

# HIV/AIDS in India: The Wider Picture

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Increasingly, voices across the world are questioning the narrow approach to a single disease, especially the huge financing for AIDS over all else in basic healthcare. Though welcome and long overdue, this debate must now move further.

Being HIV-positive does not mean death. It is the body's "red alert" warning that the immune system should be immediately repaired with nutrition through "real food", and a changed lifestyle. Despite the enormous amount of money spent by India's AIDS programme, it has failed to communicate this message. Many AIDS patients have been driven to commit suicide. An informed public debate is necessary to deal with the ignorance and prejudices.

On 5 August 2008, a young HIV-positive couple in Mumbai, Babu Ishwar Thevar and his wife Amothi committed suicide after killing their three children aged between 6 and 10 years. They had just discovered that their youngest child too was infected by the deadly virus. The stigma of AIDS has taken many lives long before the disease itself claimed them but the extent of such suicides and the reasons behind them have rarely become public knowledge. It is not known that AIDS has a critical link to the immune system and the factors that influence it. Society's limited understanding of this disease leads to innocent people paying a terrible price. At a time when we do not have a cure for AIDS, we cannot assume to know its cause. Increasingly, voices across the world are questioning the narrow approach to a single disease, especially the huge financing for AIDS over all else in basic healthcare. Though welcome and long overdue, this debate must now move further. Our approach to this disease needs to change for the sake of families like that of Babu and Amothi Thevar.

In 1993, I completed a journalist fellowship at the Harvard School of Public Health in Boston, and came back deeply influenced by teachers such as the late Jonathan Mann, a public health expert with renowned international experience. He believed that the discovery of a new disease

like AIDS was an opportunity to scrutinise fundamental issues such as the link between disease and poverty, the need to examine the workings of the entire health system, access to preventive health information and the means to support health in all its physical, mental and social dimensions. Based in Mumbai, I witnessed the unfolding of the "HIV/AIDS epidemic" in what was dubbed the "AIDS capital of India" and extensively reported on it over the course of a decade. At that time, the medical community shield away from treating this disease. As a result, patients were in the stranglehold of a small group of doctors that took every opportunity to fleece, frighten and even conduct illegal vaccine trials on the patients. Denied any support, the patients believed that HIV meant death. Mercifully, that stranglehold was subsequently broken when heightened international focus widened the circle of medical practitioners and non-governmental organisations (NGOs) willing to treat the patients.

One of the few but important gains of the focus on AIDS in India has been the emergence of a few genuine community-based groups for the first time in public health. Many of them provide an interface between marginalised groups, the wider community and public health services. This process empowers those who were previously voiceless and ignored, and who must continue to receive priority support. This success however, is marginal in comparison to the enormous havoc this narrow and ill-conceived focus on HIV/AIDS has created in India's public health system. There is an urgent need to expand the treatment to a comprehensive, primary health-based approach – one that takes into account the total health needs of communities in developing countries that cope with an already enormous burden from other killer diseases. Improving the primary health system will have an impact on a range of these killer diseases, including AIDS.

## Inflated Numbers

Contributing to this climate of fear and myopic focus were many myths that gained currency. In particular, AIDS fatality figures were severely inflated. The past

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two decades have seen warnings about the huge numbers of HIV/AIDS infected persons who would “die like flies”. The projections, provided in particular by the Central Intelligence Agency (CIA), Joint United Nations Programme on HIV and AIDS (UNAIDS) and the World Health Organisation (WHO), ranged from five million to 20 million estimated cases in India alone. Local and international groups that questioned the high numbers faced severe criticism and marginalisation. Ultimately, the sceptics were proved right. The AIDS lobby has since backtracked on its pronouncements without acknowledging the extent to which they have misled the public. UNAIDS has now reduced world HIV estimates from 39.5 million to 33.3 million but still calls for dramatically increased spending on AIDS from \$9 million to \$42 billion by 2010 and \$54 billion by 2015.

