Health & Medicine

The Full Treatment

Wafaa El-Sadr reaches beyond medical protocol to shape treatment regimens in New York and Africa.

By
Cindy Rodriguez
|
Winter 2008-09

Wafaa El-Sadr (Levi Stolove)

Wafaa El-Sadr leaned closer to her patient, an older woman who had been in and out of the hospital, suffering from tuberculosis. "If you don't continue taking your medication after you're discharged," El-Sadr told her through a face mask, "you're going to get worse."

Continue taking the antibiotics and it will kill the TB, she explained. Stop taking them, and TB will kill you. The patient looked up from her bed at El-Sadr and promised she'd return for treatment. But the doctor had a feeling that this patient, like so many others at Harlem Hospital Center, would vanish.

El-Sadr was right. The woman never returned.

It was 1992 and TB, nearly eradicated in the U.S., was back on the rise, particularly in Harlem, where a large number of people infected with HIV were susceptible to the airborne disease.

At the Columbia-affiliated hospital, only 11 percent of the TB patients completed treatment. Those who stopped midway weren't hurting just themselves; they were running the risk of infecting others. In Harlem, the TB infection rate was 222 per 100,000 people — more than 20 times the national rate — and rising.

El-Sadr knew she needed to do something drastic. But what?

The answer came to her one afternoon while she was doing rounds. In every room she noticed that the bedside tables, where flowers and magazines normally would be, were empty. There were no balloons. No get-well cards. No visitors. It hit El-Sadr: these patients didn't have anyone who cared about them. She began to think that their isolation and lack of close relationships might be the reason they were cavalier about their health.

"I realized that part of the reason they were unable to complete treatment was that they were very much alone in the world," she says. "They didn't have any strong family connections. They didn't have anybody to support them during treatment."

These were individuals who had lived desperate lives. Many had abused drugs and spent time in prison. Some also were infected with HIV. Others had been homeless.

El-Sadr knew she couldn't get their families together, so she decided to do something creative: develop a family dynamic among the patients.

In the hospital's TB clinic, where patients were supposed to come for checkups and medication as they progressed through six months of treatment, she set up a living room-style seating area. Her staff kept a refrigerator full of snacks and drinks and encouraged the patients to stay and socialize. They hung on the walls photo collages of patients taken during celebrations and group outings with the staff. On Thanksgiving, they served a hot turkey lunch. During warm months, El-Sadr and her colleagues took two busloads of patients to the Six Flags Great Adventure amusement park in New Jersey. And twice a year they held graduation ceremonies during which they gave patients completion certificates, the first award many had ever received.

A year later, at the end of 1993, the TB treatment completion rate at the clinic had soared from 11 to 89 percent. New York City health officials hailed El-Sadr's "surrogate family approach." Other clinics adopted similar models, called "directly observed therapy," in which physicians watch their patients take the prescribed antibiotics. As a result, the TB rate in Harlem dramatically declined.

Building the Capacity

El-Sadr '91PH is one of the world's top infectious-disease experts. She is the founding director of the International Center for AIDS Care and Treatment Programs (ICAP) at the Mailman School of Public Health, a behemoth operation that works directly with 700 hospitals and clinics in 14 countries, most of them in sub-Saharan Africa. The center's mantra is "build the capacity" — do what it takes to make these clinics effective. It means training staff on how best to treat people infected with HIV, but it also can mean something as prosaic as buying filing cabinets or creating a database so a clinic can track appointments.

ICAP receives more money annually than any other grant-funded center at Columbia University, about $140 million a year from various sources, including the Centers for Disease Control and Prevention, the U.S. Agency for International Development, and the National Institutes of Health (NIH).

El-Sadr, 58, is part of a global network of AIDS researchers who are doing what some critics had once thought impossible: helping to slow the spread of HIV and saving hundreds of thousands of lives. For her work, she was honored as a MacArthur Fellow this fall.

"In Wafaa El-Sadr, the MacArthur Foundation found a humanitarian, visionary, academic, and healer in one," Lee Goldman, executive vice president for health and biomedical sciences and dean of the faculties of health sciences and medicine. "On a trip to Africa in 2007, I saw firsthand why her colleagues consider her heroic and why she is a lifesaving force for millions around the world. The leadership and ideals she embodies have already made a difference to the world's most vulnerable and have put in motion a strategy for helping generations to come."

El-Sadr, a professor of clinical medicine and epidemiology at the Mailman School of Public Health, earned a medical degree at the University of Cairo, a master's in public administration at Harvard University, and a master's in public health at Columbia University. But, she says, it was her Harlem patients who taught her that the best medicines in the world are worthless if a patient doesn't take them.

Colleagues say her effectiveness comes from a keen ability to see beyond medical protocol, shaping treatment regimens that take into account cultural dynamics. Her TB patients needed familial support, so she created it. Her HIV patients in Africa have close, extended families, so she developed programs in which they are all included in counseling.

But El-Sadr is in a race with a deceptive virus, one that health officials estimate has killed more than 25 million people since the 1950s. Even with the availability of affordable, lifesaving drugs, HIV killed more than 2 million people in the world in 2007, according to the World Health Organization. Some 17,000 of those deaths occurred in the U.S.

