AIDS AND PRIVACY AS A HUMAN RIGHT

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Introduction

The first case of acquired Immune Deficiency Syndrome (AIDS) was recorded in Sri Lanka in 1986, through an infection acquired abroad. The subsequent spread of the disease until recently was through foreigners and persons who had travelled abroad. But now with the spread of the disease among Sri Lankans through locals, AIDS is naturally bound to be a major public health problem in the Island. According to the records of the Medical.

AIDS has killed 41 people in Sri Lanka. The number of persons with the Syndrome is 51 and the number of HIV + s is 158. The number suspected of being infected is about 5000. AIDS would probably be the biggest public health problem in the next decade.

The paper critically addresses confidentiality in HIV/AIDS as a basic human right aligning with the right to privacy.

In most Asian countries the AIDS patient is practically considered as a person who is going through a punishment, having no legal rights, rather than a patient who is suffering from an illness. Sometimes details of patients amounting to virtual identification are published in the media.

The medical profession and the media should not want until a litigation crisis erupt to correct themselves. We should recognize, now the rights of patients and act accordingly.

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information without consent, although it may violate ethical standards. But through time the concept of professional secrecy has evolved to gain strength as law (as apposed to a mere ethical duty) through legislature and interpretation by courts. Now many states physician licensing laws require the maintenance of patient information confidential. A doctor who violates this duty may be liable in tort and may also be found to be engaged in professional misconduct. Hospitals too have a similar duty.

Every individual has a right to his or her privacy. One has a privacy right over his or her medical information and need not give any reason or explanation why such information should not be divulged to an outsider. Maintaining the confidentiality is even more important in relation to HIV and AIDS, than in other medical conditions, as the social consequences of its breach can be disastrous. In spite of the efforts to educate the public regarding the true nature of the disease by the government and other interest groups, AIDS still remains an illness calling for stigmatization and discrimination. Some States have enacted special HIV confidentiality laws to response to its situation.

The first U.S. statute requiring written authorization for disclosure became law in California in 1985.[5] Some States gave HIV results the specially protected status ass certain other types of stigmatizing information such as alcoholism, drug addiction and mental disease. In Urbaniak v. Newton[6] it was held that a physician could be liable for breach of confidentiality under the privacy clause of the California constitution.

Breach of confidentiality in Sri Lanka, today in practice can occur more through the hospital system than by individual doctors. A number of people have almost free access to records of patients. These include the House

[5] California Health and Safety Code @@ 1630 at 199.21
[6] 277 Cal. Rptr. 354

Officers, consultants, nurses and administrators. Similar breaches occur even in the United States.[7] In the AIDS-phobic western world some hospitals have totally disregard patients' rights "testing all patients and marking their charts with stickers; green for those who did not have the virus and red for those who were infected or refused to be tested".[8]

Even in hospital which respect patient dignity, breach of confidentiality have occurred routinely through the insurance industry. An individual often has to sign a blanket release of information form when applying for life or health insurance whether he or she likes it or not. In addition with every health insurance claim field, a patient may have to sign a release from authorizing the company to access medical records, to justify payment. Some insurance companies abroad share information through centralized data banks, making the confidentiality of such information highly questionable.[9]

The doctor is obliged to record sufficient information to justify the diagnosis and treatment of a patient accurately in the Bed Head Ticket (BHT) Therefore to keep away the HIV status of a person from a medical record is not possible usually, after the test is done. Following the 1986 wave of legislation in America granting the HIV antibody related information a special status, it got protected from blanket consent release forms. This only partially served the legislatures intent, as now, a statement indicating the deletion of information from the medical record substituted the HIV related information. One way of getting out of this situation may be to have an internal policy of keeping two sets of records, one as hospital records an the other as the physicians' personal case notes. The physician's note, containing the most personal information regarding the patient, not being the property of the

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[7] Hospital Ethics, Cambridge Quarterly of Health Care Ethics (1992) 3,204.

[8] Hilts, Many hospitals found to ignore rights of the patients in AIDS testing, New York Times, 1990 Feb.17.

[9] David Eddy Spicer, Private Lives, Public Fears, Documenting HIV related information at a teaching hospital in Boston, Kennedy School Case Program.

hospital others as a cost inefficient duplication of records consuming resources which otherwise would be available to benefit patients. It may also be argued that, if a hospital is to be held responsible for their patients, it should have sufficient information about them.

Like in most other developing countries, in Sri Lanka too strict enforcement of confidentiality is difficult to implement. Most hospitals do not have even a confidential table or cupboard which only the doctor would have access to. Information available on a BHT would be freely available unofficial to anyone who would be interested. Reports on incidents related to HIV persons has been headlines to tabloids and news papers.

At least in certain teaching hospitals in Sri Lanka morally concerned doctors have got the assistance of the medical students to personally handle HIV related specimens to and from laboratories to keep the information secret.

The Community Front for Prevention of AIDS(CFPA), a Non Governmental Organization (NGO), after intensive discussions with area experts consisting of lawyers, doctors, public health officials and social workers make formal recommendations to the Government on law. Ethics and HIV/AIDS. These recommendations are currently being studied by certain agencies of the State.

