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ETHICAL AND LEGAL ISSUES RELATED TO IRIS/AIDS PATIENTS

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ABSTRACT: The emergence of the AIDS/IRIS pandemic has challenged traditional ethical values of the health care profession. Antiretroviral therapy (ART) initiation in HIV-infected patients leads to recovery of CD4+T cell numbers and restoration of protective immune responses against a wide variety of pathogens, resulting in reduction in the frequency of opportunistic infections and prolonged survival. However, in a subset of patients, deregulated immune response after initiation of ART leads to the phenomenon of immune reconstitution inflammatory syndrome (IRIS). The hallmark of the syndrome is paradoxical worsening of an existing infection or disease process or appearance of a new infection/disease process soon after initiation of therapy. The overall incidence of IRIS is unknown, but is dependent on the population studied and the burden of underlying opportunistic infections. Law & medical ethics are two disciplines with a considerable overlap. Law lays down the established rule for conduct, the violation of which creates criminal or civil liability; ethics is more about expected conduct, that is, what ought to be? The two key issues in medical ethics are confidentiality and consent. In no other disease scenario do these two take on such importance as in AIDS/IRIS. The article examines the dynamics of such issues, citing examples from India and abroad and the present status of the draft bill prepared in 2006 is that it has been and submitted to the government.

KEYWORDS: IRIS, AIDS, Medical ethics, legal issues.

INTRODUCTION: Since the diagnosis of the Human Immunodeficiency virus in the early 1980s, the disease has affected hundreds of thousands of individuals across the globe. It is estimated that by the end of 2007, there were 33 million people infected with the virus¹ and it is estimated that over 4 million people are accessing antiretroviral (ART) therapy in low- and middle-income countries by the close of 2008.² The advent of ART has had a considerable impact on the survival of the people³ and has resulted in fall of viral load and subsequent rise in CD4+ T-cells and immune restoration.⁴

However, some patients experience clinical deterioration as a consequence of the rapid and deregulated restoration of the antigen-specific immune response.^{5,6} Such a response has been termed as Immune Reconstitution Inflammatory Syndrome (IRIS) or Immune Restoration Disease (IRD) or Immune Reconstitution Syndrome (IRS).

The legal rights of an HIV-infected person and the ethical obligations of the medical profession and general public have not received careful attention till date & so have not been precisely defined. There are questions like confidentiality, consent of the person before taking blood for HIV test, discrimination of person infected with HIV infection for employment and various other issues which are present and will be explored. Law and medical ethics are disciplines with frequent areas of overlap. The parameters of each are however, distinct. Law is the established rule for conduct, the violation of which may create criminal or civil liabilities.

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Ethics is the identifications of values, while law is the expression of values and social rules. Ethics says: what ought to be? Law says: What has to be? Law and ethics thus share the common goal of creating and maintaining social good. Doctors have the privilege of regulating their own professional affairs through the Medical Councils of respective countries, which lay down their ethical guidelines.

These ethical guidelines are not just a set of rules or a code to be consulted in order to find an answer to every difficult situation. They are a set of principles which doctors must apply in each situation, together with their judgment, experience, knowledge, and skills. Some of these codes are an individual's right to autonomy over health-incorporated in public laws.

Code of medical ethics by the Medical council of India (MCI) was amended in 2002. It is called Indian Medical Council (professional conduct, etiquette, ethics) Regulation, 2002. It has two salient features which have a direct bearing on HIV-infected patients in medical practice. One is Consent and the other is Confidentiality.

CONSENT: The amended code states: Before performing an operation the physician should obtain in writing the consent from the husband or wife, parent or guardian in the case of a minor or the patient himself as the case may be. In an operation which may result in sterility the consent of both husband and wife is needed.⁷

No act of in vitro fertilization or artificial insemination shall be undertaken without the informed consent of the female patient and her spouse as well as the donor. Such consent shall be obtained in writing after the patient is provided, at her own level of comprehension, with sufficient information about the purpose, methods, risks, inconveniences, disappointments of the procedure, and the possible risks and hazards.