The National Family Health Survey (NFHS-3) was the first to provide data on what is happening at the general community level and it forced international agencies to scale down their figures. Estimates of India’s HIV/AIDS prevalence are now 2.5 million, a significant decrease from the earlier Indian official estimate of over five million infected. While HIV causes only 3.7% of global mortality, it receives 25% of all health aid. Additionally, it receives a large portion of domestic expenditure, which often exceeds domestic health budgets, says Robert England, chairperson of the Health Systems Workshop, an independent think tank promoting comprehensive primary health systems reform in developing countries. It is important to analyse how these high projections came about in the first place, and to ask how those in authority accepted these figures without asking the basic questions voiced within the community. It is vital to know what is happening on the ground and discover for ourselves India’s true experience with this disease.

During a 2008 media workshop with Asian and African journalists in Geneva, the WHO placed the blame for flawed fatality projections on the home countries. “The WHO has no mechanism for monitoring numbers and its estimates depended on the data supplied by the Indian government”, it said. Policymakers in Delhi

and Washington had applied universal yardsticks without examining local geographical and cultural traditions of health-seeking behaviour in developing countries. India’s HIV/AIDS surveillance system drew samples from the following sources within public sector institutions: Clinics for antenatal mothers; sexually transmitted diseases (STD) treatment centres; blood banks; and NGO groups catering to the needs of “men who have sex with men” (MSM), commercial sex workers and their clients. The problem with samples taken from these sources is that these segments do not represent the general population; they represent “high risk groups”. While pregnant women attending antenatal clinics in public hospitals would come from the general population, they still represent the lower socio-economic strata. The picture these samples show does not portray the total image with its manifold nuances.

Typical patients who seek the services of the urban public sector in India are migrants who come to the cities and live in stressful conditions. They suffer from malnutrition and carry a heavy burden of disease that has compromised their immune systems. If they were to undergo an HIV test, it is likely that it would show a false positive result because of a cross-reaction due to the presence of other infections commonly found in developing countries.

Data drawn from the public sector connects with another Indian peculiarity. Studies have revealed that 70% of Indians turn first to the private sector when they suffer from a health problem. They do so because the primary health service offered by the government sector is neglected and in a shambles. It is only when they run out of money or suffer the consequences of wrong diagnoses that patients turn to the public sector hospitals, resulting in the over-burdening of referral services by patients suffering from minor problems. Thus, comparative data drawn from the private sector services, which covers the majority of India’s population is the key information missing in the HIV/AIDS surveillance systems. The class of people who come here are better nourished and healthy. HIV testing done on them may demonstrate different results. Such comparative data is readily available

with all leading private hospitals in Mumbai, who subject their patients to an HIV test on admission. The administrator of one leading private hospital in the city said that the number of such HIV patients found in their hospital is, in fact, not large. Their numbers are restricted to a small group of patients who shop around for services in the city’s private hospitals because of the stigma. Strangely, the national surveillance system has completely left out this vital sector from its reckoning. Why are researchers and scientists not interested in comparing the private and public sector data on HIV/AIDS? What makes the better nourished, wealthier class of people less vulnerable to AIDS and other infectious diseases compared to the poorer segment of society?

### False Test Results

Apart from misleading estimates of those affected by HIV/AIDS, there is also a realisation that an HIV positive test result is fraught with uncertainties and causes havoc when it shows up in an asymptomatic person.

In the course of my journalistic work HIV/AIDS patients from across the country often shared their stories with me. Those were the years when the hysteria around this disease was reaching its most fevered pitch and mass HIV testing within the general population was being encouraged or enforced. The patients however reported that their experiences did not conform to the tutoring of the AIDS lobby.

