Developing communication skills in medicine

Counselling for an HIV test

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Summary

Doctors may feel uncomfortable with the prospect of discussing a human immunodeficiency virus (HIV) antibody test with their patient. This is in part because they do not enquire about high risk activity as part of a medical history. With increasing medical and public awareness of both the clinical manifestations and social implications of HIV infection, it is important that all doctors receive guidance on how to deal with these issues. Counselling is not the usual term used to describe obtaining informed consent. In the general medical setting, tests for hepatitis B and syphilis are routinely carried out without specific consent even though results of these tests may have profound effects on both the patient and their sexual partners. However society and ethical considerations have made HIV testing different. HIV testing will inevitably become more widespread, and thus become a more routine part of patient investigation and management.

Keywords: communication skills, HIV testing, AIDS

The purpose of this article is to provide a practical guide to all doctors who may need to counsel and test a patient for the presence of HIV antibody (box 1). Its aims are to answer the questions: why? when? how? where? and who?¹ Counselling for an HIV test is not a form of psychotherapy and need not take long. Large books written on the subject have added to its mystique and user unfriendliness. The skills required are no different from those necessary in any clinical situation. Namely, awareness, sensitivity and good communication.

Doctors are often too embarrassed to ask patients about HIV-related issues so information may not be shared. The patient may be concerned that the illness may be HIV-related and be afraid to ask. They may have already been HIV tested or recently donated blood in which case they will know their HIV status but consider it inappropriate to tell the doctor.

Why test?

Patients sometimes believe that as long as they are not placing anyone else at risk, a knowledge of their own HIV status is unnecessary. This is no longer the case. Time and many clinical trials have shown improved long-term outcome in those HIV-positive patients who are aware of their infection, and who are treated prophylactically at appropriate stages of their illness against opportunistic infections.² Treatment with antiretroviral agents has also improved outcome³ and may reduce the rate of vertical transmission from mother to child. The introduction of antenatal HIV screening is being strongly driven by the Department of Health in the UK.^{4,5} Detailed discussion about sexual practices and lifestyle at this stage may also allow for behaviour modification, and therefore a reduction of overall risk to the patient and their partner.

These and other issues, for which guidelines have been published by the World Health Organisation form the basis of pre-test counselling.⁶ In most instances 'informed consent' is being sought. This involves giving the patient information about the nature of the tests and the medical, social and legal implications of the result. Clearly, the information given must be tailored to the individual's needs. It is assumed that the patient has the capacity to understand the information provided, in order to assess the risks and benefits of testing.

Life assurance

Patients often want to discuss the implications of HIV testing for life assurance. There are two ground rules:

- any insurance or endowment policy taken out before 1988 remains valid
- insurance companies currently ask "Have you ever had an HIV antibody test or advice and counselling about AIDS?".⁷

Clearly it is up to the individual to be honest. In order not to discriminate against the socially responsible patient who has had a negative HIV test (who is not necessarily high risk), the Association of British Insurers has recommended that proposers should not be asked about negative HIV tests.⁸ Insurers say that they will soon ask the question "Have you ever tested positive for HIV?". This is the question asked in Canada, France and the US, where no significance is attached to a previous negative HIV test.⁹

Out-patient testing

A detailed history of sexual activities, drug use, past illnesses, foreign travel and blood transfusions is essential for the doctor to get a clear understanding of the likelihood of infection. Timing the test at least three months after risk activity ensures a reliable result. Counselling also involves assessing the patient's understanding of risk and discussing high risk behaviour. It also reassures them that everyday social and domestic activities are safe. Underlying this process are the dual aims of prevention and support. The patient should be assured of continued medical care no matter what the result is. If the risk of HIV is significant it is also appropriate to enquire how the patient would feel if the test

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Aims of counselling before an HIV test

- provide information on the technical aspects of screening
- provide information on the possible implications of being diagnosed positive or negative (eg, medical, social and legal)
- educate on the risks of transmission, and discuss behaviour that might reduce these risks

Box 1

Physical conditions which may indicate underlying HIV infection

- tuberculosis
- extensive fungal infection (eg, candidiasis)
- extensive Herpes zoster
- persistent lymphadenopathy
- persistent diarrhoea
- unexplained weight loss
- oral hairy leucoplakia
- Kaposi's sarcoma
- pyrexia of unknown origin
- lymphopenia
- thrombocytopenia
- severe community acquired pneumonia
- non-Hodgkin's lymphoma

Box 2

Examination or treatment without patient's consent

The following are examples of occasions when examination or treatment may proceed without obtaining the patient's consent:

- for life-saving procedures where the patient is unconscious and cannot indicate his or her wishes
- in certain cases where a minor is a ward of court and the court decides that a specific treatment is in the child's best interests
- treatment for a physical disorder where the patient is incapable of giving consent by reason of mental disorder, and the treatment is in the patient's best interest

Box 3

Figure Thoracic CT scan in a HIV-positive patient showing mass in the left lower lobe: biopsy revealed a B-cell lymphoma

proved positive. This may help minimise adverse psychological consequences.¹⁰ In some areas of the US written consent has been sought. In the UK written consent is only required by blood donors and purchasers of life assurance, neither of whom receive counselling. In addition, those who require tests to travel or work abroad may not receive counselling.

Post-test counselling (or information) involves a discussion of both the result and with whom the patient wishes to share the information, eg, partner, dentist and doctor. Information regarding safer sex, injecting practices, treatment options and follow-up should be given if appropriate.

These recommendations for HIV counselling are based on the out-patient setting, genitourinary medicine clinics, and same-day testing services where the worried but otherwise well person requests testing. This formula can be followed in this setting.

