related conditions,[9] suggest that calls for general practitioner involvement with the care of people with HIV infection may be meeting resistance from both general practitioners and people with HIV or AIDS.[9]

The present study provides more recent information about the use of general practice among homosexual men with HIV infection or AIDS and about those who were not going to their general practitioner for routine medical advice. It investigates when and why this group chose, or chose not, to consult a general practitioner, and the range of involvement of the general practitioner.

Method

The study group was recruited through the genitourinary medicine clinics, immunology clinics and designated wards of a London teaching hospital, between November 1988 and June 1989. The vast majority (86%) of the HIV patients registered were homosexual men and only this group was contacted. Personal interviews, using a mainly structured questionnaire and lasting an average of three hours, were carried out by trained interviewers with the subjects, usually in their own home. Questions were asked about their experiences of and attitudes towards a variety of services, such as the home support team. This is a hospital based community support team, responsible for liaison between patients, the hospital and the community. It aims to increase the role of the general practitioner in the care of patients with HIV infection or AIDS.[13] Included in the study were questions about contact with general practitioners. A subsequent interview was carried out approximately six to nine months later, which allowed consideration of any changes in the use of general practitioner services.

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Statistical analysis

Data were analysed using the statistical package for social sciences (*SPSS*). Chi square tests were used to assess the significance of associations within the data and log linear models to examine the influence of confounding variables. McNemar tests were used to assess the significance of the direction of differences between the responses recorded at the first and second interviews.

Results

Over half of all homosexual men who were HIV positive registered at the hospital were contacted. In total, 317 people agreed to take part, however, eight were ineligible for the study and were therefore not included, leaving 309 patients. Five of the men died before they could be interviewed, 13 moved away (mostly abroad), 10 could not be traced, 16 subsequently refused, and two members of the group did not complete the first interview because of ill health, leaving a study group of 263 patients.

A total of 171 people (65.0%) were interviewed at the second stage of the study, and data from this second interview are included here. Of the 94 people who were not interviewed a second time, 39 men had died, 11 had moved — several abroad, 12 refused to be interviewed again, and 32 could not be contacted.

Respondents registered with a general practitioner

At the first interview 228 respondents (86.7%) reported that they were registered with a general practitioner. Of these, 126 respondents said their general practitioner knew their HIV status, 88 respondents having informed the doctor themselves. Nine respondents did not know whether or not the general practitioner knew their HIV status. Among those whose general practitioner knew their status, 104 had experienced HIV-related symptoms or illnesses, and of these, 41 respondents had consulted their general practitioner about the problem. Eleven respondents mentioned receiving help from their general practitioner with the control of opportunistic infections, 12 had had help with pain relief and seven had had help regarding problems with appetite loss. The other 11 respondents received help for various problems.

Of the 93 respondents whose general practitioner did not know their status, 40 respondents continued to see the general practitioner for non-HIV related advice (15.2% of the total sample). Fifty seven of the 93 respondents had HIV-related symptoms.

A total of 196 of the 263 respondents had experienced HIV-related symptoms. Those who had experienced HIV-related symptoms were significantly more likely to have a general practitioner who knew their HIV status than those who had not had symptoms (104/161 versus 22/58, chi square = 12.41, 1 df, $P<0.001$). Where the general practitioner did not know their HIV status, respondents who had experienced symptoms were less likely to go to their general practitioner for non-HIV-related advice than those who had not experienced symptoms (19/57 versus 21/36, chi square = 5.63, 1 df, $P<0.05$).

Of the 53 respondents whose general practitioner was aware of their status but who chose not to go to their general practitioner for non-HIV-related advice, 38 respondents (71.7%) used an outpatient clinic for these needs, three used a private general practitioner, one used a homoeopathic doctor and the remainder felt it was not relevant because they had not been ill.

Those respondents in contact with the home support team were more likely to have a general practitioner who knew their HIV status than those who were not in contact with the home support team (74/98 versus 51/119, chi square = 23.46, 1 df, $P<0.001$).

