Patients testing positive for HIV — ethical dilemmas in India

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Attitude of doctors towards such patients

Persons testing positive for infection by HIV or showing evidence of AIDS provoke revulsion and fear in medical doctors. These reactions stem from the general knowledge that the diagnosis of AIDS is akin to a death sentence and the belief that a positive HIV test is, inevitably, followed by the development of full blown AIDS. The fact that HIV is primarily contracted through sexual intercourse and anal penetration or addiction to drugs lends added reason for disgust.

There is a close parallel between the behaviour of the doctor faced with a patient showing evidence of AIDS and that, till very recently, towards a patient with leprosy.

This illogical fear has made doctors lose sight of some fundamental medical principles:

1. Contracting an infection from a patient is the doctor’s occupational hazard. The logical step towards avoiding such infection is to take all the necessary precautions against transfer of infection. It is not logical to treat the patient as an untouchable.

2. HIV is a very fragile virus, vulnerable to all the commonly adopted measures for sterilisation and disinfection.

3. Transmission of HIV from patient to doctor in the course of medical examination and treatment is rare.

4. We are witness to individuals testing positive to HIV and continuing to lead normal lives without ever showing any trace of AIDS.

5. Tests for HIV are, at times, known to yield false positive results.

A new class of untouchables

For many patients, the ward of a public hospital is the last stopping place on a dismal journey of stigmatisation. Patients with AIDS are driven from their communities by fearful neighbours, pushed from one hospital to another by doctors and staff members reluctant to treat them and, finally, approaching death in the AIDS ward, left virtually to fend for themselves. AIDS patients have become India’s new untouchables to spend their lives being shunned. Like caste untouchables, patients with AIDS are supposedly protected from discrimination by laws, but statutes have counted for little.

In 1994, a reporter for The Statesman chronicled the death of a 28 year old fruit seller, Deepak Biswas, in a Calcutta hospital ward. The Statesman’s stories told how Biswas had been left for days on sheets stained with blood and how food had been pushed at him from a distance. After he died, weighing 60 pounds, attendants left his body untouched for eight hours in the tropical heat. Finally, the hospital superintendent helped a relative lift the body into a van to be taken to the cremation ground.

Later, neighbours pressed Biswas’ family to leave their home, saying they might infect the area. Biswas, typical of many AIDS patients, had shuttled through four hospitals before arriving at the AIDS ward. At the School for Tropical Medicine, the main AIDS advisory centre for the government of West Bengal, doctors told Biswas’ relatives there was, ‘no seat’ for him.

They referred him to a doctor specialising in India’s traditional herbal medicine, telling the family that in a case of incurable disease, ‘we can use any drug or any measure’.

Other cases recounted by AIDS workers include that of a patient in Madras who was being treated for fever. His doctor informed his office that he had tested positive for HIV. When he returned to work, he was kept out by the elevator operator and a door attendant. He went home and took a near fatal drug overdose.

There are also the cases of pregnant women with HIV who have gone from doctor to doctor seeking somebody to deliver their children. Here is a recent account of such practice. ‘A number of obstetricians will not deliver a HIV patient who comes to their private nursing home. They are afraid that if everybody comes to know that this is an HIV infected patient, they will lose their practice. Secondly, they are afraid of infecting their operation theatre, labour ward and all their staff including themselves. So they would rather say ‘No’, because they are going to get the same amount of money from her (as from other patients) and run the risk themselves. So also surgeons with private nursing homes.

A Calcutta haematologist, Dr. Asha Rao, tells of a 27 year old who returned home with an HIV infection recently after years of working in Bombay. As soon as his condition became known he lost his job in a Calcutta tannery. His girlfriend left him, and his father forced him out of the family home.

Making the diagnosis

We are witness to several unethical practices in checking for the presence of infection by HIV in our patients:

1. Doctors and medical institutions refuse to accept patients
for investigation of therapy unless they undergo tests for infection by HIV.

2. Tests ELISA, blot tests are ordered without the patient’s informed consent and with no attempt at explaining to the patient or the family the implications of a positive result.

