Health workers, AIDS and patients' rights

Informed consent or unacceptable risk?

Should health workers who have acquired the HIV/AIDS virus be permitted to conduct invasive medical procedures which have the potential to put their patients at risk? The editors of this issue of the Alternative Law Journal put this question to the following people for comment:

Julie Hamblin, Solicitor, Health and Law Ethics Group, Mallesons Stephen Jaques, Melbourne

Dr Nick Crofts, Head, Epidemiology, AIDS Unit, Fairfield Hospital Jamie Gardiner, final year law student, gay rights activist and civil libertarian

Introduction

There are very few reported cases of patients acquiring the HIV/AIDS virus from health workers. However, publicity given to the death of an Australian dentist from AIDS and cases in the United States demonstrate the need for sensible guidelines to protect patients from risk, and to ensure the civil rights and privacy of health workers.

In Adelaide during January 1992 the evening news announced the name of a practising dentist who had died from AIDS. In the ensuing climate of public hysteria, the South Australian Health Commission was found to have no guidelines or clear policies in relation to such people continuing their professional practices. It has subsequently proposed that a register of all health workers with the virus be kept. The Australian Medical Association responded by saying it would only agree to such a register if it contained the names of all people with the virus. The Health Department of Victoria was reported in the Herald Sun as stating that dentists in Victoria who are HIVpositive and who continue to practise will be charged under the Health Act or Crimes Act. In the United States a blaze of publicity surrounded the case of a Florida dentist said to have infected four patients. These cases indicate all too

clearly how ignorance and ill-preparedness for such difficult issues can lead to unnecessary public alarm and witch hunts

The debate to date has been diverse and often ill-informed. At one extreme are those who want criminal sanctions imposed. Others have called for the establishment of trust funds to compensate victims. Some contend that HIVpositive health workers should be required to inform their patients of the potential risk. Others say informed consent is insufficient in these cases. They see it as unreasonable to expect patients to accept such risks. Some argue that health workers who are HIV-positive should not be permitted to practise at all; others that they should only be allowed to participate in non-invasive procedures and should be prevented from performing procedures such as surgery, which would pose an unacceptable risk to patients.

The US courts have responded to cases in different ways. In Estate of Behringer v Princeton Medical Center 1-88-2550 a Fronton NJ Superior Court said the Princeton Medical Center had acted properly in restricting an HIV-positive surgeon's privileges because he refused to inform his patients of his HIV status. In Leckelt v Hospital District 909 F 2d 820 (1990) the 5th US

Circuit Court of Appeals in Louisiana upheld a hospital's requirement that a nurse who was believed to be at risk of contracting AIDS be required to submit test results to his employers before being allowed to return to work. The test results were required to enable the employer to comply with infection control guidelines of the National Centers for Disease Control and the American Hospital Association. The court found that the nurse had been fired because he failed to comply with the infectious diseases regulations rather than that he had a perceived handicap.

Hospitals in Maryland, California and Chicago have been obliged to contact large numbers of patients to inform them that they have been treated by HIV-positive health workers. In October 1991 the most extensive notification law in the US was introduced in Springfield. It requires public health officials to give notice of possible exposure to anyone who undergoes an invasive medical or dental procedure by a health care professional who either has AIDS or is HIV-positive. Health workers who treat infected patients must also be notified.

The ethical standards set by the American Medical Association (AMA) would allow the State licensing boards

to revoke the licences of infected physicians. This has already been done in Indiana and Georgia where two doctors have been refused licences to practise because of their HIV status. In January 1991 the American Medical Association issued a statement on HIV-positive physicians recommending that they either abstain from performing invasive procedures that pose identifiable risks of transmission or disclose their HIV status before performing a procedure. They should then proceed, according to the AMA where there is informed consent. The AMA more recently rejected the notion of compulsory testing of physicians but supported voluntary testing of physicians at high risk.

US insurance companies are nervous about the prospect of claims by infected patients. Settlements have been made with some patients of the Florida dentist, each for \$US1 million. This has bankrupted the dentist's estate leaving nothing for two other claimants. In New York a patient of a dentist who died of AIDS has filed a class action on behalf of all his patients since 1985. The action is against the estate and his insurance company and it seeks a trust fund to compensate possible victims (Strouse v Feldman 91-14249 (Sup. Ct, Suffolk Co.)).

