Introduction

Centre for Advocacy and Research

This interactive booklet has evolved out of the interactions that the Centre for Advocacy and Research has had with scores of journalists during the course of numerous meetings, events, consultations, and, last but not least, through informal conversations on the phone, by SMS or over a cup of tea. Many of the questions that are posed in this booklet reveal the doubts and dilemmas that the issue evokes not just among the journalistic fraternity but among many others.

But it must be said at the onset, that the questions that are answered here are by no means exhaustive. This is but a small beginning in initiating a dialogue with professionals in the business of health communication. Very often they are not seeking more facts or evidence. And are more interested in knowing what it all means or how it will make a difference to people's lives. Needless to say, they often played the devil's advocate. They also have their own take on how to communicate on the issue.

This booklet is a nascent step in stimulating a re-discovering of this issue. And in motivating the media, given its immense reach and large audiences, to provide information, modify attitudes, shape behavior and persuade individuals and communities to protect their health and more importantly to maintain important health issues on the public agenda.

In fact, health communication strategies are being increasingly used world over as a tool to link the domains of health and communication to improve personal and public health by influencing individual and community decisions that enhance health. At the individual level it includes creating awareness of health risks and solutions and provides information on how to access health care services and abide by clinical recommendations and regimens. At the community level it contributes to health promotion and disease prevention and in generating a social environment that encourages attitudinal changes and motivates individuals to adopt recommended behavior.

The reach and impact of health communication can therefore be immense and meaningful and which is why it is imperative for the media to use every opportunity to inform and influence individuals and communities.

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1. **When we say that HIV is a virus that may remain dormant for many years after entering our bloodstream and not manifest itself or visibly affect our health, what are we trying to convey?**

   What we are trying to say is that when a person tests HIV positive, it means that he/she has contacted the virus but they can remain healthy for many years because this is not a disease. In fact, many see no reason to test or find out his/her status.

   It is only when the virus begins to gradually attack the immune system and the person experiences recurring infections, known as opportunistic infections and is advised to get tested that he /she realizes that they could be HIV positive.

Q&A with a Doctor

If a virus is dormant in my system, can I infect another person?

Dr. JVDS Prasad, APSACS

YES you can because during this period of dormancy the virus is present in all the body fluids of the infected person. So an HIV positive person who is not aware of his/her positive status could unknowingly transmit the disease.

2. **Is there any particular reason why it would remain dormant for a longer time in some persons than in others?**

   Dr TLN Prasad, NACO

   YES, there are specific reasons why this happens. To a great extent it depends on the type of virus that the person has contracted and the immunity status of the individual. If the virus is a rapidly dividing and mutating type, the individual will rapidly progress into AIDS in a short period of time. The disease will also rapidly progress into AIDS if the person has a weak immune system.

   Other factors that make a difference are the presence or absence of other infections and the person's general health and nutritional intake. In fact, research is still going on to understand the cause for dormancy.

What media can do:

The media should use every possible opportunity to stress on the dangers of denial and complacency and the importance of going for testing and knowing one's status. It must also point out the fact that HIV is now a manageable disease like diabetes and that early detection and Anti-Retroviral Treatment (ART) is enabling scores of positive people to live normal lives.

3. **When we say that AIDS is a syndrome and not the name of a single disease, what are we trying to establish?**

   We are trying to establish the simple but important information that AIDS is a syndrome that undermines the immune system and ultimately reduces the capacity of the body to fight the different infections that any person catches in the course of his/her life.

   AIDS occurs at a later stage in a person living with HIV and causes different illness and different infections that can also affect different parts of the body. These illnesses can range from a common cold or viral fever to more serious problems like cancer.

   Therefore, when someone dies of one of these infections, we term it as an AIDS-related death.

4. Please explain why 'AIDS is a syndrome' and its progression to enable people to understand that AIDS is not a single disease but group of diseases.

Dr. JVDS. Prasad, APSACS and Dr. TLN Prasad, NACO

A syndrome is defined as a group of symptoms and signs that occur together and characterize a particular abnormality or condition.

AIDS or the Acquired Immunodeficiency Syndrome (AIDS) is the final and most serious stage of the disease caused by the human immunodeficiency virus. Symptoms begin when an HIV positive person has a CD4-cell (a type of immune cell also known as T cell) count below 200. AIDS happens concurrently with numerous opportunistic infections and tumors that are normally associated with the HIV infection.

Before the HIV infection became widespread in the human population, the occurrence of AIDS-like syndromes was extremely rarely. It was only seen in individuals with known causes of immune suppression, such as those receiving chemotherapy or those with underlying cancers.

When a person is living with HIV, the virus is continuously multiplying in the body but the immune system is able to fight the infections. Hence a person living with HIV is free from diseases during this period.

But over a period of time, the immune system gets weakened and gives way to various opportunistic infections. This is when the person enters the AIDS stage.

Without treatment, the person in the AIDS stage may die within 2-3 years of time. But if the same person is under ART treatment, their life can be prolonged for 5-7 years.

