

AIDS stigma in insurance market

David Morgan

Last spring I approached a well known insurance company to arrange an endowment policy to cover the cost of my children's higher education. The proposal asked the now standard question, "Have you ever been tested for HIV (AIDS)?" I replied that I had, adding that the test was negative and was one of a series of multiple tests to identify a suspected tropical illness after my visit to South East Asia in 1987.

I had arranged this test myself as neither my general practitioner nor the consultant to whom I was referred suggested the possibility of testing for AIDS. Neither had asked about my sexual behaviour or other likely sources of HIV infection. In my general practitioner's opinion the possibility was too remote to consider seriously in my case. I had no specific reason to suppose a test would prove positive, but my symptoms—progressive weight loss, recurrent fevers, persistent dry cough, and partial loss of sensation in my fingers and toes—suggested symptomatic, if not circumstantial, reasons for requesting a test. As the results of other investigations over the previous year had been negative I felt an unequivocal assurance was needed on this point.

No reference was made to this test in my general practitioner's personal medical report to the insurance company. My symptoms had remitted spontaneously some months before, but there was an apparent discrepancy between the information I had volunteered on the proposal form and my general practitioner's report. I was subsequently asked to attend a medical examination with an independent practitioner, which I was advised by the insurance company would include a test for HIV.

The examination was arranged by an agency on behalf of the insurance company. The letter telling me of an appointment with a local general practice enclosed a printed information sheet on AIDS. This claimed that tests for HIV were now routinely required by insurance companies considering life risks. I was assured that I would be counselled by an experienced practitioner before being asked to consent in writing to the test and that the results would be sent to my general practitioner at my request. It was also implied that my proposal would not be considered unless I agreed to the test.

On the day of the appointment the general practitioner said that he had not been told of the examination and asked me to come back at another time. I suggested that there must have been some communication from the agency, and eventually he telephoned their office. After speaking to someone who seemed to know about my case he located a package, which contained a prepaid envelope addressed to a London laboratory, printed

instructions, and a syringe. The instructions explained how the syringe should be assembled and the sample dispatched. It contained no other advice or information.

As the general practitioner prepared to take a sample I said that the advice sheet I had received mentioned counselling before I consented to the test. He glanced at the sheet and remarked that it was not necessary to go through all that, adding, "Anyway, you know about AIDS, don't you? It's a bloody

. . . you know about AIDS, don't you? It's a bloody disaster. If you've got it you're dead.

disaster. If you've got it you're dead." Nothing more was said about either the clinical aspects of AIDS or the social implications of being tested. A blood sample was taken, labelled, and placed in the envelope for dispatch.

The doctor was unable to tell me how I would be notified of the result. His attitude clearly implied that as I was not his patient what happened next did not concern him. In his opinion insurance companies "had this whole thing out of proportion" and were wasting valuable medical time. He had not ordered the test and did not expect to be told of the result; nor did he know what would happen to the laboratory report. He advised me to contact the insurance company if I wanted to know the result, but added—as if by way of reassurance—that if the company accepted my proposal I would know that I was safe.

At the end of the consultation I told him that the administration of the test had departed from the procedures described on the advice sheet circulated by the agent. I had not been counselled; I had not been asked to sign a consent form; and no arrangements had been made to inform my general practitioner of the result. He seemed unperturbed and laughingly remarked, "You don't have a tape recorder on you, do you?" I was asked to return in two weeks for a medical examination, which he regretted he was unable to complete that day.

There are several aspects of this encounter which were disconcerting to someone like myself whose understanding of AIDS is at best rudimentary. Most disturbing of all was the general practitioner's implicit suggestion that if the insurance company declined my proposal it might mean that the test result was positive. Until I hear from the company—which may take several more weeks—the outcome of the test will remain a matter of speculation and concern to my family. The

insurance company, however, might decline my proposal for any number of reasons and, as a matter of policy, are unlikely to explain why. If the proposal is refused I have no option but to seek another test on my own account. Given the doctor's assessment of the risks of HIV, waiting for the result of any subsequent test is likely to be stressful.

These anxieties could have been alleviated by more circumspect counselling and a request for the test report to be sent to my general practitioner. But, as the doctor who tested me said, I was not his patient and his lack of concern for my welfare was evident enough. He was acting for a fee on the instructions of a secondary agent of an insurance company whose sole interest was the assessment of commercial risks. The patient seems to have no control over the distribution and use of personally sensitive information and no means of appeal or redress. There is a presumption that legally the results of such tests are the property of those who ordered and paid for them. In common with other information on credit status it is possible that positive results may assume a market value among financial institutions and agencies concerned with life risks. Confidentiality means very little in the commercial world.

Furthermore, while insurance companies routinely test for AIDS, not everyone is tested as a matter of routine. Informants in the insurance industry suggest that I was selected because I admitted to a former test. From a commercial point of view a previous test (whatever the result) is likely to indicate the presence of other factors suggesting an adverse risk. These risks are generally associated with the transmission of AIDS through socially stigmatised behaviours and groups. The fact of having been screened raises the possibility of social as well as medical risks; it is thus an important factor affecting an individual's standing in the market and elsewhere. At the very least I can now expect to be subjected to further investigations and tests whenever I apply for life insurance, a mortgage, long term credit, or even a job.

These observations occurred to me after I had been commercially tested for AIDS. It is now unlikely that I shall discover the result. (The agent failed to reply to my general practitioner's request for a copy of the test report.) It is highly improbable that I am clinically at risk, but I am now touched by the stigma of the associated social risks. It is difficult to believe that my experience is unique; it is also difficult to foresee what these risks might be unless medical practitioners exercise tighter control over tests for HIV.

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