LAW & SOCIETY TRUST HEALTH AND HUMAN RIGHTS SERIES

AIDS AND THE RIGHT TO LIBERTY AND SECURITY



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HEALTH AND HUMAN RIGHTS SERIES

AIDS AND THE RIGHT TO LIBERTY AND SECURITY

by

Shanti Jayasuriya &

D C Jayasuriya

LLB, Attorney-at-Law

Ph.d, Attorney-at-law

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Introduction

To understand human rights in relation to HIV/AIDS, it is important to have a background knowledge of the disease and some socio-cultural effects it has brought about in different societies.

The Illness

How and when Acquired Immun-deficiency Syndrome (AIDS) originated is not known. Many theories have been formulated, the merits of which will probably be debated for many more years to come.

In 1981/82, doctors in the USA noted an unusual pattern of illness spreading in New York City and San Francisco. Young, otherwise healthy men were developing Kaposi's Sarcoma (a tumour involving the blood vessels) and Pneumocystis Carinii Pneumonia (a type of Pneumonia), two fatal conditions which usually occur when one's ability to fight infections (immunity) fails. Later research threw light on the cause and on many other features of the illness.

The condition was named Acquired Immuno-deficiency Syndrome; acquired - because the condition is not innate - one acquires it by being infected with the Human Immuno-deficiency Virus (HIV); immuno deficiency - because it affects the person's ability to fight infections; and syndrome - is a word used in medical jargon to indicate a collection of signs and symptoms.

Once a person is infected with the virus the person is called "HIV positive" for descriptive purposes. An HIV positive person may

remain as a healthy carrier of the disease for a long time. In 1986 a test to detect such persons was developed. However, this is not a perfect test because there are false positive and false negative results. Thus, a person having the virus may show a negative result when tested, especially in the initial phase (window period). Better tests are now available but are prohibitively expensive.

After a variable period of lag (few months to few years), an HIV positive person would begin to show features of the syndrome as his/her immune system becomes debilitated by the virus. We refer to such persons as AIDS patients. The features of AIDS include features of opportunistic infection, certain malignancies and other abnormalities which a doctor can detect. Ultimately, all AIDS patients die within a relatively short period. Currently, medication can only prolong life.

Means of Transmission and Prevention

Fortunately HIV is a very fragile virus. It cannot survive free in the environment. Therefore, its means of transmission are very limited. Thus, one is not in danger of becoming infected by engaging in casual social contact with a HIV positive person. There is no rational basis therefore to be fearful and ostracise persons having the HIV virus who you may meet casually on a day to day basis. HIV is only transmitted by the exchange of certain body fluid or tissues.

The main methods of transmission are -

- 1. sexual intercourse without the use of a condom;
- 2. sharing of unsterilised needles and syringes;

- 3. through the receipt of another's blood, blood products, organs or other human tissue, and;
- 4. from mother to child during child birth and breast feeding.

Since the virus is more concentrated in semen than in vaginal fluid, the chance of the disease spreading from a male to a female is higher than it spreading from a female to a male during sexual intercourse. Anal intercourse is more dangerous than vaginal or oral intercourse.

In view of the relatively low numbers of intravenous drug addicts in Sri Lanka, the sharing of unsterilised needles and syringes is not a significant means by which the virus is spread in this country. However, less than adequate standards of hygiene among health care personnel could result in patients becoming infected with the virus, through the use of unsterilised needles and other invasive medical equipment.

Since unprotected sexual intercourse is the primary means by which the virus is spread, sex education including the promotion of the use of condoms would be the single most important AIDS preventive strategy for our country.

AIDS Situation in Sri Lanka

The first case of AIDS in Sri Lanka was recorded in 1986, which was allegedly acquired abroad. Until very recently, foreigners and Sri Lankans who had travelled abroad were seen as the main vectors of the infection. However, with the subsequent spread of the virus among the general population, AIDS is bound to become a major public health problem in the Island in the near future.

