



Accessible to All

With the recent rollout of access to HAART around the world, more and more attention is being paid to treatment literacy—the whys and hows of each medication. Because if PHAs don't understand it, they won't take it.

Ann Silversides offers a global survey.

IN THE GAME JENGA, players take turns removing one piece at a time from a 28-cm-high tower of stacked wooden blocks. Then, each piece must be carefully placed back on the top of the tower before the next player takes a turn. The loser is the unlucky one who pulls out the piece that makes the tower—which has become taller and more precarious—finally collapse.

Among Chinese people with an average grade 4 education, playing Jenga is used to help illustrate the importance of sticking to a treatment regimen for HIV/AIDS: adherence to treatment can make a strong building; non-adherence can make it collapse.

Having fun is an important element in HIV/AIDS treatment literacy initiatives, Jennifer Ho, program manager for TREAT Asia, told participants at the XVI International AIDS Conference in Toronto last August. TREAT Asia began developing a



range of education materials and activities in 2004 when faced with the fact that a high proportion of people who started taking highly active antiretroviral therapy (HAART) did not stick with it. Ho told a conference session that up to 40 percent of Chinese patients who started taking HAART in a free program dropped out within the first three months of treatment. Study findings in China are difficult to assess—but clearly, the availability of HAART is not enough to ensure that it is used appropriately.

The organization collaborated with people living with HIV/AIDS (PHAs) and healthcare providers to create tools, such as a flip chart of culturally familiar illustrations, to help explain in simple images how HAART works, why it is important, what kind of side effects can be expected and when to seek medical help. For example, HAART's usefulness is illustrated by a dying tree that is restored to health; to illustrate potential side effects, a doctor examines a man's rash; and a trampled garden fence is rebuilt to show how the immune system can be improved.

Rolling Out HAART

With the recent rollout of access to HAART around much of the world, and the stated goal of near-universal access to treatment by 2010, policy makers are becoming aware of the urgent need for treatment literacy or, as it is sometimes referred to, treatment preparedness. The United Nations Program UNAIDS acknowledged the vital importance of this area in its June 2006 document *HIV/AIDS Treatment Education*. Providing HAART and related monitoring and laboratory tests by clinical staff is not enough, it notes. Achieving better health will also require "community, institutional and individual preparation and education."

It seems like a rather obvious observation, but in the push to get lifesaving drugs to people it is one that can easily be overlooked. "Most people are illiterate as far as drugs are concerned, and it's not enough for us to tell them 'you have a right to treatment,'" Rukia Cornelius, national manager at South Africa's Treatment Action Campaign (TAC), has said. "We have to explain why, and what's available and how it works." Cornelius made that comment a few years ago when she was director of TAC's newly minted Resource Project. Since then, the Resource Project has developed a wide range of treatment literacy tools in several languages, including colourful posters and a series of illustrated booklets aimed at different literacy levels.

Interestingly, the push to find creative approaches to

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treatment education in the developing world has parallels in North America, where the challenge is to find ways to communicate effectively as HIV moves into new populations that are typically struggling with issues such as poverty, stigma and addiction and have their own sets of cultural values and norms. CATIE, for example, has been collaborating with several organizations that serve marginalized positive populations and working to develop culturally appropriate approaches to sharing treatment

information. One such population is Aboriginal, a group whose HIV rate is now three times that of the overall Canadian population. To share information, AIDS service organizations in Canada are working with Aboriginal traditions, such as healing circles, talking sticks and the Medicine Wheel, which sums up the cycles of life. An HIV/AIDS Medicine Wheel adapts the traditional wheel to the physical and emotional stages of HIV (See "Traditional Healing," page 9.)

Unequal Access

Although Canada has a well-funded and socialized medical care system that is supposed to provide equal access to care, it is a sad fact that many Aboriginal people are not diagnosed with HIV until they develop an opportunistic infection. "We are hearing of cases of cytomegalovirus, something we thought had pretty much disappeared," says CATIE's Michael Bailey, who works with a variety of AIDS service organizations, including Aboriginal ones, across Canada.

In developing countries with under-resourced and overburdened healthcare systems, healthcare professionals don't have the time to take on the entire task of informing and educating about HAART: how it works, the importance of adherence, side effects and what to do about them. Clinic doctors in South Africa, for instance, typically see about 60 HIV-positive people each day. "It is all push-push, go-go," Prudence Mabele, director of the Positive Women's Network, told the conference. "So what happens outside the clinic is important."

