



Health e-Letter

Letter from the Editor

Some 20 kms from Pune is a small orphanage for children infected and affected by HIV. The 50-odd residents of this orphanage seemingly have no complaints: They are provided food, clothing, shelter, medicines and even education - all within the confines of their four walls, sheltered from the rest of civil society. As children, helpless and homeless, what more could they ask for?

But as adults, empowered and articulate, we need to ask some pertinent questions: Should children, already traumatized by the loss of their loved ones, be allowed to be brought up in such seclusion? Is this not perpetuating the stigma around HIV? Are homes such as these trying to show some immediate visible results to satisfy international donors? Mainstreaming these children into society may not be easy. But it is not impossible either. A few hundred kilometers from this home is another one which has made it possible.

This is the Bel-Air Hospital situated in Panchagani, a scenic hill-town. The priest, who got this once-upon-a-time TB hospital up and running, has made sure that family members stay back to care for their loved ones. This ensures that no one is abandoned and it lessens the stigma once they return to their homes.

Unicef had called attention to institutional care of children and pointed out how the number of orphanages in various parts of the world were growing in little more than a decade. It said that this trend "completely negated progress in child welfare." The one reason for this being that existing residential facilities are often unwilling to take in children whose parents are living with or have died of HIV/AIDS - and all the more so if the

children themselves are HIV-positive.

"This leaves a fertile ground for the establishment of 'specialised' residential units - often foreign-funded. Often donors and NGOs are seeking tangible and visible ways to assist," says Unicef. Lack of guidance and regulation from government helps perpetuate these responses.

Institutional care should generally be used as a stop-gap rather than permanent measure, as NGOs work towards easing a child back in the family. If a child does need to be put under institutional care, it ought to be done with considerable sensitivity. NGOs should ensure that such children do get to spend time in schools and other community activities so they are not forced to lead an isolated existence.

In this issue we bring to you several inspiring stories: the story of Bel-Air hospital, the story of a young positive couple in U.P. that has taken the first bold step of getting married in this conservative state, the story of a 72-year-old man who has dared to go against public sentiments on sex education and is challenging it publicly. At the same time we get you stories on the health mess in U.P., crash dieting and its effects and the latest on second line anti retro viral drugs.

With your response you encourage us to do more.

Kalpana Jain
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Health e-Letter

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Father Knows Best: Healing with love

By Dipti Raut

Panchgani: For most people, Panchgani perhaps is all about a picturesque getaway; for others, good residential schools; and for still others, fresh, red, shining strawberries. But at Bel-Air Hospital, located in the heart of this scenic town, red takes on a different hue: It signifies the colour of blood and HIV.

Yet, once in this place, life with HIV no longer appears to be bleak. The love, care and acceptance at Bel-Air more than prepare patients to live with HIV. Many who come to this hospital looking for a peaceful death find themselves on a miraculous road to recovery with the care that they are provided here.

"Look at this Gorakh. It is a miracle that he survived. His CD4 count was five when he was admitted. But tomorrow he is all set to go home," says Dr. Bhavna Lonkar, a doctor at Bel-Air. Gorakh is not the only one to have shown such recovery from a point where most people go into AIDS-related illnesses and eventually death.

"It is the way patients are treated here," says Father Tomy, a Catholic priest, who set up this centre a few years ago. While anti retroviral drugs are available, social attitudes have not changed all that much, he says. There is acute social stigma. Even medical practitioners are hesitant about treating people with HIV, he says.

This hospital, initially started in the early 20th century for tuberculosis patients by the Indian Red Cross Society, was compelled to start the first HIV ward when a large number of people with tuberculosis started to test positive for HIV. Today, nestled in scenic surroundings, it is an example of the finest care for people living with HIV in India.

A few years ago, a patient came to this hospital with multiple fractures. He had been refused treatment at all the other medical centres as he was HIV positive," says Father Tomy as he narrates story after story of how he changed mentalities within Bel-Air. The Father decided that the Red Cross Society should not refuse treatment to this patient. But it was a challenge to convince the staff. Eventually, he succeeded.

