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Photographs by BARRY FITZGERALD

# The Cost of Living with HIV



On a muggy afternoon in Chennai, a woman in a chador waits at the reception area of Saadhan Clinic, squiggling her toes through her black sandal straps anxiously. She is the lone woman among four or five men who have walked into the clinic for voluntary counseling and testing for the human immunodeficiency virus (HIV) that can develop into the deadly and incurable acquired immunodeficiency syndrome (AIDS). Saadhan Clinic is run by Operation Lighthouse, a program initiated in 2001 by the Population Services International (PSI), to educate people about HIV/AIDS and prevent the spread of the disease among fishermen and others in 12 Indian port cities. The outreach program includes behavior surveys of vulnerable groups, one-to-one communication, promotion of testing and counseling, and referrals to treatment. Operation Lighthouse is part of a network of HIV/AIDS outreach programs in Tamil Nadu and elsewhere funded by the United States Agency for International Development (USAID). The funding enables testing and counseling to

be done at a subsidized rate of Rs. 25. The twin DETERMINE and UNIGOLD test kits that Saadhan Clinic uses costs ten times as much in the market.

This growing national and international interest—backed by financial resources—is the good news in the HIV/AIDS story. In time it could mitigate the problematic situation that currently exists. If the woman in the chador tested positive, she would be among the 10 percent of people living with HIV in India who know their status. It is believed by those who track the numbers that an alarming 90 percent of the 4.6 million living with HIV in the country are ignorant of their positive status until they have full blown AIDS. A large percentage of them are women. The National AIDS Control Organization (NACO) estimates that there are 400,000 people living with HIV in the state, which has one of the highest prevalence rates in the country, but reported figures show only 32,000 men and 10,694 women with HIV.

In the past decade NGOs working with government agencies in Tamil Nadu and other states have made a concerted effort to raise awareness about HIV/AIDS and give men and women in high-risk groups

## Outreach organizations in Tamil Nadu are working hard to keep ahead of the HIV/AIDS pandemic

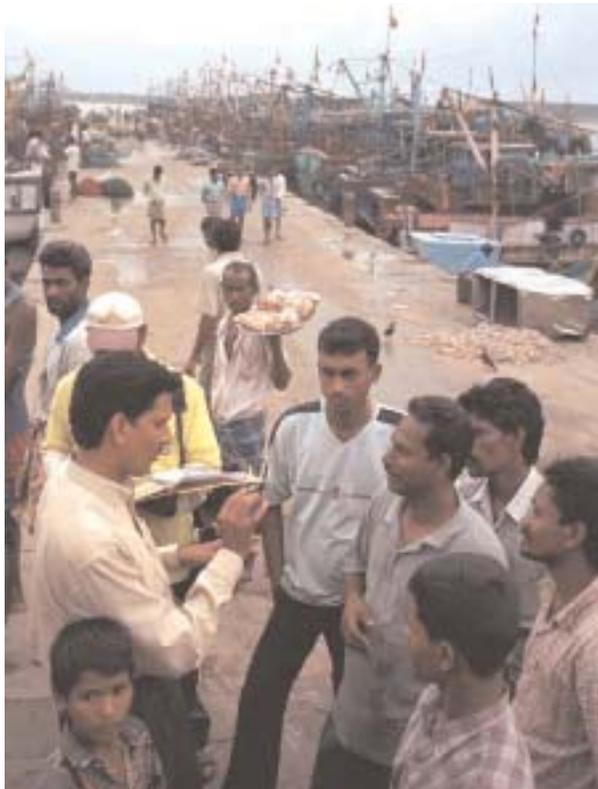
*Left: A babysitter looks after the kids at the Community Health Education Society (CHES) home. Most of the wards at the home are infants whose HIV status is not yet confirmed.*

*Right: HIV/AIDS prevention volunteers use the AIDS Prevention and Control (APAC) project's printed material for their outreach and counseling program.*

*Interestingly, one booklet (far left in photo) combines both tourist information on Mahabalipuram and HIV/AIDS awareness.*



**The knowledge of HIV-positive status is essential to prevent the spread of the disease.**



*Left: A communicator from Population Services International talks to a group of people at the Fishing Harbor in Chennai about HIV transmission modes.*

*Right: Surali Mohan doing a skit at the Fishing Harbor in Chennai to spread the message on prevention of HIV/AIDS.*

*Left: The Masti condom man walking around the Fishing Harbor attracts fishermen to the condom demonstration stand.*

