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The Patient with AIDS

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Compounding a Tragedy

In the first issue of our newsletter we had referred to the ethical aspects involved in the diagnosis and management of patients with Acquired Immune Deficiency Syndrome (AIDS). We alluded to the insistence in some hospitals on subjecting every patient to tests for the presence of Human Immune-deficiency Virus (HIV)

I and II

The Times of India dated 13 January 1994 featured on its front-page news of a tragic event. 'A sixty-year old advocate... leaped to his death from the eighth floor of the Bombay Hospital and died of multiple injuries... (This followed) the revelation that he was HIV positive ... The hospital has in the past also dismissed five employees who tested HIV positive, one of whom also subsequently committed suicide, hospital sources stated...' The next day, the front page of the same newspaper featured additional details: Dr. I. S. Gilada of the Indian Health Organization stated to the reporter from the Times of India that he had personally treated at least a hundred patients rejected by the Bombay Hospital after they were found to be HIV positive. In particular he described a patient with abnormal collection of water in the brain (hydrocephalus) on whom one of the city's most eminent surgeons refused to operate because the HIV test was positive.

The statement made by Mr. C. G. Joshi, executive director of Bombay Hospital to the Times of India (14 January 1994, Bombay edition, page 1) is intriguing: 'It is not a general policy to discharge patients. They come to us for treatment of other diseases and when they find out that they are HIV positive, they may go to other places for treatment...' Claiming that facilities for treatment at the Bombay Hospital were among the best in the city, when asked how many patients with AIDS were under treatment, Mr. Joshi replied: 'There are no AIDS patients being treated in the hospital right now. They have not stayed back to be treated.' A study of the actual reasons why, despite such good facilities for treatment, patients left the hospital might prove rewarding.

It's bad enough contracting a disease that has no cure at present. When such a patient seeks treatment from a doctor, the least that he expects is comfort and consolation. He also expects that the intercurrent illness that prompted a consultation - gastro-intestinal infection, pneumonia, tuberculosis... - will be treated promptly and effectively.

When, instead of the expected relief, the patient encounter hostility, fear and rejection, a total breakdown in morale is not surprising. The reports in the Times of India suggest that this was the chain of events in the above tragedy.

Why do doctors and others behave thus? Are they justified?

Several factors appear to combine to provoke a harsh negative response from doctors, nurses, and attendants in the wards of hospitals and in administrators. We list just two of these and the relevant scientific facts:

1. Fear of contagion: Perhaps the strongest stimulus to aversion is the fear that the patient will transfer HIV to his medical attendants. The fact that no cure exists at present for this disease makes the repugnance especially forceful. The prevailing impulse appears to be, 'Let me place as much distance as possible between myself and this wretched person. I don't want to have anything to do with him.'

Experts on AIDS have done their best to convey several easily understood facts. HIV is transmitted either via blood or semen. The mechanism of transmission of the virus is similar to that of the virus causing hepatitis B. The hepatitis B virus is the more contagious of the two.

HIV is a fragile virus, highly vulnerable to drying, chemical agents such as sodium hypochlorite and common measures for sterilization such as boiling and autoclaving. Even ordinary soap can inactivate this retrovirus.

Common sense dictates the use of simple measures for protection against the virus. Whenever one is likely to come in contact with blood, semen or, indeed, any of the body fluids of an infected patient, the use of a mask and gloves provide adequate protection. All items that make contact with blood or semen should be immersed for six hours in 10% sodium hypochlorite solution. Where the instruments can be sterilized by heat, autoclave them. Heating for 30 minutes at 60 degrees Celsius or boiling for 20 minutes also inactivates the virus. Infectious material should be collected in waste disposal bags marked **BIOHAZARD**, decontaminated by autoclaving and then got rid.

There appears to be no basis for a doctor to panic when he is face to face with an individual who has been found to be I-HV-positive.

2. Condemnation of immorality: Several individuals are known to have contracted AIDS through homosexual intercourse. The general disapproval of this form of sex is brought into sharp focus in the behavior of the doctor towards a patient with AIDS. 'Serves you right for your bestial behavior!' is the unspoken message.

Current social mores accept homosexual behavior as a variant of the accepted, normal sexual act. Even if this were not so, the total lack of logic in assuming that every patient with AIDS is a homosexual deviant was dramatically highlighted by the case of a hitherto respected middle-aged father being ostracized by his offspring when he tested positive for HIV. It was only when the arrogant progeny discovered that the virus had been transmitted by their mother that they came to their senses. (The mother had received the virus through transfused blood.)

Are we, as doctors, to judge the morals of our patients and presume to act on such judgements? The code reproduced on page 12 provides the answer: "(The physician) should be an instrument of God's mercy not of His justice....."

The Ethical Approach

a) Are the tests for the virus causing AIDS perfect? The available tests for detection of HIV in a patient are flawed. False negatives and false positives are well known. The western blot test, more reliable than the test for HIV, is also not foolproof. This is why recourse is necessary at times to tests using the polymerize chain reaction.

b) Does a positive test for HIV spell doom? We have convincing evidence that not all individuals testing positive for HIV develops full-blown AIDS on follow-up examination. We are also beginning to see patients with full-blown AIDS who survive for surprisingly long periods without obvious disability.

b) Who should be tested for HIV? There is no disagreement on testing for HIV when clear indications exist. Such a test can be justified in populations known to be at risk - drug addicts, prostitutes, and recipients of many blood transfusions.