After that the hospital and its staff were always ready to handle the most complex cases. Since 1995 close to 4,265 people with HIV have received treatment at Bel-Air. Patients are provided free food, accommodation and treatment. But they are asked to deposit Rs 3,000 for laboratory tests. There is one firm rule though: each patient must be accompanied by a family member. "This ensures that the family stays around to care for those with HIV," says the Father.

At Bel-Air, efforts are made to counsel relatives of patients. This helps in not just providing support but also ensures follow up. The first step towards reducing stigma begins with the environment Father Tomy has created within the premises. Staff members and relatives get food from a common mess.

Patients too can be seen enjoying their meals outside the ward in the lush green surroundings with their relatives.

President APJ Abdul Kalam also visited the hospital in 2003. This helped transform not just the attitude of the government but also of the people living here. The hospital attracts people from all over Maharashtra as well as neighbouring Karnataka.

Its services go beyond those provided at a hospital. Besides the team of 150 medical practitioners, a team of social workers are engaged in regular counseling; a team of outreach workers follow up with the patients at the village level; and a dietician ensures that patients get a high protein diet. Various social programmes and cultural activities are designed to develop positive energies in these patients.

A cadre of volunteers of positive people, whose lives have been transformed by this hospital, works towards transforming the lives of others. The hospital has created a legal cell to help distressed widows and those who have been denied their rights, "They are so poor that they cannot even think about asking for their rights. The issue of survival is more important for them," says Father Tomy.

Bel-Air is now involved in formulating training programmes for the management of HIV/AIDS. As a chairperson of

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National AIDS Control Societies Technical Support Group, Father Tomy would like to bring an Indian perspective to the present approach. "Though there are universal principles in HIV/AIDS treatment formulated by World Health Organisation, they are formulated with a western perspective. The socio-sexual behavior of the Indian people is different. So, based on the experience of the decade in treatment of HIV infected and affected, Bel-Air is coming up with an integrated model of this treatment," says Father Tomy. Along with regular short term training workshops for medical practitioners, he has launched Bel-Air Nursing College with a four-year course, accredited by the Maharashtra Health University and affiliated with the University of Chicago, the only nursing course in the country with the emphasis on HIV/AIDS treatment.

Father Tomy came across this hospital as a tourist. As a human being he took on the challenge of rebuilding it. Now, it is society's turn to be humane towards the issues raised by this hospital.

PROFILE

Sex at 72: Meet Vitthal Prabhu

By Shekhar Deshmukh

Mumbai: If political parties do bury their ideological differences it's more often than not on issues of national importance. But on March 30 both ruling and opposition party MLAs in Maharashtra banded together to form a moral brigade. They pushed for a ban on sex education in the State Assembly, saying it was ostensibly corrupting young minds.

They tore sex education books and demanded the subject be banned in schools. The moral brigade was joined by party workers and other political leaders who showed their support through public statements. Understandably, not many in civil society could oppose the decision, even if they supported sex education.

But one man decided to oppose the decision. Meet the fiery septuagenarian Dr. Vitthal Prabhu. At 72, when most people are content to lead a retired life, Dr. Prabhu has decided to battle on as a one-man army against the ban. He has decided to educate people so that an environment for change can be created. He has been spreading awareness about sex education through community meetings, informed speeches and guest lectures.

FOR THE RECORD

March 30, 2007: "Sex education will tarnish young minds; Indian culture is under threat." This was the pretext under which MLAs of both ruling and opposition party tore apart books on sex education at the assembly session.

March 30, 2007: State Education Minister Hasan Mushrif announces a ban on sex education in the assembly.

Teacher's training programme for sex education is cancelled.