In-patient testing

On the general medical ward extensive counselling is probably most useful for HIV-testing donors and recipients involved in needlestick injuries. In clinical practice, it is more likely that a doctor has to discuss HIV testing with a seriously ill patient who is being investigated for one or more of the conditions listed in box 2. In some instances, it may be appropriate for the patient to be directed to a Department of Genitourinary medicine for HIV testing. In other cases, if the patient is very unwell, it may be important that a rapid diagnosis be reached and it may be inappropriate to delay testing. Asking another doctor to see the patient in order to counsel them for an HIV test may delay the process and increase the patient's sense of isolation, guilt and fear.

When HIV testing a seriously ill patient in order to make a diagnosis you are acting in the patient's best interests. You should normally obtain informed consent. However, there are a few exceptions (box 3). It is helpful to talk to the patient in a quiet area where you cannot be overheard. Allow up to 15 uninterrupted minutes for the process. A discussion of diagnostic possibilities and the results of investigations to date may be a helpful introduction. If there is clinical or laboratory evidence of immunosuppression this should be disclosed. It may be useful to ask if the patient has any thoughts as to why this might be. Direct answers to questions about marital status, sexual partners and any sexually transmitted diseases should be sought. A history of transfusion, glandular-fever-like illness and drug use is also taken. Ask the patient if they think that they are at risk of HIV and if they have been tested. If their immediate management might be changed if they were HIV-positive, explain this to them. Ask them if they would be willing to have an HIV blood test performed. It is appropriate to indicate how long the test will take and who will give the results. It should be explained that if the test is positive a confirmatory test will be required on another blood sample. Further discussion regarding partners, insurance and further information about HIV can be deferred until another time. A checklist of points to cover may be helpful (box 4).

Confidentiality

Confidentiality is a very difficult problem. Many articles on counselling stress how vital it is to ensure the patient's 'absolute confidentiality'. In reality when an HIV-positive patient becomes a hospital in-patient and his diagnosis is written in the hospital notes, confidentiality is a relative thing, as it is for all hospital in-patients. Medical notes should at all times be 'absolutely confidential'. However, investigations with the patient's diagnosis and name written on them are sent to other departments or hospitals routinely. Thus, staff not immediately involved in patient care may have access to this information. The patient can be reassured that their HIV results will only be seen for 'medical' reasons by doctors and nurses involved in their care. Also information written on forms can be modified so that a diagnosis of HIV is not immediately obvious. Samples must, of course, be labelled 'high risk' but phrases such as 'low T4 count' or 'retroviral illness' may be used. The patient may often be reassured that the front of their case notes will not be changed in order to identify infection.

It is important to discuss with the patient who they want to be made aware of their HIV diagnosis: partners, their family doctor, dentist, etc. In general, information is best disclosed on a 'need to know basis' only.

Giving the result

Telling a patient they are HIV positive is not easy. It is best done by the doctor who counselled the patient and performed the test. The patient may be shocked,

Pre-test counselling checklist

- introduce self, identify role
- assess risk factors
- explain HIV/AIDS
- explain test procedures (a blood sample; confirmation of a positive result with a second sample)
- discuss possible advantages, including early diagnosis and treatment, reassurance, certainty, early treatment, better motivation for safer sex, safer drug use
- discuss possible disadvantages, including mortgage and life assurance implications, and, social/relationship prospects
- discuss coping with a negative or positive result; identify personal, social and medical support systems
- discuss how to protect sexual partner/s in the meantime (safer sex and/or safer drug use)
- if female, discuss pregnancy and fertility
- discuss who to tell/who has been told

Box 4

and afraid that they will be rejected by their partners, family, friends, and doctors. They will need a lot of support from medical and nursing staff.

Ethical considerations

In November 1995, the General Medical Council released a series of booklets concerning the duties of a doctor. One of the four booklets was entitled *HIV and AIDS, the ethical considerations*. It covers aspects of the doctor/patient relationship, a doctor's duties towards patients, duties of doctors infected with the virus, consent to HIV testing, confidentiality, informing other healthcare professionals and informing the patient's spouse or sexual partner. This booklet is essential reading for all doctors, regardless of their speciality.

Conclusion

In conclusion, by discussing HIV-related issues routinely with their patients, doctors will feel more confident about dealing with them. Doctors should not look upon HIV testing as a particular problem. It is simply yet another challenge to their skills and abilities to communicate with their patients, and improve the quality of their care.

1 Kipling R. *The elephant's child*.

2 Peters BS, Coleman D, Becks EJ, *et al*. Changing disease patterns in AIDS. *BMJ* 1991; 302: 726-31.

3 Fishel MA, Richman DD, Grieco MH, *et al*. The efficacy of azidothymidine in the treatment of patients with AIDS and AIDS related complex; an open uncontrolled treatment study. *N Engl J Med* 1987; 317: 185-91.

4 Department of Health. Department of Health guidance PL/CO(92)5, appendix 2: guidelines for offering voluntary named HIV antibody testing to women receiving antenatal care: London: Department of Health.

5 Pediatric AIDS Clinical Trials Group. Important therapeutic information on the benefit of zidovudine for the prevention of transmission of HIV from mother to infant. Bethesda, USA: National Institute of Allergy and Infectious Diseases. Feb 20, 1994.

6 World Health Organisation. Guidelines for counselling about HIV infection and disease. Geneva: WHO, 1990.

7 Barton SE, Roth P. Life insurance and HIV antibody testing. *BMJ* 1992; 305: 902-3.

8 Byrne L. Insurers relax questions on HIV. *BMJ* 1994; 309: 359.

9 Reynolds MA, Barton SE, Singh S, *et al*. HIV and insurance commentary. *Int J STD AIDS* 1994; 5: 322-6.

10 Miller R, Bor R. *AIDS: a guide to clinical counselling*. London: Science Press, 1988.