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PRIVACY ISSUES: HIV/AIDS DISCLOSURE

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ATTENTION: TEACHERS/STUDENTS
This paper is relevant to:

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Subject	**Area of Study**
English	Presentation of an Issue
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The Doctor-Patient Relationship

Everyone knows that what you tell your doctor ought to remain confidential. Hippocrates, an ancient Greek physician, first laid down this rule in the Hippocratic Oath. Doctors need to know as much about a patient and a patient's possible illness as they can in order to reach a diagnosis. Sometimes, this requires finding out sensitive and private information, which the patient would never reveal to a relative stranger under normal circumstances. If there were no guarantee that a patient's history, revealed to a doctor in the privacy of a Surgery or Clinic remained secret, then patients would be greatly inhibited in what they told the doctor about themselves. Lacking the whole story, the doctor might make a wrong diagnosis, and the patient could be disadvantaged.

Stigmatised Diseases

There are different requirements for confidentiality depending on different types of diseases. Some diseases carry a stigma because they are deemed socially unacceptable. All of the sexually transmitted diseases (STDs) fall into this category, although there is no medical or scientific reason why this should be so. Like other infectious diseases (scarlet fever, measles, rubella,etc) they are caused by bacteria or viruses. However, STDs do carry a social stigma and wherever stigma applies to a disease the need to protect medical confidentially becomes even more important because of the risk of discriminatory or harmful actions against those seeking diagnoses and treatments.

The Stigma of HIV/AIDS

In June 1981 the disease we now know as AIDS (the Acquired Immune Deficiency Syndrome) was first recognised. AIDS is the end result of infection with a virus called HIV, the human immunodeficiency virus. No disease at the present time carries a greater stigma than HIV/AIDS. HIV is only spread in three ways: by blood (especially via needles and syringes), from mother to baby, (before or during birth or through breast feeding) and by vaginal or anal sexual intercourse. Overall around the world, sexual intercourse is by far the commonest means of transmission of HIV, so **HIV is predominantly a sexually transmitted disease (STD) and thus shares the stigma common to all STDs. It also has the distinction of being an incurable and fatal STD, which adds a fear factor to the stigma.**

In Western societies, one of the main groups in the community first affected by HIV/AIDS were gay men, a segment of the community which is still subject to widespread prejudice. Indeed AIDS has become so identified with the gay community in Australia that the diagnosis of HIV in any male is seen as proof that the person is homosexual, or at least has engaged in homosexual activity in the past. The fact that this is not always true makes no difference to community

perception of the disease. Confidentiality and the right to privacy of medical information thus assumes extreme importance in regard to HIV/AIDS, because the disease carries such a powerful stigma, the risk of discrimination against those affected is very great.

Public Interest versus Individual Human Rights

Protection of the public health is an important responsibility of government. In the public interest, governments enact public health legislation which sometimes must overrule individual human rights. **It is a fundamental principle however, in a democratic and free society, that any measures taken which compulsorily infringe any person's basic human rights must be clearly and unequivocally the only effective way of limiting the spread of some serious and life-threatening infection to others in that community.**

The Example of Tuberculosis

Tuberculosis (TB) is an infectious disease which illustrates where an individual's rights end and the community's rights begin. Tuberculosis is a chronic, sometimes lethal disease which is transmitted by "droplet" spread. The bacteria which cause the disease are released into the atmosphere in droplets from the mouth and nose of an infected person.

It is obviously not in the interest of the community for someone to be coughing up highly infectious tubercle bacilli in schools, shopping malls and other public places, because an epidemic of TB could quickly result. In a matter as clear cut as this, the community interest is deemed to overrule the confidentiality interests of the patient. In fact, in most jurisdictions doctors are compelled by law to break confidentiality by reporting by name and address any patient they diagnose with tuberculosis to public health authorities.

Through legislation, public health authorities are given even more coercive powers over people with infectious TB. Patients can be compulsorily treated and isolated in single room hospital wards until no longer infectious. Their contacts (school friends, work mates, flat mates, immediate family) must all be followed up with skin tests and chest X rays.

Thus, some of the basic human rights of people with proven TB (eg the right to privacy and confidentiality, the right to autonomy, even the right to freedom) may be denied them, for a time at least, in the interests of the general community. In the case of TB there is public consensus that any less stringent public health response would be ineffective.

