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Web Exclusive: Fighting for Their Countrywomen

BY KATHY LATOUR

The women who gathered in Brisbane, Australia, for the Reach to Recovery International meeting came from 47 countries, most of them hoping to learn from other women how to advocate for breast cancer survivors in their home countries.

Among them were Mercy Tayebwa from Uganda and Cherry Hart from South Africa. One black, one white, both women are survivors from countries that struggle to provide adequate medical care and support to women with breast cancer in light of other pressing social and economic concerns.

Mercy Tayebwa

Tayebwa, who was 35 when she was diagnosed in 2005, was one of two representatives from the Uganda Women's Cancer Support Organization based in Kampala. She joined the group as a volunteer after they visited her in the hospital before her mastectomy and only a year after their formation—one of the first organizations of its kind in a country somewhat smaller than the state of Oregon but with ten times the population.

“I was lucky that I had someone to talk to,” Tayebwa says of the women who came to see her after her diagnosis. “The pioneers in this group came to see me and to tell me what to expect.”

Like the early breast cancer advocates in the U.S., information included details on her mastectomy and healing. She was not given the option of a lumpectomy, she says, because the doctors in Uganda were concerned about removing all the cancer. After surgery, which revealed two positive lymph nodes, the mother of two was given chemotherapy from one of three oncologists in the country, all of whom practice in Kampala.

Through it all, she says she was lucky—her husband stood by her. Many Ugandan men ultimately leave their wives after a breast cancer diagnosis, she says.

“There is a lot of stigma. They have breast cancer so maybe they can't get married. You lose your family and maybe your husband,” Tayebwa says. “There is a lot of abuse, and the men will leave because the woman can't have children, or they get a second wife.”

Supported by her family, Tayebwa encountered a different problem at her job as a manager of a microfinance company. When she returned to work after her treatment, she learned she had been demoted to a receptionist because management didn't want to "stress" her.

"I wasn't stressed, but that didn't matter," she says. "They decided."

Today she volunteers two days a week with the Uganda Women's Cancer Support Organization as they work to organize the other breast cancer groups that have emerged into an umbrella group that can address issues of education and support for women with breast cancer.

The 49 women in the group gather twice a year in Kampala to discuss future plans. The last meeting was a cause for celebration. The group had secured a mobile mammography unit for the northern part of the country—doubling the number of machines from one to two for a country with a population of about 30 million. Their project now is to get educational materials printed in the two primary tribal languages and to find ways to get the government to pay attention to the issue on a national level.

Cherry Hart

Cherry Hart, a 58-year-old nurse from Johannesburg, South Africa, was diagnosed with breast cancer in 2003 and today works as a Reach to Recovery volunteer in her home city.

The first problem women encounter is that South Africa does not promote breast cancer screening. Mammograms are expensive and used for diagnosis, not early detection. "If you want one, you have to pay for it," Hart says. "There is no free or low-cost mammography."

And once diagnosed, the cancer is often advanced. Hart says that while those without private insurance can go to government hospitals for free, they must often wait weeks or months for care. In addition, a lot of people don't finish treatment, she says. Women travel to the big city for their treatment not knowing that chemotherapy and radiation can be a lengthy process. Because they didn't understand the implications of the distance and they can't stay in Johannesburg, they stop treatment, she says.

Hart also sells breast prostheses and mastectomy bras to women who have had breast surgery. But more than vanity, Hart says, the women from the countryside need the prostheses because they face discrimination when they return home.

Hart and Tayebwa both discussed the uphill battle to get breast cancer on the radar in countries with so many other social issues. Uganda has begun showing strong economic growth but remains locked in civil war, while Hart says South Africa's health care system has been overwhelmed by the AIDS epidemic.

Both women say they will continue to advocate for women with breast cancer.