March 31, 2007: All MLAs welcome this decision wholeheartedly. "Instead of giving health related

information this was a plan to bring in immorality. If such a step is taken again then Shiv Sena will handle it in a way known to them" (*Maharashtra Times*)

March 31, 2007: "The decision is a victory for those who are trying to create a virtuous and evil free society." - Feroz Patel, Students Islamic Organisation of India (*Hindustan Times*)

March 31, 2007: "This is nothing but an effort to create sex gurus in school" - Nawab Mallik, MLA, National Congress Party (*Hindustan Times*)

April 8, 2007: "Instead of educating students of Standard IX and X and

trying to clear their misconceptions, it is better to train the girls in martial arts that would help them in self-protection." - Dr. Shobha Bachchav, MLA, Congress (*Maharashtra Times*)

April 6, 2007: On April 5, 2007 the controversy took a U-turn, when education minister Professor Vasant Purke suggested in the assembly the decision related to sex education be reconsidered. He said that sex education should be a part of curriculum in schools. Opinions of social scientists, educationists and NGOs would also be sought. (Professor Purke was not present in the assembly on March 30, 2007) (*Times of India*)

Dr. Prabhu is reviving memories of the fire-brand Raghunath Dhondo Karve, who started work on sex education way back in 1936, when only the feisty could have taken up the issue in civil society. Karve started a magazine called 'Samajswasthya' (Social Health) on issues related to sex education from Pune. He also worked toward spreading awareness on family planning.

Dr. Prabhu did not wait for the younger generation to take up the challenge. Instead, he decided to be the guiding light. Within a fortnight, Dr. Prabhu succeeded in bringing the masses around to talking about sex-related issues in schools. However, he has not been able to convince government officials. "I am trying to sell mirrors to those who are blind," he says. Irrespective of which party is in power, given a chance, every leader likes to do moral policing. The same has happened this time around."

"Leaders are misguiding the young generation of today by taking the 'popular' decision," says Dr. Prabhu. Banning sex education by the Maharashtra government is wrong, he says. As someone who has been working in the field of sex education for the past 30 years, he believes the leaders are naïve. He does not agree that the government has pandered to popular sentiment. "The government is being presumptuous. Whenever I have addressed a gathering on the issue of sex education it has been well received," he says.

MLAs opposed to sex education say they do not have anything against sex education as such. They have a problem only with the content. Dr. Prabhu agrees with the criticism. "The syllabus on sex education should be drafted keeping our needs in mind," he says.

Dr. Prabhu agrees. He has worked on a syllabus that is sensitive to the needs of the younger generation and the Indian culture. He recently presented a book with his syllabus on sex education to the Education Minister Prof. Vasant Purke. However, there has been no response from the government. And this has led him to question the government's intentions.

Buried in government's own files is a report by an expert committee that details how sex education should be imparted. In 1996 the State Commission for Women formed a committee headed by a former Vice Chancellor of Mumbai University, Professor Ram Joshi, to come up with a workable plan. The committee had given a report based on suggestions from educators, social scientists and teachers.

The report addresses the issue in a people-friendly manner. It says sex education should be renamed 'Kutumb Jeevan Shiksha' (Family Life Education). This education should be given step-by-step to students from Standard V to X. This subject should be optional. The report recommended separate classes for boys and girls. It said only teachers who were comfortable teaching the subject should be given this training. It also suggested covering subjects such as social and cultural development and responsible parenthood. It suggested that the subject be divided into the following sub-headings: physical growth and development, sexual behavior, inter-personal skills, relationships, sexual health, society and culture.

Unfortunately, the report was not even discussed in the Assembly. Dr. Prabhu, who was also part of this committee, says the state government did not show any initiative. The State Commission for Women did not bring it up either. When Dr. Prabhu called up the office of Women's Commission and inquired about the report, the man at the other end of the phone had a shocking yet revealing answer - "the file is lost."

Despite the absence of political support, Dr. Prabhu is not ready to give up his mission as he believes that sex education is the very basis of a healthy and happy society.

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Crash diets can make you susceptible to new bugs

By Manish Srivastava

Lucknow: Let's take a close look at fifteen- year- old Tanya's regular diet: Some fruit juice and sprouted cereals in the morning. A sandwich and soft drink in the afternoon; one soft drink in the evening; two chapattis and a bottle of soft drink for dinner. Tanya is on a diet for the past few months. She gets fever at night and sweats profusely. She spends

the night coughing. When her family took her for a clinical investigation they found she had developed tuberculosis.