These steps are blatant violations of ethical norms. The General Medical Council of Great Britain has, for instance, made a specific ruling: ‘The Council believes that the principle (of consent to investigation) should apply generally, but that it is particularly important in the case of testing for HIV infection, not because the condition is of a different kind from other infections but because of the possible serious social and financial consequences which may ensure for the patient from the mere fact of having been tested for the condition. Only in the most exceptional circumstances, where it is not possible for the prior consent of the patient to be obtained, can testing without explicit consent be justified’.

3. The patient showing a positive result on the test is peremptorily dismissed. If admitted to hospital, he is instantly discharged. In many instances, he is told that the reason for this dismissal is the positive HIV report.

4. No attempt is made to break the news gently.

5. No attempt is made to counsel the patient and family, confirm the diagnosis by blot tests or other sophisticated means, identify the route of infection and boost the patient’s morale by telling him that come what may, the doctor is by his side to help as best as he can.

6. On the contrary, the doctor patient relationship is usually terminated abruptly on receipt of the positive report.

7. Citizens of Mumbai recall vividly the sixty year old patient at the Bombay Hospital who, when told that he had to leave the hospital as his test for HIV was positive, leaped to his death from its eighth floor?

Confidentiality
Respecting the patient’s privacy
Once the diagnosis of HIV infection is made in a patient admitted to hospital or nursing home, it is rapidly broadcast to all staff members. The change in their attitude towards him is immediately obvious to the patient.

Some clinics plaster difficult to miss placards on the patient’s bed informing all and sundry of the patient’s HIV status. This is especially tragic when the placard remains in place during the hours when friends and relatives visit patients.

Other clinics print in bold letters the HIV status on the cover page of the patient’s case notes, at times underlined in red.

When questioned, doctors and administrators offer the explanation that this measure is taken in order to ensure that everyone ‘takes the necessary precautions when handling the patient’.

Informing the spouse
Since the spouse may contract the disease from her infected husband, how is she to be informed of the very real danger she faces? A recent study makes the consideration of this issue of vital significance.

57% of individuals in rural South Africa would not tell their wives about their having contracted sexually transmitted disease. If infected by HIV, 66 would withhold information from their wives. 71% of men would not inform their casual partners about their HIV infection. The same study showed that a majority of women claimed a right to know if a man is infected.

There is every reason to believe that a comparable study in India would show similar results.

How is this problem tackled in India? There are no clear guidelines on the subject issued by any authoritative agency. Most doctors do not consider this a matter warranting their interference. HIV infection has been diagnosed and the patient sent away. There, for most, the matter ends.

A few, concerned groups, notably at the National Institute of Mental Health and Neurological Sciences, have evolved a policy. They counsel each patient known to be infected by HIV, individually. At the end of the session where the diagnosis is conveyed and advice offered on available help and treatment; he is told of the possibility of passing on the infection to his spouse. He is strongly advised to inform the spouse about his HIV status and adopt the unfailing use of a condom during every sexual act. During the next interview he is asked whether the wife has been informed. If the answer is ‘Yes’, he is asked to bring the wife along during the next interview for joint counselling. If the answer is ‘No’, without any acceptable reason (such as the wife being out of station), he is once again asked to inform the wife. This time he is also told that should he fail to do so, the doctors at the centre will disclose the information to her.

This practice has international sanction. As noted by Bayer and Gostin, ‘What is crucial is the underlying ethical principle that confidentiality, while critical, is not the only ethical value. Indeed, when vulnerable unsuspecting persons are placed at risk it may be imperative to breach confidentiality? They refer to the case Tarasoff v. Regents of the University of California in America in 1976, where a central legal doctrine emerged. Under certain circumstances a clinician has an affirmative duty to warn or protect unsuspecting targets of his patient’s violent intentions. Several judges in America have held it a duty of physicians to warn family members of the presence of infectious diseases in an individual. ‘No case to date has criticised a physician’s disclosure to make limited, appropriate disclosures of a patient’s condition under circumstances in which the patient or others were reasonably at risk but for the disclosure. The legal system appears to encourage
physicians to act responsibly by making more, rather then fewer, disclosures of patient confidences under the general public policy that the greater good is served despite intruding upon the patient’s privacy.9

