

Take the HIV Test

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Part 1: HIV testing — time to re-think

Introduction

Various guidelines have stressed that HIV testing should be preceded by counselling, despite differences of opinion on the aims and content of such pre-test counselling.

Far less attention has been paid to making sure people have easy access to this valuable test. Yet not offering someone an HIV test can lead to far worse consequences than offering it ineptly or insensitively. The test can save lives, if it enables optimal treatment of HIV-related disease or avoidance of HIV transmission.

This paper aims to redress the balance. It offers advice to health professionals, especially doctors and midwives, on how to provide HIV testing straightforwardly and concisely. It reflects a growing view among health professionals that HIV testing should be "normalised" alongside other diagnostic tests and procedures.

The ethical principle remains that HIV testing should only be done with the patient's specific consent, if the patient is capable of giving it. Competent adults must not be tested for HIV without their knowledge, must be given as much information as they require, and have the right to refuse to be tested without prejudice to their care.

What does pre-test counselling mean?

One of the problems with discussion of pre-test counselling is a lack of consensus on what "counselling" means in this context. Among doctors, counselling is sometimes interpreted in terms of giving advice or information to enable a person to decide whether or not to consent to an investigation or treatment. Some information-giving remains necessary for HIV testing, although this can be done in a variety of ways.

For example, for some patients it is sufficient to provide an information leaflet in advance and then check whether they have read and understood this and whether they have any further questions.

Other professional groups, in contrast, may view "counselling" as distinct from "using counselling skills", "information-giving" or "advice", in line with the stricter definitions used by the British Association for Counselling (BAC). Counselling, in the BAC sense of the word, may be a valuable intervention in helping people to cope with an HIV positive diagnosis (or other serious problems) but has arguably never been an appropriate term for discussion prior to consent to HIV testing.

In practice, "pre-test counselling" has often been defined operationally in terms of a person needing to see a counsellor, health advisor or other professional viewed as having specific training and expertise in relation to HIV. This has acted as a barrier to more accessible testing, and in reality there is no reason why, say, GPs or junior

hospital doctors should not feel competent to provide the necessary information and obtain consent to HIV testing.

Why should testing be normalised?

Times have changed

Testing for HIV (or HTLV III as it was then called) was introduced for general use in the UK in 1985. At that time, there was no effective treatment for HIV. Support groups were in their infancy in London and virtually non-existent elsewhere. Fear and ignorance abounded, so merely being tested for HIV was perceived as stigmatising as it suggested that a person might be at risk. Even within the medical profession, there was pressure for compulsory testing and other coercive measures, contrary to human rights principles. HIV testing was understandably viewed as a major intervention which carried uncertain benefits and significant risks, so that people needed counselling in order to take an informed decision about whether to be tested.

Since then, the situation has improved substantially. In particular, although HIV is not curable, there are treatments available which are highly effective in suppressing the virus and preventing AIDS from developing. Although there is still uncertainty about the long-term impact of these treatments, there is no doubt that early diagnosis is beneficial.

Early diagnosis is vital

Newly reported AIDS cases have fallen dramatically among people known to be infected with HIV, because of the new treatments. People who are not diagnosed as HIV positive until around the time when they fall sick with AIDS now account for more than half of all new AIDS cases¹. In 1997, 531 people developed AIDS less than three months after testing positive for HIV (many of whom were only tested because of their symptoms). 42% of them had pneumocystis carinii pneumonia and 12% had tuberculosis — diseases which are serious and life-threatening, but treatable if diagnosed soon enough. Cases still occur where people die of AIDS-related illness before HIV is diagnosed. *In other words, many people develop AIDS which could have been prevented or delayed, and some die, because they are not tested for HIV early enough. Health professionals have to accept that some people may make an informed decision not to have the test, but in some cases it has simply not been offered.*

Not offering HIV testing contributes to health inequalities

Of the population groups most affected by HIV/AIDS in the UK, there is evidence that people of African origin are particularly likely to be diagnosed with HIV late, when they are already seriously ill and when the optimum time for starting treatment is past.