Tanya is not the only girl who weakened her immune system by going on a crash diet for a dream figure and a thin waistline. King George Medical University often witnesses these cases in its Out Patient Department. The girls almost kill themselves by a crash diet and end up with a deadly TB strain. A survey carried out on 30 girls registered with the department shows that all these girls were on a strict diet for that dream hourglass figure.

Associate professor with the department, Dr. Suryakant, says his research is ongoing. These girls have given up taking a balanced diet that essentially results in weakening of the immune system. The girls whose immune system is weak are susceptible to the pathogens of TB. These girls are from class- VIII to undergraduate studies.

Besides them, people visiting the O.P.D. are those who either smoke or drink. The youth of today, who are too conscious of their diet and eat sparingly, also complain of this infection. These patients initially develop fever. This is followed by a cough that is accompanied with blood traces in the sputum. Apart from people dieting for weight loss, people living with HIV/AIDS, people receiving steroids and those who have diabetes are the ones with a weakened immune system and hence are more likely to develop the infection.

EXPERTSPEAK

Dr. Anoop Mishra, Director and Head, Department of Diabetes and Metabolic Diseases, Fortis Hospital, cautions against crash dieting. The normal Body Mass Index (BMI) among Indians should vary between 18.5 to 23 kg per meter square. "The moment the BMI goes below the minimum an individual is susceptible to a host of infections, especially tuberculosis, as almost every Indian is host to latent pathogens. "Once an individual is underweight with a weak resistance to foreign bodies pathogens may get active and lead to tuberculosis." says Dr. Mishra.

Typically, people living in unhealthy conditions, overcrowded houses with unhygienic sanitary provisions are more susceptible to tuberculosis. But deficiency of micronutrients and proteins in a human body can lead to a weakened immune system that could lead to tuberculosis. Of course, all weight loss cases may not necessarily acquire tuberculosis or another infection. This is because not everyone is truly under nourished, he says.

Interestingly, an increased body weight could also lead to tuberculosis. For instance in diabetics, a perfect environment is created inside the human body for pathogens of TB to multiply, says Dr. Mishra. He suggests a balanced diet intake instead of a reckless weight loss regimen.

A FIRST IN CONSERVATIVE UP

HIV positive man ties knot with positive woman

By Manish Srivastava

Lucknow: It had none of the hoopla surrounding the wedding of the famous Bollywood couple Abhishek and Aishwarya. But at the same time, somewhere in UP a couple, whose wedding was as unique, was exchanging vows quietly. They

may not have had a celebrity guest list, but they were celebrities in their own special way.

For the first time in UP, an HIV positive young man has entered into marital bliss with an HIV positive woman. The baaraat (marriage procession) of this young man from Varanasi included people living with HIV/AIDS and officials of Uttar Pradesh AIDS Control Society.

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Thirty- year- old Sameer (name changed) from Benaras, chose 23- year- old Gudiya (name changed) of Maharajganj to be his life partner. Sameer worked as a goldsmith in Mumbai. About four years ago, he came to know he was HIV positive. He thought his life was over. He left Mumbai to return to his native place Varanasi. When his wife found out his positive status she left him too.

Only his five- year- old daughter remained with him. Gudiya, in the meantime was going through a similar story of distress. Her husband died of AIDS- related illnesses. Gudiya's family was supportive. They started her

on treatment and would often take her to the ART (Antiretroviral Therapy) centre in Varanasi for treatment. This is where she met Sameer.

Sameer was working for the Positive Network. Gudiya came close to Sameer's five- year- old daughter and soon both decided to get married. Manoj from the Positive Network narrates how their respective families opposed their union as they were from different castes. Sameer's mother was not happy about accepting a girl from another caste.

But the positive group managed to convince her. Naresh, President of UP Network of Positive People (UPNP+), is hopeful that this marriage will set an example and help in creating awareness in society. This would also help in boosting the confidence of positive people. Executive Director of UP AIDS Control Society Mukta, who was part of the ceremony, says the marriage has been made possible by the efforts of people of positive network of Varanasi and Maharajanj. Amitabh Awasthi, President of Lucknow Positive Network, echoes the same thoughts and says he too is waiting to tie the knot with a positive partner.

