The face of an epidemic

When Sylvia Khuzwayo's husband died on Valentine's Day in 1998, her doctor said the cause was throat cancer. But she suspected that wasn't true. Months later, the doctor admitted her husband had died of AIDS, and that she was HIV-positive too with a CD4 count of 210 — which means she was eligible to start antiretroviral therapy (ART).

"They weren't going to tell me because I didn't have the resources to buy drugs," says the fiery 44-year-old. "There I sat, a widow all in black. I was outraged. They at least could have encouraged me to live healthily without drugs."

That diagnosis and her subsequent outrage prompted her life's work as an HIV activist. Today, Khuzwayo is the community psychosocial supervisor for Médecins sans Frontières (MSF) in one of three zones in the Shiselweni region of the Kingdom of Swaziland. Daily she reaches out to people, encouraging them to test, encouraging them to keep taking their medications and fostering hope.

The country is battling a dual epidemic of HIV and tuberculosis (TB). About 26% of adults aged 15–49, or some 202 000 of all the citizens in this landlocked African country are HIV-positive. And since HIV patients are vulnerable to opportunistic infections, the nation's tuberculosis prevalence rate is 1275 per 100 000 population.

At the time of her diagnosis, Khuzwayo was working as a waitress in the Swazi capital of Mbabane, struggling as the sole supporter of three children. There was no way she could afford ART, but without it she knew she would die before her children grew up. Despite her dire fear of stigma and discrimination, she told her family and friends that she was HIV-positive and needed help.

"It was very difficult to disclose," says Khuzwayo. "You lose friends. They don't want to be seen with you because people might think they were positive too. And my youngest child was teased." Still, some of her friends came through with the money she needed. By 2001, she was on ART.

Barbara Sibbald

Sylvia Khuzwayo (forefront in pink), the community psychosocial supervisor for Médecins sans Frontières (MSF), enjoys a laugh with USAIDS rural health motivator Ntombi "Magie" Gamedze (in the brown headscarf) and a TB patient's mother, Tryphina Mdlovu (in the pink headscarf). In the background (left to right), is the patient Velement Mdlovu, his wife Phakamile Mdlovu, along with Fexon Ncube, MSF health supervisor for the Matsanjeni zone of the the Shiselweni region. The family, including nine children, live on a subsistence farm 16 kilometres from the nearest clinic. The primary obstacle to their health is a lack of food.

Soon after, Khuzwayo heard members of an AIDS support organization talking on the radio and she joined the organization. It wasn't long before she was volunteering in an HIV program for treatment literacy. Meanwhile, during the course of her waitressing work, she met some people from Bristol-Myers Squibb who hired her as a research consultant on a project to prevent mother-to-child transmission. The pilot enrolled 200 HIV-positive pregnant women on ART and monitored their quality of life. It ended after two years, and Khuzwayo continued her volunteer work, this time as an adherence counsellor with the Ministry of Health. Most people were afraid to disclose their HIV status or to take antiretrovirals — even if they could afford them — lest someone find out their status, says Khuzwayo.

In 2003, the Swazi government launched a pilot to see how people would access free ART at Mbabane hospital. Khuzwayo was one of those participating in skits and delivering information to encourage people to enrol. In the end, they got their 200 patients; soon after, Swaziland began a national rollout of free ART at hospitals and health centres.

MSF heard about Khuzwayo's enthusiasm and invited her to play the role of a noncompliant patient to help train doctors and nurses. Later, they invited her to Geneva, Switzerland, to strut her stuff and soon afterward, in November 2008, hired her as one of eight expert clients. "We used to be

called expert patients, but we didn't like that, because we're not sick."

Initially, she helped with recruiting and training in Shiselweni, the hardest hit of Swaziland's four regions. By 2010 there were 22 expert clients.

Expert clients are the key to MSF's emphasis on task shifting. "The current system [staffing] couldn't cope with demands," says Pieterjan Wouda, the field coordinator at MSF's project in the Shiselweni region. "It's a waste to use a doctor to do follow up. We've managed to achieve results through expert clients. It's a beautiful system."

To Khuzwayo, "expert clients are the key to reducing stigma because clients see someone who is positive and healthy, then they believe they can also live a healthy life."

"When I started, I took seven pills a day; now I'm down to one," she explains. "I tell them how much it helped to hang in there. I'm still on first-line treatment after 11 years. Some have challenges with side-effects. I show them how I coped. They can hear it from the horses' mouth which is a great thing."

Until 2010, Khuzwayo supervised Shiselweni's expert clients. Then she was called to start up another cadre of workers: community expert clients. These HIV-positive staff work at the community level conducting campaigns, teaching, encouraging chiefs to call meetings and working one-on-one with patients in more remote areas, among other duties. MSF started with six workers. Khuzwayo now supervises a dozen.

More recently, in June, Khuzwayo took the show on the road with outreach testing teams joining the expert clients to do pretest counselling, community testing and posttest counselling. "This is mobile testing; we're in tents," explains Khuzwayo. The main target is men, who are not keen to test. Currently, 33% of women go for testing, but only 18% of men.

"It's a big problem," says Wouda. MSF's outreach team includes three cars and six tents, plus a cadre of expert clients and a driver/testing technician. "It's set up, it's like a circus, seven days a week," says Wouda. They are aiming to complete 1000 HIV tests per month and are applying to set up permanent testing sites at places where men gather, like barbershops, army bases and sporting facilities. The tents will also go up in downtowns, at border crossings and at big colleges.

"Ideally, every sexually active adult should be tested," says Wouda. "We should be testing 100 000, not 26 000."

"They won't come to us, so we go to them," adds Khuzwayo.

Despite her duties as a supervisor, Khuzwayo still works with clients. "It's here," she says, tapping her chest. "It's part of me. People are still scared of disclosing to family. I encourage them to disclose to one at least. I wouldn't have been able to do it without disclosing. There is a risk of rejection, especially if you're married and your husband or in-laws chases you out. It is difficult."

"But as a long survivor I can show people you can live with treatment. Without treatment you die in five years. I am giving them hope," Khuzwayo adds. — Barbara Sibbald, *CMAJ*

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Part I: **Making sense of the world's highest HIV rate** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4315).

Next: **Responding to Swaziland's dual epidemic**