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VIEWS AND VOICES

Neglect of Hepatitis C leaves people with HIV vulnerable

Excerpt from an article by Bobby Ramakant, for AHRN

In communities where sharing of injection equipment drives the HIV epidemic, a parallel epidemic often lurks quietly in the shadows. Greater awareness about Hepatitis C, more investment of resources, cheaper diagnostic and treatment services, and improved hepatitis-related treatment literacy, are all urgently needed by individuals co-infected with the Hepatitis C virus and HIV.

Hepatitis C is a blood-borne, infectious, viral disease that is caused by the Hepatitis C virus (HCV). The infection can cause liver inflammation that is often asymptomatic, but chronic hepatitis can lead to cirrhosis and liver cancer. HCV transmission occurs when traces of blood from an infected person enter the body of a HCV-negative person. Like HIV, HCV is spread through sharing injection equipment, through needle stick or other sharps injuries, or less frequently from infected mothers to their babies.

HCV transmission rates are higher than that of HIV, and the condition is often more severe in drug users. People who share injection equipment are vulnerable to HCV and HIV infection, and in many places co-infection is very common. Up to 80% of individuals with HCV usually develop no symptoms. Initial symptoms, when they appear, can include jaundice, fatigue, dark urine, abdominal pain, loss of appetite and nausea.

There are 3 types of tests for HCV, all using polymerase chain reaction (PCR) technology:

HCV PCR viral detection test is designed to detect the hepatitis C virus.

- HCV PCR viral load test estimates the level of •HCV in the blood. It helps to monitor the effectiveness of treatment

- HCV PCR genotype test determines the specific genotype (genetic 'make-up') and subtype of HCV. This information is important in selecting a course of treatment. For example, treatment with interferon is more often effective for people with HCV genotype 2 or 3.

The cost of these PCR tests is prohibitive, close to US\$100 for the tests. People co-infected with HCV and HIV also need to monitor indicators of HIV progression, such as their CD4 count. If the CD4 count falls below 200, then HCV treatment is less effective, and its side-effects may be more pronounced. Individuals with HIV who are taking antiretroviral (ARV) drugs should consult their doctors to find out if they need to change their ARV combination before starting HCV treatment. Another challenge is the limited availability of PCR tests. In India for example, the test is available in only one city (Mumbai), although blood samples are collected from other parts of the country and sent there for diagnosis. The results can take more than a month to be returned. We clearly need more HCV diagnostic facilities, particularly in areas with high levels of injection drug use.

HCV can often be treated successfully, including among people living with HIV, but the treatment is not easy to endure. Treatment for HCV uses a single drug, or a combination of two drugs, and usually takes between six and twelve months. There is no standardized treatment protocol and clinical practice varies considerably between



Infectious material being picked up during outreach

Bhiwandi - a much needed outpost for Kalyan

Eldred Tellis.

When Kalyan Drop-In Centre was opened in April 2006, it was the first time that Sankalp had ventured beyond the Mumbai 'border' and as such the staff were aware that they would be confronted with different challenges and patterns of behaviour among drug users as they worked in a new area. Initially our Outreach workers found hectic activity on the central railway route between Thane and Ambernath and even though the clients were from regular homes on this stretch, they would be found in new areas according to the quality and availability of the drug. Therefore Outreach was always a tough task with our Outreach workers facing difficulties following up on the regular NSEP (Needle Syringe Exchange Programme) clients.

Since the clients often changed their hang-outs for the reasons mentioned above, Bhiwandi was discovered as a hotspot for heroin use. It is an area where migrants from all over the state especially from Malegaon, come for work on the textile looms which provide the main source of employment. In a town with a population of about 20 lakhs, there are more than 500 looms, each with a capacity of 12 to 20 machines of varying sizes. Bhiwandi is also a place where there are godowns for many industries and it goes without saying that there are quite a few similar 'godowns' for heroin as well which accounts for the fact that the price of the drug is half of that in Mumbai. Most people in Bhiwandi are a law unto themselves and that makes for a potentially difficult area to work in. Initially, Sankalp started only its NSEP at Bhiwandi, but when the



First inductions at Bhiwandi

with funding from the British Government's Department for International Development (DFID) was coming to an end, it became important to offer the clients Opioid Substitution Therapy and a chance to detoxify before withdrawing all services. It was not easy to do this in an area with cheap heroin; we found few takers for OST and many clients continued to ask for clean needles and syringes. This is a classic instance of a donor's agenda not necessarily meeting the needs of the client. Sankalp was forced to continue needle exchange as a service while motivating its clients to the OST.

