Medicine Masala

Though India's 4 million HIVers face everything from vicious discrimination to sky-high prices for retrovirals, some native ancient healing traditions may offer new solutions -- for their epidemic and ours.

July 1, 2000 By Sameera Khan

Sagar Mehta* is not the typical face of HIV in India. For, unlike most other HIV-positive people here, this 52-year-old Bombay-based jeweler can afford care and treatment. In fact, he enjoys the best of both worlds of medicine -- Western (allopathic) as well as *ayurveda*, an ancient Indian holistic system of healing. "I feel better physically and mentally as a result of this integrated therapy," says the bespectacled and balding Mehta, who tested positive two and a half years ago. "The antiretroviral therapy brings down my viral load, while the ayurvedic medicine boosts my immune system and enhances my strength, stamina and weight. Two years ago, I weighed 47 kilograms [105 pounds]. Now, I've stabilized at 59 [130].

Mehta's triple-drug antiretroviral regimen, which he started a year ago, costs him about 20,000 rupees ($455) per month. By comparison, the ayurvedic remedies that he has used for two years -- such as *satavari*, an antidiarrhetic root rich in vitamin A, and powdered *amlaki*, a fruit with high levels of vitamin C -- cost about $14. The income from his jewelry business funds it all.

"I'm lucky my affluence allows me to afford the treatment," says Mehta, who, like most other HIV-positive people *POZ* interviewed for this article, asked that his real name not be used, fearing discrimination. "Otherwise, I would have very little chance to make it through this disease."

Though less than 1 percent of the Indian population has HIV, the National AIDS Control Organization (NACO), which manages India's AIDS program, estimates that without successful intervention, HIV could hit at least 5 percent of the adult population -- more than 37 million people -- by 2005.

Now at an estimated 4 million, India's HIV population is already one of the largest in the world -- each one hoping for a chance like Mehta's to make it through the epidemic alive. Unfortunately, with AIDS, as with everything else in India, the wealthy few seem to be walking away with the most.

India is a massive, agrarian nation of almost a billion people. Though it has a middle class of some 150 million, at least 400 million live in dire poverty. Most Indians have no health benefits and must pay for medical care out of their own pockets. Only a privileged 10 to 15 percent -- those who work

in the government or formal private sector -- are covered by employer benefits. And even that coverage may not extend to AIDS. For example, Mediclaim, a government insurance policy that covers about 2.5 million, excludes AIDS. The government's large network of dispensaries and hospitals, which provide free or subsidized services, remains the primary source of care for most Indians.

Because of limited access to care, poor nutrition and widespread tropical infections, says Subhash K. Hira, M.D., "the natural history of HIV in Bombay shows that the disease progression of HIV to AIDS and death is almost twice as fast here when compared to the United States." Hira has spent the last 20 years chasing HIV across the globe, working for three years at an American university and for eight as director of Zambia's AIDS program. Now he serves as director of Bombay's AIDS Research and Control Center (ARCON), a program sponsored in part by the state of Maharashtra. Hira says PWAs in India face a variety of opportunistic infections (OIs) -- parasites, fungal infections, recurrent bouts of diarrhea -- but that tuberculosis tops the list, accounting for an estimated 70 percent of AIDS deaths.

As with every other Asian nation, India is obsessed more with preventing than with treating the epidemic. It's almost as if by focusing its budget -- much of it loaned and gifted by international funding agencies -- on prevention and information, the government can deny that the disease is already in its backyard.

"Even as the numbers of HIV-positive people grow, few people are showing any interest in taking care of them," says Nagesh Shirgoppikar, M.D., a gynecologist and AIDS specialist who runs an AIDS clinic for slum communities at the Salvation Army center in Bombay. "The government focuses primarily on targeted intervention among commercial sex workers and truckers, and not enough on building care, treatment and support structures for the infected."

Some of this is changing. The first phase (1992 - 1999) of NACO's project to manage AIDS in India focused almost entirely on information campaigns and blood safety. However, the second phase, currently under way -- with planned financing of $328 million over the next five years (including $191 million in World Bank loans) -- is expected to allot about 12 percent of its budget to care and treatment. This includes making available drugs for OIs and providing antiretrovirals for pregnant women at public hospitals across India, plus a new emphasis on home and community-based care.

"We have some good policies in place," says Mandeep Dhaliwal, M.D., coordinator of the Lawyers Collective's HIV/AIDS Unit, which provides legal aid to people with AIDS out of a small office in Bombay. "We now need to operationalize them."

