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World AIDS Day 2016: Is India's War Against HIV Coming Apart?

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This World AIDS Day brings a mixed bag for India's HIV Positive community as there's cheer that the country has managed to put a million infected on anti-retroviral treatment (ART) but worries mount over an important legislation that borders on the ambiguous with regard to the government's commitment to tackle the deadly disease.

India has the third largest number of HIV cases worldwide, with an estimated 21 lakh people living with HIV. Of these, around 15 lakh have been diagnosed and 10 lakh are on ART. According to a Lancet study, 1.96 lakh new cases emerged in 2015, and the number of people who died of AIDS-related complications is 1.3 lakh.

Civil society organisations complain that the government – especially the finance ministry – has failed to comprehend that in HIV/AIDS the treatment is prevention. They fear that stock outs of vital medicines and testing kits will force vulnerable people off their regimen, dissuade them from regular trips to far off hospitals and allow the virus to proliferate, possibly leading India back to the dark days when the epidemic struck first.

However, a larger cause of concern is the HIV/AIDS (Prevention and Control) Bill 2014, slated to be taken up by the Rajya Sabha in the current session.

Activists say that a line – "As far as possible" – inserted in Section 13 of the bill casts a shadow over the government's responsibility to provide "diagnostic facilities relating to HIV or AIDS, anti-retroviral and opportunistic infections management to people living with HIV (PLHIV) or AIDS".

Lawyers who helped draft the bill and public health workers fear this ambiguity will provide the government with an escape route whenever they have to be held accountable for the lack of necessary health care.

The Lawyers Collective was tasked with drafting the bill in 2002 and, since then, it has gone through "rigorous scrutiny", say health professionals, with consultations from the PLHIV communities, grassroot health workers and organisations, state AIDS control boards, and also the government of India.

Already the country's anti-HIV supply chain has been affected by funds not reaching state aids control societies on time. The situation in the national capital itself is alarming giving a glimpse to what could be happening in rural areas.

As the Delhi Network of Positive People (DNP+) listed out in an email to the National AIDS Control Organisation on November 17, hospitals across Delhi have run out of HIV testing kit 3, the highly accurate test used to diagnose infection in patients who have no symptoms but could be at risk. The email, according to the network came after a meeting with National Aids Control Programme's (NACO) Director (Finance) Ajay Singh Chauhan on November 10, where he was apprised of the situation.

In Chhattisgarh, 24 children with HIV have died because of lack of medicines this year, said activists from the state.

The anti-retroviral treatment (ART) centres and the integrated counselling and testing centres (ICTC) are the backbone of India's AIDS control programme and a lifeline for the many who live with either HIV or AIDS related complications.

Yet, these centres have found themselves in regular short supply of drugs and testing kits, as seen by DNP+ and other civil society bodies working with affected or at risk people. Media reports from the past two years have also question whether India's internationally hailed AIDS programme is falling apart at the grassroot level, with stock outs recurring frequently from 2014.

The communities fear only an escalation of this, and shirking of responsibility from the government's side.

More worryingly, an interruption of a few days from the strict 12 hourly drug schedule leads to drug resistance. It renders the first line treatment ineffective and pushes the patient to the 2nd line, for which medicines are harder to procure.

At the an award ceremony for HIV community leaders by HIV India Alliance, Wednesday night, one grassroot leader Daxa Patel, directly addressed Dr. CV Dharma Rao, joint Secretary NACO, to ask the government to remove this phrase from the Bill.

"The head of the NACO said there could be financial difficulties with the Bill," said Paul Lhungdim, from the DNP+, recounting his conversation with NC Kang, Director General of NACO. "He gave us an example, that if someday there is a drug that costs Rs 300,000, how will the government buy that for all patients?" According to Llungdim, NACO feared that the Ministry of Finance would not agree to the Bill without its current phrasing.

Leena Menghaney, lawyer and health activist, said the government never had to worry about procuring expensive drugs, as the country's health activists and civil society steadily fought against patents on crucial medicines, allowing the generic pharmaceutical industry to create cheaper versions of drugs. She argued that the government, instead of pre-emptively fearing an expensive medicine, should encourage competition in India's highly capable generic industry, so as to keep the prices down.