The Centers for Disease Control and Prevention, Atlanta, Georgia, in its guidelines, is very specific. ‘Patients who are HIV antibody positive should be instructed on how to inform their partners and to refer them for counselling and testing. If they are unwilling to notify their partners or if it cannot be assured that their partners will seek counselling, physicians or health department personnel should use confidential procedures to assure that the partners are notified.’9

Confidentiality in recording and reporting test results
Public health requirements make it necessary for laboratories to maintain records of positive HIV results. There is no difficulty as long as these records remain confidential documents. Where reporting (to public health authorities) is required by law, it is important to shield the identity of infected individuals from exposure.8

Law lags behind ethical requirements
‘There is no statutory provision regarding consent (in India) for testing. A combined application of the doctrine of unconscionable contracts, Article 14 (Equality Clause) and Article 21 of the Constitution (no person shall be deprived of his or her liberty except by procedure established by law) may help in developing the argument that consent has to be informed and supported by counselling services.

‘There is no specific statute providing for confidentiality in India. Section 126 of the Evidence Act protects from disclosure, professional communications between lawyers and their clients. No such provision exists in the case of doctors.’10

Treatment of the patient testing positive for HIV
Several centres avoid all problems concerning the treatment of such patients by turning the patient away. ‘Doctors in India have refused to treat HIV and AIDS patients in some institutions including the All India Institute of Medical Sciences, the premier public medical institute in India.’9

Describing the situation, at the largest public hospital in Madras, Chinnai (1996) reports: Patients face discrimination at every level from ward boy right up to the doctors. Surgeries (on them) are constantly postponed. She cites the names of three patients, Kavita, Murugesha and Rajeshwari, who were left outside the hospital gate and transported by the (municipal) corporation lorry to the dumping ground. Having thrown patients out of the hospital, nurses would write that the patients are absconding, when they were not even fit to walk. ‘We are told to take such patients away, but where do we take them?’, asked the wife of one such patient. Poor patients, especially women coming from rural areas, are subject to the worst forms of humiliation and violation.

We have gone to the police and the Tamil media but none are willing to do anything about it.’ one member of the Positive Action Group said.11

Another report describes similar treatment in a hospital in Guwahati. Twenty one year old widow, Jahnabai Sharma and her daughter, Karishma were seen at Guwahati Medical College after Jahnabai’s husband died of AIDS. They were then sent to the infectious diseases hospital. Two weeks later they were discharged. The high court investigating this case was told that if HIV infection was suspected, the patients were subjected to tests and if found positive, were ‘informally discharged’. In one case, a youth was discharged in haste with the saline drip attached to him. He died a few days later. An amount of Rs. 35,00,000 sanctioned by the Government of India to the hospital for treating patients with AIDS was lying unutilised.12

Where the patient is not turned away, he is made acutely conscious of the fact that he harbours an illness that is terrifying. Attendants do their best not to make any physical contact whatsoever. Sponging of the bed ridden patient is rarely carried out. When contact is inevitable, the attendant dons gloves, cap, mask and gown. We have witnessed doctors donning shielded goggles, plastic aprons and other paraphernalia such that they appear ready for a voyage in outer space.

Since doctors display fear and disgust, these percolate down the line to the humblest attendant who now tosses the patient’s linen and hands his meal to him in such a manner that no contact is made. Snide remarks implying certain knowledge of the means by which the patient acquired the infection are made in the presence of the patient and his family.

The person handling the patient’s bed pan and urinal does so almost under duress and with extreme disgust. When the patient needs suction of the larynx and trachea, these are done with the face averted to avoid infection by spray past the already formidable defences of goggles, mask, cap and gown. Whilst no one denies the need to take care when handling the patient’s body fluids and when dealing with his person, should we rob the patient of his dignity in doing so?

I am often puzzled by those who are so diligent in avoiding being infected by the patient. Wearing cap, mask, gown and gloves they suck the patient’s throat. They then stroll to the nurse’s table and plonk themselves on the chair. With the same pair of gloves on, they wipe the sweat off their own foreheads, write notes on the case paper and then replace the pen in an inner pocket. They then move on to the next patient known to have a negative HIV test and minister unto him using the same gloves, cap, mask and gown!