Unfortunately, that's what is proving toughest. Take the example of NACO's commitment to providing OI drugs to all public hospitals. A year after the decision, these drugs have yet to make their way to hospitals in Bombay.

Minni Khetarpal, an official at the Mumbai (Bombay) District AIDS Control Society -- a local arm of NACO -- explains it as a bureaucratic delay. Apparently, NACO, headquartered in New Delhi, had originally planned to provide the drugs directly to hospitals. But a few months ago, NACO asked

district AIDS societies to handle drug procurement themselves. “This change of policy has caused some confusion, but we will soon start supplying OI drugs to public hospitals in Bombay,” Khetarpal says. Small hospitals will get a drug supply from their district AIDS society, while major teaching hospitals will be given a fixed amount to spend on these drugs each year, she says. For 20002001, she says, that amount is a mere $11,000. When a hospital runs out of drugs, requesting more entails another slow, bureaucratic process.

Even these limited resources are sometimes difficult to access. Health care is routinely denied to PWAs or provided in a meager, slapdash fashion. This is so even in public institutions, which are obligated by law to treat HIV-positive people.

INDIA

Total population
960,178,000

Number of people with HIV
UNAIDS 4,148,000
Official gov’t 94,966

Number of people with AIDS
UNAIDS 430,000
Official gov’t 10,857

Number of openly positive NA

Transmission Mode
15% **Homo**
65% **Hetero**
15% **IDU**
5% **Blood products**
Faces a crisis of 37 million infections by 2005. TB rages. Asia’s worst anti-PWA stigma, including ’99 law forbidding HIVers to marry. Sex work and drug use to keep youth infections high; grass-roots prevention flourishes. One in 4 HIVers is a woman.

“The fact is that no one really wants to acknowledge our presence,” says Akshay (who goes only by his first name), president of the Maharashtra Network for Positive People, a new support-cum-lobby group for PWAs in Maharashtra state. “Often doctors and hospitals make excuses, pass the patient around or, having admitted a positive person for inpatient care, quickly discharge them

under any flimsy pretext. A few private doctors who agree to treat positive people charge them double the regular rate. And this is the case in big cities. In smaller towns, it's even worse."

Denial of care is an acute problem, says researcher Shalini Bharat, of the Tata Institute of Social Sciences in Bombay. "Differential treatment, labeling and social distancing are experienced by HIV-positive people soon after the disclosure of their status to hospital staff," says Bharat, whose UNAIDS-sponsored study on AIDS-related discrimination was published last year. "Discrimination in private hospitals takes forms such as denying treatment outright or imposing mandatory HIV testing prior to surgery or child delivery. If you test positive, you're often thrown out. In public hospitals, it means blocking access to facilities like the common toilet and physical isolation in the ward."

Sheena Pinto* knows this only too well. HIV-positive herself, 36-year-old Pinto admitted her husband, Martin*, now in the terminal stages of AIDS, to a public hospital in Bombay in January. "They treat you worse than stray dogs," she says bitterly, describing the dirty mattress presented to her husband on his arrival in the ward, the placement of his bed on a veranda where the cold wind blew in, and the general disdain that marked the conduct of the nursing staff.

Pinto holds a full-time job in addition to caring for her two young, HIV-negative children and her ill husband; the day she spoke with *POZ*, she seemed exhausted. "The more I voiced my criticism of the way they treated Martin, the more I was shunned by the medical staff," Pinto says. "It's almost as if they wanted to teach me a lesson."

According to Dhaliwal, of the Lawyers Collective, "It's essential that we realize why health workers deny care. Usually, it's on account of ignorance and fear of occupational exposure to HIV. Most public hospitals do not have access to gloves, masks or post-exposure prophylaxis [PEP]." Last year, the Lawyers Collective filed a legal petition in India's highest court, asking that the court recognize denial of care to PWAs as a violation of the Indian Constitution. "The petition also says that it is obligatory for the state to provide a safe working environment -- universal precautions and access to PEP -- for health care workers," Dhaliwal says. "Thus, it tries to balance the rights of patients and the rights of health care workers. Only by respecting the rights of both can the quality of care improve."

Antiretroviral therapy is the exception rather than the norm in India, and this remains the central concern for PWAs here. It's almost unheard of in public hospitals. "It seems audacious of us to ask for antiretroviral therapy to be made available in public hospitals when resource crunches make it difficult to afford even adequate treatments for opportunistic infections -- such as more antibiotics, antifungals, medicines for drug-resistant TB," says H.R. Jerajani, M.D., head of the dermatology department at Sion Hospital, one of Bombay's largest public hospitals. Every month, her outpatient department sees 4,000 people, about 1 percent of whom are HIV-positive. "Instead, we focus our attention on prompt treatment of opportunistic infections and making nutritional supplements available to our HIV patients," she says.

