For Debate

Attitudes to tracing and notifying contacts of people with HIV infection

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In the early years of the HIV/AIDS epidemic the notion of combating the disease by the traditional approach for controlling other sexually transmitted diseases—that is, tracing contacts and notifying partners—met with heated debate.

Though most health care workers agreed that all people infected with HIV should inform their sexual partners and those with whom they shared needles (that is, patient referral), many believed health care providers should not do the informing (that is, provider referral). Concerns were loss of confidentiality, the potential for stigmatisation of infected people, and the fear of alienating those who might otherwise have come forward for testing balanced against the rights of exposed subjects to be informed of their risk and identified.¹⁻⁶

At that early stage the natural course of the infection was poorly understood, no treatments were available, and it had not been established that personal counselling for high risk contacts resulted in sustained change in behaviour. Opponents of notification of partners believed that national education campaigns were adequate; proponents believed that these messages were not necessarily reaching people who did not suspect they were at risk.

But the situation has evolved. In the United States, Canada, Belgium, and Scandinavia notification of partners has gained favour as a legitimate approach to managing HIV infection as a result of evidence of the changing epidemiology of the infection and studies showing the beneficial effects of early antiviral treatment and prophylaxis for opportunistic infections.⁷⁻¹¹

In the United Kingdom medical staff in genitourinary medicine clinics have the major responsibility for managing people with early HIV infection. The only official guidelines for tracing contacts are those for the common sexually transmitted diseases, which were published in 1980, before the HIV epidemic emerged.¹²

Therefore, to examine attitudes and practices regarding the notification of partners in the United Kingdom we surveyed consultant physicians and health advisers in genitourinary medicine clinics.

Subjects and methods

In October 1991 we sent a questionnaire to 146 consultant genitourinary physicians who were readily identified as working in 204 (95%) of the 214 genitourinary medicine clinics known to the Department of Health; 39 (27%) had appointments at two or more clinics. We sent a reminder six weeks later to 52 (35%)

who failed to respond; completed questionnaires were eventually received from 105 (72%) consultants.

Health advisers were more difficult to identify as a group. Initially, we sent the questionnaire to 139 health advisers identified by the Society of Health Advisers in Sexually Transmitted Diseases and the Health Advisers Special Interest Group and a reminder six weeks later to the 72 (51%) who failed to respond; 22 replied. However, as so many health advisers were untraceable, a further 110 questionnaires were distributed to health advisers identified by telephoning 67 clinics, including all 23 London clinics: 52 health advisers replied, giving an overall response rate of 57% (141/249).

The questionnaire had three parts. The first requested demographic information, details of work experience, and the number of health advisers working in each clinic. Other questions inquired about training for dealing with sexually transmitted diseases and HIV counselling, access to guidelines; policies for offering HIV antibody tests, counselling practices before and after testing, and the extent to which health advisers were directly involved in referral of partners.

In the second part participants were asked if they agreed with statements about the effectiveness of partner notification programmes. Opinions were canvassed on a five point Likert-type scale (strongly agree, agree, uncertain, disagree, strongly disagree) which was subsequently converted to a three point scale because the response frequencies of the extreme categories were small. There was a low non-response rate for these items (1-4% among consultants and 0-5% among health advisers).

Finally, respondents were asked for their recommendations for counselling contacts of people in a series of hypothetical situations of high risk HIV exposure. The allowable responses were agree, uncertain, and disagree. The non-response rates for these questions were not trivial, particularly among the health advisers (7-12%), and non-response was included as a fourth category for the analyses.

As health advisers provide most of the counselling and the physicians are responsible for clinic policies we were interested to know whether their opinions differed. Also, because the four Thames regions have reported three quarters of HIV/AIDS cases in England and Wales, we compared the opinions and practices of staff in these high prevalence areas with those of staff in the rest of the United Kingdom.¹³

The analyses reported in table III are based on the underlying 2×3 and 2×4 contingency tables respectively, with χ^2 tests of significance to investigate any

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differences of opinion between the two groups of respondents.