With Government help not forthcoming for this centre, Sankalp has had to make a difficult choice -- keep Kalyan going, and shut down this much-needed outpost and a service that has in the past not been offered by other NGO.

Continued from Neglect of Hepatitis C leaves people with HIV vulnerable

individual doctors. This can add to uncertainty and confusion among patients.

The treatment for HCV is also very expensive costing an average of US\$250 per week. Interferon injections are given weekly, in addition to Ribavirin tablets. The tablets may be provided free for people paying for interferon injections. On purchasing four interferon injections, one extra is often provided free as a 'discount'. But in countries such as India, people have to bargain with representatives of pharmaceutical companies or doctors. A cheaper alternative is to use interferon injections alone, although this is reported to be less effective. High-profile donor agencies including the Clinton Foundation and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) are yet to dedicate resources to providing treatment for HCV.

Another dispute among clinicians surrounds the diagnostic value of a liver biopsy. In well-resourced countries, a liver biopsy is usually performed to determine the extent of hepatitis-related liver damage, whereas in Asian countries such as India, China, Vietnam, and

Thailand, doctors usually avoid this procedure. Consensus is needed around the diagnostic utility of liver biopsy, if nothing else in order to eliminate additional confusion for patients.

There is no vaccine to prevent HCV infection and even after successful completion of treatment, HCV re-infection can occur. During and after treatment, HCV PCR viral load testing is done at six month intervals to monitor HCV control. Individuals with HCV considering treatment should connect with those who have previously been through it. The initial days of the regime can be very frustrating and challenging, including loss-of-appetite and flu-like symptoms it helps to talk to those who have completed the regimen before. Even after successful completion of HCV treatment, it is vital to keep the HCV viral load low. Drug and alcohol use should be avoided in order to protect liver functions. Also individuals with HCV need to take care of their livers by avoiding spicy or fatty foods. For people co-infected with HCV and HIV, self-management and treatment literacy skills may be all the more crucial.

Life skills for Drug Abuse Prevention

Tukaram Konale

Sankalp Rehabilitation Trust has been involved with programmes on drug abuse prevention in schools since its inception. Yet these programmes were conducted only when the school took the initiative to invite the organisation.

When the United Nations Office on Drug & Crime (UNODC) offered their modules for developing life skills as tools for prevention of drug abuse and HIV/AIDS, Sankalp was quick to accept the invitation to be part of Project G86. This project, looks at developing a comprehensive school based programme to reach out to children and adolescents who are extremely vulnerable to drug abuse.

This is the first drug prevention programme initiated by the Government in a decade. The project entitled "Empowering Communities for Prevention of Drug and HIV in India" (IND/G86), is meant to raise awareness of



School teachers at a serious moment during the training

the vulnerabilities and consequences of drug use, including prevention of HIV, and change the behaviour among the youth. It targets both school going and out of school children.

For this project, Sankalp was able to motivate 13 schools from Mumbai and Navi Mumbai and 27 teachers from these schools were given training on the use of the modules developed for 6th to 10th grade students. The training was held at Taj Land's End Hotel, Bandra (West), Mumbai on 23rd, 24th and 25th August 2007.

The training of teachers was followed by advocacy workshops in all schools involving principals, trustees, Parent-Teacher Association, administrative staff and other teachers. This has paved the way for the smooth delivery of modules to the students.

The teachers were thrilled with the training and one of participants relates her experience below.

An unforgettable journey towards a possible dream

Valsala Vishwanathan,

On my journey to attend and be a part of the three day workshop on 23rd, 24th, 25th August, 2007, organized by UNODC and co-sponsored by Sankalp Rehabilitation Trust, I could never have envisaged that this experience would have such an impact on me. The subject was Drug abuse and HIV AIDS. I had, like most who attended, a lot of misconceptions about the it.