A log linear model was used to consider the relationship between having HIV-related symptoms, having contact with the home support team, and whether or not the general practitioner knew the respondent's HIV status. Those in contact with the home support team and those who had experienced HIV-related symptoms were more likely to have a general practitioner who knew their HIV status than those who had not had contact with the team and those who had not had related symptoms (chi square = 13.18, 1 df, $P<0.001$ and chi square = 36.04, 1 df, $P<0.001$ respectively). These two factors were independent of each other.

A similar model showed that where the general practitioner was not aware of their HIV status, those men in touch with the home support team were less likely to consult their general practitioner for non-HIV-related advice than those not in touch with the home support team (chi square = 3.87, 1 df, $P<0.05$); this association was not related to experiencing HIV-related symptoms. Among those whose general practitioner did not know their HIV status, contact with the home support team made no difference as to whether or not respondents consulted him or her for HIV-related advice.

Respondents not registered with a general practitioner in the NHS

Of the 35 respondents (13.3%) who were not registered with a general practitioner, 17 (48.6%) said they went to the outpatient clinic for all their medical advice and four used a private general practitioner. A further four were foreign nationals and had not considered registering with a general practitioner. The other 10 respondents chose not to register with a general practitioner because they did not feel it was necessary for them in their current circumstances.

Follow-up interview

One hundred and seventy one people completed both interviews. By the time of the follow-up interviews (which took place during the end of 1989 and beginning of 1990) four people who had not been registered with a general practitioner at the first interview had since registered with one. However, five people who had previously been registered with a general practitioner said that they were no longer registered and were now using the outpatient clinic for all their medical needs. Three of these respondents mentioned worries about confidentiality, illustrated clearly in the following quotes from respondents:

> 'It [using the general practitioner] would jeopardize my opportunity to achieve insurance, mortgage, travel overseas, and other business and social activities.'

> 'It [HIV diagnosis] would be on my notes and open to reading by all the clerical people.'

> 'I was uncomfortable. It's a bit of a country practice. I just wasn't happy about telling him.'

> 'Because it would have repercussions, being a small community. The receptionist lives a few doors away from me and they [the receptionists] have the right to go through files.'

and two others expressed doubts about the ability of general practitioners to deal with HIV-related illnesses. A quote from one respondent illustrates this:

'I have no confidence in him. Unless it becomes absolutely necessary I won't tell him.'

Ten respondents whose doctor had not been aware of their HIV status at the time of the first interview said that he or she was aware of it at the second, and the direction of this change was significant (McNemar chi square = 8.1, 1 df, $P<0.01$). Five of these men had the same general practitioner at both interviews, and five now had a different one. Only two of the 10 consulted the general practitioner for HIV-related advice. All the other respondents said they used the outpatient clinic for all their medical needs.

The 53 respondents whose general practitioner did not know their HIV status were asked whether they consulted him or her for non-HIV-related advice. Thirty five respondents gave the same answer to this question on each occasion. Among the 18 respondents whose reply changed, 14 said at the first interview that they did attend for such advice but at the second that they did not. The direction of this change was significant (McNemar chi square = 4.5, 1 df, $P<0.05$). The 14 respondents who said they no longer consulted their general practitioner for non-HIV-related advice said they went to the outpatient clinic for all the medical advice they required, five because they preferred the outpatient clinic, illustrated by a quote from one respondent:

'It's just easier to go to the hospital — they fulfil that [the general practitioner's] function.'

Four felt their general practitioner was unhelpful, three men said they had been advised at the clinic not to consult a general practitioner, and two men mentioned worries about confidentiality.

Discussion

A total of 87% of respondents in this study were registered with a general practitioner. Fifty five per cent of these men said their general practitioner knew their diagnosis. One third of those whose general practitioner knew their status had actually consulted him or her for HIV-related advice. By the time of the second interview there had been a significant change, with 10 respondents who had not previously had a general practitioner who was aware of their HIV status now having one. However, only two of these men consulted the general practitioner for HIV-related advice. These findings are similar to those of previous work[6-8] and suggest an underuse of general practice at two levels. First, a relatively large proportion of men (13%) were not registered with a general practitioner in the NHS at all, although younger men generally have less general practitioner contact.[14] Secondly, the respondents appeared reluctant to use the general practitioner, even when they were registered. The reasons for this reluctance were consistent with those noted by King,[6] namely lack of confidence in the general practitioner's ability to deal with HIV-related illnesses and fears about confidentiality. The majority of men not using general practitioner services said they went to the outpatient clinic for all their medical needs, which is also consistent with King's findings.[6]

