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Mexico escalating the fight against breast cancer

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On Avenue San Fernando, a tree-lined street crowded with food stands, the new wing of Mexico's flagship cancer hospital gleams like a silver airplane. Barely a year old, the light-filled structure attached to the National Institute of Cancer of Mexico (Instituto Nacional de Cancerología, or INCan) represents a national commitment to cancer care for the poor.

Just a decade ago, half of all Mexicans—52 million people—had no health insurance. As many as 4 million families a year faced financial ruin because of catastrophic illness, like breast cancer.

Today, those same families have access to treatment because of Seguro Popular. The universal health care initiative, launched in 2003 and largely powered by Harvard research, is funded with less than 1 percent of the country's GDP. It has gradually expanded to cover a range of catastrophic illnesses. Breast cancer, with its fast-rising rates and ever-younger victims, was added in 2007.

Good thing. Around the same time, breast cancer replaced cervical cancer as the No. 1 killer of women 30 to 54. To make matters worse, before 2007 about 30 percent of breast-cancer patients dropped out of treatment because they ran out of money. That figure has fallen to less than 1 percent.

The Harvard research behind Seguro Popular is part of a synergy that University experts call "evidence-based advocacy." The idea: Good

deeds and good policy in public health are driven by good data.

"Evidence makes visible the invisible," said Julio Frenk, the chief architect of Seguro Popular.

A medical doctor and a longtime student of the world's health systems, Frenk has been dean of the Harvard T.H. Chan School of Public Health (HSPH) since 2009, a few years removed from his service as Mexico's Minister of Health, from 2000 to 2006. (He was also founding director-general of Mexico's National Institute of Public Health.) At HSPH, Frenk oversees one of the key University entities in a complex web of research and alumni ties with Mexico.

Among the "invisible" that good evidence reveals, Frenk said, are the poor living at the margins of developing and middle-income nations such as Mexico. He attributed the sentiment to his friend Amartya Sen, Harvard's Thomas W. Lamont University Professor, whose book "Development as Freedom" (2000) summarizes in its title the Nobel laureate's life mission.

Data bumped Seguro Popular into existence, starting in 1994, when Frenk and a research team at the Mexican Health Foundation (Funsalud) conducted the first comprehensive accounting of public health in Mexico. "To everyone's shock," Frenk said, the data revealed that 52 percent of health expenditures in Mexico were paid privately, out of pocket, from household budgets. Most Mexicans back then, he added, believed that most health care was publicly funded. The Mexican Constitution of 1983 had guaranteed the right to health care for all. But it took national reform to make universal care a reality.

'Take it to heart'

By 2010 about 17,000 women were being treated for breast cancer under

Seguro Popular; they were assured diagnosis, radiation, chemotherapy, surgery, and follow-up appointments.

Care is no less robust for those diagnosed today, but gaps remain: access to centralized treatment centers, adequate pain management, and the palliative therapies needed by those who won't survive.

Those gaps are the worry and the passion of Harvard-trained health economist Felicia Knaul, Frenk's wife and longtime research collaborator. Now an associate professor at Harvard Medical School, Knaul directs the Harvard Global Equity Initiative (HGEI), which links research with advocacy in developing nations. The project was co-founded by Sen—Knaul's graduate school mentor—and Lincoln C. Chen, onetime director of the Harvard Center for Population and Development Studies.

Knaul's awakening to breast cancer was sudden and personal. In the spring of 2007, during a routine mammogram at a primary care clinic in Cuernavaca, Mexico, she learned she had the disease, and it was already far along. Knaul was 41, the mother of two young daughters. For the first two weeks after her diagnosis, she said, "I was upset, searching, angry, and denying treatment."

Reason and perspective returned. She underwent multiple surgeries that culminated in a mastectomy in a private hospital in Mexico City. A few days after the first surgery, Knaul went for a walk and marveled at her astonishing luck. She had health insurance, wonderful care, and support from a loving and knowledgeable husband.

She also thought deeply about women who were not so fortunate.

"Cancer takes away," Knaul would write years later, in her 2012 book "Beauty without the Breast," "but it also gives."

Early in her fight, on long walks, Knaul had started to imagine another woman with breast cancer. She too was a young mother. But she was poor. She was being treated in one of Mexico's crowded public hospitals—settings that not long ago were simply "places to go and die," said Knaul.

The woman was alone, deserted by her partner in a culture that often stigmatizes women with breast cancer. Money had run out for bus fares, treatments, and medicine. Facing financial ruin, she had no choice but to quit going to appointments. (Breast cancer treatment can take up to a year, and involve an agonizing trilogy of surgery, radiation, and chemotherapy.)