In private health care settings, HAART is available but so expensive that it is mostly out of reach. A

three-drug regimen costs $340 to $455 a month -- more than a typical professional salary here, and far more than the average per capita income of $315 per year. India has a thriving pharmaceutical industry, one of the most advanced in the developing world, and is one of only four countries (Thailand, Brazil and Cuba are the others) to have begun to produce generic versions of antiretrovirals locally. But many drugs, such as protease inhibitors, still have to be imported from abroad. With import duties as high as 60 percent, a one-month supply of a single protease inhibitor can cost $400. Thus, according to data gathered by D.G. Saple, M.D., of GT Hospital, a public hospital in Bombay, triple-drug therapy was, until recently, being used by only .04 percent of the HIV population. Saple estimates that with Indian pharmaceuticals such as Cipla now producing four antiretrovirals at around one-half the import price -- AZT, 3TC, d4T and nevirapine -- that number may rise a bit, to as much as 2 percent.

“In the United States and the developed world, treatment decisions are based on clinical factors such as CD4 count and viral load,” says Sanjay Pujari, M.D., director of the HIV project at Ruby Hall Clinic, a private hospital in Pune. “But in India, where patients bear the total cost of therapy, that decision is made on the basis of patient affordability and chances of long-term compliance. Sometimes you’ll keep aside the expensive protease inhibitor, or use it only when a patient gets more sick.”

Thus, most people on antiretroviral therapy are well-to-do professionals or those whose health care is covered by their employers. Despite the travails of his current hospitalization, Martin Pinto considers himself lucky: The government-owned company he works for has reimbursed his expenses for antiretroviral therapy for the last three years. His wife, Sheena, is far less fortunate: Her medical expenses are covered by neither her husband’s employer nor her own, so she receives no treatment at all. “If a family can afford HAART, then it usually can afford it for one member only. Most often, it’s the male head who gets preference,” Pujari says. He has 78 patients on triple-drug therapy, only seven of whom are women (though, according to UNAIDS, women make up a quarter of India’s epidemic).

With mainstream allopathic medicine proving virtually impossible to access for PWAs like Sheena, an increasing number of people with HIV are turning to alternative therapies -- ranging from ayurveda and yoga to *siddha* and homeopathy. Ayurveda, yoga and siddha are 5,000-year-old Indian medical systems -- extremely popular, but starved for institutional acceptance and research rupees. Even though these healers receive comprehensive training -- ayurveda is taught at specialized medical colleges where it takes eight and a half years to become a licensed ayurvedic doctor -- their traditional treatments are not routinely dispensed in government hospitals or clinics.

AIDS is beginning to challenge this hierarchy. Several alternative practitioners are convinced that these therapies, especially ayurveda, could provide major insights into a disease that we still have much to learn about (see “Ayurveda Unveiled”). For people with AIDS in India, the therapies are already a boon because of their cheaper cost -- as little as $7 to $13 per month -- and minimal side effects.

But do they work for AIDS?

“They certainly do not cure AIDS, but they often do lead to a better quality of life for HIV-positive people,” says Reeta Sonawat, a professor of human development at SNDT University in Bombay. Her department’s 1999 study that looked at the effects of yoga on 12 terminally ill AIDS patients, showed that twice-weekly yoga classes over four months improved sleep patterns and stabilized patients’ blood pressure. “The yoga seemed to give them both physical and psychological strength to cope,” Sonawat says.

Harish Singh, an ayurveda M.D., runs a twice-weekly ayurvedic HIV clinic at Bombay’s J.J. Hospital, where he has designed a detailed program for HIV care. "If the patient is positive but at the asymptomatic stage of the disease, we offer the *rasayana* group of ayurvedic remedies, which help maintain health, boost immunity and prevent infectious episodes,“ says Singh, the former director of a respected ayurvedic medical college. ”If the patient is suffering from HIV-related complications such as fever, diarrhea or weight loss, then we treat those symptoms with specific herbal drugs and also try to increase general immunity."