By the end of 1995 AIDS had reportedly killed over 50 people in Sri Lanka. The number of persons with the Syndrome is over 60 and the number of HIV positive is over 160. The number suspected of being infected is over 6000.

Socio-Cultural Effects

Throughout history, whenever an incurable disease has emerged, society has ostracised and segregated those suffering from the disease. This has been the case with tuberculosis, leprosy and certain mental illnesses before cures were discovered.

A similar response was generated by AIDS, with several discriminatory practices being levelled against AIDS patents and HIV positive persons. They were unlawfully and unreasonably dismissed from work, their children were marginalised in school and some were even denied the right to marry and found a family.

However, unlike in other stigmatised illnesses it was soon realised that discriminating against HIV positive persons had disastrous public health consequences, since people who are discriminated against go "underground," thus making themselves inaccessible to public health personnel. As they have no special features of AIDS (but only evidence of opportunistic conditions that would occur even without AIDS), even a doctor may take a long time to become aware of a person's HIV positive status. Therefore it is quite possible that a HIV positive person refrains from divulging his/her HIV positive status, fearing the stigma attached to the disease and the ensuing discrimination.

Severe economic losses are also occasioned by the AIDS epidemic, for in addition to the high cost of treating AIDS patients, those

at the highest risk of infection are those persons at the peak of their economic productivity, resulting in their exit from Sri Lanka's labour force. In certain countries the socio-economic impact of AIDS as measured by the human development index (HDX) has been found to be equivalent to such disasters as famine and outright war.

Since AIDS has no cure, it has managed to conjure up all our ancient fears regarding death and disease. The fear of becoming infected is so great that the response of many countries has been to sacrifice the individual rights of the infected and those at risk in the mistaken belief that it would benefit the larger community. But it soont became apparent that these measures quite apart from the fact that they violated human rights, did more harm than good to the public welfare.

Many Asian countries including Sri Lanka view AIDS as a "foreigner's disease" and the general public tend to regard international travellers as vectors of sexually transmitted diseases (STDs) and especially AIDS. There have been numerous calls to screen international travellers who land on our shores for HIV/AIDS.

AIDS and the Right to Liberty and Security

In almost all countries in the world, public health laws that provide for various restrictive measures have been in place for many decades, if not centuries. In Sri Lanka, for instance, the Contagious Diseases Ordinance and the Quarantine and Prevention of Diseases Ordinance are both 19th century enactments that have continued to remain in operation with a few amendments made from time to time. With the gradual emergence at the global level of a "human rights culture" more attention has come to be placed upon the rights, duties and responsibilities of individuals and communities, and the more modern public health statutes reflect a greater concern for individual rights.

When the first HIV/AIDS cases came to be reported in the early 1980's many countries began to have recourse to existing public health laws, particularly those that provide for the notification of infected cases, to deal with such cases. With a few exceptions, most developing countries relied on public health laws that had been on the statute books for decades. Cases of discrimination against persons with HIV/AIDS came to be documented both from developed countries with a greater social awareness of the importance of human rights as well as from developing countries where the relationship between public health and individual rights was beginning to be articulated. As these cases began to appear, human rights activists, persons with HIV/AIDS and AIDS service organisations demanded that more attention be accorded to the rights of infected persons. Discriminatory practices were documented in relation to a variety of social, economic and work place contexts. Landlords evicted or refused to rent or lease property to persons known to be HIV/AIDS patients; infected

individuals were denied admission to schools; and infected individuals were either dismissed from their jobs or refused jobs when their HIV status was known. Denial of medical treatment as well as medical insurance came to be documented even from countries that had otherwise had a good record of health services for the public.

Discrimination where it occurred, was not confined only to the infected persons. Their spouses or partners, children, parents, siblings and even other persons in close relationships with them were discriminated - a situation that was reminiscent of the reaction to leprosy in previous centuries. In a few countries, social attitudes towards persons with HIV/AIDS were such that there were calls for the establishment of quarantine centres based on the erstwhile leper colony model.