The Public Health Response to HIV/AIDS

These same public health responses have not been applied to people with HIV/AIDS in Australia, nor in most other countries. This may seem puzzling at first given that HIV is a potentially lethal infection. Indeed, since HIV first

appeared and an epidemic of HIV/AIDS has resulted in some sections of the Australian community, many people have argued that the same sort of public health measures should be applied to people with HIV, or even those deemed to be at risk of the infection, as apply to people with TB.

Some people have argued that Public health officials should have the right to test people for HIV by blood test even if they are unwilling to comply, and people found to be HIV positive should be compelled to restrict their activities in whatever way public health officials direct. If they do not do so then they should be locked up somewhere appropriate away from the general public.

People who argue in such a way are in fact arguing for quite substantial infringements of the basic human rights of HIV infected people. They often claim to be doing so out of the public interest, but in some cases one suspects their motives may stem more from dislike of the people most at risk of HIV, than from any genuine desire to enhance public health.

Why the difference between HIV and TB?

There are several differences between TB and HIV. People with infectious TB are usually unwell, whereas the majority of people with HIV are completely well in every respect except that they have a positive blood test. If untreated, people with TB will die within a year or two, while people with HIV remain well for an average period of 7 to 8 years from the time of contracting the virus. TB can be cured, and people can be rendered noninfectious by treatment; there is no cure yet for HIV and nothing can be done to stop HIV positive people being infectious.

However, the main difference between these two diseases lies in the mode of transmission. Because TB is transmitted by droplet spread, virtually everyone in a community is at risk, whereas only the sexually active or those who share needles/syringe are at risk of acquiring HIV.

A person infected with TB cannot take voluntary steps to ensure that she or he does not pass on the infection, because the very acts of breathing, speaking or coughing may make a person with TB infectious to others. Similarly, uninfected members of any community (unless they were to avoid all human contact), cannot otherwise protect themselves against contracting TB.

People with HIV infection on the other hand are a risk to others only if, they have unprotected sexual intercourse, or if they share blood-contaminated needles or syringes with them. All other **social contacts (in the workplace, in the home, at school or university, on the sporting field or in the swimming pool) pose no risk at all.**

It is obviously possible (in reasonably realistic terms) for a person infected with HIV to so govern her or his own life so as not to place others at risk. Equally, all members of the community, once they have been educated about HIV and its methods of transmission should quite easily be able to ensure that they do not

expose themselves to risks of acquiring the virus from others.

Of course, these safeguards depend on human beings acting at all times responsibly and sensibly. We all know that human beings do not always act responsibly, and not everyone has the same mental, moral or physical ability to be able to freely choose their own independent actions all the time (especially in relation to sexual activities).

Nevertheless, most public health authorities in most countries have determined that coercive provisions regarding testing and isolation of HIV infected people are not justified. In rejecting these measures, however, a heavy responsibility remains with public health authorities to ensure that people are educated about HIV/AIDS and about how best to reduce personal risks of transmitting or acquiring it.

Public Health Responses to STDs

There is a further consideration which derives from the history of public health as far as STDs are concerned. Slowly, public health authorities came to recognise over the past century that punitive and compulsory measures aimed at controlling STDs in any community did not work. It was found that the best way to control STDs was to gain the cooperation and trust of those infected and those at most risk of infection, and to provide free, easily accessed and appropriate medical services where people at risk could be counselled and voluntarily tested. Any measures which threatened the cooperation between health authorities and people at risk were found to be counter - productive.

As HIV is predominantly an STD, the same approach was adopted. There is clearly some justification for this, particularly as it upholds the basic human rights of both people at risk of, and people with, HIV. However, it is important to appreciate that the present public health response to HIV/AIDS is controversial, and there is a vocal minority of doctors and public health experts who argue that the same sort of measures applied to TB should be used to control HIV/AIDS.

Informed consent

Just as people have a right to expect that their health care provider will maintain their confidentiality, they also have a right to expect that they will not be subjected to any medical tests or treatments without their consent. In order to be able to consent fully, the person needs to be provided with sufficient information to allow her or him to make an informed decision based on facts. For example, she or he will need to know what the benefits and the disadvantages of the proposed intervention are, how much discomfort it will involve, whether there is any risk to life, whether there are any short-term or long-term side effects, and what the result of NOT having it will be. These considerations are true for any medical test or treatment, but they have even more cogency for the HIV test.