It is important to recall the American Medical Association Code of 1847 - an assertion that is representative of prevailing international sentiment: ‘And when pestilence prevails, it is their duty (the duty of doctors) to face the danger and to continue their labours for the alleviation of suffering, even at the jeopardy of their own lives.’7 (emphasis added).
Some frequently made arguments and rebuttals

1. I must know whether or not a patient has AIDS. If I know that his test for HIV is positive, I can take appropriate care to ensure that he does not pass his infection on to others.

There can be no argument about the need for a doctor to know all he can about his patient provided such knowledge is obtained in the best interests of the patient.

When information is sought merely for the protection of the doctor, or, worse, to the detriment of the interests of the patient (as when he is thrown out of the consulting room or hospital merely because his HIV test is positive), the search for information becomes perverse, unethical and immoral.

2. I have a life to lead and a family to look after. Why should I involve myself in treating a patient with a fatal, communicable disease?

Such an attitude is born of ignorance and prejudice. HIV is a fragile virus that is easily destroyed. Ordinary precautions taken in the course of the management of any patient are more than sufficient to ensure that the treating physician does not get infected. Despite the hundreds of thousands of documented patients with HIV infection, and AIDS the world over, there are hardly any proven cases of doctors being infected by the virus when the usual precautions were taken.

3. I have a right to refuse to treat any patient. What is wrong if I refuse to treat a patient with AIDS?

Refusal to treat on the basis of prejudice or fear is not expected of the good doctor. The law does permit any doctor to refuse to treat any patient provided such refusal is not likely to result in irreversible harm or death. By using this provision of the law, the doctor will be acting legally but it will be against all ethical and moral norms.

‘There is no specific statute or rules or regulations obliging the doctors to treat HIV patients. However, all doctors and medical personnel have a common law duty to treat patients brought to them.’

Some questions that are never answered by doctors

Since you demand that each of your patients gets himself tested for infection by HIV and shows you the result, is it not fair that you get yourself tested for HIV as well and announce the results to each of your patients?

What proof have you that patients can transmit HIV to you? Can you provide references in the medical literature to such transmission?

Since you insist on wearing cap, mask, goggles, gown and special protective shoes, could you provide references in the literature to prove that these are effective in preventing transmission of HIV?

When the literature shows that items used in the care of the patient who tests positive for HIV are easily sterilised by soaking them in bleach and then autoclaving them or sterilising them by glutaraldehyde or ethylene oxide, why do you destroy them?

Why do you charge patients testing positive for HIV more than you would other patients?

Where surgery is necessary, why do you charge a patient with HIV more than you do another with diabetic gangrene or peritonitis?
Public health strategy on AIDS

Prevention and treatment

Drugs effective against the AIDS virus (such as AZT or zidovudine) are not freely available to help those infected with HIV. Programs in India largely consist of advising people how AIDS is contracted, encouraging blood tests and handing out condoms. This is especially regrettable as India is a signatory to the Paris AIDS Summit Declaration (1 December 1994) which rightly states:

‘Mindful that HIV/AIDS prevention and care and support strategies are inseparable, and hence must be an integral component of an effective and comprehensive approach to combating the pandemic, we declare our obligation to act with compassion for and in solidarity with those with HIV or at risk of becoming infected and undertake in our national policies to protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS through the legal and social environment.’

Special care centres for AIDS sufferers, or hospices that might allow them to die with dignity, are virtually unknown. As a result, for many AIDS sufferers, the miseries of death are compounded.

The government’s failure to set up effective AIDS programmes means that much of the burden falls on private efforts. Those attempting to stem the tide of infection by HIV battle against the taboos of a society that discourages sexual candour, against ancient superstitions that discourage the use of condom use and against indifference, sometimes even hostility, from local officials.

To take just one vulnerable group, the seriousness of the AIDS problem among Indian truckers can be gauged from discussions with them and their ride-along helpers. The drivers have an average of 150 to 200 sexual encounters a year with women and with girls.

Sex workers of foreign origin

We have amidst us girls and young women who have been lured or kidnapped from neighbouring countries - Bangla Desh, Nepal, Myanmar. The manner in which we deal with them once we find that they are infected by HIV needs serious reconsideration.

Our current approach has elicited the following comment from a citizen of Nepal on the Internet: ‘Acting on instructions from the Bombay High Court, police on 5 February 1996 raided some of the city’s brothels. Four hundred and fifty six girls were rounded up, among them 218 Nepalese. Since there is no law against prostitution in The court ruled a long while ago. We have yet to see the ruling translated into practice.

