

Dilemmas in the care of patients with AIDS in India

The patient was lying curled up in bed, with her husband and sister in attendance. In a very feeble voice she informed me that there was a fire in her stomach. The attending doctor told me that she had advanced AIDS and was suffering from acute cytomegalovirus (CMV), meningitis, and other severe complications. They had begun treatment for CMV, but there was no provision for ARV drugs. Since I had nothing to offer in terms of medical advice, I stepped back to talk to the two student doctors, Bharat and Veena.

Bharat told me that the husband claimed that the patient had received blood transfusion during surgery 9 and again 5 years ago. She had fallen sick some weeks ago, was an in-patient for 18 days at a small town hospital where doctors failed to diagnose the disease, and finally was brought here. Bharat suspected that the husband, even though still healthy, had been infected first.

We went into a side room to talk. Before I knew it, and in part due to my enthusiasm, I was faced with counselling the family. The husband said he had been told that his wife had AIDS, and wanted to know if she would get well. Fumbling for words, I informed him that it was likely that she would recover from this particular infection but would be sick again. The best guess was that she had three to six months to live. I assured them that the hospital would provide the best care but the disease was incurable. In a meek and low voice the husband asked if this was the disease they had heard of on TV. I could barely open my mouth to say yes.

With a great deal of hesitation the husband asked whether he should bring his wife back to the hospital if she fell sick again. Underlying the question was the financial hardship of hospitalisation. The sister broke down

at this point and he asked her to leave the room. Bharat told the husband that the hospital would care for his wife, but it was clear that he was not thinking of the cost. At this point I took it upon myself to counsel him. Yes, the hospital would take care of his wife if and when she fell sick, but without the anti-retroviral drug therapy, whose cost was completely out of their reach, one could not tackle the underlying HIV infection. Hospital care could, perhaps, buy her an extra month, but he should weigh that against the costs. She may be equally well, or even better, served at home by their love and care during her last months. Bharat and Veena nodded in agreement. The final decision was his — hospitalisation or home care.

The consideration that led me to this course of advice were the following: The husband's monthly wages were Rs. 3000, whereas each hospitalisation was costing Rs. 20,000 to 30,000. To pay these bills they would have to borrow from loan sharks who charge interest rates of up to 100 percent. Very often families in such situations are forced

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to sell their children to the sex industry or as bonded child labor. One is, therefore, forced to decide between the best possible care for a loved one versus the ruin of the rest of the family and possible victimisation of the children! It is clear that society will have to repeatedly grapple with such ethical questions as the number of AIDS cases increase.

The last question we discussed was

who should be tested for HIV. The attending doctor, to provide complete mental satisfaction, had recommended all, the husband and the four children, again without considering the cost (Rs. 450 per person). Since the youngest child was 11 years old, all the children were very healthy, and considering the low risk of transmission from mother to them while tending their cuts and bruises, I did not think it necessary to test the children, and told him so. This raises an ethical question: how should doctors balance family's financial hardships versus care in such terminal cases?

As we got up to leave, the husband thanked me for being honest, and we perceived a certain calm in his manner. He reiterated that he would provide all the love and care for his wife, and we, that the hospital would do its best.

There are many questions that still haunt me. Had we given the right advice? Should HIV patients with essentially no immune system left and with infectious diseases like TB be treated in common general wards, hoping that none of the other patients contract TB or vice-versa? Or are HIV patients, with no access to ARV drugs, better off with home care? Had we convinced the family that HIV has no cure and to not waste money on quacks with miracle cures?

This is but one example of the social and medical cost heaped upon us by the HIV/AIDS pandemic. We will increasingly be faced with similar gut-wrenching stories. How will we keep our sanity when these stories become millions of similar stories, all with the same tragic conclusion?

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Rajan Gupta, a US-based physicist, is promoting AIDS awareness and prevention in India by giving lectures and motivating friends, relatives, and associates. He recounts this experience during a visit to a private hospital in India. The full text and other articles are available at <http://t8web.lanl.gov/people/rajan/AIDS-india/mywork.html>.

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