Mushtaq’s (name changed) experience is consistent with that of the many “patients” I met. While seeking a work permit for the Gulf, he tested HIV-positive during a mandatory test. Although subsequent tests conducted by a reputed private hospital laboratory showed a negative result, the Gulf Board rejected the “HIV-positive” candidate. Sadly, stigma from the flip-flop testing still sticks to him wherever he goes. In another case, a private hospital denied admission to two pregnant women after a positive HIV test. Their babies were later administered a course of the toxic and controversial AIDS drug, AZT. However, a routine second HIV test showed negative results on both women. Those interacting with HIV/AIDS patients are well aware of the innumerable cases of men and women who seek repeated testing at

leading laboratories and still come up with conflicting results. Cases where a pregnant woman tests positive during her pregnancy and negative after giving birth have no explanation. There is no explanation for “discordant couples” wherein one partner is HIV-positive while the other remains negative despite practising unprotected sex. The government-run J J Hospital in Mumbai which has documented such cases, also points to patients who show other symptoms of immune suppression, such as lymphatic cancer or skin lesions. Such cases of false HIV-positive results or unusual symptoms are only the tip of the iceberg. The extent of such incidents remains unknown because the AIDS lobby and the health authorities have no system for monitoring such cases across the country or the desire to know why they occur. These cases however reveal how an HIV test conducted on those with no clinical symptoms of AIDS can cause havoc in their lives. In fact, many patients accept their first “HIV-positive” result as a death sentence.

The poor cannot afford to do a second confirmatory HIV test as per subsequent WHO guidelines. These stipulate a requirement of at least three confirmatory tests, to eliminate the possibility of picking up other infection markers. They clarify that a single HIV test is not enough to label a person “HIV-positive”. For the poor however, a single HIV test continues to remain the norm across India and in most developing countries. The health authorities in Mumbai acknowledge that there is a problem. A senior official at the Mumbai AIDS Society attributes it to the many private laboratories in the city that lack accreditation and technical expertise to assure standardised testing. Beyond the urban metros, the situation is worse, particularly in the rural districts. Most developing countries have not built up a cadre of trained microbiologists or laboratory infrastructure to ensure accurate diagnoses. The absence of professionals and technology also has an adverse impact on the monitoring of patients on anti-retroviral (ARV) drugs treatment. Unable to bear the high costs of HIV testing, public hospitals in Mumbai no longer insist on an HIV test on admission. They rely instead on clinical symptoms such as repeated bouts of

diarrhoea, fever, rapid weight loss or tuberculosis (TB) – the common symptoms of AIDS-associated illness – that warrant suspicion and the need for a confirmatory test. Private hospitals in Mumbai, however, insist on a routine HIV test for all admissions. At various times fly-by-night NGOs in Mumbai have called for mass HIV testing. Such insistence of HIV testing serves the interest of test kit manufacturers but is fraught with consequences for those subjected to it. Manufacturers of testing kits also admit that the HIV test is unreliable. Abbott Laboratories’ printed literature states that their product is not specific to the detection of HIV antibodies. Thus in developing countries, the poor and malnourished who regularly suffer from infection and disease are likely to test HIV-positive because the antigen cross-reacts with the host of infections already present in their bodies.

### Quality of Tests

Scientists have pointed out that false positive-HIV test results may show up in 70 different conditions, which include malaria, TB or influenza and even in pregnancy. Thus the ground reality in most developing countries is that a death sentence is passed on the basis of a single test conducted by ill-equipped laboratories and poorly trained technicians who are more likely than not to have erred. The test conducted on a poor class of patients who are malnourished and in poor health is therefore likely to produce misleading results.

Meanwhile, even if a test is clearly HIV-positive, it only means that a person suffers from a severely compromised immune system. Many eminent western scientists are now questioning the assertion that sexual transmission is the sole cause of AIDS, raising the possibility that the presence of the virus merely represents the marker of a suppressed immune system. The real cause of AIDS, these scientists say, is the assault of toxins and deficiencies on the body’s immune system. These factors include antibiotic abuse, recreational drug abuse and nutritional stress, all of which are major public health problems in India. Evidence both within India and outside, suggests that the damage caused to the immune system is reversible even without drugs.