Evidence suggests that some general practitioners may be uncertain about the risks of transmission of the HIV virus,[11] and may underestimate the risks from heterosexual sex while exaggerating the risks from non-sexual contact.[12] However, a study in north west Thames found that younger doctors were generally more knowledgeable about HIV, and general practitioners who had actually seen HIV positive patients (42% in this area) were closer to specialist opinion, regardless of their age.[15]

In a study within the Parkside district health authority nearly half the general practitioners knew of HIV positive or AIDS patients in their practice. A relatively large proportion (23%) of the general practitioners said they would never be willing to care for HIV positive homosexual patients. However, experience of HIV positive patients was pivotal, with 90% of those with experience being willing to care for HIV positive homosexual patients, compared with 56% of those without experience.[10]

This suggests that there are general practitioners willing to care for homosexual men with HIV infection and who are doing so but, for a model of care to be put into practice, such as Bebbington and Warren's,[5] a greater number of such doctors would be needed. It raises issues about how far health care can be seen to be acccessible at the point of delivery, if the nature of the illness affects the likelihood of receiving treatment.

Because many of the men in the present study lived in the north west Thames area the findings of these earlier studies[10,15] (which are from the health authority covering most of this area) may be particularly relevant. Indeed, it might be expected that our study would tend to over-represent general practitioner use, and yet many respondents still regarded general practitioners with little confidence, as exemplified by many respondents being reluctant to use their general practitioner for their HIV-related needs.

Those in touch with the home support team were more likely to have a general practitioner who was aware of their HIV status, but among those whose doctor was not aware of their status, those in contact with the home support team were less likely to go to him or her for non-HIV-related advice. Both these relationships were independent of the respondent having experienced HIV-related symptoms.

It seems that a complicated relationship exists between the use of the home support team and the general practitioner. Perhaps, in line with their policy of encouraging general practitioner involvement and finding a sympathetic doctor where necessary,[15] the home support team is trying to encourage clients to inform their general practitioners of their HIV status. This would be consistent with a recent finding that 79% of a sample of home support team clients had a general practitioner who was informed about their HIV status.[16,17] However, it may also be that where the person with HIV infection or AIDS does not wish to inform the general practitioner, the team discourages the use of the doctor for non-HIV-related advice.

A total of 43% of those whose general practitioner was unaware of their HIV status, continued to consult for non-HIV-related advice. This is of concern since the general practitioner may not be able to treat the patient appropriately if he or she is unaware of the patient's HIV status.[18]

By the time of the second interviews, there was a significant change with 14 respondents switching to the outpatient clinic for all their medical needs rather than the general practitioner. There seemed to be several reasons behind this choice, including convenience and anonymity.

This finding has general relevance to the shift towards more community care, in that encouragement from hospital based staff, together with seminars or other forms of information dissemination for general practitioners, might begin to increase informed general practitioner involvement.

It has been noted that the imbalance between hospital and community care for people with HIV infection or AIDS cannot be sustained indefinitely, particularly in areas with a high prevalence of infection, such as London.[1,16] It is recognized at the study hospital that services for HIV infection have been mainly hospital based, with little general practitioner involvement, and the development of primary and community care is now a major objective. As a result of a survey of general practitioners the aim is to develop a better exchange of information, and shared care of patients, between the hospital and local

general practitioners.[10] However, this and other calls[1,5,17,18] for a greater role for community care will remain difficult to fulfil while a preference for outpatient clinics over general practitioners for all forms of medical advice still exists among a large proportion of those with HIV infection and AIDS. Facilitating care in the community will depend upon the development not only of a better working relationship between general practitioners and hositals, but also on an improvement in the confidence that people with HIV infection and AIDS have in general practitioners, and in general practitioners' willingness and belief in their own competence to care for such patients.

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