Singh, who has treated HIV-positive people with a repertoire of 20 ayurvedic remedies for six years, observes these benefits: an average weight gain of 3 to 4 kilograms (7 to 9 pounds), a reduction in recurrent infectious episodes, an increase in appetite and energy, and an overall sense of well-being. “After three months of ayurvedic treatment, patients usually report an increase of 20 to 30 percent in their CD4s,” he says. “However, in only a few patients has the viral load gone down.”

He says his patients on HAART also respond well to ayurveda. Besides boosting their immunity, the ayurvedic preparations allow for better absorption of antiretrovirals.

But with ayurveda, it’s not just medication that makes a difference; it’s also adherence to the basic principles of ayurvedic care. “Ayurvedic treatment should always be accompanied by lifestyle changes, attempts at stress reduction and regular sleep, as well as conforming to dietary guidelines,” says Prakash Bora, M.D., a Bombay-based allopathic doctor and trained ayurveda expert.

“The dietary rules are crucial,” Singh concurs. “About 30 to 40 percent of my patients follow the correct diet, and this makes them respond better to the ayurvedic medicines.” Singh, who hands out a dietary pamphlet to all his HIV patients at J.J. Hospital, recommends drinking boiled or filtered water; eating six to eight dates daily to increase body mass; drinking coconut water or lemon juice daily for instant energy and as an antidiarrheal; regular intake of peanuts, palm sugar, fruits such as pomegranate (for iron content) and gooseberry (for vitamin C), protein-rich lentils, pumpkins and vegetable soups made of bottle gourd, carrot or cabbage; and taking a few spoonfuls of clarified butter daily.

Both ayurvedic experts agree that in the terminal stages of AIDS, ayurveda is not as useful.

At the Government Hospital of Thoracic Medicine in Chennai (formerly Madras), the efficacy of siddha medicine is being tested on several HIV-positive people. Siddha is an ancient medical system practiced among the Tamil-speaking people of southern India. Like the more popular

ayurveda, siddha views disease as a product of imbalanced life forces, and its diagnostic tools (examination of the mouth, tongue, eyes, skin, urine and feces) are similar. Its remedies are somewhat different, though, with a greater emphasis on the use of minerals and metals, including pearls, coral and gold, in addition to herbs.

“Currently, our institute has almost 600 HIV-positive people undergoing inpatient care using siddha,” says C.N. Deivanayagam, M.D., superintendent of the Tambaran Sanatorium, which houses the hospital. Most of his patients also have tuberculosis, and many use a combination of siddha medications and OI drugs.

According to Deivanayagam, the first 72 patients tested after usage of siddha medication (with anti-TB drugs) in 1998 showed a significant increase in their CD4 counts that was maintained for more than four months. “In our current batch under study, 33 patients have shown good reduction in viral load and the majority have shown increases in CD4 and CD8 counts,” he says. “All the patients have gained weight.”

Despite side effects including abdominal discomfort, loss of appetite and transient rashes, “no one has been forced to stop the combination of siddha drugs due to side effects,” he says.

Others warn of more serious side effects from siddha and other alternative therapies if they are not taken under expert guidance; they say that assessing toxicity with each patient is critical with medications that utilize dangerous metals such as mercury or sulfur (though they’ve been processed to be safe). Each Indian state has an ayurvedic board that registers licensed practitioners; Bora, the ayurvedic expert in Bombay, encourages patients to check whether their doctor is legitimate. “Beware of quacks who say ayurveda or any of these alternative systems can ’cure’ AIDS,” he says. “Ayurveda will improve the quality of your life is all that I guarantee, no more.”

Many allopathic doctors remain extremely skeptical of alternative therapies. “I don’t recommend them because you can’t be too sure that the better feeling being reported by the patient is not just a placebo effect,” says Pujari, the director of Ruby Hall Clinic. “Patients are known to report feeling better just because they are getting some treatment.”

Ashok Rau, an executive at the Freedom Foundation in Bangalore, which runs an HIV care facility, says that until there’s proven clinical benefit, suggesting alternative treatments “is just using patients with HIV as experimental guinea pigs.”

Scientific proof, at least for ayurveda, may soon arrive. In a state-of-the-art laboratory just outside of Bombay, researchers sponsored by ARCON and the Mahatma Gandhi Mission’s Medical College are using modern lab techniques to assess the validity of ayurveda as an AIDS treatment option.

For the last four years, we’ve been testing the effects of 12 pure ayurvedic herbal and plant-based extracts on HIV-infected human cells,“ says ARCON director Hira, who coordinates the study, along with doctors Bora and Singh. ”It’s been an arduous process of integrating two systems of medicine and subjecting an ancient science to the rigors of modern scientific investigation."