The recommendations include a general policy of maintaining strict confidentiality, adopting a legal definition for confidentiality through the Quarantine and Prevention of Disease Act and amending Regulation 473/22 made under this Act regarding notification of AIDS.[10] Other organizations such as the Health and Human Rights desk of the Law and Society Trust and

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[10] Recommendations on Sri Lankan Law , Ethics and HIV/AIDS, NORAD/CFPA, at Page 21, 1995.

the Lanka HIV Law. Ethics and Human Rights Network have backed up the implementation of strict confidentiality related to HIV/AIDS.

A doctor's ethical duty to keep medical information confidential is not absolute He may have an overriding duty towards society, when the benefit of disclosure outweighs its harm. This utopian argument is even more convincing when an HIV patient is acting irresponsibly, engaging in risky behavior without warning the partner. All persons who have a compelling interest, such as sexual partners, needle sharers and medical and nursing personnel must be provided with this information. It should extend to the funeral directors and relevant mortuary personnel who handle the body when the patient dies.

In litigation arising out of alleged HIV transmission caused by blood or Hogan donation, the plaintive may seek the identity of the donor through discovery. As a matter of policy such discovery should not be allowed as it can deter people from donating. The benefit of disclosure is often only to one individual, where as the benefit of blood and organ donation is on broad society. The need for blood and organs far outweigh the amount available.

The duty to disclose confidential medical information in appropriate circumstances is not only an ethical duty, but a legal one under public health law.[11] The U.S. supreme court upheld this principle in Whalen v.Roe,[12] when physician and patient brought action challenging the constitutionality of a New York state law regulating the prescription of controlled substances. The law requiring a copy of certain prescriptions having the name and address of the patient, be sent to the government for monitoring was held to be a legitimate exercise of state power. Even in Sri Lanka notification of infectious diseases is an established privileged communication.

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11 Robert Jarvis, Public Health Law, West Nutshell series, 255.
12 97 S.Ct. 869, 51 L.Ed 64.

Notification can be anonymous or with identification. The main purpose of this is to update the epidemiological data of the disease with the aim of implementing preventive measures. Most of these measures such as education, condom distribution etc. can be done on vulnerable populations, determined by analysis of epidemiological data, even when the reporting is anonymous or confidential. Additionally when the identity is known, partner notification and contact tracing can be undertaken.

In a public health point of view, partner notification seems an important mode of disease prevention specially in AIDS since it s incubation period is rather long and an HIV positive person can continue to infect others for a long period of time. This is not the case in a communicable disease which makes an infected person bedridden in a few days. The parterre of an HIV infected person may be considered to have a right to information that is directly relevant to his or her health. Knowing the HIV status is helpful in planning for the future. Important reproductive decisions such as delaying becoming pregnant and abstaining from donating blood until the person is appropriates confirmed HIV negative, are some such examples.

In progressive organized society we cannot live as individuals independent of society. In a crisis the government may have to suppress some rights to tide over a critical situation. We should be prepared to give up some of our rights to society , in return for a sense of safety. Obviously this privilege of the state should be construed very cautiously.

All contact tracing or partner notification programs in the U.S. are currents done on a voluntary basis, partner notification against the wishes of the patient can have its ill effects. It may lead to a lessor number of people getting tested in the first place, leading to a reduction of the total public health information available. Although substantial symptomatic treatment is

available such as pentamidine prophylaxis for pneumocystis carinii pneumonia (PNP) and vaccination for pneumococcal pneumonia, since there is no true cure for AIDS still, getting an HIV antibody test is more a benefit to society than to an affected individual.

Partner notification has been a major preventive public health measure against, sexually transmitted diseases (STD) such as syphilis since the 1940s . But comparatively it is quite costly as the target is an individual and not the broad society. Planning and implementing a notification program in a high group can sometimes be practically impossible. The notifying official may even have to travel to other provinces to perform his duties.

In homosexual transmission, studies show that most men will reduce their high risk sexual practices after they come to know that they are HIV positive.[13] This is consistent with the socio-biological hypothesis that strict homosexuals are genetically altruistic.[14] Keeping in line with the same theory of altruism one can expect at least in homosexuals, that the majority would themselves voluntarily tell their partners if they are infected and take active preventive measures when engaging in sexual activity.

Partner notification should be ideally done by the affected person. The physicians and the counsellors should encourage the patients to notify their partners, convincing its importance and reminding them of their ethical obligation. A person is likely to be less uncomfortable hearing the bad news from the known contact rather than through an unknown government officer who he or she has never seen before. The possibility of legal liability of not

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[13] Samual W.Perry & John C. Markowitz, Counselling for HIV Testing, Hospitals & Community Psychiatry, 39,7 (July 1988) at 731

[14] Attraction to the opposite sex which is absent in true homosexuals is a basic instinct necessary for sexual reproduction. Instincts are thought to be at least partly determined genetically . Reproduction or propagation of oneself's genes to continue as the next generation, can be considered as selfish or non altruistic behavior. Attraction to the same sex therefore can be considered altruistic behavior as it has no survival value.

informing should also be communicated to a uncooperative patient . State sponsored partner notification should be the last resort.