Results

The overall response to the questionnaire was 63% (246/395) and was significantly lower among health advisers than consultant physicians (57% (141/249) v 72% (105/146); $p<0.002$) because of the significantly lower response rate among health advisers in the Thames regions compared with elsewhere (44% (36/81) v 63% (105/168); $p<0.01$). The rates were similar in physicians within and outside the Thames regions (75% (27/36) v 71% (78/110)).

Eighty one (77%) of the 105 physicians were male, and 98 (93%) identified themselves as "clinic directors." They worked in 146 (72%) of the 204 clinics surveyed and identified 206 health advisers as colleagues (about two each). In contrast, 129 (91%) of the 141 health advisers were female. Most (102, 73%) had nursing or health visitor qualifications, 12 (8%) were trained principally in counselling and social work, and 27 (19%) had "non-medical" qualifications. Health

advisers in the Thames regions and those outside had similar qualifications. Physicians and health advisers differed in their work histories: 63 (60%) physicians had worked in genitourinary medicine for more than 10 years compared with only 27 (19%) health advisers ($p<0.00001$), and they had been in their present posts for longer (mean 9.3 v 4.3 years).

HIV antibody tests were available in almost all clinics and only a few staff would never offer the test to clients (table I). Physicians were significantly more likely than health advisers to offer the test to selected clients, and especially those with high risk behaviour. Written informed consent of clients before testing was required in 20-32% of clinics. Almost all health advisers (136, 98%) and physicians (103, 99%) said they had given pretest counselling (data not shown), but proportionately more health advisers had received training in counselling than physicians.

Sixty three per cent of all respondents had available written guidelines for counselling HIV infected patients, usually drawn up by clinic staff, only 24% of which contained recommendations for notifying partners (data not shown).

TABLE I—Number (percentage) of affirmative answers relating to counselling and testing for HIV and policy for notifying partners

	Consultant physicians (n=105)	Health advisers (n=141)	p Value
<i>Counselling and offering HIV test</i>			
Is HIV antibody testing available in your clinic?	104 (99)	139 (99)	
Which of the following approaches do you personally advocate?			
Offering the test to all clients	46 (44)	83 (59)	<0.05
Offering the test to selected clients	55 (52)	38 (27)	<0.0001
Never offering the test to clients	2 (2)	8 (6)	>0.1
Is written informed consent required?	22 (21)	44 (32)	>0.05
Have you had HIV counselling training?	67 (64)	113 (81)	0.004
<i>Policies for notifying partners</i>			
Is it important to identify the contacts of HIV infected patients in order to provide them with counselling and follow up?	97 (92)	81 (57)	<0.0001
Do you routinely discuss contact tracing/patient notification during pretest counselling interviews with clients?	58 (55)	91 (67)	>0.05
Do you encourage patients with HIV infection to refer their contacts during post-test counselling interviews?	103 (98)	102 (81)	<0.0001
Do you offer your services (or services of your staff) for getting in touch with contacts of HIV infected persons if the client is reluctant to do so?	59 (58)	71 (55)	0.1

TABLE II—Attitudes among consultant physicians and health advisers to partner notification programmes for HIV infection