The experience of developing countries shows that the presence of microbes in the body does not necessarily indicate progression into disease, for much depends on the status of the immune system. In Asia and Africa, where TB is rampant, even healthy people are carriers of the TB germs and may have a positive report if they undergo a diagnostic test. Their ability to live with the microbes and prevent the downslide into disease depends on their nutrition and immune status. The same analogy works for AIDS. Africa is a continent in the throes of AIDS. Health historians say that AIDS in Africa is a consequence of the depletion of the body’s nutrition pool over the generations and the destruction of the immune system. As sub-Saharan Africa plunged deeper into the cycle of poverty, malnutrition and civil war, it also suffered epidemics of Ebola and Marburg or Lhassa fever, which stayed within the population for decades. AIDS could be the result of this depletion of the nutrition pool.

Until now, India despite its poverty and malnutrition like many other Asian countries, has not seen an impact of AIDS similar to that of sub-Saharan Africa. Barring pockets of malnutrition in tribal areas of India, the last major Indian famine took place in Bengal during the British rule. In both cases malnutrition and famine was, and remains, a consequence of poor public food distribution services, corruption, maladministration and lack of purchasing power. The African experience of the structural adjustment programme (SAP) led to the loss of local food security when international donor agencies compelled these countries to convert their agriculture to cash crop cultivation of coffee. The subsequent crash in international coffee prices plunged these countries into economic, political and social chaos which in turn led to the health consequence of AIDS. India took up the SAP in the early 1990s and similar consequences are beginning to show here as the country plunges along the path of unequal economic development, throwing vast segments of the population into deep poverty. At stake are the issues of local food self-sufficiency and national sovereignty in determining agriculture and development policies. It is this wider picture that must now come into focus.

Over the past decade, women diagnosed as HIV/AIDS patients in Mumbai and whose husbands died of AIDS have become “long-term survivors”. There are three factors that have helped these women to live well without having to resort to ARV therapy. They found support from women who were similarly afflicted and counselling groups that gave them hope; through these groups they got access to doctors who treated their opportunist infections in time and they learnt how to look after their health through a combination of diet and precautionary measures.

When first detected as HIV-positive, their vulnerability to cold, cough, fever and diarrhoea increased and they also suffered from weight loss. These women believe that their physical vulnerability was more an outcome of the tension, fatigue after caring for their sick husbands and economic burden rather than AIDS-induced infections. They believe that their men died because of addiction to alcohol, tobacco, neglecting to take medicines and refusing to change their lifestyles. As Lata, Sharda and the others point out, they do not eat and drink outside (this has helped in reducing bouts of diarrhoea, cold, cough and fever), are no longer careless about medication and keep themselves busy by volunteering to help other patients when they cannot find paid work. Their diet primarily consists of *dal* (lentils) and rice. Seasonal fruits and green vegetables that they desperately need are a rare luxury but they are learning that food that is cheap, seasonal and locally available is a powerhouse of energy that can boost the body’s immune system in fighting AIDS-related opportunistic infections. A daily diet consisting of a banana, some lemons and a couple of dates, along with seasonal fruits and vegetables like gourd, has been very helpful. Some key issues that would make a difference in the care and support of the AIDS afflicted, the women say, is ensuring access to TB treatment along with nutrition support for those on therapy; the presence of well-trained doctors in rural areas; security for their children and organisational support in solving legal and other disputes with family members.

This phenomenon, taking place within the general population in Mumbai, is

important to monitor. Following a cohort of 900 HIV patients from within the general population in Mumbai, the Salvation Army, for instance, found that only 15 had died in the course of a decade. The main causes of death were TB or malnutrition, often coupled with alcohol abuse amongst the men. Such evidence calls for broad-based interventions, through policies that focus on access to real nutrition (as opposed to chemical-based supplements) and comprehensive primary health services, which include addiction treatment.