Increased lifespan raises demand for newer HIV drugs

By Shivani Parihast

New Delhi: Forty- nine- year old Petra from Germany has been living with HIV for the past twenty-four years. President of the UP Network of Positive People Naresh Yadav explains how the availability of up to six lines of Anti Retro Viral (ARV) drugs in Europe has made living with HIV as easy as diabetes or any other non communicable disease.

"In the West, a whole series of drugs are available, especially Protease Inhibitors," says Dr. Ashok Rau, CEO, Freedom Foundation. Protease Inhibitors are critical for the second line treatment. But they are very costly. Therefore, in India only three first line drugs are available under NACO (National AIDS Control Organisation) roll-out programmes."

Anti-retroviral therapy has enabled people with HIV to live longer and healthier lives. However, the drugs are highly toxic and resistance tends to set in quickly. When this occurs, the first line of therapy needs to be replaced with the second line therapy. The government has been unable to provide the second line therapy so far, as it is expensive.

The National AIDS Control Organisation does not see any possibility of providing second line drugs in the near future. Officials say infrastructure will also need to be improved and doctors' training scaled up before it can include second line drugs under the government programme.

"Access to second-line drugs is extremely urgent". Eight to ten thousand people in India are now urgently in need of second line medication, says Mr. Yadav. He warns of a looming 'ARV access crisis' that could sabotage efforts to control the epidemic. "In the past few months we have already lost eight to ten persons due to lack of availability of second line ARV," he says . At the Varanasi ART Centre alone about 80 people are in urgent need of second line drugs.

ABOUT ARVs

Antiretroviral drugs are medications for the treatment of infection by retroviruses, primarily HIV.

The antiretroviral drugs available in India under the National Programme are *Zidovudine (AZT)*, *lamivudine (3TC)*, *stavudine (d4T)*, *nevirapine (NVP)* and *efavirenz (EFV)*.

The initial or baseline regimen of ART is known as first line medication. It comprises drugs such as *zidovudine*, *lamivudine*.

Treatment may eventually lead to drug resistance. It is then that the second line of defense against HIV is introduced. The second line drugs may include *didanosine (ddl)*, *tenofovir (TFV)*, and *ritonavir boosted lopinavir (LPV/r)*.

The cost of first line ARV was Rs.15,000 per month. It has now come down to Rs.8,000 per annum per person.

The second line drug regimen may cost anywhere from Rs.12,000 to Rs.18,000 per month per person. Generic versions of several of these drugs are available in the Indian market but their cost is high.

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On World AIDS day (December 1), around 50 positive people from 25 states organized a rally in Delhi to press the government for second line medicines. Government officials say if second line treatment is offered they would not be able to afford enough medicines or increase the number of people on drugs.

In the past few years the cost of first line of therapy has come down drastically from Rs.15,000 per month to Rs.8,000 per year per person. However, second line treatment is still prohibitive. It can cost anywhere between Rs. 12,000 to Rs. 18,000 per month per person. Additionally, the CD4 count test, critical for knowing the stage of HIV infection, may cost anywhere between Rs. 200 to Rs. 300, says Dr. Rau.

"At times the cost of investigations is more than that of drugs and not many can afford it," says Dr Rau. Elaborating on other issues, he said, at many ARV centres, because of the time lapse between procuring the drugs and distributing them, the drugs reach their expiry date (which varies between two to three years from the date of manufacture).

Drug resistance is often a result of missed regimens. The drugs are highly toxic and can lead to severe side effects. As a result, people living with HIV, tend to skip doses or stop them altogether for days. "A good physician should alter the dosage in order to delay the resistance that may develop" says Dr. Rau.