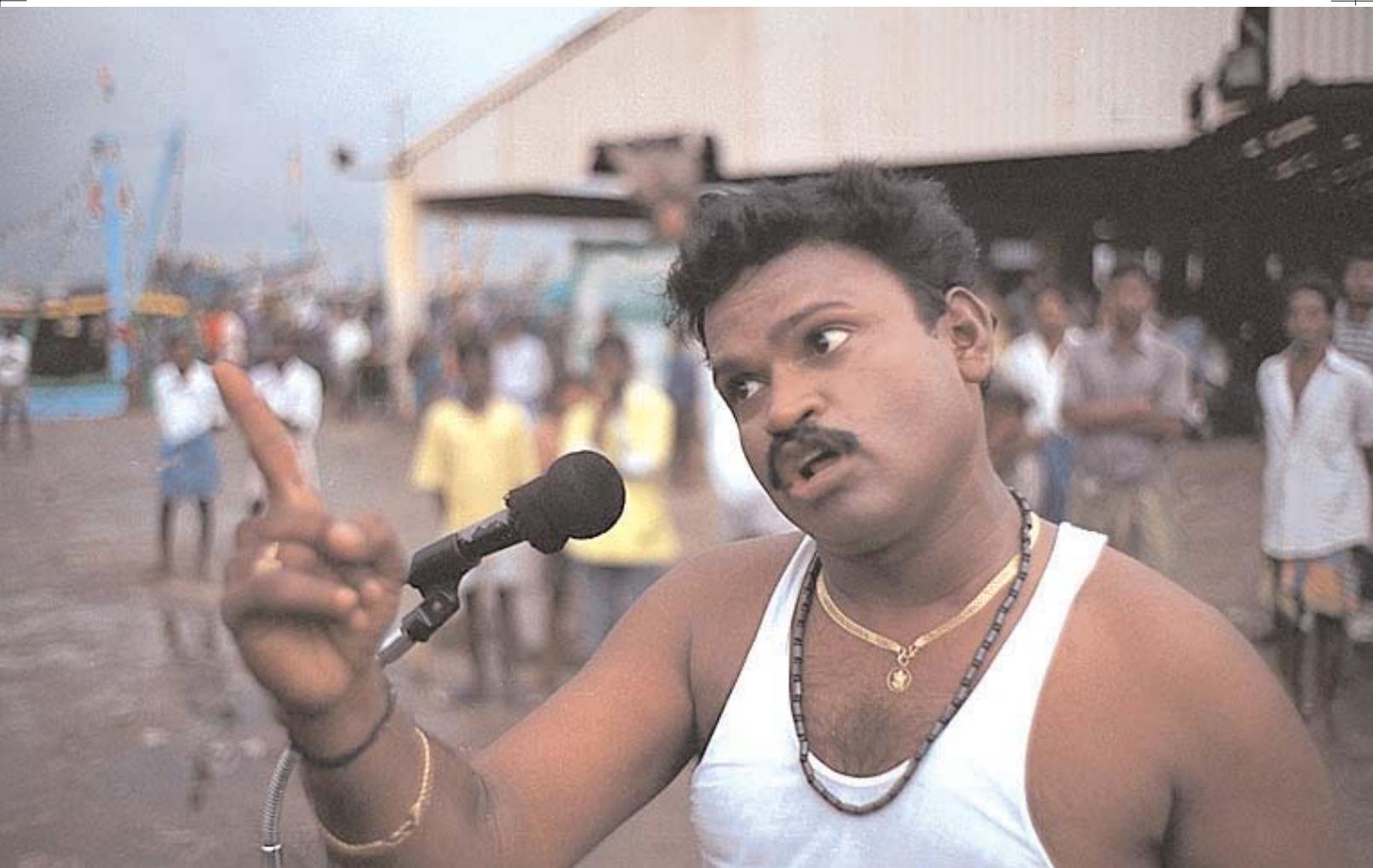


the means to protect themselves from transmission. Encouraging the use, distribution and sale of condoms among those most likely to engage in unsafe sex is a high priority. Fishermen, dock workers, truckers, sex workers and their spouses are the people Operation Lighthouse wants to reach. The next step is treatment, but so far Saadhan Clinic has no facilities to treat HIV/AIDS patients. The clinic refers people to local doctors or to Tambaram

Hospital, which has a special HIV/AIDS treatment center. Yet treatment remains a crucial component of the fight against HIV/AIDS, according to K.K. Abraham, president of the Indian Network of People Living with HIV and AIDS. "Treatment is also a part of prevention. We believe that prevention is an outcome of treatment." He explains that when there is affordable treatment for HIV, a sense of hope is instilled and people will come forward to

seek help. "Only if there's care and support and treatment, people will go for voluntary testing," he says.

Certainly, given the social stigma that afflicts those infected with HIV/AIDS, there is little incentive to come forward for testing unless adequate treatment is offered. Yet knowing who is HIV-positive is essential to stop the spread of this pandemic. Dr. Bhasker Anand at Saadhan Clinic asserts that testing by itself has an obvious advantage, even if there is no antiretroviral therapy on hand to slow down the onset of AIDS. He maintains that knowledge of their HIV-positive status helps people "look out for the future not only in terms of protecting themselves, but also in terms of stopping the spread of infection to others." When people know they are HIV positive, they can alter their behavior, notify those with whom they have had sexual contact so they can be tested, and be treated themselves, at least for opportunistic infections. "A person who's not aware of his HIV-positive status is still going to continue with the same lifestyle, of say having sex with some other partner," he says.