“Experiments have been replicated several times over and not a single one has contradicted that result,” Hira says. Another 520 experiments are now planned to confirm their findings. “We’ve found that fine-tuning the experiments is crucial because only at a certain level of dilution do the ayurvedic extracts show immune-modulating power. In fact, in certain concentrations, the same extract worked as an immune suppressor.”

The researchers hope to announce their results by year’s end. “This is exciting. It could mean that we may have a class of drugs made from ayurvedic extracts that may minimize the side effects of allopathic antiretroviral therapy and offer a therapeutic alternative for as little as a few hundred rupees,” Hira says. “Ayurveda holds a lot of hope -- there are 58,000 preparations in ayurveda, and we’ve just scratched the surface.”

Meanwhile, outside the labs, other experiments in care are under way. The one-stop HIV service unit at Bangalore’s Freedom Foundation was created with the participation of HIV-positive people. From testing, treatment and counseling to short- and long-stay facilities and a hospice for the terminally ill, Freedom Forum has it all, including a mini-ICU, a complete medical unit and a legal services team.

“There was discrimination within mainstream health care, so we said, ’Why not create an alternative care structure for HIV-positive people?’” says Rau, the Freedom Foundation executive. The foundation is now replicating this model in Hyderabad and Bellary, and recently began an initiative to obtain antiretrovirals for poorer HIV patients. In the last year, the foundation arranged for individual philanthropists to sponsor triple-drug therapy for seven HIV patients.

Meanwhile, ACT-PACE, a Christian NGO in Bombay, is building a core group of home-based care volunteers. Each regularly visits and counsels an HIV patient in their area, and facilitates medical aid. “As more and more of our HIV-infected population becomes seriously ill, our existing health care systems will not be able to cope with the sheer numbers of patients,” says Shirgoppikar, of the Salvation Army clinic in Bombay. “That’s when we’ll need to fall back on alternatives such as home-based care and community support.”

It’s taken a disease of the magnitude of AIDS to shake up Indian attitudes toward alternative treatment and care, As the efficacy of traditional systems such as ayurveda is validated by modern clinical experiments, even the remaining skeptics may quiet down. Certainly Sagar Mehta is confident. “Through this entire ordeal of dealing with HIV, ayurveda has been the most marvelous discovery for me,” he says. “For so little money, it provides a good deal of stamina and a great sense of well-being.” Perhaps this is an experience that Mehta will soon be able to share with people with AIDS around the world.

* *Names marked by asterisks have been changed.*

ARURVEDA UNVEILED

Ayurveda is a holistic system of healing that evolved among the sages of India some 5,000 years ago. The word ayurveda is derived from two Sanskrit words, ayur, meaning “life,” and veda,

meaning “knowledge.” The method is built on a distinct theory of disease causation, with a comprehensive system of diagnosis and therapy.

Ayurveda describes three universal energies that regulate all natural processes on both the macro- and microcosmic levels. That is, the same energies that control galaxies and star systems are operating on the human body. These forces, which govern all of our life processes, are known as the three doshas, or simply the tridosha.

The three are vata (wind), which controls movement and the nervous system; pitta (sun), which is hot and rules the digestive processes and metabolism; and kapha (moon), which has a cooling effect and governs the body’s organs, as well as cell growth and tissue development.

When in balance, the doshas are life-supporting, but when out of whack, they are the agents of disease, including AIDS. Ayurveda focuses on maintaining a balance of these life energies, rather than treating individual symptoms.

Thus, to diagnose an imbalance, the ayurvedic vaid (doctor) not only responds to the physical complaint but also examines a patient’s history and daily habits, paying special attention to diet, the tongue, breathing, sleeping patterns and emotional and mental states.

Typically, vaids treat ailments with herbal remedies—made using indigenous plants, according to traditional formulas—or mineral-based remedies, along with various forms of yogic cleansing, fasting and special diets. Vaids also advise patients on exercise, patterns of breathing, relaxation and meditation, and recommend practical interventions such as massage and enemas.

Most vaids consider allopathic medicine to be the standard remedy for some AIDS-related infections, such as tuberculosis. Others, such as diarrhea, vaids treat using ayurveda: First, a vaid would diagnose whether the diarrhea is of vata, pitta or kapha origin. Then he or she would prescribe a group of medicines to restore balance in the body. If the diarrhea were of vata origin, for example, that remedy would consist of powdered bel (Aegle marmelos) and a decoction (concentrate) of nut grass (Cyprus rotundus).

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