In 1988 the World Health Organisation adopted a resolution entitled AIDS: Avoidance of Discrimination in Relation to HIV-infected People and People with AIDS. It called upon Member States to:

foster a spirit of understanding and compassion for HIVinfected people and people with AIDS through information, education and social support programmes; [and] to protect the human rights and dignity of HIVinfected people and people with AIDS and of members of population groups, and to avoid discriminatory action against and stigmatization of them in the provision of services, employment and travel.

In the following year, the United Nations Centre for Human Rights and the World Health Organization convened an international consultation on AIDS and human rights. Participants recommended that:

Governments ensure that measures relating to HIV/AIDS and concerning persons already infected conform to international human rights standards, and that they re-examine the measures already in force for the protection of human rights in the light of the particular issues raised by HIV/AIDS.

Since then various organs within the United Nations system that deal with human rights issues as well as other influential human rights groups, such as Rights and Humanity, have addressed the issue of human rights within the specific HIV/AIDS context. The Declaration adopted at the Paris AIDS Summit on 1 December 1994 called, among other things, for national policies to "ensure equal protection under the law for persons living with HIV/AIDS with regard to access to health care, employment, education, travel, housing and social welfare."

The theme for the World AIDS Day on 1 December 1995 was "Shared Rights, Shared Responsibilities." In the international arena, the stage has been set for the HIV/AIDS issue to be considered in the light of internationally accepted human rights norms and standards.

Public Health Context

In most instances, the transmission of HIV requires the deliberate and conscious action of at least two individuals. With the exception of perinatal transmission from an infected mother to the foetus or to the new born before, during or immediately after child birth,

other situations involve two or more individuals engaging in an activity - that may or may not be legal - that results in HIV transmission. Transmission of HIV through sex and through exposure to infected blood as a result of sharing HIV contaminated needles and syringes or through transfusions of unscreened blood are the more predominant ways of acquiring HIV.

Most HIV/AIDS cases that have been documented have involved drug users who inject drugs intravenously as well as commercial sex workers and their clients. In many countries drug use is a criminal offence. Prostitution per se is also illegal in many countries, while in some countries what entails criminal liability is the running of commercial sex establishments or the procurement of individuals for commercial sex. A few countries have a system for licensing commercial sex establishments and/or their workers.

With the possibility of HIV transmission through means that are often illegal or unauthorized, it has been observed that the use of coercive or penal measures will only result in driving the individuals concerned underground or away from the public health services. Evidence also indicates that peer group influence is the key to bringing about behavioural changes that will help minimise the risk of HIV transmission. In several countries where the gay community, in particular, had been disproportionately affected, members of that community have taken the lead in providing educational care and other support services with encouraging results.

Rights and Freedoms in the HIV/AIDS Context

Internationally accepted rights and freedoms can be enjoyed by all persons irrespective of their race, colour, sex, language, religion

and so on. The standard formula used in this context also includes the term "other status." This is wide enough to include the HIV status of an individual, if such status can be the basis for differential treatment or for discrimination.

The international human rights instruments such as the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights recognise a variety of rights and freedoms. Other conventions that deal specifically with women and children, for instance, are structured around these general rights and freedoms but these also provide for additional rights or for the special application of certain rights in particular circumstances.

The following rights, in particular, are directly or indirectly relevant to the HIV/AIDS context:

- Non-discrimination/equality before the law
- Privacy
- Liberty
- Freedom from inhuman/degrading treatment
- Freedom of movement
- Freedom from forced servitude
- Health
- Education/information
- Work
- Social security
- Seek and enjoy asylum
- Marry and found a family

Constitutions and Bills of Rights or similar instruments that conferrights and freedoms set out the conditions under which some rights and freedoms can be curtailed or restricted or modified in their

application. While the conditions differ to some extent from one jurisdiction to another, it is internationally accepted that States wishing "to justify any interference with, or limitation or restriction of any declared right, has the burden of proving affirmatively that the restriction was

- prescribed by law;
- 'necessary'
- in a democratic society
- for the protection of one or other of the listed interests."