Typically, peer counsellors in South Africa do not call a meeting to discuss HIV or medication. "If you say, let's talk about HAART, they think you are crazy, because this is not their first concern," says Mabele, who was diagnosed with HIV in the 1990s and began treatment a few years ago. Instead, the "entry point" is usually participating in meetings with women around issues such as water and food supply. When the discussion does turn to HAART, "we make

ourselves examples and we tell the truth. If there is a problem with a medication, we talk about it. And we have to be creative.”

Because of stigma, her groups sometimes rename drugs—nevirapine, for example, becomes “Nelly” so it can be talked about in public. And women, who typically experience discrimination because of their HIV status, share ideas such as hiding their daily medication in bananas. Of course, because stigma and discrimination discourage people from accessing services, reducing these kinds of attitudes is another important goal of treatment literacy.

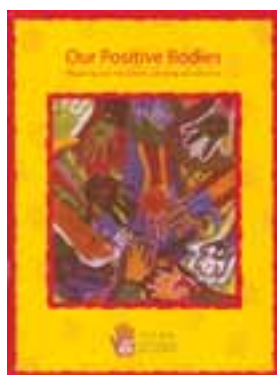
Mabele’s network also engages with traditional healers, as 80 percent of South Africans rely on them. “So why not explore African medicine?” she asks, and think about ways that the use of herbs can be incorporated with HAART. On the other hand, when peer counsellors go into homes where people believe that a bottle of olive oil and a lemon will treat AIDS, “we have to explain to them that that won’t work.”

Women’s Lit

SAFAIDS, the Southern Africa HIV/AIDS Information Dissemination Service, has developed a women’s treatment literacy toolkit—packaged in a colourful, multi-pocketed cloth bag—that peer counsellors use to stimulate discussion and share information. The kit contains items for a range of literacy levels, including picture cards, information sheets, an audiotape and a “gender clock” so women can outline how they spend their time and where medication fits into their lives.

“Part of our role is to keep things positive, for example, talking about staying alive for the sake of the children,” program manager Rouzeh Eghtessadi told conference participants. But a typical session using the toolkit also encourages women to collectively list and discuss “hot topics” such as sexual coercion and abuse, the lack of libido experienced by many on HAART and the pressing issue of women’s lack of inheritance rights. “A husband dies and you’re asked to leave the family home and you lose your own access to treatment,” Eghtessadi explains.

Body mapping, an experiential form of art and narrative therapy involving full-size self-portraits, is another approach to exploring issues around HIV/AIDS and treatment, as well as women’s overall health and well-being. This use of body mapping, pioneered in African countries, was showcased at the conference by two different groups—TICAH (The Trust for Indigenous Culture and



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Health), based in Kenya, and REPSI (the Regional Psychosocial Support Initiative), which provides support to organizations in 13 African countries.

“The hospital pretends they know all about us,” Amina, an HIV-positive woman from Kenya, told a TICAH session as she stood next to a colourful life-size self-portrait of her entire body. But Amina prefers to rely on her own approach to guarding her health, and the painting outlines the way that she is taking care of herself and managing her HIV with good nutrition and herbal remedies. “My children give me strength, hope, reason to live,” reads the caption under a picture of three children, drawn just underneath one of her hands. Art, she says, “opens your heart. It brings up fears and hopes and aspirations. . . . To disclose this way takes the weight out.”

Drawing on Hope

Those profound benefits have been documented by Jonathan Morgan, REPSI’s knowledge network manager, in the book *Long Life*, which showcases the body maps and accompanying narratives of several South African women. One of those women, a young widow named Noloyiso, has drawn herself lying on her side. The dots on her body represent rashes she’s had, and one lung is black because of her diagnosis of a TB co-infection. “HIV, it’s like one word but lots of sickness,” she writes in a narrative accompanying her painting. “I represent HIV like a storm. If a storm comes there is heavy rain, thunder, storms, lightning and wind. I represent HIV like that. I did have rash, thrush, falling of hair, coughing and headaches.”

CATIE has recently entered into a partnership with REPSI with the goal of marrying treatment information expertise with the psycho-social body mapping approach. (Visit www.catie.ca for more on body mapping.) The hope is that such a partnership will help address, in community-based support settings, some of women’s social, emotional, health and also HIV/AIDS treatment information needs. As part of that collaboration, two South African women with extensive body mapping experience will be coming to Canada to conduct workshops with HIV-positive women. It is, after all, a global pandemic, and one that calls for sharing on many levels. +

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