Motor-biking through rural India on an HIV mission

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At the break of dawn, the nightly sounds of croaking frog choirs resonating from the rice fields fade into those of the awakening communities: women preparing breakfast or sweeping the porch of their hut, the vendor on his bicycle chanting ‘uppu’ (salt), the background sounds of Tamil movie songs and honking cars. As we're cruising on a motorbike along the country roads and passing small villages, we see people leaving the comfort of their simple huts, farmers leaving to work in the field, women in beautiful saris, with flower garlands in their hair, boys and girls in clean uniforms carrying their school-bag, and walking bare-footed or in sandals through the muddy tracks caused by last night’s rain, smiling with surprise to see a ‘white man’ in this area. Despite the material poverty and harsh living conditions here, most people manage the dedication to look surprisingly clean and well-dressed. The birds and butterflies, the many farm animals wandering around for some food – oh, it’s not hard to fall in love with this place. Yet, at the same time, I realize that these people are largely unaware that a rather invisible enemy, HIV, has already started to erode these colorful communities, and is slowly combing out villagers.

In remote rural areas such as here (Andimadam, in Perambalur district, Tamil Nadu, India), the HIV epidemic thrives on ignorance and indifference, fuelled by socio-economic conditions of poverty, high illiteracy, poor basic health care infrastructure, and cultural traditions that consider sexual topics as taboo. Due to their lower status, women are especially vulnerable to infection, violence, stigma and rejection. Add on top of this a few more ingredients (high-mobility populations in a drought-prone area, major trucking routes, sex work that is dispersed and casual unlike that in many large cities, and quacks who spread false information about HIV/AIDS), and it is obvious why rural Perambalur district has, relative to its population (~1.2 million people), a disproportionately high incidence of AIDS cases. Despite being the fifth smallest district in Tamil Nadu and having very limited voluntary counselling and testing services, Perambalur district ranked fourteenth in cumulative reported AIDS cases among the 29 state districts (Tamil Nadu State AIDS Control Society, report 2000).

A survey performed by a network of nongovernmental organizations (NGOs) led by Rural Education and Action Development (READ) from November 2001 until March 2002 revealed that the level of HIV awareness in this district was dangerously low. Of 10 000 respondents (from different occupational groups), overall only 41% answered they had heard about HIV/AIDS, and only 63% of these ‘knowing respondents’ (i.e., 26% of the total population) were aware about HIV transmission through ‘unsafe sex’, while 68–74% of ‘knowing respondents’ wrongly identified touch and sharing the same house or clothing as transmission routes. Statistics only become meaningful to me with a face on them. One evening I had met in private with a young HIV-infected school teacher; her husband, who worked in north-India, and with whom she had slept only four times, had died of AIDS, and her ‘doctor’ had advised her to starve out the virus by fasting. While talking to us, her infant daughter (whose HIV test was fortunately negative) was sleeping on her lap... but the mother was in fear of infecting her daughter by hugging or eating from the same plate, and in her motherly love, she was seriously considering leaving the child, her main beacon of strength and purpose for living, with her parents in a different state...

It is no surprise that such low awareness is a breeding ground for stigma, and that upon talking to villagers anecdotal stories of rejection, abandonment or suicide emerged readily. The few HIV awareness programs that had been done in this area in previous years clearly suffered from several problems: a limited target audience, and the lack of open dialogue with practical
information in an understandable vocabulary. HIV prevention programs are unlikely to succeed unless integrated into a broader movement that attacks the roots, by improving socio-economic development, empowering these underprivileged communities, and creating an environment conducive to proper communication, behavioural change and risk reduction.

The NGO READ, since its birth in 1994, had been cementing such foundation in this area: schools and skill-training programs for children and youth; the formation of youth groups and women self-help groups. The women self-help groups, with their savings, credit and micro-enterprise activities, have had a tremendous impact: the improved economic status of

Fig. 1. To draw the attention of the villagers (a), the cultural team of READ combines song, traditional dance (b) and sketches (c) in their street theater performance. A story is told in which several drunk men go to the house of a sleeping prostitute (d). Following unsafe sex, the HIV virus destroys the white blood cells that protect our body, eventually leading to opportunistic infections (e); the social worker is notified and comes to help the affected family (f,g). The women self-help groups participated in an HIV awareness rally on World AIDS Day 2003.
these women has helped to uplift their social status and gain respect from their spouses, families and communities. It was clear to me that the good community rapport of these existing socio-economic programs could be used as a foundation to incorporate HIV awareness programs.