In one study of African people with AIDS in South London, 61% were not recognised

as HIV positive until they developed AIDS². The average CD4 count at HIV diagnosis was less than $100 \times 10^6/l$ for both sexes, suggesting severe immune deficiency. Another research report refers to African people as often being diagnosed while hospitalised and "as a consequence of pressure from hospital staff"³. Clearly this indicates a need for cultural sensitivity as well as education within the African community. But the fact that people belonging to an already disadvantaged ethnic minority group are failing to access effective preventive treatment may be viewed as a more serious problem than the possibility that some patients may feel pressurised to undergo testing which appears to be clinically indicated. It could be perceived as a racially discriminatory denial of appropriate care for a professional to withhold the opportunity for an HIV test for fear of being thought to be putting pressure on an African person.

Most patients regard HIV testing as acceptable and ordinary

In a recent study, only 24% of patients at an Edinburgh hospital said they would have been upset if they had been tested for HIV without their consent⁴, even though this would breach professional ethical guidelines. Moreover, of those who had had blood tests, 23% believed they had been tested for HIV anyway, including some who thought that they needed this test. The consequences of this are startling. People with HIV may assume they have been given a clean bill of health, when in reality they have simply not been tested. The onus should be on professionals to offer the test, so that people understand it will *not* be done unless they agree explicitly.

Testing can help to prevent HIV transmission

HIV testing (and counselling) has not been shown to have much impact in encouraging people to change to safer sexual or drug-taking behaviour. Hence HIV/AIDS experts have rightly argued that simply promoting testing is unlikely to be effective in controlling the HIV epidemic. Now, though, a more sophisticated analysis of the relationship between testing and prevention seems to be emerging:

- Antenatal HIV testing is important in preventing vertical transmission, since it enables infected women to take antiretroviral treatment which substantially reduces the risk to the baby. The Royal Colleges are united in favour of normalising antenatal HIV testing⁵. It should be recommended to all women in higher prevalence areas (eg London) and any women who might be at risk or who wants the test, nationwide.
- Among gay men, there is a move towards greater sophistication in prevention messages. Some health promotion specialists support "negotiated safety" as a suitable strategy for some men in regular relationships, ie where both partners are tested so that if both are negative they may have unprotected sex with each other on the basis of a clear agreement on avoiding unsafe sex with people outside the relationship. This is not suitable for everyone and carries some risk that the agreement may be breached, but for some couples

it may be more achievable, and hence safer in the long run, than trying to avoid unprotected sex altogether.

People are entitled to a choice of ways of getting the test

In some districts HIV testing has become a near-monopoly of genitourinary medicine (GUM) clinics. These clinics usually provide an excellent service, and are popular among some people at high risk of infection, eg some gay men. However, the fact that these clinics often employ specialised counsellors heightens the mystique around HIV testing and feeds the misapprehension that non-GUM professionals cannot offer the test⁶.

Referral to a GUM clinic is an unnecessary barrier for people who would find it more convenient or congenial to be tested elsewhere. All GPs and midwives should be encouraged to offer the test, as well as hospital doctors seeing medical patients with possible symptomatic HIV disease. The Royal Colleges have agreed that in higher prevalence districts the test should be recommended to all antenatal patients at the booking appointment⁵. This should be implemented as a high priority, while working to make antenatal testing the norm across the country.

De-bunking some myths

Myth: Pre-test counselling is necessary to prevent the person suffering if they are given a positive test result.

Fact: It's not surprising that a positive HIV result can provoke distress. Some people react violently (eg crying) or with stunned silence. Others may initially seem quite calm, especially if the result was expected, though they too may suffer considerably over the ensuing days and weeks. Good support is therefore essential for people who have recently been diagnosed as HIV positive. However, there is no persuasive evidence that pre-test counselling affects how someone feels when given the result. Some pre-test discussion can be helpful, for example in helping the person to assess his or her risk, prepare for the result and identify potential sources of support, but counselling is not a panacea. Health professionals therefore should not assume that a patient's suffering could have been avoided if the test had been managed differently.

Myth: Being tested for HIV causes insurance problems even when the result is negative.