A registered medical practitioner shall not publish photographs or case reports of his/her patients without their permission, in any medical or other journal in a manner in which their identity could be made out. If the identity is not to be disclosed, the consent is not needed.

There is no mention that one has to take consent before taking a blood test for HIV. In the western world it is obligatory to take consent and they have ethical codes on this issue.

Why a person refuses an HIV test? There is stigma of HIV infection; there is fear of loss of confidentiality and fear of discrimination. Above all it is 'denial' to the possible reality. There has been such situation in the past. Such a fear existed with syphilis in the pre-penicillin era and with leprosy in the pre-multi drug therapy era.

In spite of some controversy, the consensus is to take consent, because it is a question of respecting an individual's right to autonomy over health-care decisions. This right is critical because of the overwhelming stigma that continues to color this infection and because of the enormous personal, social, and medical consequences of the diagnosis of HIV infection.

Unlike other common law countries such as the UK, US, and Australia, where a patient's consent is required for any medical test or procedure, no such legal principle is recognized here. Accordingly any challenge to compulsory HIV tests would probably need to rely upon extension of constitutional rights to privacy.

The prevailing view of Health Professionals in India is mandatory HIV testing for patients as it is desirable for the protection of health professionals and other patients, although there is no recognized scientific an operation the physician should obtain in writing the basis for such a policy.

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In the US a national survey⁸ of 864 physicians and 1339 members of general public revealed that 63 percent of Americans believe that mandatory HIV test would improve the overall health of the US population.

In some countries there are public debates on mandatory HIV testing of new borns.⁹

In United States the conflicts are:

Fetal rights vs. Women's rights: Public Health Welfare (Preventing HIV transmission) vs. civil liberties & privacy rights under normal conditions, the consent to test for HIV is mandatory in the US. In case of minors the consent of parents is taken. In this situation the conflict is between the rights of the mother and the newborn. If the mother does not give consent it is the State which has to decide in the interest of the new born. The government or the state has 'parents patria powers'.

CONFIDENTIALITY: This is the next important issue in HIV-infected patients and medical practices.

Confidentiality is a paramount concern for people with HIV/AIDS. This infection not only carries the stigma of a sexually transmitted disease but also the association with homosexuality and/or injection drug use. Workplace, housing, and insurance discrimination have been (and, in some areas, continue to be) barriers to disclosure of HIV status and seeking treatment.

Children with AIDS have sometimes been barred from attending classes, and in at least one instance, a family home was burned after one member of the family developed AIDS. All medical records are confidential and must be maintained in a manner that protects that confidentiality, using an approach consistent with the Privacy and Security Rules promulgated by the federal government in the Health Insurance Portability and Accountability Act (HIPAA).

Client information must be kept strictly confidential, and records should be managed and stored in a secure manner. Confidential information includes any material, whether oral or recorded in any form or medium, that identifies (or can readily be associated with the identity of) a person and is directly related to their health and care.

All information related to an individual's HIV/AIDS status is protected under medical confidentiality guidelines and legal regulations. Recognizing the sensitive nature of these conditions, medical record protection for HIV and AIDS, like those for substance abuse and mental health, are protected more rigorously than other medical information.

Confidentiality of medical information means that any information that can be related to a specific patient may not be disclosed to anyone except under specific circumstances. This usually means that the individual signs a release-of-information form, but there are exceptions.

The most common circumstances permitting disclosure of confidential patient information are:

- Existence of a separate, signed release-of-information form
- Release to another healthcare provider for related on-going medical care
- A life-or-death emergency
- Release to a third-party payer (insurance provider)
- Reporting modifiable conditions to the local health jurisdiction or the Department of Health.¹⁰

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HIV Infection and Criminal Behavior: A number of persons acquire HIV infection through sex between man and man or injecting drugs. There are laws which criminalize these types of behaviors, which can lead to police harassment and other punitive measures, which obstruct efforts to support, encourage safer sex, and safe drug using practices.

There is an urgent need to bring the criminal law into harmony, with an effective HIV strategy, whether by decriminalization of certain conduct or by negotiations and cooperation with law enforcement agencies.