This can be best understood when we talk to people like Aruna and learn from their experience

Aruna (30), resident of Mehboobabad, Warangal district stated: My husband, my daughter and I tested HIV positive in July 2006. My husband refused to take ART and died in 2007. When I tested positive in 2006 my CD4 count was 135 and my weight was 38 kgs. I was also suffering from joint pains and fever and had lost my appetite. Doctor Emmanuel at Osmania Hospital prescribed ART for me and gave me medicines for opportunistic infections. This was in 2006 and I did not have any side affects after starting ART. The Doctor also said that it was essential to take nutritious food so I took care to do so. My health slowly improved and my weight increased to 50kgs. Now I am regularly taking ART medicines, which I am getting from the MGM Hospital, Warangal. Presently my CD4 count is 350 and I am leading a healthy life."

5. Since HIV is a virus that may later lead to AIDS, is there any difference between the two?

Yes, scientifically there is a difference. A virus is an infectious, parasitic agent that causes various diseases in plants, animals and humans. The virus named as HIV or Human Immunodeficiency Virus is associated with "human beings" because it is a parasite that can survive only in the human body. It infects 47 types of cells in human body, but principally the cells in the body's immune system and uses the nutrients provided by the cell to grow and replicate.

AIDS, which is caused by the HIV virus, stands for Acquired Immuno-Deficiency Syndrome. It denotes a group of symptoms and signs that occur together and characterize a particular medical condition.

A person living with HIV may be at a stage when he/she is just living with the virus. And not at the AIDS stage or affected by the syndrome.

That is why it is important to make a difference. A person who is HIV positive would not like to be labeled as an "AIDS patient" because this implies that he or she is in a far more advanced stage of the problem.

The common perception is that the "AIDS stage" is a terminal condition and this often creates misconceptions about people living with HIV.

Moreover, people living with HIV want to put out the message that by adopting a healthy and balanced lifestyle and practicing "positive" prevention, they can lead a productive and meaningful life.

Q&A with a Doctor

What causes HIV to progress to AIDS? And what exactly is meant by 'positive prevention'?

Dr.JVDS.Prasad, APSACS and

Dr. TLN Prasad, NACO

The causes for HIV progression to AIDS are:

1) The rapid development of the virus

2) A fall in the number of CD4 cells

3) Opportunistic infections

4) Poor nutritional status

5) Practicing/continuation of unhealthy & risky life styles

When the CD4 count of a person living with HIV drops to 200 or less there is a great chance of the person contracting many infections and this accelerates the progression to the "AIDS" stage.

"Positive Prevention", also known as secondary prevention, is when the person living with HIV (PLHA) is committed to ensuring that he/she does not transmit the HIV virus to others. In the state of Andhra Pradesh, the PLHA network called 'Telugu Network of Positive People' (TNP+), which issued the 'Hyderabad Declaration' of 2007 made it clear that they were committed to strengthening "Positive Prevention"

This is evident from the testimony of Srinivas, PLHA, 23 from Ibraheempatnam, Krishna District. He stated:

"I got to know my HIV status in 2005. My wife is also HIV positive. We had two children. One of them died due to HIV-AIDS. The second child is HIV negative. When I tested positive I lost all hope and was so depressed that I wanted to end up my life. At the same time my health was also deteriorating. But when I got linked with the PLHA network through one of the network members, I got a new lease of life. I came to know that one could lead a normal and happy life even if one had the virus by adopting prevention measures. The network also referred me to the ART centre in Guntur and since my CD4 count had come down to 3 in 2006 the doctors prescribed ART. Fortunately, I did not have any complications after I started using ART. Within a year, my CD4 count increased to 300 and I now feel I have got a new life. After joining the PLHA network, I also received a lot of love and affection and the motivation to lead a positive life. My experience has taught me that even people living with HIV can live a normal life like everyone else."

What media can do:

- Media must, whenever the story/ feature permits, explain in the simplest of terms the difference between HIV and AIDS.
- While doing so the media must also reassure its reader/audience that both HIV and AIDS are manageable.
- This is vital because there continues to be a lot of fears, doubts and misunderstanding among the general population about HIV and AIDS. In fact, it is not uncommon to come across people who say they have heard of AIDS but not of HIV.
- The lack of understanding can prove to be very heartrending and even demoralizing for people living with or affected by HIV.

6. **We often read in newspapers that even in premier hospitals HIV testing methods are not foolproof. Many people have been known to test "falsely positive or falsely negative." So, are existing testing methods reliable?**

Dr Akshaya – NACO

The World Health Organization (WHO) after standardizing the testing methodology has come to the conclusion that to confirm HIV status we must test the blood sample three times by using three different types of antigens and three different testing principles.

If a single confirmatory test is required we have to use the testing technology called the Western Blot.

NACO has meanwhile made it mandatory to test three times. And to avoid testing errors of false negative and false positive it adopted Operational Guidelines on HIV Testing in March 2007.

The Guidelines also stipulate that clients must be given proper pretest counseling during which he /she is informed about HIV; how it is transmitted; how it is not transmitted; the term 'Window Period'; the possible need for testing; false negative and false positive tests and risky behavior. They must also be given information on the treatment, drugs and services that are available and the networks that provide support for psychosocial and other problems. This information has to be constantly updated and conveyed in a language understood by the client.

So to go back to the question, yes, it is true that there are instances when test results are false. In some instances, they occur due to faulty kits and in some cases due to various clinical and technical reasons. They are being addressed.

7. **The term 'Window Period' is often mentioned in the context of HIV-AIDS. What does it mean and why is it important?**

The term "Window Period" refers to a period that can range from 6 to 12 weeks and in rare cases even extend to six months. This is the time when the person who contracts the virus is in the process of developing HIV antibodies.

