MEDICAL PRACTICE

*Contemporary Themes***HTLV-III: Should testing ever be routine?**

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The clinical and epidemiological features of human T lymphotropic virus type III (HTLV-III) or lymphadenopathy associated virus are now well established.^{1,2} The following three modes of transmission have been identified:

Sexual activity—HTLV-III may be acquired by homosexual and heterosexual contact, passing from male to male, male to female, and female to male. Convincing evidence also exists for transmission from artificial insemination by a donor.

Bloodborne—There are two main risk groups associated with bloodborne transmission: (a) haemophiliacs and (rarely) recipients of other blood products, transfusions, or organs, particularly when the donor pool is large; and (b) intravenous drug abusers, who may share needles, syringes, and drug preparation equipment extensively contaminated with infected blood.

Maternofetal—Vertical transmission from mother to baby is thought to occur mainly in utero. There is also evidence for transmission through breast milk. In addition, pregnancy may lead to otherwise asymptomatic infection in the mother being expressed as disease.³

There is no evidence for transmission of HTLV-III by any other route—for example, saliva or casual or intimate non-sexual contact—apart from one definite instance of seroconversion after micro-inoculation during a needlestick accident with blood from an infected patient.

HTLV-III antibody test

The HTLV-III antibody test was introduced, together with self exclusion by blood donors, to reduce the risk of transmission from infected donors in the Blood Transfusion Service. The test was provided at other sites, mainly to avoid the possible but inappropriate use of the service by people at high risk seeking to establish their antibody state. This was important because the small number of false negative test results would become significant only if many high risk subjects donated blood. Heat treatment of factors VIII and IX now makes the risk of future transmission from these materials negligible.

Since the antibody test became available it has been requested at other sites for four main reasons: as a test for acquired immune deficiency syndrome (AIDS); to confirm infection; for reassurance about non-infection; and as a stimulus to changing sexual behaviour. In every instance when the test is requested precounselling is essential and must include discussion of the following five issues:

Nature and limits of test information—A confirmed positive HTLV-III antibody result is a marker of prior infection with this retrovirus. Enough time must have elapsed since exposure to the virus for development of an antibody response—two to three months in most, but not all, instances. The antibody test cannot determine when exposure to the virus or seroconversion occurred. Nor does it measure infectiousness, though the potential for this must be assumed from the nature of the virus. It has no predictive value in terms of clinical illness. The test is not foolproof, though the chances of false positive and false negative results may be minimised by repeat and confirmatory testing. Further, the antibody test is rarely a means to establish a diagnosis of AIDS except in very few cases—for example, B cell lymphomas.

Consequences of positive result—Considerable psychological and emotional morbidity may occur in a patient on learning that he or she is seropositive to HTLV-III, and this is especially so when the test was conducted without

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consent or precounselling. Psychological shock, unremitting uncertainty over prognosis, and the reactions of others may lead to severe anxiety, depression, obsessive disorder, and sometimes suicidal acts (we know of six suicidal attempts by patients recently informed that they were seropositive). These burdens are reflected in the high consequent levels of broken relationships, unemployment, and social dysfunction.⁴ Psychological and behavioural adjustment may take weeks or years. In all cases detailed and time consuming follow up will be required if a negative or fatalistic response is to be avoided. Numerous practical consequences also follow from being identified as seropositive. For instance, people who know themselves to be seropositive are barred from taking out life insurance or endowment mortgage policies in Britain. Almost all patients have reported severe difficulties in obtaining basic dental treatment; some have even had difficulty in getting medical treatment, whether in hospital or in general practice, once their viral state was known or suspected. For those who have told their employers, or who fail company medical examinations because of a positive antibody result, dismissal, premature retirement, or redundancy have often followed swiftly. Inevitably there are then financial and accommodation problems, compounding an already difficult personal, medical, and psychological situation. The prospects of compulsory screening for insurance, immigration, or employment (already being enacted in the United States and Saudi Arabia) can only add further pressures.

Safe sex techniques may help prevent not only the risk of spreading HTLV-III but also the risk of acquiring other sexually transmitted diseases that may act as cofactors in the development of disease in people infected with HTLV-III. The same advice about these techniques, however, may also be offered to those who are not infected so that they may avoid contracting HTLV-III infection. Thus everyone must be encouraged to adopt these precautions regardless of whether they are seropositive or seronegative.⁵

Presenting symptoms—Many patients requesting antibody testing are well but anxious or have a variety of symptoms, many of which may be interpreted by the anxious patient as symptoms of AIDS.⁶ Appropriate discussion of the sexual history and the symptoms and process of anxiety states will often provide appreciable and long term benefit.

Confidentiality and informed consent—Patients must be reassured that any test results will be kept strictly confidential and not be disclosed to outsiders without their consent.⁷ Antibody testing must proceed only with informed consent.