The panel of four included Mr. Pratik Kumar, Ms. Bidisha Pillai, Dr. Sudha, and Dr. Shastri, who successfully dispelled my misconceptions about the problem. Mr. Tellis joined the team on the last day bringing clarity and a new awareness to the subject.

The ice-breaker session on the first day facilitated communication between participants and the panel. I felt and established a bond with them; we were like a small family. The level of communication was fantastic. Interaction formed the very basis of the sessions. Various games depicting peer pressure, society as a whole, awareness of HIV/AIDS, Drugs, positive thinking, personality development, behavioural problems, parental care and many more relating to adolescents were enacted. The audio-visuals, helped me to understand the situation more thoroughly. The organizers were very hospitable and treated us with class.

Medical practitioners enlightened us on the major causes of drug abuse and its consequences, HIV/AIDS. Different study materials like books, pamphlets etc., were made available. The last session ended with a commitment ceremony wherein each participant committed himself or herself to do our very best to create awareness of drug abuse and HIV/AIDS. "I DECIDE" was the tag-line. At the end of the session we were felicitated with certificates.

Hats off to the organizers and the expert panel for their efforts in making this training enjoyable, educative and enlightening. This workshop was one of the best I have been associated with. Being the first project of its kind in India by UNODC, there is obviously, a long road ahead.

A suggestion to UNODC and Sankalp Rehabilitation Trust, let there be many more fortunate teachers involved in this campaign so that together we can make "I DECIDE" truly possible.

Our Community Care Centre with Avert Society

Experience sharing and review meeting (ESRM) at Igatpuri, Maharashtra.

Dr. Aslam Malik

The meeting, sponsored by AVERT Society and organised by the NGO Krupa Prasad Kendra was held from 31st July 2007 to 2nd August 2007. The venue was the picturesque resort of Satayagiri in Igatpuri near Nasik City.

Teams from Community Care Centres (CCC) and voluntary counselling and testing centres from all over Maharashtra participated. Each NGO presented its project highlights, which was followed by group discussion and question and answer sessions.

Team Sankalp comprised of seven members viz. the project coordinator, medical officer, two outreach workers, a nurse, one PLHA and the accountant.

On the second day, Sankalp was scheduled to give its presentation. Our precise and to the point presentation was well appreciated. It was adjudged the best project presentation and awarded the first prize. The presentation

showed our target and achievements, hospital referrals and the management of opportunistic infections and other cases were explained. Nutritional support, outreach work, individual counselling sessions, support group formation and monitoring of all the above was presented and explained. Special needs and difficulties encountered with the seropositive injecting drug users were highlighted.

The same evening, every NGO presented a street play. Sankalp presented a skit depicting drug abuse, outreach work and a mock Drop-In-Centre/ Outpatient's Department in operation.

On other days there were group exercises on subjects like SWOT (Strength, Weaknesses Opportunities and Threat) Analysis of the NGO, Advocacy and other topics.

The final day concluded with a fun-filled lakeside picnic, followed by folk and film songs in the evening.

Self Care for Homeless PLHA

Thomas George

A Self Care workshop was organized on 7th August for Drug Users living with HIV, as part of the activities of Project Nivara. There were about 24 PLHA participants along with 5 staff from the various centres of Sankalp. The focus during the day was on spiritual aspects like meditation, Awareness and self help programmes like Narcotics Anonymous. Besides this Dr. Sachin presented the facts about Antiretroviral therapy and Sankalp's Director Mr. Tellis used role-play to look at how discrimination and the reality of premature death was handled. The participants enjoyed the day and a good indicator of this was that none left the premises in spite of heavy rains and news of flooding!!