Dr. Anand is cautious about antiretroviral treatment, which, he says, is needed when the infected person's CD4, or T-cell, blood count is very low. The level of these lymphocytes indicates how compromised a patient's immune system is, and if the person is in danger of dying. He concedes that by reducing the viral load in an infected person, antiretroviral drugs can prolong life expectancy, but there is no guarantee against premature death. Dr. Anand points out that the consequences of discontinuing antiretroviral therapy midway are serious for the individual, whose health goes into a tailspin as the virus multiplies. It may also have wider implications, if discontinued therapy results in mutated, drug-resistant virus strains, as is the case with antibiotics. As monitoring the therapy is critical and drugs are expensive, organizations extending care and support to people living with HIV are reluctant to start it. Cipla, one of the four Indian drug companies working with the William Jefferson Clinton Foundation in providing cheap generic antiretroviral drugs to poor African and Caribbean countries, has been able to bring down the price of the regimen to Rs. 1,602

per month. However, the price of the alternative drug cocktail for those who cannot tolerate the first is substantially higher, at Rs. 2,136. Yet another course of drugs sometimes requires costs Rs. 4,500 per month. Second-line drug regimens, which patients need after they develop resistance or reaction to the basic drugs, cost between Rs. 3,768 and Rs. 9,159 per month. (Figures provided by Cipla). The expense is prohibitive for the average Indian family, whose monthly income is in the range of Rs. 2,000-3,000.

Another organization involved in caring for HIV infected individuals is the Community Health Education Society (CHES). At the CHES home for children on the outskirts of Chennai, community organizer Joel Sundarsingh says that not knowing where the money will come from next year is a deterrent to starting infected children at the home on antiretroviral therapy. Funding agencies expect the programs they fund to become self-sustainable in due course, and do not continue to fund the same NGOs forever.

It is to maintain this self-sufficiency that nongovernmental organizations like the

Indian Community Welfare Organization (ICWO) say they are scaling back on free condom distribution. In their project area in Mahabalipuram, one of the "hot spots" of sex tourism where bus stops are pick up points, only sex workers are now given free Nirodh condoms. At Krishna Hair Dressers, for example, where barber Palani helps ICWO by talking to customers in his chair about HIV/AIDS prevention, a box that says "Free Condoms Available Here" in Tamil contains only brochures. Palani has been instructed to tell people that condoms are available at the store next door. "If we give out free condoms, then it will affect sales," says K.P. Ravinchandar, project coordinator of ICWO in Mahabalipuram. "We want people to get into the habit of buying condoms. When we started our project, there were only seven shops that sold condoms; now there are 51." Condom sales are monitored and graphed at their office on Othavadai Street. For January 2003, the histogram showed 6,350 condoms sold. Sales climbed through the year to 7,040 for July 2003. The numbers for STD referrals and treatment, however, are much more modest.

They're still in double digits and often under 100. In March 2003, 39 people were referred to two of the local doctors; of these 34 went for treatment. In June 2003, 52 people were referred; 42 went for treatment. The numbers are calculated from referral cards collected at the two clinics in Mahabalipuram that work with ICWO.

Neither clinic has doctors who offer medical advice for HIV/AIDS. Dr. Gladys Indira, one of the doctors on the ICWO referral list, has 30 years of experience in

financial and technical assistance from the U.S. Centers for Disease Control, which also collaborates with the Indian government to discover the best ways to meet the HIV/AIDS challenge.

Since most Mahabalipuram sex workers are itinerants from Chennai, going to Tambaram Hospital is not very difficult for them. But those living farther away sometimes have to relocate to get treatment. Ravi, 38, has been at the Pondicherry-based Community Care

Tambaram Hospital. "They said the CCC would give shelter and care to destitute people with HIV like me." Ravi spent two weeks at the hospice a while ago and decided to come back now that he has full-blown AIDS. This time, he was offered a watchman's job at the hospice. The job carries a salary of Rs. 1,500 per month, for which he plans to open a savings account. Ravi gets his staple medication from Tambaram Hospital and drugs for minor opportunistic infections at the CCC free of cost. "I haven't spent a paisa on treatment until now," he says. The Society for Development Research and Training receives USAID funding for its HIV/AIDS program.