Arguments in favour of routine screening

CLINICAL DIAGNOSIS

Physicians may consider that the antibody test is a useful diagnostic tool, but its value in diagnosis is very limited and dependent on the risk group examined. The main range of HTLV-III related illness had already been clinically identified before antibody testing. It adds little in the vast majority of clinical settings. It may be useful when a low risk subject such as a neonate presents with a clinical syndrome resembling, say, AIDS; confirmation of an HTLV-III related disorder may help in defining management and prognosis; and it also has a place in epidemiology. In high risk subjects with illnesses apparently unrelated to HTLV-III a negative result may help exclude a disorder associated with HTLV-III. A positive result in a member of a high risk group in whom HTLV-III infection is relatively highly prevalent, however—for example, homosexual men in London, haemophiliacs anywhere in Britain—will not indicate a causative relation between the retrovirus and disease.

In the context of high prevalence of infection it may be thought that screening provides a useful basis for clinical monitoring to detect early evidence of disease. Physicians, however, will need to be alert to the possibility of HTLV-III related disease in all members of a risk group whether known to be seropositive or not. Furthermore, many people at risk will not identify themselves as such, making selective serological monitoring a less viable approach than achieving a thorough understanding of the infection.

CONTROL OF INFECTION

A further argument advanced for routine screening of subjects at high risk relates to the need to protect clinical and laboratory personnel against occupational infection with HTLV-III. There is already a substantial body of evidence showing that this risk is negligible provided that basic standards appropriate for the care of all patients are applied.⁸ Even in "needlestick" injury the risk appears to be extremely small (only one definite instance of seroconversion in more than 650 accidents)—and substantially less than for hepatitis B. All patients and samples must be handled in a way that avoids risk of inoculation injury. The adoption of precautions as for hepatitis B is,

in effect, a way of reinforcing standards that should already be in operation. Given that there is such a low risk of occupational infection and that many patients will remain untested, it is questionable whether any benefit is to be gained from screening for this purpose. The difficulties of identifying all high risk subjects, the potential for generating individual psychosocial casualties, the false negative rate in screening, and the efficacy of precautions against hepatitis B all suggest not.

Importantly, if patients suspect that knowledge of their membership of a risk group or antibody state may result in less than optimal medical (or dental) care they will increasingly be disinclined to disclose such information. The overcautious practitioner will then be unable to implement such precautions as he or she may otherwise think necessary.

Guidelines for infection control and safety have been drawn up for many occupational groups⁹⁻¹¹ and clearly should now be consulted and applied as a matter of routine. Medical staff must take a lead in allaying public anxiety by an appropriate approach to infection control. If after precounselling a patient is against personal testing it is sensible to assume that he or she is seropositive and to use routine precautions as suggested. If, however, staff base their judgments and practices on ignorance and irrational fears, how can they expect society to do otherwise?

PUBLIC HEALTH

A common argument favouring routine screening rests on the issue of public health. It is suggested that identifying seropositive subjects will allow the source of HTLV-III to be isolated so that spread to a wider community may be prevented or contained. Our understanding of the virus at present, however, suggests that people who are infected remain so for life, so is it really realistic or appropriate to suggest lifelong (sexual) isolation? Many patients facing an infection with potentially fatal consequences may fail to accept a suggested lifetime restriction of sexual behaviour, particularly in the context of severe psychological pressures. This highlights the need for guidelines on safer sex to be presented in a considered and sensitive way—not as rigid do's and don'ts that may be interpreted as prescriptive moralising.

Sexual spread of infection requires a tacit compliance between two people, one infected and one not; this suggests that, instead of source isolation, it would be more effective to advocate behavioural change in both. This may be achieved through individual counselling and public education. Guidelines on safer sex must apply to all at risk, irrespective of viral state. It does, after all, take two to tango, and the steps soon falter if only one partner knows the right moves. Confining such counselling to infection "sources" has been found to be effective, in the short term at least, only in the context of wider social counselling within peer groups.¹² Personal knowledge of antibody state seems to be a less important motivator for behavioural change than sustained and consistent counselling from various sources (hospital and community).

Selected settings for routine screening

Our argument so far has been against routine screening, particularly without precounselling and informed consent. If a person wishes to be tested after precounselling and informed consent has been given it should of course be provided. Further, in the following specific medical contexts antibody testing has definite benefits:

- (1) Screening of blood donations ensures the use of HTLV-III negative blood.
- (2) Screening of transplant donors, including donors of kidneys, livers, hearts, lungs, corneas, bone marrow, and so on, ensures the (re)use of HTLV-III negative materials.
- (3) Screening of donors of, for example, semen and growth hormone ensures the use of HTLV-III negative products.