Mr. Tellis addressing participants at workshop

Friendship Day at Nivara

Abhijit Raul

**"YE MAT SOCH, KI JINDAGI MEIN
KITNE PAL HAIN,**

**YE DEKH, KI HAR PAL MEIN KITNI
JINDAGI HAIN."**

Sankalp Rehabilitation Trust (SRT) took the initiative to bridge the gap between people living with HIV/AIDS (PLHA) and the general community through the Avert society supported project, Nivara. It celebrated Friendship Day between people living with HIV/AIDS and a group of University students. Although Friendship Day is normally celebrated on 5th August, the group decided to celebrate it on Independence day for the convenience of the students involved.

Ten Mumbai University Students from the psychology department and seventeen support group members of Sankalp celebrated the importance of friendship and communication. A student from Tata Institute of Social Science (TISS), Tu Wenwen from China made a big contribution. With the support of group members, she prepared the invitation poster card for the students participating in the programme. She was also deeply involved in the Greeting Card competition, one of the activities for the day.

The programme began with the introduction of participants. The participants were divided into groups of three and each member of the group interviewed one other member and then introduced their 'new friend' to the larger group. After a small session of singing by the college students, it was time for the Greeting Card Competition. Each participant was given an opportunity to contribute his or her ideas and concepts of friendship in colours. Some of the support group members displayed great talent in drawing and designing, which was an encouraging indicator of their willingness to live positively. Decorative material was provided by the students to make the competition more interesting.



Mr. Kunjappy from Sharan giving away prizes

Making the cards was a learning experience for the entire group.

The psychology students understood the needs of the marginalised group they were interacting with and did their best to give a positive feedback and contribute to making the occasion an exercise in self-worth. Sankalp Rehabilitation Trust has decided to present these awesome cards to the well-wishers of the organisation, who have extended their love to the needy at Sankalp in some way or other either through donations or in kind.

Chandu, an active member of "Jagrut", a support group of Sankalp used the occasion as a platform to share his experience. He had never spoken openly about himself. He emphasized the meaning and value of making friends and their importance in his life.

Mr. Tellis explained the meaning of friendship and its vital role in human life. The programme ended with an exchange of friendship bands between the members of the support group and the University students with a promise of "Positive Living". Mr. Kunjappy from Sharan, New Delhi gave away prizes to those winning the competition.

*This Newsletter Comes To You
with our Christmas Greetings
and our very Best Wishes for a
Happy and Peaceful New Year*





Present

Jazz

On Friday, 22nd February 2008

At St. Andrew's Auditorium

Magistrates' Workshop on Civil Rights.

Lawyers Collective HIV/AIDS Unit has been committed to provide legal services to persons affected and infected with HIV/AIDS. The Unit has also made efforts to extend its legal services through Civil Rights Initiative (CRI) to drug users, sex workers, male who have sex with male and other communities vulnerable to HIV/AIDS. However, statutory laws like the Immoral Traffic (Prevention) Act, 1956 (ITPA), Narcotics Drugs and Psychotropic Substances Act, 1985 (NDPS), Section 377 of the Indian Penal Code (IPC), criminalise the activities of these vulnerable communities, thereby making them more vulnerable to HIV/AIDS.

One initiative undertaken by CRI is at the Arthur Road Jail Mumbai, in association with the Sankalp Rehabilitation Trust. They provide legal services to drug users who are undergoing the rehabilitation program with Sankalp. Our experiences at Arthur Road Jail have shown that there is a vicious circle of vulnerability to HIV and arrests. Most of the persons picked up by the police are very poor and are booked under petty offences like theft, consumption of

drugs, triable by the Magistrate's Court and have no money to avail of bail, thereby they either plead guilty or languish in jail for months on end.

In our legal system, Magistrates are instrumental in not only providing justice, but also in assuring that the poor and those vulnerable have access to legal aid and are given bail or released on personal bond, thereby breaking the vicious circle of vulnerability and arrests. The need to sensitise and create awareness amongst Magistrates about socio-legal and ethical issues faced by communities vulnerable to HIV and how their situation is worsened by the criminal procedure and the criminalization of their lives was the reason for holding a workshop for Magistrates.

Eldred Tellis presented the problems faced by drug using clients of Sankalp and this was corroborated by the testimony of one of the clients. It was a real eye-opener for the magistrates who pledged to be more sensitive to such clients.

SANKALP REHABILITATION TRUST

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