Statement	Opinion (% (No))			p Value*
	Agree	Uncertain	Disagree	
<i>Value of intervention</i>				
(1) Early medical intervention can be beneficial for HIV infected persons with no symptoms				
Physicians (n=104)	64 (67)	24 (25)	12 (12)	0.05
Health advisers (n=139)	73 (101)	21 (29)	6 (9)	
(2) People are adequately informed by media campaigns about their risk and would not benefit from personal counselling				
Physicians (n=103)	6 (6/103)	3 (3/103)	91 (94)	0.6
Health advisers (n=138)	4 (6)	5 (7)	91 (125)	
(3) Informing high risk contacts of their exposure is of no value in controlling the epidemic of HIV and AIDS				
Physicians (n=104)	4 (4)	7 (7)	89 (93)	<0.001
Health advisers (n=139)	12 (16)	22 (31)	66 (92)	
<i>Likely effects of programmes</i>				
(4) Publicised policies for contact tracing/patient notification by clinic personnel would deter potential clients from seeking the test				
Physicians (n=101)	52 (53)	28 (28)	20 (20)	<0.01
Health advisers (n=140)	71 (100)	19 (26)	10 (14)	
(5) Contact tracing for HIV infection by clinic personnel undermines the confidential nature of the professional client relationship				
Physicians (n=101)	31 (31)	11 (11)	58 (59)	0.01
Health advisers (n=139)	45 (63)	17 (24)	37 (52)	
(6) People contacted and told of their HIV exposure would be made unnecessarily anxious				
Physicians (n=103)	19 (20)	23 (24)	57 (59)	0.01
Health advisers (n=134)	37 (49)	26 (35)	37 (50)	
<i>Rights of patients</i>				
(7) Contacts have a right to know of their exposure to HIV infection				
Physicians (n=103)	73 (75)	19 (20)	7 (8)	>0.05
Health advisers (n=140)	60 (84)	25 (35)	15 (21)	
(8) Contacts have a right <i>not</i> to know of their HIV exposure				
Physicians (n=105)	29 (30)	18 (19)	53 (56)	<0.01
Health advisers (n=141)	43 (61)	26 (36)	31 (44)	
(9) It is the sole responsibility of the patient to inform and refer his or her contacts for follow up				
Physicians (n=102)	28 (29)	18 (18)	54 (55)	>0.05
Health advisers (n=137)	37 (51)	23 (32)	39 (54)	
<i>Are resources adequate?</i>				
(10) Limited resources for AIDS prevention would be better spent on public education campaigns than on individuals at risk				
Physicians (n=103)	18 (19)	21 (22)	60 (62)	<0.05
Health advisers (n=133)	32 (42)	25 (33)	44 (58)	
(11) Existing services cannot meet the demand for counselling and support that would be generated by increased partner referral				
Physicians (n=104)	33 (34)	21 (22)	46 (48)	<0.001
Health advisers (n=138)	60 (83)	12 (17)	28 (38)	

*Values <0.05 indicate a significant association between the professional roles of the respondents and their expressed opinions.

TABLE III—Attitudes among consultant physicians (n=105) and health advisers (n=141) to informing partners of people infected with HIV of their exposure and counselling according to situation of exposure

Situation	Opinion (% (No))				p Value
	Agree	Uncertain	Disagree	No response	
Sexual contacts of an infected homosexual man who were identified and contactable, who had unprotected exposure during previous year					
Physicians	83 (87)	10 (10)	5 (5)	3 (3)	<0.001
Health advisers	57 (81)	21 (30)	13 (19)	11 (18)	
Traceable casual female contacts of an infected bisexual man, who had unprotected exposure during the past year and were unaware of their risk					
Physicians	82 (86)	10 (11)	5 (5)	3 (3)	<0.001
Health advisers	56 (79)	21 (30)	14 (20)	9 (12)	
Identified male sexual contacts of a woman with a diagnosis of AIDS over the past year					
Physicians	77 (81)	10 (11)	7 (7)	6 (6)	0.1
Health advisers	57 (80)	21 (29)	12 (17)	11 (15)	
Identified male sexual contacts of a woman with a diagnosis of AIDS over the past 5 years					
Physicians	49 (51)	35 (37)	11 (12)	4 (4)	0.1
Health advisers	43 (61)	30 (42)	15 (21)	12 (17)	
Wife of an infected bisexual man who has had unprotected exposure and is unaware of her husband's bisexuality. The husband does not want to divulge his bisexuality					
Physicians	72 (76)	20 (21)	4 (4)	4 (4)	<0.001
Health advisers	43 (61)	31 (44)	15 (21)	11 (15)	
Identified and traceable contacts of an infected intravenous drug user who have shared needles with the patient over the past year					
Physicians	85 (89)	9 (9)	4 (4)	3 (3)	<0.001
Health advisers	55 (78)	22 (31)	13 (18)	10 (14)	
Identified and traceable contacts of an infected intravenous drug user who had unprotected sexual exposure and are unaware of their exposure over the previous year					
Physicians	83 (87)	11 (12)	3 (3)	3 (3)	<0.001
Health advisers	53 (75)	24 (34)	13 (18)	10 (14)	
All identified and traceable heterosexual partners of infected persons with haemophilia who are unaware of their exposure over the previous year					
Physicians	77 (81)	15 (16)	5 (5)	3 (3)	<0.001
Health advisers	53 (75)	23 (33)	13 (18)	11 (15)	
All identified and traceable heterosexual partners of individuals infected through sexual exposure in Africa—over the previous year					
Physicians	79 (83)	12 (13)	5 (6)	3 (3)	<0.001
Health advisers	55 (77)	21 (30)	13 (18)	11 (16)	