Employment and HIV Positivity: There are many instances where applicants with HIV positivity are denied jobs. Mr. X was denied a job by the State Bank of India because he was HIV positive. On Jan 16, 2004, Bombay High Court Upheld employment of PLWAHA.

The court said that protection and dignity of HIV-infected persons is essential for the prevention and control of HIV/AIDS.

Andhra Pradesh Revised Police Manual prohibits entry of persons who are HIV positive into government service. The Government, however, feels that there is no public health rationale for mandatory testing of a person for HIV/AIDS. The ministry also guarantees equal rights to education and employment as to other members of the society. HIV status of a person should be kept confidential and should not in any way affect his right of employment, position at workplace, marital relationship, and other fundamental rights.

Existing Legislation and Policies:

1. Goa Public Health amendment of 1985 (Section 53.I.v11) allowed the public health authorities and police discretion to isolate people with HIV/AIDS; repealed in 1996.
2. Railway Board Administrative Notification of 1989 designating HIV/AIDS as an "infectious disease" which can allow denial of passage. Rescinded in 1996.
3. In 1992 Administrative Notification from Ministry of Health (GOI) to all state governments directing them to ensure nondiscriminatory access to treatment and care of PLWHAs in all central and state government health care institutions.
4. The Government has, by administrative orders, required the screening for HIV of all units of blood testing to be used for transfusion purposes.
5. May 1997 Mumbai High Court judgment held that employers cannot base employment decisions on HIV status, for employment.

There is, however, no comprehensive legislation in India addressing HIV/AIDS. There have been some court decisions, which also have been changing with the better understanding of the disease by the public and lawyers.

Considering the importance of this subject an advisory group was set up to initiate the process of creating legislation in 2002, by Mr. Kapil Sibal and the Project Director of the using National AIDS Control Organization (NACO).

The presence of a nationally applicable statute would lend consistency, clarity, and predictability for certain the courts to effectively pass judgment in HIV/ AIDS cases. They approached an NGO (Lawyers Collective Unit) to draft legislation on HIV/AIDS.

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The Lawyers Collective HIV/AIDS Unit (LCHAU) has consulted all the concerned organizations and involved people and drafted legislation. The Union Health Ministry has sent the bill for a feedback from the state and union territory governments, which have been approved.

The key elements of the draft bill¹¹ on HIV/AIDS are:

1. Prohibition of discrimination related to HIV/AIDS within public and private spheres.
2. Resurgence of Informed Consent for HIV-related, testing, HIV-related treatment, and HIV-related research.
3. Guarantee of confidentiality of HIV-related information (including HIV + status) and exceptions to it.
4. The right to access treatment related to HIV/AIDS as a part of the right to health, recognized under the Indian Constitution.
5. The right to safe working environment for health care workers and other persons whose occupation may put them at risk of exposure to HIV.
6. Protection of strategies for risk reduction, which otherwise are subject to criminal sanction under various laws, which have severely impeded risk reduction work in the past.
7. Prohibition of quackery in the context of HIV/AIDS.
8. Norms for Information, Education, and Communication (IEC) programs and materials.
9. Creation of innovative implementation mechanisms including institutional grievance redressed machinery and HIV/AIDS Commissions. This will be supported by special procedures to be followed in courts, including suppression of identity, and speedy trials.
10. Special provisions for those who are disproportionately affected by the epidemic, particularly women, children, persons in the care and custody of the State, who due to social, economic, legal, and other factors find themselves more vulnerable to HIV.

The draft bill after approval of Health Ministry was sent to the Ministry of Law in August 2007, which has stalled it. It has deleted two chapter's one on treatment of HIV/AIDS, and the other on risk reduction. The draft bill says that people living with AIDS and HIV infection should get treatment as a matter of right.

The chapter on risk reduction, which sought to grant immunity to various targeted intervention programs, which provide condoms to sex workers and homosexuals, and clean syringes for intravenous drug users (IDU), to prevent the spread of the disease, are in conflict with the Indian Law. Under the law, all these are seen as abetting the crimes of prostitution, homosexuality, and drug abuse.

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