Informed Consent and the HIV antibody test

The HIV antibody test is done on a sample of blood drawn from the vein of a person - a simple enough procedure. However, a positive result has enormous and far-reaching effects on that person's life and future. It means she or he is infected with a virus for which there is no cure, that there is a very high risk that AIDS (a singularly unpleasant disease) will develop in an indeterminate number of years (2 to 15 or more), that AIDS will lead to death, and that she or he is potentially infectious to any sexual or needle - sharing partner for the rest of their life.

As well, it means that the person now belongs to a group of people who are stigmatised and frequently subjected to discrimination in a number of areas of life, and that present possibilities of curative or remedial treatment are not very hopeful. The implications are enormous; life will not be quite the same for that person ever again. It is true that the blood test itself is not the cause of the person's unfortunate situation, but rather the infection which the blood test has revealed; however, medical technology has made it possible for people to have knowledge of an unpleasant infection some years before that infection will show its presence by causing ill health. Such knowledge is not easy to come to terms with.

Arguments for compulsory HIV testing

Because of the above, the case for performing an HIV antibody test on anyone without their informed consent would have to be very strong indeed. There are three main arguments given for trying to introduce compulsory HIV testing: one is the public health argument, which has been dealt with above; the second is the somewhat more compelling argument which involves testing people who are likely to put health professionals at risk; and the third is the suggestion that people may be able to benefit from better medical management if they know their status. As will be seen in the brief discussion below, none of these arguments are strong enough to override the basic human right of informed consent.

Compulsory testing to protect health professionals

Surgeons or other doctors involved in invasive procedures are naturally concerned that they might acquire HIV from HIV positive patients (through accidental cuts, needle stick injuries, splashes of blood in the eyes etc). There is a risk to health professionals from HIV positive patients (it's low, but not zero), but there is no proven evidence that knowing the HIV - status of a patient prior to an invasive procedure actually reduces the risk.

Indeed, what evidence there is from one of the busiest HIV Units in the world (San Francisco General Hospital) implies that accidental needle-sticks etc may be more common because of anxiety amongst inexperienced staff when a patient's status is known before surgery. The standard answer to this call for compulsory HIV testing is that in this era of AIDS, health professionals must simply regard everyone as being potentially infectious, and practise the highest standards of

infection control (by enforcing so-called "universal precautions"). Universal precautions against patient-to-health professional (and vice versa!) transfer of blood borne infections are now clearly described and well implemented in hospital and clinic practice.

Compulsory testing for the patient's benefit

Treatments for HIV infection are now available which may extend life and improve the quality of life for people with HIV. Only those who know that they carry the virus can benefit from these treatments. However, the effectiveness of presently available therapy is not so clear - cut and absolute that a case for compulsory testing can be made. It is important that anyone at risk of HIV is told about these new treatments, but only as additional information in helping that person make up their mind about whether voluntarily to have the test.

Protection of confidentiality

In Australia, protection of confidentiality in relation to a person's HIV status rests ethically, and under common laws on the duty of confidentiality owed by all health professionals; and legally, on some State and Commonwealth Privacy legislation. For example, the Commonwealth Privacy Act (1988) establishes rules of conduct which apply to personal information held by Commonwealth government departments. It would be against the law for any Commonwealth government officer who had come to know a person's HIV status (say through that person's application for a Disability Pension) to reveal that information to anyone else without that person's permission except for certain reasons specified in the Act. Not only is it important that such provisions exist to uphold a person's basic human right to privacy, but also to protect HIV positive people against discrimination.

Duty of confidentiality against duty to warn

In 1976 in California USA, a very famous decision (the Tarasoff Decision) was handed down by the Supreme Court, when it found a psychotherapist negligent for failing to warn the girlfriend of a patient, that the patient had threatened to murder her on her return from an overseas trip. The psychotherapist notified the police that the girl's life might be in danger, but did not inform her or her family. The girlfriend was indeed murdered, and the Court held that the psychotherapist had a duty to protect her, which overruled his duty of confidentiality to his patient.

Australian courts have not yet considered whether a health care worker owes a duty to warn a third party about the risk of HIV if they become aware of an HIV positive patient putting that third party unwittingly at risk through unsafe sex or needle sharing. However, if this kind of information were released without the patient's permission many people would be reluctant to present for testing and there would therefore be a much greater risk of unknowing infection of others, including regular sexual partners. The law in Australia supports the latter view

and it is common practice for doctors and other health care workers to counsel the HIV diagnosed person on the need for safe sex and to offer assistance to the client in informing and counselling partners.