I remember asking myself back in 2001 “why can’t the skilled social workers just go out into the villages to talk about HIV as part of their ongoing programs?” However, these field workers, being villagers themselves, were initially hesitant to discuss sexuality-related issues. So some extra push was needed, and I understood that the solution wasn’t going to fall from the sky, but that the man in the mirror had to start. So at a first workshop for READ’s field workers, I had to overcome my own inhibitions and shyness (from having been raised in a strict Catholic environment in Europe long time ago). So with Mr. Selvam (CEO of READ) as translator, we discussed specific information on HIV and AIDS, gave a condom demonstration, and then passed the wooden model and extra condoms around the table, to give hands-on experience to the social workers, whose giggles and sweat drops betrayed some nervousness too. Although our program was short and was limited by my inability to speak Tamil, we achieved a first step: we somehow punctured the silence.

Over the course of the following year, the field workers received more training in their native language on issues of gender and sexuality, sexual and reproductive health, HIV and AIDS basics, communication skills, counselling, and support. These trainings instilled confidence among the field workers to address these issues with rural people. Field workers are now using locally relevant ways of education to spread correct HIV/AIDS awareness and promote better behaviour: folk songs, street theatre, HIV rallies, brochures, stickers, and one-to-one communication. Despite very limited financial resources, field workers have started to provide assistance to individuals and families affected by HIV, including counselling, referrals, a positive support group and orphan programs.

Late one evening, as I sit on the backseat of his motorbike, Mr. Selvam and I are returning to our village along small, dark country roads. I feel tired but satisfied after having spent the whole day in various corners of the district. In several high schools, we had patiently answered many questions written anonymously by students eager to clarify the many doubts about sex and HIV that occupy their minds, but for which they had nobody to ask (“you don’t get HIV from mosquitoes, or from swimming in the same lake as a menstruating woman”, “a wet dream doesn’t mean you have HIV”, “you don’t get weak or dumb from masturbating”). Teachers were also thankful for understanding HIV beyond the rather vague terms of their school syllabus (“HIV is transmitted through immoral sex”). After the school programs, we had travelled to a remote village, for a street theatre performance of READ’s cultural team, and witnessed how at the end of the program, community leaders summarized the main messages (Fig. 1). Being part of this movement provides me with some of the happiest moments in my life, and I feel grateful for the lessons I am learning here about the true essence of life.

As the motorbike continues to cruise through many interspersed small villages, the smell of food emerging from the huts only boosts my hunger. Overlooking the dark fields, the countless stars in the sky remind me that despite the difference we’re making there is no reason for complacency. This is, after all, only a small rural area in such a large country, and in so many villages, in India and other countries, little or nothing is being done about HIV. This is not an issue of “it’s too big, we can’t do it”, because if we, humans, succeed quite well in using brain technology to link rather remote corners in the world with mobile phones and other gadgets, why does basic knowledge, solidarity and compassion fail to do so?

Ignorance and indifference exist at so many levels. It takes relatively few financial resources to spark and maintain low-cost efforts to spread HIV awareness in rural areas, and potentially avert a major HIV explosion there. Yet, with rare exceptions, most national and international agencies don’t give enough attention to such rural areas. Most HIV scientists, instead of also being HIV advocates and educators, confine themselves to unravel the mysteries of HIV within the sterile comfort of their laboratory or office cubicle; but afraid (or ‘too busy’) to set foot in a developing country, how much do they really know the true face of HIV?

Finally, the motorbike pulls up into the guesthouse. My frustration subsides a bit after a delicious Indian meal (chapattis with chutney), prepared by the cook, a dedicated grandmother. With my energy revitalized, I realize that culture, traditions, lack of training, can be obstacles but are too often used as excuses to defer responsibility to others and to justify our own relative silence, complacency, ignorance and indifference. Barriers can be broken with determination and dedication, but the spark for change has to come from within us. The people here show this is possible...

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