Restrictions, however, must

- be proportional to achieving the aim;
- be the least restrictive means available; and
- in fact achieve or help achieve the stated aim.

The Right to Liberty and Security

'Liberty' is generally understood in the sense of the physical liberty of the person, while 'security' means protection against arbitrary interference with this liberty.

In the public health field, the following measures are generally considered as involving a deprivation of liberty:

- Compulsory blood tests;
- compulsory quarantine, for example, by enforced confinement or isolation in a hospital or a hospice; and
- compulsory internment in a colony removed from society.

To justify such restrictions, the State will have to prove

(a) In the case of compulsory blood testing, that it was necessary to prevent the spread of infection; and

(b) In the case of detention, both that the individual concerned had the infection and his or her detention was necessary for the prevention of its spread.

Given the modes of transmission and the illegal or unlawful nature of some of the activities that result in exposure to HIV, compulsory testing will deter those who stand to benefit by education and counselling from seeking medical care. Consequently, HIV infection will be effectively driven underground, when the need is to bring the infected and those at risk into the mainstream of prevention and educational activities.

As far as quarantine and isolation are concerned, given that the virus spreads only in limited ways and not through normal social contact, that infection is life-long with a long period of good health, and that there is no vaccine or drug to eliminate the virus from the system, these restrictive measures serve no practical purpose.

Other Rights

With regard to the other rights enumerated above, Table A sets out in respect of each such right its application to HIV/AIDS and the public health rationale. It will be seen that there is limited public health justification for the imposition of restrictions on rights and freedoms. Indeed, experience suggests that the way to effectively slow the spread of the virus and to deal with infected persons, their families and communities, in a compassionate and humane manner is to create a supportive environment that helps integrate infected individuals and those who need to minimise the risk of exposure into the mainstream of daily activities.

According to Jonathan Mann, the Director of the International AIDS Center of the Harvard AIDS Institute:

....we have learned that the HIV pandemic flourishes where individual capacity to learn and to respond is constrained. The major way in which this capacity is constrained is by belonging to a group that is discriminated against, marginalized, or stigmatized. This suggests that to the extent that societies can reduce discrimination and promote respect for the rights and dignity of all their members, they will become increasingly successful in preventing HIV transmission. To this extent, they will be uprooting the HIV/AIDS pandemic rather than simply addressing its surface features.

TABLE A
HUMAN RIGHTS AND HIV/AIDS

Human Right	Application to HIV/AIDS	Public Health Rationale
Non Discrimi - nation/Equality before the Law	promote access of disadvantaged groups to HIV prevention and care programmes prevent discrimination against HIV positive or those suspected in employment, travel, health care, education, social assistance	1) prevention/care efforts should reach all, including those difficult to reach 2) almost no threat of transmission in these settings
Privacy	1) prevent mandatory testing 2) prevent routine or hidden tests 3) ensure confidentiality 4) ensure informed consent before tests, treatment or research	mandatory testing: 1) can never reveal identity of all HIV positive 2) may involve false test results 3) drives people away from prevention/health care efforts 4) results in psychological trauma if no counselling 5) involves diversion of resources better spent on education/health care
Liberty	prevent arrest/detention on account of HIV status alone prevent isolation or segregation in administrative setting on account of HIV status alone	detention/isolation: 1) no public health rationale; does not prevent spread 2) is costly and impracticable since life-long
Freedom from Inhuman/ Degrading Treatment	1) promote measures to protect against sexual violence/sexual coercion 2) prevent compulsory isolation or segregation of HIV positive prisoners 3) prevent forced abortion/sterilization of HIV positive women	any coerced sex increases risk of transmission no public health rationale for isolating prisoners; more useful to make available information, clean needles, bleach and condoms only I out of 3 babies born to HIV positive mother is infected; much less if AZT used
Freedom of Move ment	prohibit testing of returning nationals prohibit testing of entering foreigners regarding cost of care, HIV/ AIDS be treated the same as other contagious diseases	exclusion does not prevent spread as HIV is already present exclusion gives false sense of security better to use resources on education/security