It is important to be aware of this because during this period the virus cannot be detected by an HIV antibody detection test. This is because the antibodies are not fully developed in the blood.

Therefore, to get a final confirmation of the person's HIV status it is necessary to repeat the HIV test after the third and the sixth month.

Q&A with a doctor

Does everyone have to undergo repeated testing?

Dr.JVDS.Prasad, APSACS

If there has been unprotected sexual exposure or an accidental needle prick, the individual has to undergo baseline HIV testing (immediate testing) and the test has to be repeated any time after 6 weeks to 6 months. If the test result shows non-reactive at the end of 6 months, the person is said to be negative.

What media can do:

The media has a critical role to play in conveying all this information to the public and creating a scientific understanding of this issue. Moreover, when we come across people facing untold suffering due to erroneous testing it is important for us as the media to not only expose the mistake but also insist that right testing kits, methods and protocols are used.

Modes of Transmission
Dialoguing on the Issue:
Clarifying Information and Key Messages

APSACS

Centre for Advocacy and Research

1. It has been said that there are four ways of transmitting HIV. So do we need to give more importance to some routes of transmission than others?

Yes. HIV is transmitted in 4 ways - through sexual contact, mother to child transmission, blood transfusion and injecting drug use. Of them the sexual route is the most widespread route of transmission. According to NACO surveillance figures 85% of HIV spreads through the sexual route. Therefore, we need to ensure that we are fully protected against HIV and STI by using condoms consistently and correctly.

It is mistakenly assumed that we do not need to protect ourselves and use condoms if we are having sex with a "healthy" human or a person who is not a sex worker. This kind of selective practice of condom use will not help people to protect themselves from HIV.

What media can do:

The media must repeatedly reiterate the importance of adopting the ABC formula:

- A for sexual abstinence,
- B for being faithful to one partner and
- C for the regular use of condoms. The media must also warn people against multiple partners and the assumption that only with some safe sex practices needs to be adopted.

2. Why is the sexual route the most wide spread mode of transmission?

It is clear from all available information that HIV can be transmitted any time through unprotected sex because sexual contact involves the exchange of bodily fluids. Therefore the risk of contracting the virus increases if an individual has multiple sexual partners or practices unsafe sex. In Andhra Pradesh, the sexual route of transmission accounts for 93% of the HIV prevalence rate.

3. Can HIV transmit through anal and oral sex? How does it happen and how do we protect ourselves?

Dr. TLN Prasad, NACO

YES, HIV can be transmitted through anal or oral sex because there are chances of mucosal tears that may lead to transmission of HIV. During anal sex, the trauma caused will enable the virus to enter the anal cavity and the cells in the cavity become the receptors for the virus. The virus gets attached to these cells and enters the person's body. The same process happens during oral sex, but the risk is a little less.

4. Since people need to protect themselves against all the 4 routes of transmission, what are the safe practices they should adopt and advocate others to adopt?

1. The best mode of prevention of sexual transmission of HIV is by practicing safe sex practices like "A B C – Abstinence of sex before marriage; Be faithful to one's partner and adopt correct and consistent use of Condom". In fact the regular use of condoms can give an individual and their partner the protection up to 95% from HIV.

2. The transmission of HIV through blood transfusion can be prevented if the donor ensures that he is not HIV positive and by mandatory testing of the blood by the blood bank. The enforcement of a standardized and quality blood safety system in AP has reduced HIV transmission through blood transfusion from 4% to 0.48% in the State.

3. HIV transmission among injecting drug users can be reduced by 100% through the use of disposable syringes and needles.

4. Mother to child transmission can be reduced to 9-11% by giving One tab. Nevirapine 200mg to the mother with the starting of true labour pains and One dose of Nevirapine syrup @ 2mg/kg body weight to the baby with in 72 hours. By the time baby is passing through the birth canal, Nevirapine given to the mother will reduce the viral load in the birth canal there by reduces the risk of disease transmission. The Nevirapine syrup given to the baby prevents establishment of HIV infection in the baby.

What media can do:

- The media has a critical role to play in creating awareness about the four routes of transmission and in consistently advising and motivating people to reduce risk by adopting certain simple precautions. It can be pointed out that adopting the ABC method and safe sex practices like consistent and correct condom use will protect both the person and the partner from contacting HIV.
- Similarly, the IDU community should be made to realize that HIV transmission which is known to occur when people share needles to inject heroin or other drugs can be greatly eliminated by adopting simple precautions such as cleaning the needles with a bleach solution or using fresh needles each time.
- Women, especially those in the child bearing age group and pregnant mothers, must be made to realize that it is in their hands to prevent mother to child transmission which occurs during pregnancy, during birth or by breast feeding by seeking correct medical intervention and advice.
- And transmission through blood can be completely eliminated through proper screening of blood and its procurement from licensed blood banks.

Lakshmi (29), who is working since 2006 as a peer counselor in the Prevention of Parent to Child Transmission Extension programme (PPTCT+), Koti Government Maternity Hospital, Hyderabad, is an example of how HIV transmission from mother to child was halted by administering Nevirapine at the time of delivery.