Infected blood

A significant number of commercial blood donors test HIV positive. Although government policy requires hospitals and blood banks to test blood for HIV infection, surveys show that at least 30 percent of all blood used is not tested, and that this may account for as many as 12 percent of HIV infections.

The medical profession has failed to take action to prevent tainted blood from entering the blood banks. It was left to social organisations such as Common Cause and the Courts to compel the profession to act.

In an attempt to ensure safer blood supply and lessen malpractice, malfunctioning and corruption in our blood banking system, the Supreme Court told the government to create a National Council for Blood Transfusion. The judges advised the government to enact separate legislation for regulating the collection, processing, storage, distribution, and transportation of blood and the operation of blood banks. The order also called for all of India’s blood banks to be licensed within a year. A quarter of them were unlicensed when the order was passed.

Other provisions in the judicial order included the ending of professional sale of blood within 2 years, verifying that trained drug inspectors check the banks, and allowing 100 percent exemption on income tax to people donating money to the banks. The court’s directive came in response to a petition filed by Common Cause.

The court ruled a long while ago. We have yet to see the ruling translated into practice.

Infected semen

At the seminar on medical ethics organised by Max Mueller Bhavan, New Delhi and All India Institute of Medical Sciences on 8 9 October 1995, a call for caution in the use of sperm supplied by private sperm banks, which have mushroomed in many cities, was sounded. Dr. Lalita Badhwar, a New Delhi gynaecologist pointed out that most
Grants for fighting AIDS—how are they spent?

The Indian government has sent out conflicting messages. At times it has described AIDS as a national crisis and at others treating it as a menace that will go away. The government announced a $100 million five year AIDS programme in 1992, with $85 million of the money in the form of a loan from the World Bank. But as we near the end of the programme, only $35 million has been spent.

It is not just the authorities that are at fault. Those claiming to work on AIDS are not blameless.

According to Western experts, much of the money has gone on expensive conferences, planning sessions and reports. The sums spent on programs to improve blood screening, increase AIDS awareness, promote condom use and create clinics have been pitifully meagre.

Research on AIDS one unwelcome Indian example

Desperation will lead people to do almost everything. This is a story about what happened to 10 people in Mumbai when an American veterinarian came calling with what he said was a miracle cure for AIDS.

These ten, all HIV positive, became guinea pigs in a secret test of an experimental vaccine whose effects, according to international health experts, are still largely unknown. The vaccine, based on Bovine Immunodeficiency Virus (BIV) has never been tested on animals and most scientists doubt whether it could offer any remedy to stricken humans.

But ten middle class, educated people in Bombay were persuaded BIV could save their lives. One of the patients who took part in the trials recalled the vet’s pitch: ‘He was saying the vaccine has come and you are very lucky people. He said we will become HIV negative - 100% HIV negative. That’s what he told us.’ After the trial was abandoned, the patients were left with no medical support.

Clandestine drug trials are unethical and against the law. But it can take years and hundreds of millions of pounds to carry out an authorised vaccine trial in the West and the American vet was in a hurry to exploit his patent application.

Bhairab Bhattacharya, aged 67, the Calcutta born inventor and naturalised American who says he has a Ph.D. in veterinary medicine, has spent several fruitless years trying to persuade the scientific community of the merits of BIV.

Bhattacharya was in correspondence with Dr. I. S. Gilada. Dr. Gilada and a social worker, Maya Gogte, assembled a list of trial participants. ‘As such, our lives are useless,’ said one participant. ‘If something could come out for humanity, it is good. I have a scientific background and it sounded logical.’

Dr. Bhattacharya delivered a brief lecture in English about the properties of BIV. Participants were given no printed information about the vaccine and there was no translation for those who spoke only Hindi or Marathi. They signed consent forms, on which it was promised that the clinic would give them follow up medical support.

After they received the injection, Dr. Gilada handed each participant an envelope containing Rs. 1000. According to the sketchy notes taken by one of those who supervised the first injections, one of the participants was already in the terminal phases of AIDS, was suffering from diarrhoea and had a temperature of 104 degrees F. The man eventually died of AIDS-related ailments.

