Personal View

While helping to prepare the paper on 22 February (p 527) I became aware of various ethical questions relevant to research into human T cell lymphotropic virus type III infection (HTLV-III) in intravenous drug abusers. I offer some of my thoughts to stimulate discussion of these neglected questions.

Is it reasonable to test sera from a certain group of individuals for evidence of HTLV-III infection without first asking the permission of each individual?

The answer must be yes. The information obtained is essential for anticipation and planning of health care provision for these individuals (and others in similar groups). Such screening is not unprecedented. Although the context is different, society deems it acceptable to screen blood for various infections (such as for syphilis in antenatal clinics) without patients being routinely asked.

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As a survey had been conducted results were available for individuals (in this context coding the sera would have been a device that some researchers use to avoid facing the reality that laboratory results apply to individuals and to avoid facing some of the questions I pose). Should we then identify and inform HTLV-III positive individuals of their positivity and its importance? Turning the question around, if we know that a person is HTLV-III positive can we decide on their behalf not to tell them?

An HTLV-III positive intravenous drug abuser who exposed a non-abuser sexual consort to infection might well be furious to learn that his HTLV-III positivity had been known but not communicated to him: the consort would certainly have such feelings.

Should contact tracing, screening, and counselling occur?

The conventional answer seems to be no. The result? We have contact tracing to prevent infection with relatively trivial diseases such as gonorrhoea and syphilis but not for the much more serious untreatable HTLV-III infection. Why do we not want to prevent HTLV-III infection by the only means currently available—identifying and educating those infected and those most at risk from contact with those infected? Contact tracing would undoubtedly create anxiety in index patients, but they should, with our sympathy, accept responsibility for actions that cause them to be an index patient in order that others might be spared their anxieties.

What can we do to help intravenous drug abusers to minimise the spread of infection?

Obviously, intravenous drug abusers should be given advice about sexual contacts and told not to share needles or syringes if they persist with the abuse. They are not known, however, for modifying their behaviour as the result of advice: if the suggestion that needle and syringe sharing was responsible for the high prevalence of HTLV-III infection in intravenous drug abusers in Edinburgh is correct it seems sensible to arrange easy purchase of needles and syringes for them. This suggestion may be dismissed as tantamount to condoning intravenous drug abuse, but are such judgments a luxury when confronted with such a dangerous infection?

To whom does a general practitioner's responsibility lie when an HTLV-III positive intravenous drug abuser and his (presumably negative) regular sexual partner are both his patients? Ideally, the general practitioner should tell the drug abuser and ensure that he or she then tells the partner. But if the partner was not told should the general practitioner say nothing? If the HTLV-III negative partner were female and became infected this would affect her sex life, make pregnancy risky for her, and provide a substantial mortality rate for her babies. Is this too high a price to pay for the luxury of silence?

Opinions will differ depending on whether you think control of a potentially lethal infection is the paramount consideration.

Should a hospital patient who has been found to be HTLV-III positive have this result routinely communicated to the general practitioner even if the patient would prefer that the general practitioner be kept ignorant?

There are two reasons why HTLV-III positive patients might object to their general practitioners being told.

Firstly, the patient may wish to conceal from his general practitioner embarrassing (but medically relevant) facts. Secondly, he may be worried about breaches of confidentiality. If this is the case the medical profession needs to be able to guarantee that routine communication of information within the medical profession does not leak outwith the profession (such an exclusion would cause problems as it would have to apply to paramedical staff such as secretaries and receptionists). General practitioners (who are the only people in a position to integrate all medical information about a patient in the patient's best interests) surely should be told relevant, indeed vital, information necessary to ensure that his patient will receive optimal treatment if illness develops. A general practitioner who had been unknowingly treating an ill HTLV-III positive patient (and sending, unmarked, high risk specimens to laboratories) would, in my view rightly, be furious that his patient management was less than optimal because of lack of highly relevant information that had been withheld.

Despite widely reported statements that "information about [acquired immune deficiency syndrome] AIDS patients is in the same class as information about any other sexually-transmitted disease, and no one can be told, other than people whom the patient wants to be told," the Department of Health and Social Security's draft code on confidentiality of health data states, "professionally qualified persons employed by a health authority have professional obligations to keep personal health data confidential and to ensure that they are disclosed only to those who need them for the health care of the patient." So the general practitioner can, and I believe should, be told.

Can anything else be done to prevent further spread of infection?

The high prevalence of HTLV-III infection in certain groups should be publicised so that their contacts (both sexual and needle) will know the risks that they are running. Certainly in Edinburgh (with about 51% HTLV-III positivity rate) intravenous drug abusers might well become the modern equivalent of lepers. This would be their fault as they have already made a decision to behave outwith conventional society values. To be fair that decision may be influenced by multiple factors, some of which will have been outwith intravenous drug abusers' control, and conventional society often seems to have little to offer them as an alternative.

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Some of my comments will elicit controversy and ought to elicit more productive discussion than has currently occurred. Such controversies had better be resolved quickly for, if we do nothing, the extent of HTLV-III infection in intravenous drug abusers in Edinburgh and possibly elsewhere in Britain will at least be perpetuated and may well become worse. A particular worry is that HTLV-III infection may spread further into the general population via heterosexually active intravenous drug abusers.

Those who are not alarmed do not realise the potential of the AIDS problem.

I should like to acknowledge support from the Roseanne Campbell Hepatitis Research Fund. Roseanne Campbell, who had never abused intravenous drugs, died from hepatitis B acquired from contact with someone who had.

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