In each of the above cases it is helpful to regard the donations as gifts and there is an obligation to ensure quality control for the sake of the recipient. In two other crucial settings the benefits lie primarily in the welfare of the seropositive patient:

- (4) In patients receiving haemodialysis there is a strong argument for screening for HTLV-III antibody (with consent), for in these patients the use of therapeutic immunosuppressive drugs may lead to a genuine risk of clinical deterioration. It may be advisable to maintain these patients with long term haemodialysis or chronic ambulatory peritoneal dialysis. There is no evidence of risk of infection to staff in haemodialysis units, who should be adequately protected by hygiene and safety techniques for hepatitis B and non-A, non-B hepatitis; the widespread use of disposable dialysis systems clearly facilitates this.
- (5) Women in high risk groups who are contemplating becoming

pregnant or are in early pregnancy may benefit substantially from screening (with consent). Pregnancy has been a definite cofactor in expression of maternal disease and there is a high rate of HTLV-III infection and disease in infants of seropositive mothers; here again the "gift" relation applies.

Conclusion

Aside from the selected settings mentioned, the arguments for "routine" screening are not as logical as they at first appear; at best they confer very limited benefits that can be as easily, if not better achieved, by other approaches. The risks to the individual patient of indiscriminate screening are considerable. If a potent vaccine or an effective anti-HTLV-III treatment were to become available the balance would abruptly change to the benefit of the individual. The HTLV-III antibody test is not "just another test"—testing should be anything but routine in view of the potential consequences for those found positive. Too many patients have already suffered from a failure to appreciate this single fact. If we are to have any meaningful impact on the spread of this infection and its tragic consequences counselling on safe sex and positive behavioural change must be taken into the public arena without further delay. In the present circumstances before testing doctors must ask themselves: Why are we testing and what benefits, to the individual or to society, derive uniquely from testing? How can we achieve the benefits of testing by other means? Is the potential harm resulting from the patient justified by the benefits? Do we have the means to deal with it?

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"Don't tell me on a Friday"

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I am a gay man who discovered last summer that I had antibodies to human T cell lymphotropic virus III (HTLV-III). For me there are two central strands to the question of whether or not people should be tested for such antibodies: firstly, will knowing that you are positive help your own health; and, secondly, will it make you more or less likely to infect others?

Like many people, when I first discovered that I was antibody positive I felt shock and disorientation. I woke up in the mornings shaking, had problems sleeping, and lost my appetite. I wrote a will, drank heavily, and seriously considered suicide. I thought, like others, that I was bound to develop acquired immune deficiency syndrome (AIDS). (*Capital Gay* recently reported that a Newcastle conference on AIDS had been told of six people who had killed themselves on discovering that they were positive.)

But, through good counselling from both the doctor at the special clinic and a clinical psychologist, after three to four weeks I got used to being positive. I was put in touch with a gay self help group in London (which now has imitators in other parts of the country) called Body Positive. The support, both practical and emotional, that both the psychologist and Body Positive gave were all important for me. Where I should have been without their help I dare not consider.

Such help should, I believe, be available to everybody immediately that they find out that they have antibodies. This belief explains my title because people should not be given this news if an appointment with a psychologist cannot be arranged until after a weekend—the first 72 hours are the worst. Given the restricted counselling facilities that are as yet available, I think it inevitable that doctors are going to have to make full use of voluntary organisations such as Body Positive.

Knowing that you are positive gives you a chance to alter your lifestyle. It becomes more likely that you will adopt a healthier diet and cut down on alcohol, tobacco, or cannabis. As an actor I decided that stress was my main problem, and I took up yoga for the first time in my life with great success.

The most important question is—will knowing that you are positive alter your sexual behaviour? Gays in this country have up until now followed a free and easy existence. All we risked living in the "fast lane" was, it seemed, the occasional social disease. Clearly we must adopt a more responsible attitude, and it does seem that gay men who are discovered to be positive *and* who are properly counselled do behave responsibly and change their sexual practices. They follow the "safe sex" guidelines suggested by organisations such as the Terrence Higgins Trust.

While in a perfect world all gay men should for the last two years have adopted safer sexual practices, including the use of condoms, this is not a perfect world and they have not. The reality is that at one o'clock in the morning after four or five pints in a gay pub or club gay men go home with each other without checking that one of them has condoms.

I do not advocate the compulsory testing of gay men. But so long as we understand the test and its limitations and so long as good counselling is available I think we should be encouraged to take the test—both for our own good and that of the community, gay and straight. The decision must, however, remain a personal one. My experience—and that of St Mary's Hospital—is that those who change their behaviour most are those who are tested, found positive, and properly counselled.

Thomas Richards is a pseudonym.