Photo: Partners In Health/Joia Mukherjee, 2003

A community health worker delivering daily ARVs to a patient in rural Haiti

The impact of comprehensive HIV/AIDS care on stigma and testing

Learnings and experiences from Haiti

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Haiti is by far the most impoverished country in Latin America and, not coincidentally, the region's most HIV-affected country, with an adult prevalence of around 6%. Since 1988, Zanmi Lasante – Partners In Health (PIH)'s sister organization in Haiti – has provided voluntary counselling and testing (VCT) for HIV free of charge to the population of the Central Plateau. Since 1998, in the framework of the HIV Equity Initiative, PIH has purchased antiretroviral drugs to treat patients living with HIV/AIDS, also free of charge. Preliminary data from research in rural Haiti suggest that the introduction of quality HIV care can lead to a rapid reduction in stigma, resulting in increased uptake of VCT.

Supported by an already existing tuberculosis-control infrastructure, in 2001 we provided directly observed therapy (DOT) with antiretroviral therapy (ART) to about 60 patients with advanced HIV in and around Cange, a rural squatter settlement that hosts the Clinique Bon Sauveur, PIH's largest hospital in Haiti. By the end of 2005, our clinical staff will be following 7500 patients, of which 1800 are receiving ART. A group of over 900 community health workers – supervised by the clinical team – make daily visits to patients at their homes to provide both the daily doses of ART and a range of associated support services. Of the HIV patients currently under treatment, the majority have achieved undetectable viral loads and they are able to live normal, active lives despite their chronic disease.

To illustrate how AIDS-related stigma is generated, we explored the history of one of our patients in rural Haiti:

In 2001, Samuel Morin was dying of AIDS. Until then, Samuel, 40 years old, had farmed a small plot of land and had a tiny shop – which sold everything from matches to soap – in a town in central Haiti. He considered himself poor but was able to send his four children to school. Samuel was an active member of his church and sometimes used his meagre earnings to help neighbouring families in crisis, providing food if their crops failed, or helping with school fees. He also supported his sister and her three children after his brother-in-law died of AIDS.

When Samuel became ill in the mid-1990s, his wife had to assume all responsibility for the farming, although he could still sit and mind the shop. But after a while, Samuel recalled: "the disease transformed me. I looked like a stick." He continued to lose weight and then developed visible skin infections and thrush; he had difficulty swallowing food and began to cough. It was at this time that he felt that people stopped coming to his shop. His children had to leave school because they were needed to help in the fields and because Samuel and his wife could no longer afford the school fees. Eventually, the shop failed completely. His wife left him and returned to her parents' home in Port-au-Prince, Haiti's capital city.

In July 2001, when Samuel weighed only 80 pounds, he decided to use his last 10 Haitian dollars to pay for a truck ride to the Clinique Bon Sauveur in Cange. Since then, Samuel has been receiving free ART under the supervision of a community health

For additional information on the programme in Haiti:

- A. Castro & P. Farmer, Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 2005, 95 (1), p. 53-59
- P. Farmer, F. Léandre, J.S. Mukherjee, et al., Community-based approaches to HIV treatment in resource-poor settings. *Lancet*, 2001, 358 (9279), p. 404-409: www.thelancet.com (free pdf, search on author name)
- *The PIH guide to the community-based treatment of HIV in resource-poor settings*. Partners In Health, 2004 (261 p.): www.pih.org/library/aids/PIH_HIV_Handbook_Bangkok_edition.pdf

worker. After three years of therapy, Samuel has not missed a dose; he has responded clinically, and has gained 30 pounds. He has normal skin colour, feels 'great,' and has an undetectable viral load.

Moreover, his family has returned to him, his children are back in school, and he has reopened his shop. He also volunteers with the local Partners In Health team in HIV-prevention efforts. Of his recovery, Samuel said: "I was a walking skeleton before I began therapy. I was afraid to go out of my house and no one would buy things from my shop. But now I am fine again. My wife has returned to me and now my children are not ashamed to be seen with me. I can work again."

Lessons learned

- The introduction of antiretrovirals has had a positive impact on the demand for VCT.
- Improving clinical services can raise the quality of prevention efforts, boost staff morale, and reduce AIDS-related stigma.
- Social services must be part of a comprehensive project, as must attention to tuberculosis and primary health care needs.

In reflecting on Samuel's experience, it is possible to argue that AIDS treatment can start a 'virtuous social cycle.' Access to comprehensive AIDS care saved Samuel's life; returning to work and securing school fees for his children has allowed him to surmount some of the miserable conditions faced by the majority of Haitians. There are the links mentioned by Samuel: proper HIV/AIDS care can transform a disfiguring and consumptive disease into a manageable condition that is invisible to others.

Integrating people living with HIV into the workforce of a community health programme – at least 5% of our current staff are persons living with HIV – permits them to earn steady wages and send their children to school. Further, the demonstrably favourable response of Samuel and others to antiretroviral treatment has sparked interest in VCT. Together, these processes have contributed to lessening the impact of the AIDS stigma.

Impact on VCT

The Haiti project already demonstrates that individuals who can access effective care are the most likely to get an HIV test. The introduction of antiretrovirals has had a positive impact on the demand for VCT. Since 1998, when we introduced the first free and comprehensive AIDS programme in rural Haiti at the Clinique Bon Sauveur, demand for such services has grown exponentially.

Samuel Morin was diagnosed and treated initially in Cange. But looking at his hometown of Thomonde, where community-based AIDS care was introduced only in 2003, is instructive. Our preliminary data suggest that VCT may increase rapidly when comprehensive prevention and care are introduced. In Thomonde, VCT sessions per month have skyrocketed from 0 to an average of 870 in the second quarter and up to 1450 in the fourth quarter; at the Clinique Bon Sauveur, the number of VCT sessions are stable, averaging 2120 per month.

Comprehensive services

As so many of our patients have noted, there is no motivation for learning one's serostatus when there is no possibility of being treated for opportunistic infections or of access to prevention of mother-to-child transmission during pregnancy. Much less so if there is no possibility of being treated with antiretrovirals when needed. Can we blame these public health failures on stigma alone? The Haiti experience suggests that improving clinical services can raise the quality of prevention efforts, boost staff morale, and reduce AIDS-related stigma. Our team's experience suggests that the full participation of community health workers will be required if HIV prevention and care are to reach the poorest and most vulnerable communities. Social services must also be part of a comprehensive project, as must attention to tuberculosis and primary health care needs.

The transformation of AIDS from an inevitably fatal disease to a chronic and manageable one has decreased stigma dramatically in Haiti, as Samuel's story shows. Our own experience in Haiti suggests that it is clear that the impact of a 'low-tech' HIV prevention-and-care project could be measured without importing a new and costly evaluation infrastructure. The most daunting challenges for which scale-up projects must be prepared are those having to do with the poverty of patients. ■

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