In Australia there have been cases concerning infection by blood transfusions but, to our knowledge, there have not been any cases involving infection of patients by health workers. The issue is one, however, which will have to be faced and, as Dr Nick Crofts points out (below), it is vital that data be available to enable adequate policy responses. Julie Hamblin considers that there is no simple or universally applicable answer to the question of whether HIVpositive health workers should be permitted to carry out invasive procedures and she highlights some of the complexities. Jamie Gardiner puts the debate into perspective by setting the record straight on some factual matters and advocating proper infection control, care and protection for those unfortunate enough to have become infected.

A humane response to a complex problem

Julie Hamblin

It is an unfortunate fact that AIDS is not the same as most other infectious diseases prevalent today. This is not so much due to distinguishing medical features as to the social construction of the disease and the stigma which is attached to HIV infection. People infected with HIV have had to deal not only with the prospect of a fatal illness but also with social alienation and widespread discrimination in accommodation, employment and access to services.

It is for this reason that respect for the rights of all people infected with HIV is critically important. Paramount among these is the right of people with HIV to remain integrated in the community and to continue to lead a productive and fulfilling life for as long as they are able to do so. This right is fundamental to the question of whether a health worker infected with HIV should be permitted to continue to work without restriction. Any restrictions on a health worker's right to work will be justifiable only if they are unavoidable in order to protect other more compelling rights or interests.

The argument that health workers should not be permitted to carry out invasive procedures rests on the premise that it is unethical ever to expose a patient to a risk of HIV infection in the course of receiving medical treatment. People in need of medical care are already in a vulnerable position by reason of their illness and therefore require

special consideration and protection. In these circumstances, it could be argued that exposing these people to even a very small risk of HIV infection is unjustifiable. Moreover, there is a public interest in containing the spread of HIV generally which supports the view that an HIV-infected health worker should not be permitted to carry out any procedure that poses a risk of HIV transmission.

Such a rigid stance, however, fails to appreciate the range of competing considerations, both ethical and practical. First, there is the argument that any risk posed by an HIV-infected health worker can be adequately addressed in other ways, such as by ensuring that all health workers adopt appropriate infection control procedures to avoid transmission risks. Unforeseen accidents may still occur, but proper infection control procedures can reduce an already small risk of HIV transmission to one that may be considered to be within acceptable limits.

Second, any decision to prevent HIV infected health workers from carrying out invasive procedures will have repercussions far beyond the consequences for the particular health workers concerned. It will represent a further way in which people with HIV are excluded from participating in the community on an equal basis and in which they may become isolated from necessary care and support. This, in turn, may obstruct

other HIV prevention strategies which aim to encourage voluntary testing and the adoption of the behaviour changes necessary to reduce the risk of HIV transmission.

Third, there is the issue of patient consent. It could be argued that the critical question is not whether an HIVinfected health worker carrying out an invasive procedure exposes the patient to an unacceptable risk of HIV transmission but whether the patient him or herself has been given the opportunity to make an assessment of the risk and to decide whether to assume that risk. If the patient has been able to make an informed decision to agree to be treated by an HIV infected health worker, many of the ethical concerns outlined above may disappear. Patient autonomy would become the governing ethical principle.

While patient autonomy is undoubtedly an important consideration in this context, one must question closely whether it can be relied on as a complete solution. Because of the inherent vulnerability of people who are sick and in need of medical treatment and the authority generally accorded to the medical profession, it may be unrealistic to suggest that patients can make a truly free and autonomous decision. For this reason, the notion of patient autonomy must not be used to give decisions a legitimacy they do not deserve. We may feel more comfortable about permitting

HIV infected health workers to carry out invasive procedures when their HIV status has been disclosed to the patient, but the 'consent' of the patient may not in itself be a sufficient justification.