Fact: Insurers do not ask applicants whether they have been tested for HIV, but only whether they are HIV positive. This results from a change of policy by the Association of British Insurers (ABI) in 1994. The ABI has also made it clear that doctors need not disclose prior negative HIV tests when writing insurance medical reports on their patients. If asked whether a person has ever been tested for HIV, the doctor should refuse to answer. The RCGP and BMA also advise that GPs should not answer questions about their patients' lifestyle risks of acquiring HIV.

Myth: Being tested for HIV by a GP rather than at a GUM clinic causes insurance problems.

Fact: Applicants for life insurance have to tell the insurer their HIV status, whether or not their GP knows about it. People with HIV find it difficult or impossible to get new life insurance, in the same way as for anyone with a potentially life-threatening disease.

Not disclosing one's HIV status when applying for insurance makes the policy invalid, even if the person dies of something completely unrelated to HIV. It could lead to prosecution for attempted fraud. Sometimes insurers require applicants to have an HIV test anyway.

Existing insurance policies are unaffected by a positive HIV test result, providing the person did not withhold information when the policy was originally taken out.

Myth: People being tested for HIV need to sign a consent form.

Fact: This is unnecessary. Signed consent is needed for operations and other major procedures, but not for HIV testing. Making people sign a form is unnecessarily bureaucratic and may act as a barrier to HIV testing. Consent can be given orally by the patient, and simply noted in the records by the health professional.

<p>Remember: The test does not <i>make</i> a person HIV positive, it only reveals infection that is already present. People who have HIV usually find out about it anyway, by being tested while asymptomatic or if and when they develop symptoms — or when their baby or their partner does so. It's better to be tested sooner when more effective treatment can be offered.</p>

Part 2: How to do it — HIV testing made easy

This section offers advice to health professionals on how to offer HIV testing in practice. It includes wording that can be used when discussing the test with patients, but these are only suggestions. Each professional has his or her own personal style, and the ideas in this pamphlet can be adapted to suit. Some points also need modification to suit different clinical settings, eg general practice or hospital medicine.

Offering the test

The patient with symptoms suggesting HIV disease

Because of the benefits of early diagnosis, the test should be offered if HIV infection

Remember: If a person cannot give consent (eg is unconscious) then you should do the test without consent if this is necessary in the patient's immediate clinical interests. Consent can be sought from a parent in the case of a child who is not mature enough or is too ill to give valid consent. You should not ask a relative or partner to consent on behalf of an adult who cannot do so him/herself.

is possible but unlikely, not just strongly suspected. Familiar problems such as herpes zoster, intractable vaginal thrush or uncomplicated pneumonia can sometimes be HIV-related, especially if there's no obvious underlying cause. Say for example "It is possible that your problem might be related to infection with HIV, the virus which causes AIDS. [*If true, you could add: I don't think this is very likely, but*] we can't be sure unless we do a test for HIV. This would help us to understand what's wrong and to offer you the best possible treatment. Do you agree that we can do a test for HIV infection? We will only do the HIV test if you specifically agree to it."

The patient who asks for an HIV test

It is often wise to start by asking why the person wants the test — it could be because of misunderstanding of how HIV is transmitted, or as a way of expressing anxiety about something else, eg trying to come to terms with homosexuality. It's best to try to deal with the person's underlying concerns first, but if there's a sensible reason for the test, then respond positively, eg by saying "Anyway, I'm glad you've asked for the test. It's a good idea to have it done because if it's negative it could help to put your mind at rest, but if it's positive there are treatments which can keep people with HIV healthy and reduce the risk of developing AIDS. It can be done here if you would like. We will only do the HIV test if you specifically agree to it." It may be appropriate to recommend testing for other STDs and/or hepatitis viruses as well.

Someone who discloses that they have been at risk, or who is being tested/treated for other STDs

If a person appears to be at risk, the onus is on the health professional to introduce the topic of HIV. Some people may have actively decided against testing in the past, so you should highlight the reasons for possibly reconsidering this decision: "I don't know whether you have thought about being tested for HIV. We recommend the test to people who have been at risk, because now there are good treatments which can keep people with HIV healthy and reduce the risk of developing AIDS. Would you like to have an HIV test now, or would you prefer to think about it and come back another time? We will only do the HIV test if you specifically agree to it." You may also need to discuss the timing of risk behaviour since the test does not detect recent infection prior to seroconversion, which usually occurs within three months of exposure.