Asked whether it was important to identify the high risk contacts of HIV infected patients to provide them with counselling and follow up, significantly fewer health advisers than physicians agreed (81/141 (57%) *v* 97/105 (92%), *p*<0.0001; table I). In the Thames regions, only 14/36 (39%) of health advisers agreed compared with 67/105 (64%) elsewhere. Among physicians, over 97/105 (92%) agreed in both areas.

When counselling patients before testing, about half of the physicians and two thirds of the health advisers discussed partner notification routinely and there were no differences between Thames and outside regions. A high percentage in both groups (98% and 81%) also encouraged HIV infected patients to inform their contacts after testing but far fewer (55% and 58%) offered their services for referring contacts if clients were reluctant to do so themselves. Again, significantly fewer staff in the Thames regions than elsewhere (11/25 (44%) of physicians and 10/34 (29%) of health advisers compared with almost two thirds (109/172, 63%) in both groups elsewhere) would offer these services (*p*=0.0002).

Opinions about the probable effectiveness of notification of partners varied. Most physicians and health advisers agreed that early intervention could benefit persons with asymptomatic HIV infection. They disagreed, however, with the statement that people are generally well enough informed about the risks of HIV infection and therefore would not benefit from extra counselling. Health advisers were significantly more likely than physicians to agree that informing contacts was of no value in controlling the epidemic and would deter clinic attendance, threaten confidentiality, undermine the professional-client relationship, and make informed contacts unnecessarily anxious (table II).

Physicians seemed more likely than health advisers to agree that contacts have a right to know of their exposure, although this was not significant. Health advisers were more likely to agree that contacts had a right *not* to know, but they were also more undecided about this (questions 7, 8). Opinions were divided about the responsibility of patients to inform their contacts (question 9). However, a higher percentage of

health advisers in the Thames regions than elsewhere (21/36 (58%) *v* 30/105 (29%)) believed that only patients should do this. Health advisers were also significantly more likely than physicians to agree that existing services could not meet an increased demand for partner referral (questions 10, 11).

When presented with several scenarios of HIV exposure a significantly higher proportion of physicians than health advisers in each case agreed that the contacts should be informed, but in most cases a higher proportion of health advisers were uncertain in their replies (table III). In the Thames regions up to 45% fewer health advisers than physicians agreed; indeed, between 19% and 25% (seven and nine) of the 36 health advisers in the Thames regions and between 4% and 8% of the 105 in the other regions refused to respond to these questions.

Discussion

Counselling and testing for HIV infection is widely available in genitourinary medicine clinics in the United Kingdom, and staff generally agree that notification of partners is important, although they are reluctant to become directly involved. The health advisers, whose traditional role has been to promote referral of partners, are particularly sceptical, especially those in the Thames regions. Elsewhere, in low prevalence areas, staff seem to favour a more traditional approach, in which health advisers are directly involved in notification.