A person having a STD or a communicable disease has a legal duty to take precautions against transmission. In Berner v. Caldwell[15] the U.S. Courts held that one who knows or should reasonably know that he has genital herpes is engaging in risky behavior.

If a doctor how knows that a patient has an STD , fails to convince a patient that he should tell his partner, he is faced with the dilemma whether to protect the confidentiality of his patient or prevent a possible contraction of the disease to another person . In the case of AIDS, since it is a deadly disease, it is only ethical for the doctor to disclose the possibly life saving information.

Argument against partner notification, such as that the partner is another independent individual capable of taking personal precautions for him or herself and therefore must be responsible enough to practice universal precautions, does not significantly weaken the view supporting notification. For example a woman planning to have a baby cannot be expected to practice universal precautions. There may be so many other personal reasons why a partner cannot practice strict universal precautions. This is specially so in heterosexual relationships as a woman, due to her social unequal status, is unlikely to be able to insist that a man wear a condom.

The ethical dilemma, whether or not to inform , encountered when the doctor's relationship with the patient is non therapeutic, such as in a controlled clinical trial for an anti-AIDS drug or a vaccine is even greater if the research subject has not come to the doctor for his or her own benefit. (although often patients have financial and therapeutic incentives) A breach

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[15] 543 So. 2d. 686

of confidentiality will send a message to the community discouraging participation in clinical trials, the results of which may perhaps save innumerable lives. It is an even worse dilemma when the research is unrelated to AIDS.

In spite of the apparent consequences on the community, my initial tendency was to vote for a policy that a doctor should divulge the information at least until a cure for the disease was found. But if we stick to such a policy we may not be able to find a cure in the first place by discouraging research. Perhaps the best way out of this dilemma is to seek refuge in the concept of informed consent. A person registering for a clinical trial, as a research subject must be told in advance that the partners may be notified. Then he or she can make an informed decision weather or not to take part in the trial, evaluating risks and benefits according to his or her own standards.

In order not to jeopardize the continuation of clinical trials notification should be only directed to sexual contacts, having a substantial chance of benefiting from such information. A policy requiring notification to public health officials for epidemiological purposes is not justified. A research subject may be one in a hundred in a clinical trial, but may be just one in thousands, in epidemiological data, making the former much more significant than the later.

A doctor's legal duty to protect an individual from harm caused by a patient of his, was discussed in Tarasoff v. Reagents of the University of California.[16] Action was brought against doctor for not adequately warning and taking steps to prevent a murder by his psychiatric patient who had confided in the doctor his intentions.

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[16] 17 Cal. 3d. 425

It was held that, although common law does not impose a person to control the risky conduct of another or a duty to warn a person endangered by such conduct, that an exception arises when there is a special relationship. When there is a therapeutic relationship the doctor has a duty to care to all persons who are fore-seeably endangered by the patients conduct. Application of this doctrine not only empowers a doctor to carry out his ethical obligation of notifying a person at risk from HIV infection, but also makes it a requirement. Both the American Medical Association[17] and the American Psychiatric Association[18] have recommended warning partners who are known to be at risk after all other efforts to persuade in HIV positive patient to inform his or her at-risk partners have failed. In certain U.S. states such as Michigan this is required by statute.

A basic difference between the Tarasoff ease and the AIDS situation is that in Trarasoff, the patient had a strong intent to commit a crime. But an AIDS patient has no such criminal intention. A policy of mandatory notification without giving a discretion to the physician is justified when he knows that a crime is happening such as when a child presents to him abused or when a crime is about to happen such as when (and if) and AIDS patient says he intends to kill a person by having sex with him.

An obligatory partner notification requirement by statute without leaving any power of discretion to the doctor is not a good idea, even though it may make the doctor's job easier by relieving him of the responsibility of using his judgment in this serious dilemma. Although in AIDS under the current state of circumstances, with no treatment available, it seems that obligatory notification should be the rule , it sets a bad precedent. Whether or not to inform a partner of a sexually transmissible disease against the patient's

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[17] American Medical Association board of trustees : Prevention and control of Acquired Immune Deficiency Syndrome: an interim report, JAMA 258:2097-2103, 1987

[18] AIDS policy : Confidentiality and exposure, Psychiatric News, Jan. 15, 1988, at 27

wishes, should be left for the clinical judgment of the doctor. He should consider all aspects of the disease together with the social and medical implications. For example if we are fortunate enough to have a cure for AIDS in the future, the patient should have the option of being in hospital and getting cured confidentially if he so wishes. As long as he is not a threat to the partner, the partner need not have a right to know . But this is not possible under a statutory requirement of mandatory notification.

The legislators of the mandatory AIDS notification statutes should also consider the perspective of women have AIDS , where it is a man to whom the information has to be divulged. The consequences would be pathetic if a doctor is required to notify a husband who is perhaps battering his wife.

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