The antenatal patient

It's best to offer the HIV test alongside other antenatal tests. Ideally, the patient should be sent or given a leaflet outlining the various tests prior to her appointment, and the GP can mention HIV testing when a woman first presents with a positive pregnancy test. Whether or not this has been done, the midwife might say "One of the tests we recommend is the test for HIV, the virus which causes AIDS. It's a good idea for all pregnant women have this test, because if a woman is HIV positive then there are treatments we can give to reduce the risk of her transmitting the virus to her baby, as well as to prolong her own health. Would you like to have this test now, or do you want some time to think about it? We will only do the HIV test if you specifically agree to it."

Arranging the test result

Where possible, a positive HIV test result should be given face to face. This can be arranged as follows:

- If someone is having several tests, you could say "We will ask you to come back if there is anything wrong with any of your tests — even if it is something very minor". Negative results can then be given by post or phone, as a recall does not necessarily imply a positive HIV test. However, patients who are recalled should be seen quickly, because some worry is inevitable.
- If a patient is only having an HIV test, book an appointment for the result, whether positive or negative.

Giving positive test results

If the person may not be expecting their HIV test result:

- Prepare for bad news, eg "We asked you to come back because there is a problem with one of your tests. It is to do with your HIV test".

- Pause, then give the result, eg "Your HIV test is positive, that means you are infected with HIV, the virus which could lead to AIDS".

If the person is attending for their HIV test result:

- Check by asking "Have you come for the result of your HIV test?", and if so give it fairly quickly. Breaking the news gradually can merely prolong the agony of suspense.
- So say "Well, I have your result, and it is positive. That means you are infected with HIV, the virus which could lead to AIDS".

Either way, continue by pausing to let the patient react. If s/he is silent, ask a question, eg "Would you like to ask me any questions?"

For the rest of the consultation, listen and respond to the patient, check s/he has understood the result, and answer any questions, but don't expect him/her to take much in. The result itself is overwhelming enough. Book a follow-up appointment, preferably less than a week later. Emphasise that HIV is not a death sentence and that the person will have plenty of time to consider a range of options. Convey optimism by saying that when you next see the patient you will be able to arrange referral to a specialist centre which can provide more information, including about the latest treatments. Exceptions are if the person has symptoms, may be seroconverting, or is an antenatal woman who has presented late, in which case you should refer immediately. Detailed prevention advice and partner notification can wait, though you might remind the person that s/he can transmit HIV through unsafe sex or sharing injecting equipment. It's useful to give a leaflet and helpline number in case the person becomes anxious between appointments, as well as information about local support groups⁷.

Remember: It's a good idea to use all three words "HIV", "infected" or "infection" and "AIDS" (without implying that someone has AIDS if they don't). This reinforces the message and helps to make it understood. It is also encouraging as it shows that you are not scared of talking frankly.

Giving a negative result

Start as above, then say: "I have your result, and it is negative. That means you do not have AIDS and you are not infected with HIV, unless you have been exposed in the last three months." Most patients will be relieved, though sometimes people can be shocked (eg if they have an HIV positive partner). Check that the result has been understood. If the reason for the test was because of high risk behaviour and/or other STDs, it is appropriate to remind the person that s/he could still get HIV in future if s/he has unsafe sex or shares injecting equipment. Lengthier advice probably

won't be taken in. Where a person has recently been at very high risk, has no symptoms, but may be in the "window period" before seroconversion, then emphasise the possibility of a false negative result and the need for repeat testing after about three months (consult a specialist if you suspect a patient has symptomatic seroconversion disease).

Answering common questions

Although patients need basic information about what the HIV test is and what it's for, it isn't necessary to overload them with all the information which might conceivably be relevant. However, the patient is entitled to as much information as s/he wants, so the health professional should always invite further questions and be prepared to answer them. Some common ones are as follows:

Do I need to see a counsellor?

No, unless you would like to, to discuss why you want the test and what it involves. Now that treatments for HIV have improved, and there's much better support available for people with HIV, it's not considered necessary for everyone to see a counsellor before the test. If you tested positive, then it would be a good idea to see a counsellor at that stage. But if there is something you're particularly worried about, then let's discuss it and if you want I can arrange for you to see a counsellor before you decide about the test.