"But a generic company may not want to produce a drug which has a small market, say the 15-20,000 people on 2nd line treatment or the 200 people on third line," said Dr. R Gangakhedkar, Director In Charge of the National Aids Research Institute, Pune, offering a counter argument. He cautioned against alarm, saying that the government was aware of its responsibility and "as far as possible" did not dilute the right to life, as the community feared.

However, he too agreed that inefficient management of the supply chain and unprofessional handling of transport had created many blockages in getting drugs and kits to the people in dire need.

DNP+ records of their daily monitoring of Delhi's ART centres show shows the urgency of the situation, as the team's report from November 17 shows that the ICTCS in Ambedkar hospital, Safdarjung hospital, the All India Institute of Medical Sciences, and the National Institute of Tuberculosis & Respiratory Diseases do not have kit 3 and the staff does not know when they will be restocked. The email also lists eight different times DNP+ has tried reaching different authorities in 2016 itself, over the kit 3 stockout.

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Complacency breeds failure: Consolidate efforts to end AIDS by 2030

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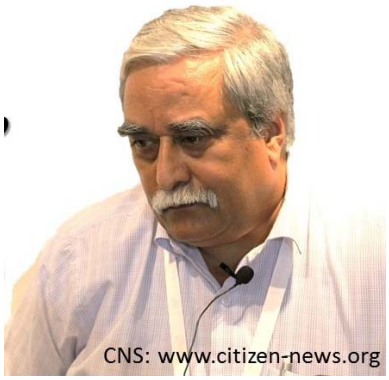
By Shobha Shukla, CNS (Citizen News Service)

Success breeds complacency and complacency breeds failure. When the number of people affected by a disease decreases, there is a tendency to disregard it as a public health problem.

Even as the HIV/AIDS epidemic is on the decline in India, we have to intensify, and not dilute, our efforts to have virtual elimination of the disease, emphasised Dr Raman R Gangakhedkar, Director-in-charge at National AIDS Research Institute (NARI), Indian Council of Medical Research (ICMR).

He spoke with CNS (Citizen News Service) at the sidelines of the 9th National Conference of AIDS Society of India (ASICON 2016). This interview is part of CNS Inspire series – featuring people who have decades of experience in health and development, and learning from them what went well and not-so-well and how can these leanings shape the responses for sustainable development over the next decade.



Dr Gangakhedkar, an eminent clinician and epidemiologist, has been intensely involved in devising guidelines for HIV management, as well as policy making for HIV/AIDS control programmes at the national level. Initially trained as a paediatrician, he jumped headlong in the field of HIV/AIDS in 1989, at a time when even the mention of this dreaded disease was a big No-no. He later shifted from Mumbai to Pune when NARI was established in 1993.

Game Changers For HIV/AIDS Control In India

Mentioning major milestones in HIV/AIDS management in India, Gangakhedkar said, "It was community involvement in decision making that proved to be the most important game changer. Going beyond just community mobilization, it involved sex-workers, MSMs and injecting drug users representatives sitting with the experts, and giving their opinions on policies and programmatic strategies to reach them".

Another bold step, according to him, was the national investment for prevention of parent to child transmission (PPTCT) programme for the mainstream population in 1999, when the Indian government started to invest its own money rather than depend on international donors. It also paved the way for free anti-retroviral therapy for people living with HIV—for the first time in the country's history, the government committed itself to give free treatment for a chronic disease that required life long treatment.

Community Empowerment

Even though India has prioritised interventions among key sub populations (like sex workers, men who have sex with men, injecting drug users, migrants), one of the larger goals that still remains is to ensure that community itself leads the targeted interventions, with NGOs acting as only gatekeepers, feels Gangakhedkar. "Community led structural interventions should have complete control on all kinds of prevention and control services. Community based HIV testing should improve and even ART centres for these sub populations should be hosted in community based organisations with some technical support (by a doctor or pharmacist) from outside. Once community starts managing their own programmes they will also manage their other day to day non health related problems as well".

"The marginalized and disempowered communities have to be empowered in a more holistic manner so that they do not remain vulnerable to just HIV/AIDS, but to other diseases too. Community voices have to become stronger and inequity between main-stream and key sub-populations reduced substantially. We must be advocates to provide the right kind of support to the community organizations so that they lead by themselves; but we should not be part of these organizations. This is the kind of advocacy I foresee myself doing in the coming years," he said.