"My HIV status was detected in 2003 at the ICTC in Warangal Government Hospital when I was in the fifth month of my pregnancy. Since I tested positive I aborted my pregnancy. Then I came to know that HIV transmission from mother to child could be halted for pregnant women desiring to have children. So I became pregnant again and received regular counseling at the

Vijayameri Maternity Hospital, Khairathabad from the initial days of my pregnancy. I delivered in the same hospital on December 25, 2006 and my child and I were given Nevirapine at the time of delivery. My daughter was referred for HIV testing on completion of eighteen months and she was tested HIV negative. Now she is three-year-old and studying in a nursery school."

5. I read a newspaper report of how a person was deliberately bitten by an HIV positive man with the intention of infecting him. Is it possible for HIV to be transmitted through such an act?

Transmission of HIV though a human bite is very unlikely because HIV can be transmitted only through direct blood-to-blood contact and not by exchanging saliva

Unless the infected person has blood in his/ her mouth and is able to penetrate the skin of the other person or the uninfected person has open sores or cuts in the mouth that allows for blood to blood contact a human bite will not lead to HIV transmission.

Dr. JVDS Prasad, APSACS

Body fluids such as sweat, tears, saliva, urine, motion and vomit do not contain the virus. Hence these fluids are not infectious.

What the media can do:

- Given the fact that all these pre-conditions are necessary for the transmission of HIV it is important that the right information is conveyed when reporting such acts.
- The media while exposing such misdeeds must not sensationalize the issue or pronounce that HIV has been transmitted.

6. Can we safely donate blood or receive blood transfusion without worrying about getting HIV?

Dr. (Prof) M.N. Kishore, M.D, Joint Director (Blood Safety), APSACS

Yes, we can safely donate blood or receive blood transfusion.

Blood donor is evaluated in terms of fitness like age, weight, blood pressure, blood sugar, Hb% etc. Histories of previous illnesses are elicited. The blood donor is bled by a sterile needle which is made up of special alloy, which ensures minimum pain and less pressure, while piercing the vein. The donor will be under observation for about 20 minutes and given light refreshment after donation. Hence blood donation is safe.

The donated blood is subjected for 5 mandatory Screening tests like,

a) HIV b) HBSAG c) HCV

d) Malarial parasite e) Syphilis

Hence recipient should not worry about getting HIV.

The National AIDS Control Programme – II focused overwhelmingly on setting blood safety standards. And the Supreme Court in response to a writ petition issued vital directives that led to the registration of blood banks and stopped the use of professional blood donors.

The blood banks also have to adhere to other guidelines such as age (between 18-55), appropriate weight and hemoglobin count and ensure that the donor has had no clinical disorders of any kind at least three months prior to donating blood.

What the media can do:

- It must convey to the public the information that it is essential to both donate blood and access blood from an approved donation centre.
- This is because it is mandatory for all registered blood banks to test the donor for HIV/AIDS and other infections before they are permitted to give their blood. So the person receiving the blood is protected.
- At the same time the donor is safe because the blood banks are required to ensure that all equipment is sterile and blood collection needles are not reused.

7. Even as we are claiming that every effort is being made to make blood safe through licensed blood banks and stringent guidelines, the media is reporting cases of contaminated blood infecting people with the HIV virus.

Dr. (Prof) M.N. Kishore, M.D, Joint Director (Blood Safety), APSACS

Recently media has reported that a 13 year old girl tested reactive for HIV 12 days after under going Blood Transfusion.

To get the HIV test reactive (Positive) a minimum of 6 weeks (42 days) is required. Normally it requires 6 weeks to raise the circulating HIV antibodies to detectable levels which is called as window period. Therefore media should restrain from giving false information to general public otherwise the normal healthy eligible blood donor will get scared to donate blood, since he/she may be labeled as HIV positive.

What media can do:

- It must constantly alert the public to the need to use licensed blood banks
- Motivate people to voluntarily donate blood and
- Last but not least expose unregulated and unlicensed practices.

8. To what extent do infected needles and syringes contribute to the transmission of HIV?

Dr. (Prof) M.N. Kishore, M.D, Joint Director (Blood Safety), APSACS

This route of transmission accounts for 3.71 of the HIV prevalence rate in A.P.

While infected needles and syringes in hospital and clinical settings have resulted in HIV transmission to unsuspecting individuals, the more serious challenge is that of addressing the rapid rate of HIV transmission that is occurring among injecting drug users (IDUs) who inject drugs into veins.

This is because they generally belong to groups of 3-4 drug users who share the needles and/or syringes. So if one member of the group is infected with HIV, the infection is quickly transmitted into the blood stream of other members of the group.

All available evidence shows that HIV does not spread through touch, tears, sweat, and saliva. Or by:

- Being around people who are HIV positive
- Breathing the same air as someone who is HIV positive
- Touching a toilet seat or doorknob after an HIV-positive person
- Drinking from a water fountain after an HIV-positive person
- Hugging, kissing, or shaking hands with someone who is HIV positive
- Sharing plates and utensils with an HIV-positive person
- Using the same exercise equipment at a gym
- Or from mosquito bites.

Given the urgency of the problem it is imperative that steps be taken to reduce the enormous risk and harm being experienced by IDUs.

One way of reducing this risk is to use fresh needles or syringes each time. This is why HIV prevention programmes targeting IDUs now include harm reduction interventions that provide free needles and syringes in the form of 'needle exchange programme'.

What is also important is to remember that initially it may be a behavioral problem, with many IDUs making personal choices and getting into the habit due to peer pressure or for short-term relief. But in the long run, the addiction can become a medical and clinical problem.