Epidemiologist and former director of the All India Institute of Medical Sciences (AIIMS), Dr L.M Nath, says, "The drugs can have serious side effects, such as liver failure and abdominal pain. Regimens can be complicated, requiring patients to take

several pills at various times during the day. Counselling is necessary as it ensures psychological support and adherence to treatment."

This, however, is easier said than done. At AIIMS, the premier medical institution, one of the counselors at the Voluntary Counseling and Testing Center (VCTC) indicated that only two full-time counselors were struggling to provide support to 1500 people with HIV registered with them. Such staff shortages present real obstacles in providing adequate information.

NACO at present is aiming at covering more people under the first line drugs and improving adherence. It aims to provide first line of drugs to 100,000 people living with HIV in the next seven months or so. At present 69,000 people living with HIV are being covered.

It also aims to increase adherence to 97 per cent from the current 91 per cent. This alone would delay the need for second line drugs. There are presently 127 ART Centres across the country. NACO is aiming at opening 250 ART Centres by 2011-12, the end of National AIDS Control Programme - III (NACP - III).

Delivering on a bullock cart in 21st century

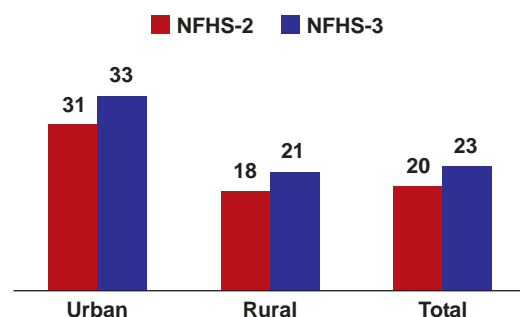
By Sudhir Mishra

Lucknow : It was a chilly winter night when Manju began having her labour pains. Her husband, Shivnarayan, rushed her to the nearest Pediatrics and Maternity Ward in posh Indiranagar. The hospital demanded that the entire fee had to be deposited in advance for Manju to be allowed entry to the labour room. With little money and no time to look for a cheaper hospital, a helpless Shivnarayan left his wife on a bullock cart, where she delivered her baby.

Media glare on this shocking incident ensured that the guilty were punished. But the episode itself raised a larger issue: the condition of pregnant women in rural parts of Uttar Pradesh, where maternal mortality as it continues to be very high. These women urgently need safe and affordable places for delivery.

TRENDS IN VACCINATION COVERAGE

(Percentage of children 12-23 months who have received all recommended vaccines)



Not that the money is lacking. According to the NGO, Healthwatch, in the last six years the UP government has received millions of dollars to improve health care systems. It says that funds to the tune of \$110 million were given by the World Health Organisation and a whopping \$325 million by the USAID to upscale health care.

In reality, results have yet to become visible. Figures available from the National Family Health Survey 2005-06 (NFHS-2) also show that in the past years not much has improved. Money has been flowing in but thanks to the apathy of politicians and policymakers, it did not reach those it was meant for.

In some areas the situation has worsened. Infant mortality in UP was 63 per thousand in NFHS-2, conducted in 1998-99. This has now gone up to 64 per thousand. The situation in rural areas is even worse.

Immunization coverage has not shown much improvement either. The average number of immunized children between 12 to 23 months remains almost the same as NFHS-2. And those figures are not encouraging. Only 21 per cent of children in rural areas receive their full immunization. The last NFHS had pegged it at 18 per cent. The condition is no better in the urban areas, where only 33 per cent are being immunized.

The state of affairs in rural areas is extremely disappointing. As per the last survey, 94 infants were dying for every thousand live births; while currently 75 infants are dying out of 1000 live births. If we take an average of both rural and urban sectors the figures would reach a 73 per thousand. Previously the number was 89.

Yashodhara, who is associated with Health Watch says that "in the last six years the percentage of pregnant women and infants who are anaemic has seen a significant increase. Hundreds of children are dying due to Japanese Encephalitis. Around 40,000 women are dying since maternal health has been ignored." The status becomes more conspicuous through the data collected by the Ministry of Family and Health Welfare. Comparing the difference in the figures of the data of NFHS-2 and NFHS-3, one may conclude that not much has changed.