This implies the need for a hard look at our trade and development policies (which have caused the loss of local food self-sufficiency) and our narrow approach to health issues through “vertical programmes”, all of which are leading to adverse health outcomes. Fixated on the sexual transmission theory of HIV/AIDS, mainstream western science has resisted such evidence and held fast to the view that the answer to AIDS lies in condoms, sex education and ARVs alone. The public messages communicated at great financial expense, insist that HIV/AIDS spreads through multi-partner sexual activity and bodily fluids, and knows no barriers of class or social status. Now the wheel has turned full circle and the AIDS lobby is steadily backtracking on its earlier pronouncements. Forced to come down on its earlier inflated estimates of the numbers affected by HIV/AIDS, it now admits that AIDS assails only the marginalised and specific segments of the population.

### Crucial Link

This reversal is evident in a new report by the Asia Commission on AIDS, tabled in the UN in March 2008. It states that the epidemic is restricted to specific and vulnerable groups engaged in “high-risk” activities. Such people, says the report, are those who engage in unprotected paid sex (commercial sex work), injecting drug users who share contaminated needles and syringes, and men who have unprotected sex with other men. This assertion appears to be correct and conforms to the trend noted in cities like Mumbai during the course of two decades. Here, the reality on the ground has clearly shown that those who suffer a rapid downslide into AIDS and death are primarily those from

the low socio-economic group and commercial sex workers, injecting drug users, homosexual men and alcoholics appear to be more vulnerable.

The intense pressure by drug companies to launch patients into ARV treatment is meanwhile not without problems. Evidence from the JJ Hospital reveals that this treatment is helping patients whose CD4 count falls below 200. Access to treatment however, is still not available to the most marginalised segments such as commercial sex workers. The hospital data also points to the severe, toxic effects of ARV drugs. Patients who are poor and malnourished cannot maintain long-term drug adherence. It points to gross and widespread malpractice within the private sector whereby patients are given wrong prescriptions through sub-therapeutic drug combinations and dosages. Earlier data shows that there is resistance to the first line of ARV drugs and a second line of treatment is required. Undoubtedly, patients who seek ARV treatment must have the right to access available treatment especially when it is a matter of life and death. All the same, these drugs do not offer a cure and they are expensive to sustain on a lifelong basis, even when it is the cheaper, generic version. Besides, there is no guarantee of indefinite free supply of ARV therapy. More importantly, it is suicidal to promote it when the infrastructure to administer and monitor it is non-existent in most developing countries. For these reasons, ARVs can never be the drug of first choice; the quest for solutions through research in traditional medicines is a crying need of patients in developing countries.

There has been far too little analysis of what these strands of information from the ground mean within the wider picture of health. They raise one key question: Assuming that the better off segment of the population is as sexually active (maybe even as promiscuous) as the poor, why are we seeing two different trends, where only the poor are more vulnerable to AIDS? Is it time to re-evaluate the theory of sexual transmission of this virus as the only factor leading to immune suppression and a disease called AIDS? When we do not have a cure for AIDS, why are we assuming to zero in on only one factor of causation?

This rigidity of approach has done great disservice to the cause of public health including the treatment of AIDS.

There is a crucial link emerging between nutrition and immunity. A joint statement by two UN agencies, the WHO and the Food and Agricultural Organisation confirms that,

A good diet is one of the simplest means of helping people live with HIV/AIDS and may even help delay the progression of the deadly virus...The nutritional aspect of HIV/AIDS has been ignored for a long time. The attention was always focused on drugs... The message was always: 'Take two tablets after meals'. But they forgot about the meals.

Unfortunately, this insight has not translated into action. For AIDS patients in Mumbai who desperately need access to a nutritious diet of fresh seasonal fruits and green vegetables, such food is a rare luxury. The millions spent in the name of AIDS have facilitated the survival of the AIDS lobby but not the patients. Our policy planners have yet to understand the vital role of local food self-sufficiency, national food sovereignty and public education on what the body needs to stay healthy. Preventing this comprehensive health approach is a western donor-driven agenda, says a growing movement of health policy experts. While southern realities cry out for access to real, nourishing and affordable food, clean water, sanitation, means of economic survival and access to comprehensive healthcare – interventions that would have an across-the-board impact on health – there appears to be little shift in the northern perspective.