The diversity of factors that must be taken into account when determining whether an HIV infected health worker should be permitted to carry out invasive procedures means that the question defies a simple or universally applicable answer. The balancing process required will be different in each case. One must

consider matters such as the extent of the infection risk by distinguishing, for example, between abdominal surgery and the mere taking of a blood sample. One must look at the consequences for the particular health worker. Could he or she be assigned to other duties that do not put patients at risk and are measures available to preserve the confidentiality of the health worker's HIV status? Are the circumstances of the patient such that he or she is in a position to make a free and informed decision as to whether to assume the risk?

In all cases, the only truly effective approach will be one that involves a careful consideration of all these factors and discussion and mediation between the individuals concerned. The very complexity of the problem suggests that there may be creative solutions in individual cases that harness the co-operation of both health workers and patients in achieving the common goal of reducing the risk of HIV transmission and responding humanely to the needs of people with HIV.

Health care workers, HIV and informed debate

Nick Crofts

Policy should be based on data. As an epidemiologist, my role is to collect such data, attempting to free it of as many biases as possible, and understanding and describing its limitations, so that policy can take account of the current state of human knowledge. Before attempting to answer the question, I wish to discuss some of the processes that underlie epidemiology's ability to provide data for the formulation of policy.

The knowledge we have which raises this question is epidemiological. Epidemiological method alone cannot prove anything; it can adduce evidence until a conclusion is reached on a balance of probabilities; not unlike the operation of the law, as I understand it. It is not 'proven' that smoking causes lung cancer; to me, however, as to most other epidemiologists, the conclusion is beyond reasonable doubt because of the weight of evidence. It is not 'proven' that the dentist in Florida transmitted HIV to his patients, nor, if this is the case, how it was transmitted. That he did so is a conclusion reached on a balance of probabilities, perhaps not as strong as 'beyond reasonable doubt'.

There are many aspects to the concept of risk in relation to HIV-infected health care workers (HCWs). These include the risk of transmission of HIV from the infected HCW to the patient, the risk of HIV neurological disease impairing the HCW's judgment, the risk of transmission of other infectious diseases from an immunodeficient HCW to an immunodeficient or immunosuppressed patient (for example, tuberculosis), and the risk of stigmatisation and

discrimination of the infected HCW contingent on any breach of confidentiality. Epidemiology can deal with only a few of these.

Risk as a concept, outside its strict epidemiological definition, is poorly defined, and quantification of risk is a task fraught with dangers. Calculation of the risk of transmission of HIV from an infected HCW to a patient can be approached in three ways:

- by direct measurement of experience: how many infections have actually occurred after how many 'exposure-prone' procedures by how many infected HCWs? Such observational evidence is always problematic, because we cannot know of all infected HCWs, or of all transmissions, and so on. In this instance, 'risk' is really a summary of past experience, which may be incomplete (because of lack of observations or lack of understanding).
- by argument by analogy: in this case, the most fruitful analogy being with hepatitis B, which is transmitted in the same ways as is HIV, but perhaps two orders of magnitude more efficiently. We certainly have experience of hepatitis B virus having been transmitted to patients by HCWs who were carrying the virus and were infectious, and this experience gives us some general understanding of 'exposure-prone' situations. However, we do not understand the factors influencing transmission of HIV, particularly those influencing infectivity, and so we cannot at present fully understand the limitations of this analogy.
- by argument from first principles: theoretically, given what we do know

about HIV and its transmission, we can build a picture of situations in which there is a real possibility of transmission from infected HCW and to patient.

'Risk' defined by these latter two methods is a theoretical concept and difficult to quantify except within wide bounds.

All three methods are used to advance our understanding of the epidemiology of HIV: argument from first principles and from analogy provides hypotheses to be tested by observation, where this is possible; observation helps advance our understanding of the basic principles, and the limitations of analogy.

All three methods indicate a common conclusion at present: that there is a real possibility of HIV being transmitted from an infected HCW to a patient, given the right combination of circumstances. This conclusion is not proven beyond any doubt, perhaps not even beyond reasonable doubt. It is likely. What epidemiological method cannot do at present, however, is to quantify that possibility in anything more than the most general of terms. For instance, the Centers for Disease Control have estimated that a surgeon infected with HIV presents a chance of transmitting HIV in performing 3500 'exposureprone' procedures (an estimate of the working life of such a surgeon) of between 0.8 and 8%, i.e. of infecting between 28 and 280 patients. Such a calculation can say nothing about the 'risk' to any particular patient during any particular procedure by any particular surgeon; it simply defines the limits of our ignorance.

