

AIDS victims and family are still social pariahs

Most of us are far removed from the grim realities of AIDS. But for those who are affected life can be an unimaginable torture. Like it was for Aruna who is in her early twenties and a widow. The loss of a husband is not the only tragedy to have hit her life. She lost her husband to AIDS and that has changed her life immeasurably. For not only did she have to deal with loss of income as her husband fell ill, but also had to live with the cruelty of discrimination.

Aruna lives in the slums of Yerwada and it was the AIDS status of her husband that changed everything. Says Aruna who has two sons, aged 9 and 7, Since my husband could not go to work because of the TB caused due to AIDS, I took up a job as a maidservant. We had to leave our jhopadpatti and came to live with my in-laws. But my mother-in-law and her son made life hell for us. As it is I had to shunt from home to work to Naidu hospital. But because he was a full blown victim of AIDS they refused to touch him, refused to give him food, clean him up or help him go to the toilet. My husband in fact told me that it would have been better if he died. The discrimination Aruna had to put up with did not stop with her immediate family. Soon the neighbors came to know of Hari's HIV status and announced a dictate. Aruna was not allowed to draw water from the municipal tap till all the women had finished doing so. Says she It was so humiliating. My husband died a thousand deaths when he came to know of this. Mostly because the neighbors were told of his illness only by my mother-in-law. As it is I had trouble with money, now I had become an untouchable because of my husband.

Aruna's tragedy did not end even with the death of her husband. When he died, no one in the family was willing to touch his body. No one was willing to do the last rites. Finally it was Roger Khuma, a social worker with Sahara Alhad a project that helps AIDS victims, who did the last rites. Says Khuma, People fear not just the fact that they may contract AIDS, but this also becomes an issue with the family members to abandon such people, as they did with Hari. To help such victims, Sahara Alhad has started a creche that looks after children of HIV infected parents. Aruna has been given a job as she has been thrown out of her marital home upon her husband's death. Had it not been for Sahara, like the many nameless women, Aruna too would have been on the streets, victimised for no fault of her own.

(Names have been changed to protect their identities)

Commercial Sex Workers

Pune has 4000 residential Commercial Sex Workers (CSWs) and 2000 who make up the floating population. Since sex and AIDS are so intrinsically linked, it makes sense to see how this spreads in the red-light areas. According to Dr. A. N. Joshi, assistant director, Health services, Pune circle, the chance of infection through sex is very low. "Just 0.1% to 1%, whereas from [blood transfusion](#) this chance is 95 to 100%. Yet 90% of HIV infections are transmitted through sex. This is because blood transfusions are few and far between and utmost care is taken at such times". But the story is altogether different, when it comes to sex. According to Joshi, 60% of CSWs are HIV positive. Each CSW gets about three to four clients a day, which means that the daily transmission of HIV in Pune's red-light areas is anywhere from 12 to 120 persons.

Despite the fact that almost all CSWs know that condoms are the only way to save their lives, its use is limited to just 50%. Says Nitin Bora, director, Kayakalp, "This is because condom use

does not just depend on awareness. It depends a lot on attitudes. If a woman is dying of AIDS, asking her to use condom to protect the life of another does not make sense to her. She is more worried about the food she needs for her next meal, about her children, so condom use is last thing on her mind”.

But unless she does not use condoms, the HIV sword will continue to dangle over our heads. And obviously awareness has not worked. But Kayakalp has managed to overcome this hurdle in a unique way. This is evident in the fact that in March STD infections were down to 5 per 1000 whereas in January the clinics in the redlight areas reported about 40 per 1000 CSWs. Says Bora, “You cannot just hand condoms to the CSW and expect her to use it. By just creating awareness, the CSW will not start using condoms, you have to ensure its use. We feel that this is because she is so depressed and feels so hopeless that she lacks a health seeking behaviour. The doctors in the redlight areas do not treat them right. If a customer is charged Rs 20, he will charge a CSW Rs 50. Then he is the man responsible for their poor health, many a time. This is because most of the time they are given third degree antibiotics and often they develop an immunity to them. You have to understand that she is a human being and more than just a CSW. She has feelings, she has children and in my experience I have seen that a CSW has generally lost all hope and has become totally apathetic. The only thing she cares for is her child”. By showing her how she can help herself, her child, the CSW begins to feel an interest in life, she begins to see hope. Then she becomes amenable to adapting health seeking behaviour. We do not talk about condoms, rather we emphasise on her child’s health, her anemia and she is the ready to listen to what you tell her. Therein lies the key to condom use.

These women are either addicted to alcohol and need To tackle this problem the WHO introduced the Syndromic Intervention Programme, herein four NGOs have been allotted the acre of 1000 CSWs each.