But as Ravi discovered, free treatment at select centers has hidden costs. According to Allada Padmaja, general secretary of the Positive Women Network, "even for opportunistic infections, to get this free of cost treatment, people have to travel and to stay outside their homes for a long time, which means giving up their jobs, leaving their families....Do you know how difficult it is to find a place to stay?" Padmaja wants the cost of any antiretroviral regime—first or second line—slashed. "Any drug combination should cost a maximum of Rs. 500 per month." She thinks this price tag would put HIV treatment within reach of a significant percentage of people.

Dr. Anand agrees. "Let's say if the drugs that now cost Rs. 1,500 come down to Rs. 400 or Rs. 500, I think a common man should be able to afford it." He also wants the trend of always referring people living with HIV to Tambaram Hospital or other specific places to change. "Medical practitioners should be given an orientation on how to handle HIV-positive people....And [there must be] a rule or something that they have to treat HIV-positive people; that they cannot neglect HIV-positive people and they have to treat any opportunistic infections or even start them on an antiretroviral drug regimen. You know, like how tuberculosis is now being treated by general practitioners."

Significant work on raising doctors' awareness has already been done. Under the umbrella of the AIDS Prevention and Control (APAC) project in Tamil Nadu,



Mahabalipuram. She says she sends people who come in with complaints for venereal disease and HIV testing to Victoriya Clinical Laboratory, the only lab in Mahabalipuram that does HIV testing. It charges Rs. 250 for a Retroquic test because it is a private facility and not subsidized. The recommended confirmation test—the costly Western Blot—is not available in Mahabalipuram; Chennai is the nearest place where it is available. The local government hospital, according to ICWO workers, only has an outpatient facility and doctors there do not deal with HIV at all, except to refer such cases to Tambaram Hospital, which is the leading government center of HIV treatment in Tamil Nadu. Tambaram Hospital receives

*Barber Palani talking to a customer about HIV prevention at his shop in Mahabalipuram.*

Centre (CCC) of the Society for Development Research and Training since November 2003. He found out that he was HIV positive when he went to Tambaram Hospital with a tuberculosis complaint five years ago. Ravi is originally from the Madurai region, but moved to Chennai for treatment at Tambaram Hospital. Because he felt too debilitated to do the strenuous work that restaurant cooking demands, he had little money. He lived on Tambaram Hospital premises to cut the cost of rent and did a few cooking stints periodically to earn spending cash. He was told about the Community Care Centre while at



*Children poring over their primers at the CHES-run kindergarten located on the outskirts of Chennai. Two of the children are HIV positive.*

**The good news is the political will shown by governments—with the help of NGOs—to fight HIV/AIDS.**

doctors are trained in providing HIV/AIDS care. “APAC has contracted different institutions such as the Meenakshi Mission Hospital in Madurai, PSG Institute in Coimbatore and Tamil Nadu Voluntary Health Association in Chennai to train different levels of health-care providers,” says Dr. Sanjay Kapur, project management specialist at the USAID health office. The program, funded by USAID through NACO, started in 1996. So far, more than 3,000 doctors have been trained in Tamil Nadu. The APAC program, fully funded by USAID, has done impressive work networking and assisting many other NGOs with interventions, bringing much-needed educational materials and training to professionals and non-professionals alike. Meri Sinnitt,

division chief of HIV and Infectious Diseases at the Health Office of USAID in New Delhi, says USAID’s focus is to support the Government of India in its efforts to control AIDS. She says, “USAID’s goal is to be a development program” that is in a long-term partnership that supports capacity-building and system-strengthening, and that phases out gradually. “The issue is what needs to be done. We want to do whatever needs to be done.”

And there is more good news on the horizon. The Indian government recently announced a plan to provide free antiretroviral treatment by April 2004 to HIV-positive new parents, children under 15, and eventually to all people with full-blown AIDS in the six states with the highest rates of incidence, of which Tamil Nadu is one. “It’s a very good sign that India is showing the political will to commit resources to this problem,” says Sinnitt.

Between USAID, the Centers for Disease Control and Prevention and the National Institutes of Health (NIH), the U.S. government dedicates about \$30 million a year to combat the AIDS pandemic

worldwide. Significant prevention research is being done in India, jointly by the NIH and the Indian Ministry of Health. U.S. Chargé d’affaires in India Robert Blake recently told a Mumbai audience, “These are not just financial commitments; these represent alliances between our two great nations as we partner to share knowledge, technology, research and resources. We are looking for solutions that transcend borders because HIV knows no borders.” Other Americans are weighing in as well. The Bill and Melinda Gates Foundation has pledged \$200 million spread over the next five years in India alone. The William Jefferson Clinton Foundation, Richard Gere and the Elizabeth Glaser Pediatric AIDS Foundation are all committing funds and energy to contain the scourge of AIDS and protect future generations from it. The key, advocates say, is for governments, businesses and social leaders to come forward and support HIV/AIDS education and outreach. Millions of lives depend on it. □

**About the Author:** *Nachammai Raman is a freelance writer based in Chennai.*