This quantification exercise is fundamentally important, because in the end the answer to our question rests on a balancing of risks, to patient, to the HCW and to society, in a particular moral framework. To do this effectively requires a reasonable understanding of the magnitude of these risks, or in the absence of this, an understanding of the potential magnitude and the limits of uncertainty. This balancing is a dynamic process, involving the operation of the law, of the political process, and of those mechanisms that exist for negotiation between HCWs and patients and between HCWs and their employers.

Quantification of 'risk' is therefore a necessary but by no means a sufficient component of the process of answering the question.

A profoundly important guiding principle for all HCWs is that of primum non nocere— first, do no harm. As much as ethical absolutes can exist, this to me is one. The possibilities of transmission of HIV to a patient, of neurological disease impairing clinical judgment, or of transmission of another disease to an immunocompromised patient would weigh extremely heavily on any ethical HIV infected HCW. In the sense of this guiding ethical princi-

ple, which comes from the HCW's ethics, the question which our question begs is answered: if the risk exists, steps should be taken to eliminate or minimise it. As an epidemiologist, I am reasonably convinced that a risk exists. What we have is an operational, not a moral or legal, question: permission to put their patients at risk having been denied by the ethical standards of their own professions, how is this to be reasonably accommodated with the rights of HCWs to privacy and the practice of their profession?

In most cases such accommodation can be found, through counselling of the infected HCW based on a clear understanding of current knowledge regarding transmission and risks, and of the limitations of these risks. There is, however, a need for legal sanction for those, probably extremely few, cases in which the ethical and social processes do not minimise or eliminate risk. This argument is somewhat clearer in relation to the question of risk posed by the neurologically impaired HCW, for which useful analogies exist in relation to drug use, particularly alcoholism. Standards for practice in these circumstances are in place, for which legal sanctions exist as a matter of last recourse.

Given the ethical responsibility of the HCW, and the demonstrated and theoretical risks of harm to the patient, if there is access to adequate counselling and support it does not seem to me to be defensible for an infected HCW to not know what situations are risky, and not to absolutely minimise their involvement in such situations. Informed consent to such involvement, if such a thing is indeed achievable, may lessen the patient's claim on the HCW, but in no way affects the ethical responsibility of the HCW. A corollary is that it is therefore indefensible for a HCW involved in patient care with potential risks of transmission and calls upon clinical judgment not to know their HIV risk and status. What remains is the provision of adequate, accessible and confidential counselling and support for HIV infected HCWs. The necessary accommodation rests on a recognition of the HCW's rights and their balance with their ethical responsibilities. It seems to me that the provision of such counselling and support, of all the issues around this question, is the need which requires the most urgent atten-

Public health and private interest: the lessons in the Florida dentist

Jamie Gardiner

Partly because AIDS was a new and mysterious and apparently fatal disease, but even more because it was in the West linked to gay men, gay male sex and taboo lifestyles, it provoked and provokes a phobic reaction which causes the professions, the media, and the public to treat it as much more dangerous and infectious than it is. To catch AIDS is, at a deeper symbolic level, to catch homosexuality; and the facts that homosexuality cannot be caught at all, and AIDS is fairly hard to catch, and cannot be caught casually, play no part in the equation.¹

Against this background the public health goal has been to reduce the harm done by this epidemic, both medically and socially. This involves minimising the transmission of the HIV virus, treating those who are sick, and seeking scientific advances to prevent or cure the infection. It also involves preventing the secondary harmful effects of the epidemic manifested in discrimination and prejudice, whether gross or subtle.

As often happens, the individual interest and the public interest may, and usually here do, conflict. The public health interest is in reducing the overall incidence of the disease and the harm it causes. The private interest of each individual is in avoiding all personal risk of the disease.

This Grail of perfect safety is of course unattainable, but many who should know better — the medical profession, and Australian surgeons in particular, have been especially foolish in

still pursuing it. And now we have the case of the HIV-positive dentists.