Ends AIDs By 2030

As of today, only 14 lakh (1.4 million) of the estimated 21 lakhs (2.1 million) PLHIV in India have been diagnosed. This leaves an estimated 7 lakh (700,000) PLHIV who are not even aware of their HIV positive status. Gangakhedkar called for prioritizing and intensifying community based testing all over the country. "But rapid scale up of services should not be at the cost of quality of services. Only by improving quality of services and intensifying our strategies will we be able to achieve the last 90 of the UNAIDS goal of maintaining virological load suppression for elimination of HIV/AIDS".

There is also a dire need for implementation research in HIV/AIDS, to not only identify the gaps but also the solutions at each level of implementation. A completely decentralised approach for decoding of evidences and modification of policies is vital. There is no one size that fits all. We have to build the capacity of those involved with the interventions so as to be able to interpret the evidences and have strategies that are locally adapted, he said.

Some Proud Achievements

When Dr Gangakhedkar started his career in HIV there was no treatment available. At times he would feel frustrated that as a doctor he could do nothing beyond counselling his patients. But he persevered and, in his own modest way, brought about many changes in the HIV/AIDS control scenario. His landmark study, done in India at a time when stigma around HIV was very high, found a very high prevalence of HIV amongst married monogamous women. This was contrary to the existing perceptions, as till then HIV was presumed to be prevalent in only high risk populations like sex workers, MSMs, and injecting drug users. "But my study proved that a very high percentage of married monogamous women acquired HIV infection—not because of their behaviour but because of the risk behaviour of their husbands. The study results were extensively used for HIV related advocacy work all over SE Asia region. It also led the policy makers to have women centric prevention approaches. The focus was suddenly shifted to women in mainstream population, resulting in interventions like PPTCT".

Gangakhedkar was also instrumental in the roll out of the PPTCT programme in India. "I realized that one cannot make the system responsive unless one goes for mainstream population. I thought PPTCT was one of the key areas for mainstreaming, as treatment was

available then (in the late 1990s) to prevent mother to child transmission by providing short course zidovudine. I submitted a proposal, which was also supported by UNICEF, to the government of India, Thus began a feasibility study at 11 centres with zidovudine based Bangkok regimen, which was later replaced by the more feasible single dose nevirapine regimen. And in 2001 the PPTCT programme in India was started".

Apart from an impressive array of professional achievements, Gangakhedkar feels fortunate that working in this field has improved his personal sensibility of social justice and social equity. He shared candidly, "As a typical Indian male from a conservative Indian society, I initially felt very awkward when I started going to the red light areas for creating awareness about HIV/AIDS control. I had no idea who the sex workers were and how they lived. But over time, I saw from close range the problems faced by them. It made me understand what social exclusion was, making me more committed to my cause.

Subsequently, I started working on community led interventions, taking these women to the policy makers table and to understand from them how the epidemic could be controlled. In the aftermath of the Mumbai bomb blasts, we took special permission from the police to deliver simple meals (through kind courtesy of donors and philanthropic hotels) during curfew time to the sex workers every day. Their earnings had dwindled and I was apprehensive they might start practicing unsafe sex with their clients to make both ends meet. I do not hesitate to go to see patients in Pune's red light areas when some woman is sick and calls for help. These small gestures have increased their trust in me. One needs to be not only committed but also sensitised enough to be able to work for the good of the community."

The Way Forward

Gangakhedkar insists that, "It is imperative to consolidate our efforts of past several years to end AIDS by 2030. We can definitely do better in ensuring quality of services for PPTCT and the free ART programme. Today treatment as prevention is regarded as the biggest component of controlling HIV infection. So if we could improve the quality of service then perhaps we should be in a better place to control the epidemic. Doctors must treat all patients as their equal, irrespective of their social class or caste. A prescriptive approach cannot be healthy for anybody. Doctors also need to have good communication skills to be good advocates as well. Also, unless we empower key populations we will never be able to eliminate HIV/AIDS. If they are not empowered, then even if they are free of the HIV infection today, their behavioural and social vulnerabilities might provide a chance for HIV to hit back again".

- Asian Tribune -