The differences of opinion we observed between the physicians or supervisors and the counsellors, although striking, may not be typical of the profession and should be interpreted with caution. The sample of physicians was small and made up almost entirely of experienced clinic directors who were perhaps more likely to view partner notification as a "disease control" measure. On the other hand, although we questioned a larger sample of health advisers, responses came mainly from those with nursing and health visitor training. The views of health advisers with other backgrounds, especially in counselling, may be under-

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represented. This may be particularly true in the Thames regions, which have the highest concentrations of counsellors and people with HIV or AIDS but the lowest response rates in the study. The regional differences in attitudes and practices are probably a reflection of clinic workloads, the mix of HIV exposure groups among clients, and the resources available for counselling and follow up. Resources may be adequate in low prevalence areas with small numbers of HIV infected clients who have few contacts; but in busy clinics in the south east staff may feel unable to deal with the many mobile and potentially untraceable partners of a large number of clients.

Practices in notifying partners may have changed after the decline of gonorrhoea and infectious syphilis over the past decade. For instance, provider referral is now less common in these infections, and patients are being encouraged to be more involved.¹⁴ There are no national surveillance data, however, to confirm this.

PROVIDER REFERRAL PROGRAMMES

Since the mid-1980s provider referral for the contacts of patients with HIV infection has been increasingly incorporated into sexually transmitted disease programmes world wide. Programmes have been established in Europe, Scandinavia, parts of the United States and Canada, Australia, and countries in Africa and the Caribbean (M L Rekart *et al*, fourth international conference on AIDS, Stockholm, 1988).¹⁴⁻¹⁷ Some programmes emphasise counselling all contacts whereas others focus on those at high risk who are possibly unaware of their exposures—for example, women of childbearing age and those with heterosexual exposure to bisexual men and intravenous drug users. These programmes have been evaluated for their operational performance, cost effectiveness, and cost benefit and for the reactions of medical staff and clients (N Padian *et al*, J M Woo *et al*, J E Kristofferson *et al*, fourth international conference on AIDS, Stockholm, 1988¹⁸⁻²¹; E M Blankenship *et al*, N Spencer *et al*, V Arendt *et al*, fifth international conference on AIDS, Montreal, 1989). The outcomes have also been somewhat controversial.²²⁻²⁴ However, as they frequently identify infected persons who might otherwise have been unaware of their risk the main debate has centred around their cost effectiveness.

Partner notification programmes for HIV infection have not been widely adopted in the United Kingdom, most probably because of continuing concerns about client confidentiality, doubts about their cost effectiveness, and operational questions.

Although the physicians and health advisers seemed reluctant to be directly involved in partner notification for HIV infection, there is evidence that patients attending genitourinary medicine clinics are far less opposed to it. In a recent pilot study of the attitudes of 75 clients attending a general genitourinary medicine clinic in London over three quarters of women and half of men felt that notifying partners in HIV infection should be standard practice and were not unduly concerned about its potential impact on themselves or their contacts (S Wanigaratne, personal communication).

USEFULNESS OF PARTNER NOTIFICATION

Internationally and in the United Kingdom AIDS from heterosexual exposure is increasing at a faster rate than that from male homosexual exposure and

injecting drug use, a trend especially affecting women and children.²⁵ There is therefore an urgent need to re-examine the usefulness of notifying partners in HIV infection, especially in situations in which contacts may be unaware of their exposure and risk.

Because of the apparent confusion surrounding this issue in the United Kingdom we recommend that there should be national guidelines for notifying partners for areas of low and high HIV prevalence, especially for people who may be unaware of their exposure and auditing of the effectiveness of current practices in genitourinary medicine clinics with focused operational research into cost effectiveness and cost benefit of notifying partners. This will involve reviving the alliance between clinicians, policy makers, epidemiologists, and patient advocates to establish well justified policies appropriate for the United Kingdom to develop rational programmes for the prevention of new HIV infections and management of those already infected.

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