Those who want to test all surgical patients (though not, apparently, all surgeons) before every operation completely miss the public health point, and thereby endanger individual health too. As the World Health Organisation has long pointed out, universal infection control procedures are essential. For HIV infection is not the only fatal disease which can be transmitted through blood, and is certainly not the most easily transmitted, as Nick Crofts points out. So uniform and routine infection control procedures will protect surgeon, dentist and patient against more than just HIV. This is particularly relevant with HIV, since testing of either party cannot ensure that they are uninfected,



because HIV infection does not show a positive test for up to a few months. Measures to exclude the infected breed a false (and dangerous) sense of security; if proper infection control is ignored, then patients, or health care workers (HCWs), will get infected. Indeed, treating HIV-positive patients or HCWs as special cases leads to the mistakes which come of unpractised, non-routine procedures. In most of the few cases where HCWs have been infected the patient's HIV-positive status was indeed already known.

The case of the American dentist at first sight appears alarming. The immediate reaction of many is to call, as in Adelaide, for HIV-positive HCWs to be removed from patient care. However, the instincts of those who, whether on public health or related civil liberty grounds, oppose such reactions prove to be correct. For it seems that the Florida mentist did not infect patients on whom the operated, but rather that his colliagues did, by failing to follow routine sterilisation procedures on the instruments used when they did work on his treth.²

Thus the wrong defendant was sued and bankrupted, yet another panic was started, and the wrong lesson was once again drawn by the media. Perhaps, if the media had maintained interest long enough to find out the results of the detailed investigation into how the patients were in fact infected, there would have been a worse panic. For the possibility of HIV-positive dental patients passing on their virus to the

next patient — albeit by the *novus actus* interveniens of the negligent dentist — might be even more frightening.

The other issue raised by this case is the myth of perfect safety. If there were no social costs to its pursuit, then it would not matter. But there are and it does. The costs are the individual and social harms of discrimination and loss of productive capacity. While the objective risks of HIV transmission by a surgeon or dentist are, say, one in a million, it makes no sense to deprive those who are HIV-positive but well, of their livelihood, nor the community of their services. For when the risks of infection are some orders of magnitude below those of ordinary life, or certainly of ordinary medical practice, no socially useful purpose is served by exaggerating them.

This would be no consolation to the unlucky individual in whom a genuine one in a million misfortune materialised, but this is no new problem. Public health policies — such as immunisation campaigns, for instance — can seldom point to specific individuals who did not get sick; only statistical research can demonstrate their value. Yet the rare individual who suffers from a side-effect of the generally beneficial policy is very visible.

A proper policy will, of course, include provision of the fullest assistance for those who do so suffer: not as tort compensation for individualised negligence, but as part of the public cost of a public benefit.

This conflict has a parallel in some fundamental problems of the modern tort of negligence: two people who suffer identical harms are treated utterly differently depending on whether an adequately resourced or insured individual can be found and held guilty of negligence.3 Furthermore, the unlucky, negligent defendant will usually not have been guilty of any personal moral culpability, by the time an arcane investigation of duty of care and lengthy chain of causation has been pursued. The public interest would be better served by a public insurance scheme which supported all victims of misfortune, rather than only those who can find someone the law will impose responsibility on, and who is worth suing; the rare 'lucky' tort plaintiff will get a lot less, most likely, though the much more common victim of misfortune who at present gets nothing would get something.

The public interest is better served by ensuring that proper infection control practice is routine and universal, and that all who are affected by HIV get the fullest health care and protection from discrimination. The alternative is to pursue individualised remedies which 'compensate' the lucky victim and stigmatise the others as second class citizens, and to waste resources singling out known HIV-positive dentists and surgeons and patients for special treatment, leaving the rest of us to the sort of carelessness which infected patients in the Florida dentist's practice.

References

- See also Gardiner, J., 'Legal Rights and Discrimination' in Monash University Centre for Human Bioethics, Proceedings of the Conference: AIDS, Social Policy, Ethics and the Law, Melbourne, 1986, p. 59.
- 2. Carr, A., 'How the Dentist Infected his Patients' (1991) 103 Out Rage 72.
- See Malkin, I., 'Unequal Treatment of Personal Injuries' (1990) 17 Melbourne University Law Review 685.