Therefore we have to address this problem at two levels - behavioral and clinical.

According to APSACS-"During NACP-III, APSACS will expand the number of targeted interventions in the state, including the ones aimed at Injecting Drug Users (IDUs). We have launched five new interventions at Hyderabad, Krishna, Warangal, Visakhapatnam and Nellore since August 2008. This is in addition to the intervention being implemented by India HIV/AIDS Alliance at Tirupati (Chittoor district). While an estimated 300 IDUs are being covered in each of these interventions, AP State AIDS Control Society is taking up fresh mapping of this community across the state very soon." Kailash Ditya, Joint Director (Targeted Interventions), AP State AIDS Control Society.

What media can do :

- Media can play a critical role in regularly drawing public attention, especially that of youth, to the concern.
- Not just in terms of a medical or clinical problem resulting from injecting drug use, per se but also in terms of making them vulnerable to HIV/AIDS.

Twenty-year-old Sampurna shares her experience as a partner, care-giver and most importantly as a person living with HIV.

"After my marriage, I noticed that my husband was frequently injecting drugs. When I asked him why he was doing so, he gave different reasons. After a year of marriage, his health deteriorated and he died six days before I delivered my daughter. When my daughter was a year old she started having continuous diarrhea. The doctors tested her for HIV and it was detected that she was HIV positive. Doctors then suggested that I undergo the HIV test and I was also found to be HIV positive. I felt very frustrated after learning about our HIV status. As the health of my daughter deteriorated rapidly, doctors suggested ART and she received it from Chennai for a year. Now she is 3 years old and she is getting ART from the District Hospital, Nellore.

"Because I was very depressed, I became very close to a friend who had the habit of injecting drugs. After a few days, in her company, I also got into the habit of injecting drug. Due to the IDU intervention, I learnt about preventive methods and have also reduced my drug intake."

9. We are all exposed to various kinds of vulnerable situations. How can we be sure that these situations have not resulted in infecting us with the HIV virus?

Dr. JVDS Prasad – APSACS

This is a very important question because it makes us realize the fact that unless and until we perceive our own risks and vulnerabilities we will not be able to address the problem.

However, this is easier said than done. The programme led by APSACS and its partners has ensured that this process is adequately supported on the ground through outreach workers and peer educators who are trying to reach out to vulnerable people and give them necessary information and support.

They help people to recognize their risks and vulnerabilities. And also link them to service providers who can counsel them, remove their fears and enable them to address their concerns instead of getting depressed and brooding over it.

For instance, Rajeshwari, an outreach worker who works with Spandana Mythri Sangham (SMS), Eluru, West Godavari, found that Jyothi, who was living in the lane next to hers was going through a lot of anxiety about her health after her husband had died of causes related to HIV-AIDS. Rajeshwari first established a relationship with Jyothi and used every interaction with her to educate her on the issue, answer her questions, remove her doubts and concerns and gradually build her confidence. Once Jyoti's doubts and misgivings had been cleared Rajeshwari took her to the clinic run by SMS. At the clinic Jyothi came across many other women who were coping with the problem in a decisive and courageous manner. This also helped to clear any doubts she had about testing and with support from Rajeshwari's she went to the ICTC Centre.

What media can do:

- Constantly remind and caution their readers and audiences of the risks and vulnerabilities they are exposed to and tell them how they can protect themselves.
- Also normalize HIV and reduce stigma and discrimination against people living with HIV

Nagamma (28), Navapeta Mandal, Mahabubnagar District who experienced terrible stigma and discrimination shares her experience.

Her husband died due to HIV/AIDS in 2007. She has 2 sons who are 6 and 4 years of age. "My husband did not reveal his HIV status to me and led a normal life with me. As a result of this my younger son and I contracted the virus. Our HIV status became known to the people after he died.

"Since then, the stigma and discrimination towards me by the villagers, neighbours, relatives and even petty shopkeepers has been unbearable. Before others came to know my status I was invited to attend functions in my village but now that my status is known, no one invites me to their functions. When they see me, they turn their faces away and avoid talking to me. Once, my neighbours forced me to vacate the rented house I was living in because they feared they might be in danger. I feel very disheartened when shopkeepers drop groceries into my bag and maintain a distance. When I went to a close relative's house, they did not ask me to sit or even offer water to me. I observed that they were very uncomfortable with my visit and waited for me to leave their home. When a friend of my husband, who was very close to us before our HIV status became known, came to see me he refused the tea I offered him. We are more depressed and demoralized because of all the humiliating treatment that we experience in our day to day life."

STI/RTI Prevention and Treatment Dialoguing on the Issue: Clarifying Information and Key Messages

APSACS

Centre for Advocacy and Research

1. In your information module you state that there is a strong link between STI/RTI and HIV-AIDS. Given the fact that women rarely access services for treatment how can we ensure that their vulnerability to STI and HIV is addressed

Dr. J. V. D. S. Prasad - Andhra Pradesh State AIDS Control Society

- A majority of women are indeed reluctant to access services.
- It is also true that women with untreated STIs are highly vulnerable to HIV.
- It would be interesting to hear from peer educators and outreach workers on how they help women to perceive this vulnerability and motivate them to access services.