Exploring alternative routes

The AIDS virus is a silent killer. The scars it imparts are both physical and psychological. At stake are both human life and an individual’s dealings with society – social stigma dealing the strongest blow. Loss of a job and ostracisation are the harsher truths. Then there are the costs of medication. The Human Immuno Deficiency virus kills indiscriminately and still lacks a potent cure. Now, alternative medicine is trying to help stem the rising costs of treating HIV as well as offering treatment to at least curb if not completely stop the onslaught of the virus. Many Ayurvedic doctors in Pune have begun offering alternative medicine and treatment to many HIV positives and those diagnosed with AIDS.

As of now the only hope an AIDS victim has is to prolong life by getting on to Anti Retro Viral therapy (ARV). The hitch? At Rs 3 lakhs a year, it becomes prohibitively expensive for most patients. Which is why Pune’s Ayurvedic doctors now seek to treat such patients with Ayurvedic medicines. Dr. Vilas Nanal at the Janakalayan Blood Bank and Dr. M D Shastri at Inlaks and Budhrani hospital are both involved in a project which helps HIV patients through Ayurveda.

Dr. Nanal’s aim has been to make a patient HIV negative. However, this hasn’t been feasible now. What Ayurveda does is help relieve symptoms and increase immunity to enable a person to lead a relatively normal life while being positive. “I have been treating patients with

ayurvedic medicines for the past three and a half years. Initially we used a lot of medication, (all ayurvedic) about 12. But slowly we took them down to just five”, says Dr. Nanal.

There are even more patients at the Inlaks hospital. About 600. All of these have remained asymptomatic so far and have not infected their spouses and children. So does Ayurveda work? It might be too early for an answer. However, there have been five deaths at Inlaks, which, while a good success rate, still doesn't answer the question of Ayurveda being a cure. {mospagebreak} The concept is different from modern medicine too. It is based on general immunity which again depends on how much a person has acquired and the person had at birth. “We improve the immunity through panchkarma which removes toxins, which cause blockages and affect the metabolism of the body”, says Dr. Shastri.

But the efficacy is still questioned. Says Pujari, an HIV consultant, “Most patients remain asymptomatic for eight to ten years after acquiring HIV. Also, Ayurveda doesn't have a control group wherein one batch is given treatment and the other is not, to enable us to compare the efficacy of the drugs. Then most people also use the P 24 test which can give a false negative too”.

Dr. Dilip Wani, medical director, Janakalyan Blood Bank admits one cannot vouch for Ayurveda's validity. Funding is also another problem area. “The patients coming to us have either full blown AIDS and other complications like diarrhea and weight loss, or are already HIV positive and symptomatic. But if they have been coming for the past three and a half years, there must be something to it”, says Dr. Wani.

The gray area remains testing. The CD4 and the CD8 tests that modern medicine requires to test for the efficacy of a drug cost Rs 1500 per month. These are necessary every three months, and the cost adds up to Rs 6000 a patient. Since not many people can even afford this much, whether Ayurveda works or not cannot be ascertained. For the treatment to be accepted on a much larger scale, Ayurveda will need to prescribe to its drugs testing.

Like Pujari says, “If only we could find a way to modulate the immune system! As of now Ayurvedic doctors continue to prescribe their treatments to patients to continue to remain healthy without doctors knowing how or why. For the patients, this is not a great cause for concern”.

Gender issues

“The highest risk an Indian woman can take today is to have sex with her own husband”, says Dr. Sanjay Pujari, HIV consultant. “This is because in my own experience, 90% of HIV positive women have been infected by their own spouse”.

Women do get shortchanged when it comes to the issue of their rights, but the AIDS virus seems to be a bigot. For women get infected for no fault of their own, in most cases at least. Take Veena (name changed) from Pune who got married five years ago to Ganpat. Ganpat was HIV positive and deliberately kept this information from his wife. Says Veena who is now a full blown case of AIDS and spends her time in and out of hospitals, coping with T.B. “It all started with a genital rash that would not heal. The doctor wanted to meet my husband, but he

never told me that I had contracted HIV. My husband at first refused to meet the doctor and it was only when I got pregnant that I was informed of my HIV status". {mospagebreak} Veena had an abortion and last year lost her husband to AIDS. Now it seems to be her turn. Says she "My family is so upset that I was not told of his HIV status. Had I known I would not have had any "relations" with him. When my family came to know, they wanted to sue him, for he willfully passed on the infection to me, but now he's dead so what's the use?"