What will happen if I test positive?

Then I'd would like to arrange for you to see a specialist who has a lot of experience in caring for people with HIV. I'd still want to be involved in your care, but the specialist would be able to explain things in more detail. S/he would probably suggest some tests to see how well your immune system is working. Based on these tests, s/he might suggest some medicines to protect your health. These treatments are not a cure, but they do appear very effective in suppressing the virus inside the person's body and so reducing the risk of developing AIDS. At the specialist centre, there are also counsellors who you could talk with and get advice about healthy living with HIV, as well as discussing who to tell about your infection. They could also put you in touch with voluntary support groups, so that if you wanted to you could get to know other people with HIV and help each other.

What are the drawbacks in being tested?

For most people the advantages of the test outweigh the disadvantages, but it has to be your choice. If the result is negative, then that's reassuring and there are no drawbacks of having been tested. If the result is positive, then of course it may come as a shock to find out that you have HIV. But you would gain the benefit of specialist care and attention. The worst situation is if someone is HIV positive and doesn't know it, so they can't do anything to protect their health.

It's true that people with HIV sometimes suffer discrimination, eg at work. It makes sense to think carefully about who to tell if you are HIV positive, so as to reduce the risk of discrimination. We would keep your test result confidential.

People sometimes worry about whether they would need to tell their family and friends if they test HIV positive, and how these people will react. We would encourage you to tell your partner, as s/he might also be at risk. Beyond that, it would be for you to decide. It does now seem that the public in general are more supportive towards people with HIV than in the past, though of course only you can judge how your own family may behave.

What about life insurance?

People often worry that being tested for HIV might cause life insurance problems, even if the result is negative. In fact, that's not true. Insurance companies have stopped asking people whether they've ever been tested.

If you are HIV positive then, yes, you will have problems with future insurance applications, the same as for anyone with a serious health problem. But if you already have a life insurance policy, the test shouldn't affect it at all.

If I'm positive, does that mean my partner/husband/wife might be infected?

Possibly, but it's not certain. There's definitely a risk, and we'd recommend that s/he gets tested. But even if people have unprotected anal or vaginal sex, that doesn't always transmit the virus. The risk varies a lot, depending on the amount of virus in the infected person's body as well as on how often a couple have unprotected sex and on the presence of other infections which can increase the risk. As a very crude guide, the rate of transmission for a stable heterosexual couple who have unprotected sex may be around 10% per year. [Male to male transmission occurs most readily, followed by male to female and then female to male.]

What will happen if I test positive [antenatal test]?

I'd want to arrange for you to see specialists in HIV and obstetrics. They would explain to you in more detail what your options are, but the main point is that pregnant women with HIV can take a medicine which suppresses the virus inside the woman's body and reduces the risk of passing it on to the baby. You might perhaps be advised to take other medicines as well to protect your own health as well as that of the baby. There are other possible things that could be done to reduce the risk of transmitting the virus to the baby, which the specialists would be able to discuss with you. However, it would be entirely your choice which treatments to accept. [If you want to give further information about avoidance of breast-feeding and possible elective caesarian section, then be sure to emphasise that it would be for the woman to decide whether to accept these interventions.]

If I don't have treatment, would my baby definitely be infected?

No. The best estimate for the UK is that if a woman with HIV doesn't take any treatment, then there's about a 12-13% (one in eight) risk that her baby might get the virus, or more if she breast-feeds. This means that most babies are not infected.

With treatment, the risk can be reduced even further. Recent research suggests that for women who both take medicines and have a caesarian section, it is as low as 2%. Even if you chose not to have treatment, your baby could benefit from being looked after by a specialist paediatrician who cares for babies who may have HIV.

If I tested positive, would I have to have an abortion?

No, not at all. The reason for the test is so we can do the best for you and your baby, not to stop you from going on with the pregnancy. Even if you test positive, there's a very good chance that you can have a healthy baby. [Occasionally, women do find a positive HIV test such a shock that they don't feel able to carry on with a pregnancy and decide to have an abortion, but that's not why we recommend the test.]

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