Dr. Bhattacharya made no attempt to secure official permission for his experiment. The central government and health authorities in Bombay and the state of Maharashtra say they were deliberately kept in the dark. Dr. Bhattacharya argues that the search for a cure for AIDS is too urgent for him to bother with formalities.

The trial was abandoned because of a dispute (between Bhattacharya and Gilada) over money. By the time the second or booster shot was administered on April 12, 1994, the experiment was effectively over. A tenth man who could not be present at the clinic was so desperate to get his shot that he borrowed money for the train fare to New Delhi to track down Dr. Bhattacharya. He was shocked to find that they had not heard of him at the addresses Dr. Bhattacharya was supposed to be available. Dr. Bhattacharya travelled on to Calcutta where he says he injected four prostitutes who have HIV with the vaccine and distributed milk infected with BIV to several other women in the red light district.

Raju, a designer aged 38, who took part in the experiment said, ‘They shouldn’t have dumped us. They left us on the streets like stray dogs. It was completely inhuman.’

A draft code to be adopted by all doctors

We need to evolve a code of conduct which must be wholeheartedly subscribed to by all doctors. A draft code is offered. This could form the basis for the evolution of a definitive document.

We recognise the following truths:

1. The Human Immunodeficiency Virus (HIV) is a virus capable of infecting humans.

2. It is a fragile virus that is easily killed by the standard techniques for sterilisation.

3. It is commonly transmitted by one person to another through homosexual or heterosexual intercourse, transfusion of infected blood or blood products, or through unsterile hypodermic needles used for injection into a person already infected by HIV.

4. Such transmission of the virus can be avoided by the use...
of. simple measures such as the use of a condom during sexual intercourse, screening of blood donors for HIV and the use of sterile hypodermic needles.

5. Infection by HIV produces a chronic, manageable illness.

6. We support the rights of infected patients to be treated without prejudice in their workplace, home, and health care.

7. Some individuals infected by HIV may go on to develop Acquired Immuno deficiency Syndrome (AIDS).

8. At present we have no cure for AIDS. The diagnosis of AIDS is, in most cases, tantamount to a death sentence.

9. Patients with AIDS may suffer a host of infectious diseases and suffer considerably before they die.

10. There is considerable prejudice in many minds against persons known to be infected by HIV or suffering from AIDS. This augments the agony of such individuals.

As aware and concerned physicians, we therefore resolve:

1. We are morally obliged and bound by duty to provide the best possible treatment to patients known to harbour HIV or suffer from AIDS, just as we would to any other patient entrusting himself or herself to our care.

2. Such care of patients known to harbour HIV or suffering from AIDS, will be provided under the umbrella of ethical principles, special care being taken to ensure confidentiality in view of the prevailing general prejudice against such individuals.

3. Patients will be offered counsel on the best course of action to prevent transmission of infection to spouses, other sexual partners and the population at large.

4. Where the patient is seen to act irresponsibly, we may find it necessary to intervene in the interest of the spouse or the public at large.

5. The function of the immune system improves with proper diet, exercise, healthy living and can be assisted by therapeutic means. We shall do all we can to reduce the possibility of inter current infection and maintain a state of health in such patients.

6. We shall discuss scientific knowledge on HIV and AIDS at every forum at our command so as to inform the public, empower it to take measures at preventing the spread of disease and ensure that those infected by HIV have free access to the best possible medical care.

Acknowledgements

I am obliged to Dr. Rakesh Tandon, Professor of Gastroenterology, All India Institute of Medical Sciences, for reawakening interest in this subject and ensuring that I disciplined myself into preparing a formal document on it.

I am grateful to Dr. Gabriel Britto and Mr. S. K. Neelakanth of the National Addiction Research Centre, Anheri, for providing many important references. They enabled me to consult these references in the comfort of my own office by transporting them to and fro.

I have benefited greatly from discussions with several workers in the field and with my colleagues in the Forum for Medical Ethics Society.

References


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On the following pages we reproduce the revised South African code of ethics in HIV and AIDS. It provides a powerful example of how the national medical association of a country can instruct and guide its members and other personnel in the health services. We desperately need such guidelines in our own country.