It is not just the poor, uneducated women who get taken for a HIV ride by their spouses. According to Pujari, even wives of industrialists, doctors and professionals get infected. Says he "In fact when a male is infected, he gets plenty of support from his family, but when it is the wife, who in most cases contracts it from her husband, she hardly ever receives any family support. The Anti Retro Viral therapy which costs Rs 25,000/ a month, is often denied to HIV positive wives. It is mostly the male who receives treatment in such cases". Despite this there is very little a doctor can do to help the wife of an HIV positive male. Though the Supreme Court ruling states that if asked a doctor can override his patients right to confidentiality, very few women will actually think of cross-checking this fact with a doctor. Says Bianca Talwar a housewife, "What's the use of this information. By the time a wife finds out that her husband is HIV positive, chances are that she is infected herself by then". Which again raises the issue of a woman's right to refuse sex in a marriage. Says Sunita Wahib, HIV counsellor, "In our country, how many women have the right to say no to sex in a marriage? So even if she knows she could get infected by her spouse, what can she effectively do about it?"

Wahib quotes the case of a couple where the husband was infected with HIV and the wife who was negative, wanted to have a baby only to prove to her in-laws that she was capable of producing a son for the family. "All this after being counselled about the ramifications of having a baby of a HIV positive man. The woman was willing to risk her life, only to prove that she was fertile". Obviously the issue here is not just of the HIV infection, but of the attitudes that are present in society. Till such time that men learn to practice safe sex, till such time they take behave responsibly in matters related to sex, women will continue to face the risk of getting infected.

More money for less condoms

In the red-light areas of Pune, you pay more for less. More money for less condoms. The Government may try its level best to ensure that condoms reach the Commercial Sex Workers, free of cost, but that does not mean that it will be used.

Says Dr. Pooja Yadav of the Akhil Bharatiya Devdaasi Sanstha, Every CSW is aware that condom use can save her from HIV. Yet condom use is about 50%. This is because though we can create awareness, we cannot change attitudes overnight. According to Dr. Nitin Bora, director Kayakalp, an ngo that works with the CSWs in Pune, at least 2 lakh condoms are distributed free every month. Says he By now, CSWs and even the clients are aware of the benefits of safe sexual practices. But we have noticed that about 20% of the CSWs use this propaganda to their own benefit. When a client visits them, they ensure that they put on two or three condoms.

"The reason again cited is health. Sometimes the condoms are defective as everyone is

aware of by now and so the numbers are justified. Now not many people will agree to three condomned sex, so if the client insists on removing them, these women ensure that he pays for it". The removal of every condom is charged – at Rs 10 or 20 depending on the CSW. So though safe sex would cost a man Rs 50 on an average in Budhwar Peth, condom less sex would be around Rs 80 to 100. But why would a CSW indulge in an act that could endanger her own life? Says Bora, "The reasons for this are many. First of all most CSWs do not have an interest in life. They are simply existing. If she is told that she has contracted HIV or some other disease, she is not committed enough to care about passing on this infection to others. They just do not care. Then more than half of them are addicted to either drugs or alcohol. And like every other addict, they use every given opportunity to make more money so they can fund their habits". Given this scenario, it would make more sense for the authorities to not only distribute free condoms for AIDS prevention, but better still, create the right atmosphere that would ensure its use.

Helping kids of AIDS victims

AIDS comes with a baggage of social discrimination. Not only does the patient have to live in guilt and neglect as they are denied proper treatment and care, but even their families have to suffer the scourge of AIDS. For AIDS patients most often leave behind a family that is no position to fend for itself economically or emotionally.

Probably the worst affected are children, as AIDS is taking its toll on not just the male member, but also his wife who gets infected by the husband. The result? "Orphans" says Father Felix, director, Sarva Seva Sangh. With no one to care for such orphans, SSS has undertaken the task of providing shelter to them.

Says Felix "Since we do not want to label them as children of HIV positive parents, as that too can have severe repercussions on them, we put them in various hostels in the city. Even their class mates are unaware of their family's HIV status, so that these children can get some chance of living a normal life". It is not necessary that a child be an orphan to avail of this service. says Felix "Even if one parent is HIV positive, we take the child in, because often when the father falls ill, the family income is reduced to nil. Besides, it becomes very hard for children to live with the stigma of HIV".

As of now SSS has helped 52 such children whose parents are HIV positive. These children live as boarders in various schools in Pune. All their needs, for education, food, clothes is looked after by SSS. Any queries, any help required by families of AIDS infected persons can be directed to Father Felix who will be only too happy to offer support.