The focus of major funding and policy diktat from the north remains obsessed with the pumping of more technological interventions – drugs, vaccines, diagnostic kits or food fortification therapies (a pre-dominance of expensive lab produced chemicals to fortify food as against natural, real food). This approach is contrary to their own achievements which were gained through a revolution in hygiene, sanitation and water services. Southern experience shows that a technology driven approach cannot have a tangible impact on malnourished populations who lack the means for basic survival. Conditions of poor health infrastructure are abysmal in developing countries of Asia, Africa and

Latin America. During field studies done in Uganda and Haiti, our group of health journalists found conditions similar to that in India. Health centres have no doctors, drugs or electricity. Access, particularly for those living in the interior areas, is difficult because of poor roads and absence of public transportation. There is high maternal and infant mortality; TB, malaria, high blood pressure and a host of other diseases. Acute and chronic malnutrition is rampant and it remains the main hurdle in bringing these countries out of poverty. Health agencies such as the United Nations Children's Fund (UNICEF) are clear that drugs and food therapies do not address the key issue – national production of food and restoration of agricultural self-sufficiency. The bulk of international aid money coming to developing countries focuses on HIV/AIDS and involves "very big players" for whom "money is not a problem" says UNICEF. At the forefront is the US, which is a major supplier of pharmaceutical drugs. Its major concern however is not with the needs on the ground but how aid money can be ploughed back to US industries which have invested heavily in HIV/AIDS drugs and diagnostics. The Bush government for instance, initiated the "President's Emergency Plan for AIDS Relief" (Pepfar) which is a major programme to provide ARV drugs and the diagnostic kits for detection of HIV/AIDS. Haiti in the Caribbean Islands has recently scaled down its inflated HIV/AIDS estimates, but US funds for AIDS drugs to Haiti have steadily risen from \$28 million in 2004 to the present \$100 million in 2008.

### Aid That Distorts

ARV drugs presently provided free by the US government cost \$15,000 as compared to \$300 through the cheaper, generic versions made available by countries such as India. Here too, the US provides no guarantees that free drugs will be available indefinitely. While initially the World Food Programme supported patients on the ARV programme with food, it has now stopped doing so. Like in India skin diseases, stress, TB, diarrhoea, STD are amongst the many problems also faced by AIDS patients in Haiti, but there is no access to support and treatment. There is no doubt that such money in the guise of "international aid"

would be ploughed back to boost western research and industry, even as developing countries fall deeper into a debt trap and poverty. Meanwhile aid that comes with conditions has served to distort national priorities.

"Haiti's family planning programme also started like this", says Marie Mercy Zevllos, Director of the Hope Centre, which provides AIDS counselling in the capital, Port-au-Prince. "Initially we received all the support – technical and financial. But then when the government changed in the US, the programme ended. The current approach is good for the pharma industry in the US, it is helping us to help themselves", she said. International health experts in Geneva reveal that although 75% of health expenditure comes out of the pockets of the poorest in developing countries, they have no say in setting the priorities. Meanwhile money from the donors – up to \$16 billion until 2006, according to the WHO – has come with conditions that distort national health priorities. Money poured into technology interventions is considered inadequate while the gains in health remain intangible. There is little understanding of the wider linkages that affect access to health or concern for research in the neglected diseases that add to the burden of ill health and death.

For health journalists looking at the wider picture a key insight gained is that technology by itself can never be a magic wand. It can be a boon and a gift of life when it is based on other broader interventions that have to be in place first. In view of the emerging food and energy crisis – key issues for the coming years – it is crucial for the developing world to evolve its own sustainable solutions that promote health and prevent AIDS.

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