According to Lalitha, from Nellore, Who was having STI for many years and did not know how to address it. Jayashree, a peer educator, took her to the STI clinic for a check-up and she was diagnosed as having Syphilis. The counselor at the clinic counseled her and she was also given treatment by the STI clinic medical officer. Today, Lalitha tells all the women not to silently suffer from STI and to go for counseling and treatment.

Similarly Chukkamma, outreach Worker from Khammam, spoke of how during her interaction with the community, she used to share her own experience. After listening to her experience, Deepa confided to her that she had STI symptoms. When Chukumma offered to take her to the clinic, Deepa was very clear that she would do so only if strict confidentiality was maintained and no one got to know about her condition. Once confidentiality was assured she went to the clinic and got treated.

What media can do:

- Regularly give information on the symptoms of STIs and where women can access services.
- They should also motivate women to seek treatment for themselves and their partners.

2. Is it easy for women to access services for STI/ RTI prevention and treatment?

- STI prevention & treatment services are now available in all STD clinics of government hospitals in the State at the free of cost.
- An approach, known as Syndromic Case Management which enables 'on the spot' diagnosis and treatment of an STI syndrome is used.
- The treatment given to the patient also addresses other needs of the patient and includes education of the patient about the infection, how STIs are transmitted, risk reduction, the importance of partner treatment and the consistent use of condoms.
- As per the NACO-III guidelines all STI clinics must have teams of qualified and trained counselors.

- he team must provide counseling on the need for partner treatment, the importance of completing the course of treatment and of adopting HIV prevention methods such as condom use and if possible even abstinence from sexual contact.
- The link between ICTC and STD clinics has also been established so if the need arises, the patient can be referred to the ICTC for an HIV test.
- Most importantly there are outreach workers and peer educators who motivate, educate and facilitate women to seek STI treatment.

Sharing her experience, Revathy from Warangal stated:

"I had severe STI and though I underwent treatment in both government and private hospitals I was not cured. When I explained my problem to the peer educator, she referred me to the Mythri Clinic run by the NGO Alliance. They diagnosed the problem as severe Gonorrhea and gave me medicines and I was completely cured in just four months. The clinic had a friendly and supportive environment and during this period I received a lot of support from peer educators, counselors and doctors".

Prevention of Parent to Child Transmission Dialoguing on the Issue: Clarifying Information and Key Messages

APSACS

Centre for Advocacy and Research

Answers given by Dr. Chakrapani, Consultant - PPTCT, APSACS

1. Can you explain what Parent-to-Child transmission of HIV means?

It means that an HIV infected mother can infect the child in any of the 3 stages viz.,

1. in the womb
2. at the time of birth when the baby is exposed to the mother's blood and
3. to some extent through breast milk.

Transmission from an infected mother to her baby occurs in about 30% of cases. And the baby is more at risk if the mother has been recently infected or is in an advanced stage of AIDS.

2. Since transmission of HIV from Parent -to-Child is one of the key routes of transmission, can this be prevented?

Yes, it is possible to prevent the transmission.

- But to do that all pregnant women should know their HIV status,
- Know about HIV-AIDS and prevention services available at ICTCs.
- There are 677 ICTCs in district hospitals, maternity hospitals and teaching hospitals in the State besides 200 plus ICTCs in 24hr PHCs and private maternity homes in Andhra Pradesh.
- They should also visit the ICTC and receive counseling and then undergo the HIV test.

Pregnant women who test HIV positive must get medical services. And it is imperative that the delivery takes place in the hospital so that

1. The exposure to HIV virus will be minimized through safe delivery and
2. Tthe mother and child can be administered Nevirapine tablet and syrup respectively to prevent HIV transmission during the delivery stage. After the delivery they should follow the suggestions of the doctor about breast-feeding and other health measures.

3. Can HIV be transmitted through breast-feeding?

- The virus has been found in breast milk in low concentration.
- However, in poorer countries and communities, where infant morbidity and mortality is high due to childhood infections and diseases, breast milk often protects an infant's health and benefits both the mother and the child.
- In fact, in these communities the slight risk of an infant becoming infected with HIV through breast-feeding is therefore thought to be outweighed by the benefits of breast-feeding.
- So it is suggested that an HIV-positive women breastfeed exclusively for six months and refrain from practicing mixed feeding.

4. How is it that my second child tested HIV positive while my first child tested negative?

This is because it is not necessary that every child of a woman who has tested HIV positive should contract HIV. Transmission from an infected mother to her baby occurs in about 30% of cases. And a lot depends on the viral load at the time of HIV transmission.

It is only when the viral load increases tremendously in the mother that it is transmitted to the child. And it may take months and years for the viral load to increase.

Because of this the first child might not have been infected with the virus.

But it is important to note here that it is now possible to prevent HIV transmission from an infected mother to her child by giving Nevirapine tablets to the mother during labor and Nevirapine syrup to the baby after the delivery.

Sharing her experience, Kameshwari (26) from Kurnool district stated:

"Both my husband and I came to know about PPTCT services during a meeting organized in our village. After that we decided to avail of the services because my husband, my elder son and I had tested positive. I was in the third month of my pregnancy at that time. The counselor explained all the precautions I should take to prevent the transmission of HIV to my infant. I strictly followed all the instructions and my delivery took place in the hospital. Both my child and I were administered Nevirapine. Now, my child is 6 months old. Till now he has not had any health problems. I am not breastfeeding him."