His address is: sss@pn2.vsnl.net.in

A toll free number for AIDS

Do you worry that the visit to the barber could have infected you with HIV? That the last time you kissed maybe you picked up the deadly virus? Do you also feel embarrassed to ask your doctor or a health care professional about this? Then all you need to do is call 1097 (in Pune) and rest assured that you will get correct medical information about any query related to AIDS. On January 11, 1999, the Maharashtra AIDS Control Society introduced the AIDS hotline in Pune. Says Dr.P.S.Patki who is in charge of this hotline service, "Many

people do not have access to the correct information about AIDS. Here we provide the correct information and since anonymity is guaranteed, people feel more free to call up". Upon calling this toll free number or if that is busy one can call 6126506(this call is not free) and choose the language in which they'd like to communicate. The choice so far is between Hindi, Marathi and English. After that the caller has five options. One will simply tell him what is AIDS. The second option informs him about symptoms, the third is about the places where AIDS testing can be done in Pune. The fourth option is about treatment and lastly one can also ask a personal question, which will be answered in 48 hours. Says Patki, "So far we have successfully answered 10,325 queries on what is AIDS. Questions related to symptoms were 7438 and 4164 calls were about AIDS testing, 2244 callers wanted to know about treatment and personal queries were 16,671".

Most people want to know things like "can one get AIDS if one had sex during menstruation? what treatment does one give to the widow and two year old child of a man who died of AIDS does homosexual sex cause AIDS?" Says Patki, "earlier people used to be quite inhibited about asking questions, but now we see them opening up and freely asking us questions".

So now a simple phone call to 1097 will now remove all doubts about anything related to AIDS.

Tackling AIDS: A National priority

While our fellows have been instructed to live on a diet of abstinence, and keep their libido in check, they have oscillated between exultation and frustration. Exultation for being awarded a special medal for their celibate lifestyle and frustration on seeing army men of other countries reveling in carnal pleasures, the AIDS scare notwithstanding. While AIDS continues to remain the scourge of our times with no cure or vaccine in sight yet, more and more individuals the world over continue to fall prey to it, sometimes for no fault of theirs. It is of course an established fact that the HIV virus could be transmitted through body fluids like blood and semen. So, even an innocuous blood transfusion could turn out to be quite fatal, if the blood transfused into your body has not been properly screened for HIV, and poor you happen to be the unlucky one to receive it. Health care in our country has always left much to be desired. Government hospitals are the pits when it comes to maintaining even the basic standards of hygiene.

Patients are often treated like guinea pigs meant for experimentation or sub-human specimens in a laboratory. So many people donate blood at these hospitals without proper screening. Most of them do it for money, particularly the desperately poor. Many of them are addicted to alcohol or narcotic substances and donate blood for money that would buy them their daily fix or swig, as the case may be.

Leave alone government hospitals, sometimes even private clinics are guilty of negligence. Cases of bottles of saline or glucose have been reported to have contained fungus or some other foreign matter. And what about blood? How reliable is the infrastructure we have in place? Are those who man these centers efficient and vigilant enough? These are hard questions with no easy answers. However, for many who have, at some time or the other, to depend on them, it could well be a matter of life and death. Hence, it would not be overstating the point that the authorities cannot possibly take it lying down. While a handful of soldiers may be goaded to abstain from sex in a faraway African nation, making use of handy tools like religion, among

other things, what about the teeming millions in our own country? Not that any of our soldiers doing duty overseas is expendable at all, but the question remains, what about their countless, hapless, hopeless countrymen back in Bharat mahan? So many sex workers don't even know the disease exists. Most of them service several clients in a single day. Recently, one TV channel showed a beaming sex worker declaring boastfully of having had sex with more than 200 clients in a single day! She did it ostensibly to have her name entered in the record books. Wonder how many of her clients were HIV positive. Wonder how many of them were married men who weren't infected to begin with, but who went back home to their wives with the virus in their blood stream. In our country where talking about sex still largely remains taboo and it is all gupt gyan, meant to be kept under wraps, awareness levels remain abysmally low. City dwellers know vaguely that the disease exists, but how many of them know how fatal it really is and how it could be transmitted. Sex workers when interviewed have revealed more than once that they can never possibly coerce their clients to use condoms. After all, they say, their daily bread depends on their trade however lowly it might be, and they cannot afford to be too fastidious.

So, even as research for the evasive cure for the dreaded disease continues, and until such time that we have a viable, clinically proven vaccine that is readily available to the common man even in Third World countries, prevention is the best way to combat the menace. A massive awareness drive is called for to educate and enlighten our multitudes about the disease and all its repercussions. Even our adolescents need to be informed about AIDS, safe sex etc. They are our future citizens. Teams of volunteers need to penetrate our villages and tell people living there in as simple a manner as would be possible about the deadly disease. Slums in cities are also often the breeding ground for diseases of all types for more than one reason. They need to be targeted too. Those who have already been infected need to be taught how they could prevent its spread and contribute towards preventing it from assuming epidemic proportions. Unless these and many more such measure are adopting without wasting any more precious time we are surely headed for disaster!