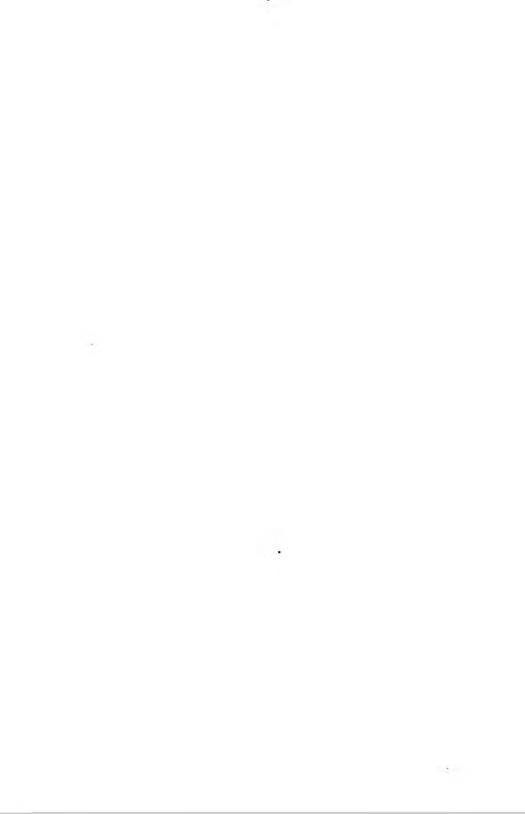
TABLE B
HUMAN RIGHTS AND HIV/AIDS

Human Right	Application to HIV/AIDS	Public Health Rationale
Freedom from Forced Servitude	prevent trafficking in women, men or children prevent forced prostitution or involuntary servitude for sexual purposes prevent harmful traditional practices, e.g. marriage of minors, wife inheritance, female genital mutilation	1) any cocreed sex increases risk of transmission 2) difficulty of access for prevention and care 3) harmful traditional practices can increase social and/or biological vulnerability
Health	promote equal access for disadvantaged, vulnerable groups to HIV health prevention and care programmes prevent discrimination against HIV positive persons in health care promote confidentiality in health care setting promote blood safety through screening of all blood, body parts and fluids	1) prevention/care should reach all people, including those difficult to reach 2) if universal precautions used, little risk of transmission 3) should maintain confidence in health care
Education/ Information	I)equal access for disadvantaged, vulnerable groups to HIV prevention education/information Prevent discrimination against HIV positive people in access to education facilities	prevention/care should reach all people, including those difficult to reach virtually no risk of transmission in educational setting with basic precautions
Work	prevent pre-employment or during employment mandatory testing prevent isolation or termination due to HIV status ensure reassignment/accommodation according to health needs ensure same employment policies for HIV/AIDS as for any comparable disease ensure confidentiality in work place	almost no risk of transmission in work place with basic precautions HIV positive persons can and should be productive for a long time

TABLE C
HUMAN RIGHTS AND HIV/AIDS

Human Right	Application to HIV/AIDS	Public Health Rationale
Social Security	promote equal access of women to social security and other available benefits in case of termination of marriage/employment prevent discrimination against HIV positive people in access to social security	1) women should have alternative to relationships that threaten them with infection; and for support, if husband dies 2) HIV positive people need means of support
Seek and Enjoy Asylum	1)prohibit <u>refoulment</u> on basis of HIV status 2)promote humane/generous grant of asylum for HIV positive people	no public health rationale to deny asylum refugee cannot return home to face persecution
Marry and Found a Family	1) prevent pre-marital mandatory HIV testing 2) prevent prenatal mandatory HIV testing 3) provide information/counselling regarding risks/ prevention	1) HIV positive married people can practise safe sex 2) only 1 in 3 babies born infected if mother is infected, much less if AZT used





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