HIV and Discrimination

Because of the stigma associated with HIV, and because of irrational fears about AIDS, people with HIV infection have been subject to many types of discrimination. Employees have lost their jobs, students have been barred from school, applicants for life or health insurance have been turned down, people have been evicted from rented accommodation, patients have been denied various forms of health care and even family members have been banished from the family home - all because of being HIV infected (or sometimes just because of belonging to a risk group for HIV).

Discrimination against people with HIV is as wrong as is discrimination against people of a different skin colour, a different nationality or religion, or other physical or mental disabilities. It is also counterproductive to public health goals, as the World Health Organisation has recognised in Resolution WHA41.24, which can be briefly summed up:

> "The WHO Global AIDS Strategy emphasises the need to protect the rights and dignity of HIV-infected persons".

We have seen already that cooperation and maintenance of trust between health authorities and people with HIV/AIDS is essential if the public health is to be protected. Fear of discrimination is a very potent reason why people with HIV/AIDS (or at risk of the disease) might refuse to come forward for testing, medical care etc.

Human Rights Legislation

Australia's committment to international human rights standards such as the Labour Organisation Convention No. 111 which is incorporated in **Federal law in the Human Rights and Equal Opportunity Commission Act ensures that people with HIV/AIDS impairment can be protected against discrimination in employment and occupation.**

Australia has also taken the strong step of enacting legislation against discrimination on the ground of disability. In the Commonwealth Disability Discrimination Act 1992, disability is defined to include the presence in the body of organisms causing (or capable of causing) illness or disease. The definition further includes a disability that presently exists, may exist in the future, or *is imputed to a person.* The Act is designed to eliminate as far as possible discrimination against persons on the grounds of disability in a very wide range of areas of life (employment, housing, access to services etc).

Role of the Law

It is sometimes argued that the Law can never change peoples' *attitudes*, and therefore it is useless to expect the Law to address bigotry, prejudice, or unkindness. However, the Law can punish discriminatory *behaviour*, which denies or infringes the human rights of some members of a community. In relation to HIV/AIDS, the **Disability Discrimination Act provides a strong symbolic and morally persuasive message to the community at large, that discrimination against people with HIV/AIDS is simply unacceptable in any civilised society.**

QUESTIONS FOR CLASS DISCUSSION

1. CONFIDENTIALITY

A 24 yr old bisexual man asked his doctor for HIV testing and was found to be positive. The man was married and told the doctor he still had regular sexual intercourse with his wife. His wife was unaware that he was bisexual and that he occasionally had casual sex with male partners. He stated that he could never tell his wife about his HIV status because it would mean she would find out about his bisexuality. He also said that he would have to continue having unprotected intercourse with her, otherwise she would be suspicious there was something wrong.

What options are open to the doctor, and where does his/her duty lie?

2. INFORMED CONSENT

An 18 yr old woman has a sexual relationship with an injecting drug user with whom she has lived for a year. She has just become pregnant and wants to have the baby. She tells her doctor that her partner openly shares needles and syringes with at least three other people on a regular basis, and she is worried he might have picked up HIV. However she is "too scared" to have an HIV test.

In view of her pregnancy, is her doctor justified in ordering an HIV test without her knowledge?

3. DISCRIMINATION

A 28 - yr - old known HIV positive homosexual man is admitted to his local country hospital with an acute appendicitis. Prior to this time he has been

completely well. The surgeon in the country town tells him he needs an emergency appendicectomy, but that he is unwilling to perform the operation because in his judgement the patient's HIV infection poses too great a threat to himself and the operating theatre staff, none of whom have had any experience of HIV before. The surgeon advises the patient to get someone to drive him 500 km to the nearest capital city for the operation, although he admits that his appendix may rupture on the way. The surgeon adds: "it is foolish for you to live in the country anyway; your sort belong in the big cities!"

Is the surgeon justified in his /her decision not to operate?
Does the patient have a case against the surgeon and the hospital, and if so, on what grounds?

4. PUBLIC HEALTH RESPONSE TO HIV/AIDS

The present public health response to HIV/AIDS is based on preventive education, and voluntary cooperation between health authorities and people with, or at risk of, HIV.

List arguments for and against this approach.
What developments in the future might encourage governments to opt for a more coercive approach?

Biography

David Bradford

David Bradford is the Director of the Sexual Health at the Cairns Regional Health Authority. A former President of the Australian Venereology Society, he is a doctor specialising in sexually transmitted diseases, and a large number of his patients are HIV positive.