Worst of all, thought Knaul, as this woman lay dying, she was dying in pain.

Only one in 10 cases of breast cancer in Mexico is detected early, during Stage 1, when treatment is most likely to be successful. Few poor women ever get mammograms; four out of five do not have annual clinical breast exams.

What is more, despite Seguro Popular's successes, access to treatment remains difficult for many since it often requires extensive travel. "We still have the women moving, instead of the care moving," said Knaul. To mitigate this problem, she is working with Mexico's Ministry of Health to learn a lesson from the Harvard-affiliated Dana-Farber Cancer Institute, which has set up satellite clinics for breast-cancer treatment throughout New England.

Another major issue is pain management, which is not available for most poor women in Mexico and in most of the developing world. It is a gap in care that "shocked and horrified" Knaul—and which was outlined in a recent Human Rights Watch report on palliative care in Mexico.

Also lacking is professional education. Many primary care providers in Mexico, said Knaul, are not fully aware of the disease or its prevalence, in part because the data on breast cancer are "so new and surprising." Many women go to their doctors worried about a lump in the breast, and are sent home with an antibiotic. Many primary care physicians, she said, "think you're terribly mistaken," especially if the patient is young. They believe breast cancer strikes only older women, rich women, and women from other countries.

Education is the counterweight and will guide practitioners, said Knaul. "We have to share the right data."

Beginning in 2008, Knaul underwent postsurgical chemotherapy treatments, a painful ordeal that evoked the same powerful tugs of empathy. During those moments Knaul created the idea of Cáncer de Mama: Tómatelo a Pecho, a nonprofit launched to educate poor women about breast cancer. The name means "Breast Cancer: Take It to Heart"—that is, take it seriously.

A hub for care

The new wing at Instituto Nacional de Cancerología, just a few blocks from where Knaul was treated in 2007, is state-of-the-art. One day last fall a young medical student in a lab coat paused to talk. The hospital's new building, he said, is "seven floors of full attention."

In the main waiting area, where a crucifix hangs on each wall, a social worker reads names from a clipboard. Many of the patients, more women than men, wear surgical masks. When patients are called, they file into a secondary waiting room.

Guadalupe Leticia de Garte Sosa, a breast cancer patient in her 40s, remembered how aggressively the disease attacked. "I couldn't believe it

could happen in such a short time." The first sign was in a nipple, "so monstrous I couldn't believe it," she said.

Around her, the waiting room was crowded. Every chair was taken. This was a sign that success—universal access—comes with a price. "The advantages of more having coverage for breast cancer has also had consequences," said Héctor Arreola Ornelas, an HGEI scientific researcher and collaborator and economic research coordinator at the Mexican Health Foundation.

A 17-year veteran of health-systems research, Arreola Ornelas lost his wife, a physician in her 30s, to breast cancer in 2006.

Centers such as INCan, he said, are typically in large cities. Trips for appointments can be expensive and often require a companion and a place to stay.

For Sosa, home was an eight-hour bus ride from INCan—impossible during a treatment cycle. But a stranger she had met in a restaurant was letting her sleep over in Mexico City. "I had the good fortune of finding a person."

In a corridor nearby, Marta Berta Cerqueda Quiroga waited on a metal folding chair for her chemotherapy session, her head wrapped in a bandana. Having to relocate for her long course of treatment had been its own ordeal. "I am here with a nephew. It's uncomfortable," she said, since the nephew's new wife, "shouts at me while giving me food."

Months earlier, Quiroga recounted in Spanish, she had resisted the idea that she had cancer at all. Standing up from the chair, she mimed the argument she had had with her doctor. Sitting back down, she wept.

Young and determined

For now, Abish Guillermina Romero Juarez is past tears. A cancer survivor still in her 20s, she is a master's degree student at the National Institute of Public Health of Mexico in Cuernavaca, a school Frenk helped found less than a decade ago.

More than half the women diagnosed with breast cancer in Mexico are in their premenopausal years, when the disease is most aggressive. "We don't have a full explanation for this," said Knaul. The same trends, she added, are taking hold all across Latin America and the Caribbean.

Juarez's mother died from breast cancer in 2010, just as her daughter was finishing her university studies in Mexico City. Juarez moved to Boston to work as an au pair—but the next spring was diagnosed with breast cancer herself. When her U.S. insurance would not cover care, she reached out to Knaul, who had an immediate solution: Get on a plane, you will be covered in Mexico.