5. How can we reach out to positive pregnant women to ensure that they avail the prevention services?

- The government working through NGOs and Positive Networks has appointed PPTCT outreach workers (ORWs) to reach out to pregnant women with information about PPTCT services.
- The outreach workers coordinate with ASHAs, Anganwadi Workers and ANMs in their respective areas in collecting the information regarding all the pregnant women residing in the area and their HIV status.
- The outreach workers report to the counselors of the healthcare centres and work closely with village anganwadi workers.
- This enables them to interact with pregnant mothers during the monthly Pregnant Mother's Meetings and give information about PPTCT services.
- They also do regular home visits and in the case of women who have tested HIV positive, they provide support to them till the time of delivery.
- Strict confidentiality is maintained about the woman's HIV status and the outreach workers also counsel their families.

Other services provided to HIV infected pregnant women and the infants born to them:

- Knowing the CD4 count is must for all pregnant women before their delivery. If the CD4 count is less than 350 the mother will be provided with ART.
- The infant born to HIV positive pregnant woman will be tested for HIV at 6 weeks, 6 months and 18 months of infant age.
- The infant will also be provided cotrimoxazole prophylaxis at ICTCs till the confirmation of HIV status is done at 18 months of age.

Sharing experiences of PPTCT services, Swarna, Hyderabad, stated that:

"During my health check-up at the Government Maternity Hospital, Nayapul, Hyderabad doctors referred me to the PPTCT centre. The hospital staff there have been very friendly and supportive and also ensured confidentiality. They have advised me to come to the hospital for delivery so that they can administer Nevirapine. I assured them that I would definitely go to the hospital for delivery. The outreach staff has also given me a lot of moral support".

Chennamma, from Hyderabad had another kind of experience:

"I got tested for HIV just before my delivery. Earlier, I had visited a private hospital where they did a general health check-up but did not recommend an HIV test. Then, just before my delivery date my neighbors suggested that I go to Nayapul Hospital for a health check-up. Ten days before my delivery I tested HIV positive. I had my delivery in the hospital and both my child and I were given Nevirapine. My child is now seven months-old and his health is good. Since I am worried about the health of my child, I visit the hospital every month for a check-up".

Renuka, from Lingala Ghanpur village, Warangal district. shares her experience as a rural woman who had to decide whether to avail PPTCT services or not. She stated: "For six months the outreach workers, Pullamma and Krishna from the PPTCT centre would regularly visit me but I was reluctant to listen to their advice. Finally, they succeeded in convincing me to visit the PPTCT centre, Janagaon Area hospital. I tested HIV positive and was very depressed for a month after finding out my HIV status. But the regular visits by the outreach staff and the counseling I got from them helped me. I also realized the importance of institutional delivery and when my delivery took place in the hospital my daughter and I were given Nevirapine. My son is HIV negative and my daughter who is 8 months will be tested when she is 18 months old. All of us are doing fine."

HIV Treatment, Care & Support Dialoguing on the Issue: Clarifying Information and Key Messages

APSACS

Centre for Advocacy and Research

Dr Akshaya, Regional Coordinator, National AIDS Control Organisation

1. Why ART is given only to the PLHA whose CD4 count is below 200 cells/mm3?

The optimum time to start ART is before the Person Living with HIV/AIDS (PLHA) becomes unwell or presents with the first Opportunistic Infections (OI). The progression of the disease is faster in PLHA when the CD4 count falls below 250 cells l. As per NACO guidelines, ART will be provided to the PLHA whose CD4 count falls below 250 cells. In case of a PLHA with pregnancy or TB, the cut off is 350 cells.

2. Why is drug adherence in ART so important?

At present, the preferred treatment for PLHA is the first line ART, which is available in Andhra Pradesh. Poor adherence to this treatment leads to drug resistance and finally leads to the ineffectiveness of the drugs. In such cases, the PLHA may need to be put on Second Line ART. The Second Line ART is costlier than the First Line drugs and if the Second Line ART fails, there is no other alternative. So, to improve the longevity and quality of life of the PLHA, it is always advisable to have longer duration of treatment on the First Line ART and the success lies in better adherence preferably missing not more than 3 doses in a month.

Prakash, Warangal district speaks of the challenges, which caused him to discontinue ART. "My wife, mother and five sisters deserted me after they got to know of my HIV status. When I went to attend a marriage in my sister's house they were shocked to see me. They humiliated me by telling me to leave immediately because they were afraid of what people might say."

"Since I lived alone I had to cook my own food. This led to a poor nutrition intake and I could not continue the medicines."

"However, after a few months, B. Lawanya, a staff member from the Treatment and Counseling Centre (TCC) of the ART centre at the Government General Hospital, Warangal, came to my house in Pedamandyal and took me to the ART centre. After that I re-started my ART. I was also referred to the Care and Support Centre in Karunapuram by the Treatment Counseling Centre (TCC) staff".