Testing blood donors for the HIV and hepatitis virus is also within the bounds of reason.

It appears counter-productive and, at times, as illustrated above, catastrophic to test each and every person seeking our help for HIV. An otherwise cheerful, healthy individual will be reduced to a cowering mass of despair on receipt of the knowledge that he suffers from an incurable disease. Worse, society at large and even those he considered near and dear to himself, will treat him with the same revulsion that was once the fate of the leper.

If the logic of testing each and every patient for HIV was to prevail, we should start by checking those most likely to convey AIDS to others - doctors, nurses and other hospital staff members. By the same token, these hospital personnel and all patients should be tested for all sexually transmitted diseases, infective hepatitis and a host of other communicable diseases.

Since the patient with AIDS is especially vulnerable to infection, all personnel attending to him should be tested for all communicable diseases.

c) How should the test for HIV be carried out? In the absence of general education on AIDS (so obvious even amongst members of the medical and paramedical professions), it is obligatory on our part to discuss this test with the patient, explaining the need for it in simple terms. It must be emphasized that as with all other interventions, the test can only be performed with his consent.

d) Informing the patient of his disease: There can be few facts as traumatic to an individual today as the knowledge that his blood shows infection by HIV.

The patient deserves all the compassion, tenderness and humanness that we can summon. The blow must be cushioned heavily. The news must be broken gently. Where possible, pessimism must be kept to a minimum. There is enough scientific evidence that not all individuals testing positive for HIV go on to develop full-blown AIDS. Not all those developing AIDS die a lingering death. Some have developed antibodies against the HIV virus. Dormancy of the disease in AIDS and burnt-out disease has yet to be recorded as a frequent occurrence but anecdotal reports of such events are available. These should be pointed out to the patient and relatives.

e) Counseling the relatives: Whilst the relatives must be provided all the facts on the disease, it is important to do one's best to abort a sense of horror and disgust in them. Measures by which they can protect themselves from the transmission of disease should be clearly and simply discussed and demonstrated.

It is vital that relatives be helped to gather around the patient in his hour of need and assisted in his care.

f) Management of the patient with AIDS: It is high time that society at large insisted on a formally laid down code of management of patients with AIDS. With the medical councils in disarray and unconcerned about this issue and with the medical profession generally reacting hysterically, the public must take it upon itself to lay down such a code. It is necessary to make this code legally enforceable with drastic punitive action against institutions and individuals infringing it.

The code must insist on the following minimum standards:

i) The patient testing positive for HIV or presenting with full blown AIDS will be treated with the same compassion, care and dignity, as are other patients.

ii) Such patient shall not be segregated or ostracized in any way.

iii) No pressure will be brought upon such patients or their relatives to leave the hospital on any grounds other than those ruling the discharge of any other patient.

iv) Whilst the hospital and its staff members will take every precaution against preventing the spread of infection from the patient, equal care will be taken to ensure that this very vulnerable individual does not contract any infection from his surroundings, other patients or the staff.

v) All therapy, including life-saving surgery, will be offered promptly and efficiently.

All our hospitals - in the public and private sector - share a common characteristic. They function in secrecy. It is extremely difficult, if not impossible, to extract any reformation from the authorities in charge. When the information requested pertain to complications suffered by one or more patients in the hospitals, the clamp down on information is complete. In confidence, directors of private hospitals voice their concern on the use of the provisions under the Consumers' Protection Act against them should data on accidents or misadventures in their wards and operation theatres become public knowledge.

A similar concern underlies the unannounced decision made by those running private hospitals on not treating 'medico-legal cases'. Included in this category are patients who have suffered assault, non-accidental burns, poisoning and other conditions which would necessitate registration of details with the local police station and subsequent testimony by doctors of the institute in a court of law. Such patients are directed to government or municipal hospitals.

The stated reason for doing so is either non-availability of a bed for the patient or lack of facilities for treating such a condition. As matters stand there is no way an outsider can directly check on the veracity of either statement but simple observation often nails the lie. Soon after a patient who has attempted suicide has been refused admission, a patient with a myocardial infarct is admitted without any fuss.

It is high time this anomaly and others of equal or graver import are subjected to public scrutiny. A step in the right direction has been taken by two hospitals in the public sector, though even this fall far short of the ideal. The K. E. M. Hospital and the Lokmanya Tilak Memorial General Hospital in Bombay have set up panels that process and investigate complaints made by patients and relatives on their sorry experiences in the outpatient department or the wards. Whilst these are welcome, a suspicion that matters inconvenient to the authorities may be played down or white-washed is inevitable as their panels are composed only of members of the staff, outsiders being excluded.

Similar panels - consisting of public spirited senior citizens of unchallenged integrity such as Mr. Justice Lentin or Mr. J. B. D'Souza - should be appointed to every major hospital. They should be empowered to ensure fair practice, accountability to the public and the due process of the law, and take disciplinary action where necessary.

(We are respecting a request for anonymity but will forward comments and opinion to the author so that further discussion can take place. Editor.)