Back home, it took Juarez just an hour to register with Seguro Popular. The plan's Fund for Protection against Catastrophic Health Expenditure covered her care. It's a separate and untouchable fund, segregated by law from the Ministry of Health's regular budget, which is subject to periodic erosion.

Laura Torres, a law student, was diagnosed with breast cancer at age 24. Unlike the impoverished woman Knaul had imagined, Torres had a place to stay after her diagnosis: her parents' house. She even had private health insurance. Her luck, however, failed to allay the terror and pain of the disease or the time she lost to it. "Being sick," she said of the two-year ordeal, "is a full-time job."

Still, the experience left Torres with a new passion: saving poor patients from pain. "As a cancer patient, I know pain treatment is vital," she said. "You can't wake up from a mastectomy and take Tylenol. It's a vital

aspect of treatment, even if people are not facing a life-threatening condition."

Torres and others are working to change laws that Frenk called "antiquated" and that Knaul said are frozen in place partly because of concern over drug cartels.

Last spring, HGEI organized "Closing the Pain Divide," a two-day seminar at the Radcliffe Institute for Advanced Study. Just before, Knaul had blogged on the issue for the Huffington Post. She quoted World Health Organization estimates that every year 5.5 million terminal cancer patients die in pain—and that four of five people live in countries with limited access to prescribed opioids.

"No one should die in the torture of pain when the drugs to stop that pain are available and so affordable," Knaul wrote, remembering her father's death from cancer when she was 18. "Denial of access to pain medication is a form of torture."

HGEI has established a palliative-care institute in Guadalajara. In the fall, the group launched the HGEI-Lancet Commission on Global Access to Pain Control and Palliative Care, whose co-director, with Knaul, is Paul Farmer, the Kolokotrones University Professor of Global Health and Social Medicine. Meanwhile, Knaul is drafting a national policy for access to palliative care in Mexico.

The global inequity of access to pain management is also a core issue with the researchers and public health experts of the future. Mexico native Thalia Porteny, S.M. '14, who has worked with Knaul and is doing a Ph.D. in health policy at the Graduate School of Arts and Sciences, is a co-founder of the Young Leaders Network for Health Equity. With about 21 active members from 10 countries, the group is developing ways for young researchers from low- and middle-income countries to

collaborate on common issues. "We're trying to build momentum," she said, with global universal care as the ultimate goal.

Mexico has at least "achieved a milestone" toward such coverage through Seguro Popular, she said. "All countries are on the path, but to really have it is something really difficult to attain."

Mexico as a model

For Frenk, Knaul, and others at Harvard, Mexico provides a working example of how affordable comprehensive health care is possible for those who could never afford it on their own.

The example is not perfect. Out-of-pocket expenditures persist, and there are bottlenecks in some specialized areas of care, like radiology. Access in rural areas remains problematic.

But the Mexican case, supported and studied so widely at Harvard, also shows the potential for government action in health care—a blueprint for separating health care from the labor market. Such a "decoupling," as Frenk puts it, ensures that those who don't earn a salary—farmers, the self-employed, homemakers, the elderly—are protected from the financial shocks of illness.

There's also an opening for helping citizens stay well—20 percent of Seguro Popular funding goes to prevention, through measures such as vaccines and routine health screenings. (This is another protected fund, and includes epidemiological surveillance based on techniques developed at Harvard.) Markers of public health have improved in the decade since Seguro Popular was launched. Life expectancy is up, and rates of both maternal and child mortality are down. Among illnesses causing the highest rates of hospitalization, more than 95 percent are now covered.

"It tries to fund the whole circle," Frenk said of Seguro Popular, from prevention, diagnosis, and treatment to palliative care. In turn, he added, concentrated efforts—against breast cancer, for example—display an "external positive effect": Single improvements in a system drive general improvements. More community health care workers, in this case, and more radiological services and improved surgical platforms can help against a range of illnesses.

Seguro Popular is not a direct template for change in every country in search of universal health care, Frenk said. "It's not a question of adopting, but adapting." Mexico's plan came from studying health systems all over the world for 20 years. The best lessons were the negative ones, he said; knowing what doesn't work means you don't have to try it again.

Finally, Harvard and Mexican health authorities are at the center of an experiment in collaboration that could go global. It's designed to create, said Frenk, "a mechanism for shared learning across countries."

More information: "Mexico: Needless Suffering at End of Life": www.hrw.org/news/2014/10/24/me … s-suffering-end-life

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