3. What are the services being provided to the PLHA under ART?

The services that are being provided through the ART centres are as follows:

- Pre-ART registration which includes clinical assessment, Laboratory evaluation including basic investigations, Liver Function Test (LFT), Renal Function Test (RFT), CD4 testing, nutritional assessment, Pre-ART counseling
- Referral services and screening for TB / STIs
- Assessment & management for Opportunistic Infections (Ois)
- Post exposure prophylaxis
- In-patient facility for treatment of side effects of drugs, OIs and other associated illnesses
- Anti-Retroviral treatment

4. Why ART has to be continued life time?

ART is not a cure to eliminate the virus from the body. The drugs only suppress the replication of the virus in the body. This is only possible when the drug levels in the body/blood are maintained by consistent high-level of adherence to ART. If the drugs are stopped in between or treatment is irregular, it leads to development of drug resistance or drug failure. So it is always advisable to continue ART life long so as to have a sustained viral suppression, thus resulting in longer survival and a better quality of life.

5. Is ART required for every PLHA?

Anyone found positive for HIV is deemed to be HIV infected. But all those who are HIV positive need not be put on ART.

- Initiation of ART depends on many factors such as presence of Opportunistic infections (OIs)/TB, CD4 count etc.
- So, once the PLHA are registered in the ART centre for Pre-ART Care,
- She/he is evaluated for the eligibility for initiation of ART and
- If necessary as per the National AIDS Control Organisation (NACO) ART guidelines, ART is started.
- If the CD4 count is in between 250-300, the PLHA is called for a follow-up CD4 testing after 4 weeks, and if above 300, after 6 months.
- Depending upon the follow-up testing results, the eligibility is decided for initiation of ART.
- At any point of time, if the PLHA develops any Opportunistic infection, s/he must be managed for the OI and also could be assessed for ART initiation.

6. What is the coordination between ICTC, ART and Care and support centres?

- All the individuals at risk/suspected to have HIV get a counseling & testing facility in ICTC and if found positive for HIV, are referred to ART centre for HIV care.
- From the ART centre, those who are in need of short-term stay for ART initiation are referred to the nearest Community Care Centers (CCC).
- Besides the short stay facility, the CCCs also provide medical facilities for minor OIs, Post Exposure Prophylaxis, facilities for nutritional education & supplementation, adherence counseling, psychological support, positive prevention counseling, shelter & protection, referral services for treatment of T.B., STI, and even linkages with Govt. / NGO schemes.

7. What are the key facts one should be aware about ART treatment?

- The basic key facts required for the PLHA to know about the ART are as follows.
- HIV treatment helps in extending the lives of the patients. However, ARV drugs do not offer a complete cure.
- Not all people living with HIV need ART treatment. A majority of them can live a healthy life by taking proper nutrition and following a balanced lifestyle.
- Patients should be able to make an informed choice of whether to take ART treatment or not after getting complete information on the benefits, limitations and possible negative effects. Once started, it is a life long treatment.

Stigma and Discrimination Dialoguing on the Issue: Clarifying Information and Key Messages

APSACS

Centre for Advocacy and Research

The biggest challenge we face is the high level of stigma and discrimination that HIV+ people are experiencing. Unless we address this issue we will not be able to reach out to those who are silently bearing the burden of HIV. This is particularly important because it is now possible for people living with HIV to manage the problem and improve their quality of life. It has been found that the greater involvement of HIV positive people is the best way of addressing the problem of stigma and discrimination.

Speaking about this, Kumari, an Outreach Worker at Jagruthi, Khammam stated that:

"I feel proud of the work I am doing for my peers because I realize I am making a difference in the lives of people living with HIV and more importantly in changing the attitude of the general population towards us. This is evident in the way my neighbors are treating me. Now they are inviting me to their functions and also approaching me for information on HIV-AIDS and STIs and HIV prevention services."

According to Ramesh, President of AP State Telugu network of Positive People, Guntur, it is possible to reduce stigma and discrimination and change people's attitude to HIV positive persons. Citing the AASHA campaign held in 2005 and 2006 he said: "The campaign was a major milestone for the PLHA network because it enabled 2,500 HIV positive speakers from across the State to actively interact with rural populations. It provided them with an opportunity to motivate HIV positive people to get over their feeling of hopelessness and tell them they could lead a productive life even after getting HIV."

A baseline survey that was conducted by the Centre for Advocacy and Research, in 2007, in Chittoor and Krishna districts among a small sample of 134 respondents to quantify their attitude to people living with HIV produced very mixed results. While 52 respondents were completely free of any biases and did not stigmatize people living with HIV, an almost equal number of 42 respondents bordered on extreme stigma and phobia against people living with HIV. In the case of a majority of respondents media was a major source of information.

However, what makes the findings interesting is the fact that when two categories of respondents were compared we found that the higher the exposure to information the greater was the comfort with and acceptance of people living with HIV.

1. What is the National Policy on Stigma and Discrimination?

The National AIDS Prevention and Control Policy clearly enunciates that "discrimination against people living with HIV/AIDS denies their rights to access healthcare, information and other social and economic rights guaranteed by the Constitution to its citizens."

NACP-III proposes to address stigma and discrimination at all levels through evidence-based research and advocacy, capacity development and partnership building. This would include preventive and redress strategies.

Some key activities include:

- Developing and implementing guidelines for the direct involvement of HIV positive people in the delivery of services.
- Undertaking advocacy and reaching out to the media with information to generate broad-based awareness about the proposed HIV/AIDS Bill;
- Advocating with members of Parliament and members of legislatures, Panchayat leaders, women's group leaders, youth leaders and faith-based organizations on a rights-based approach to HIV; and
- Implement a communication plan, including sensitization of the media that directly addresses issues of stigma related to sexuality, condom use and unsafe sexual practices.