"There's a misperception by many in the U.S. that AIDS is not something we should be worried about anymore, that it is somewhere out there in Africa," says El-Sadr. "Unfortunately, there's been a lack of attention to what is happening here. Part of my work over the last couple of years has been to try to highlight the hidden HIV epidemic in the U.S."

El-Sadr is currently investigating ways to prevent HIV transmission among two groups of African Americans: women, and men who have sex with men — a public health term concerned with sexual behavior not with labeling men as gay, bisexual, or heterosexual. Although these two groups have disproportionately high rates of infection, it took persistence to get clinical research funding for these studies, according to Jessica Justman, associate professor of clinical medicine and epidemiology at Mailman.

In the fall of 2006, the NIH allocated most of its HIV prevention money to international sites and funded just one site in the U.S., says Justman, who had worked on prior grant proposals with El-Sadr. "Her response was, 'We can't just sit back,'" Justman says. So along with other colleagues they started writing letters to members of Congress and NIH officials. The letters led to meetings in Washington, D.C., and the pressure led to NIH funding the studies in the spring of 2008. Justman says, "She doesn't like to take no for an answer when it's something she believes in."

A Family Approach

El-Sadr was raised in Cairo by her parents, Rasmia Mowafy and Mahmoud El-Sadr, both physicians. Though her mother and father would have been considered part of the intellectual elite, they lived a simple life, El-Sadr says, and spent a good part of their free time volunteering to help the poor.

When she was six, El-Sadr and her family left bustling Cairo to spend the first of what would be many summers in a camp along the Mediterranean Sea in Alexandria working with more than 120 impoverished children.

The first few summers, El-Sadr and her younger brother, Hany, complained about the cold showers, having to eat lentils and rice every day, and the constant gritty feel of sand on their skin. But as the summers passed, El-Sadr came to see the impact of her parents' work. At the camp, the children learned trades such as carpentry and construction, as well as life skills, such as cooking, hygiene, and how to present an argument. El-Sadr watched as timid children transformed into confident ones.

By the time she was 12, El-Sadr would rush to set up the family tent so she could run and play with the other kids. High winds would still sprinkle sand onto her lentils, but it didn't matter as much to her.

Mystery Virus

In the early 1980s, El-Sadr was working as a physician at the New York Veterans Administration Medical Center, watching as people withered from a mystery illness. "People would come in to the hospital, and then many would just die, very quickly," El-Sadr says. "It was a time of frustration, because we didn't know what to do. We were frantically trying to treat one symptom after another without really understanding the root of all of these illnesses."

Scientists throughout the world were racing to understand how HIV worked so they could find a cure. They are still searching, but their research led to the emergence of a new class of drugs, called antiretrovirals, which inhibited the growth and reproduction of the virus. By the time El-Sadr became chief of infectious diseases at Harlem Hospital in 1988, HIV was increasingly affecting heterosexual people of color. The surrounding neighborhoods were being ravaged by crack cocaine. Many addicts were careless about using condoms; others did not use them, thinking of AIDS as a gay white man's disease. Even as health officials were issuing public health warnings, HIV rates among the poor continued to rise because many people didn't know they were infected.

In the early 1990s, around the same time that El-Sadr was figuring out ways to get her TB patients to return for treatment, several of the HIV-positive female patients she was following were missing appointments. Again, she had to come up with a plan to lure them back.

"These women were taking their children to the pediatrics clinic but were neglecting their own health," El-Sadr says. "It became clear to us that if we wanted to help these women, we had to think beyond just trying to convince them to come to the clinic. We needed to think of shaping our programs to identify their needs as mothers."

So she designated one day of the week as mother-child clinic, bringing together pediatricians and adult doctors so that mothers could get a checkup at the same time as their children. Her mother-child model became a success. Within a few weeks, she says, whole families were coming in for care. The experience shaped El-Sadr's thinking about using a family focused approach to treatment, which she would later use in Africa.

By 2000, HIV had reached epidemic proportions in sub-Saharan Africa, with an adult prevalence rate of about 5 percent. Global health care workers in Africa were pleading for aid and access to HIV treatment drugs for their patients, which only few well-off Africans could afford. Many experts and researchers cautioned against using antiretroviral drug therapy in these poor countries, arguing that in rural African communities, patients would miss their dosages because they weren't used to taking daily medications. They warned it would lead to virulent, drug-resistant strains of HIV. The best approach, they said, would be to focus solely on preventing new infections rather than also trying to treat those who had HIV.

To El-Sadr, that approach would be the same as a death sentence. At medical conferences, she spoke out for what she called the "ethical imperative" to bring life-saving drugs to those who needed them. She said she knew, from her experiences treating patients in Harlem, that it was just a matter of figuring out the right approaches for the population being served. "We couldn't just let a generation die when we knew we had medicines that could save lives," she says.

Even with a growing chorus of researchers, celebrities, and protesters pressuring industrialized nations to offer more money to fight AIDS in Africa, the amount being spent on global AIDS relief was insufficient. In 2001, UN Secretary-General Kofi Annan said a war chest of about $10 billion was needed annually. Later that year, President George W. Bush committed $15 billion over five years to fight AIDS. Among those who received the President's Emergency Plan for AIDS Relief grant was El-Sadr, who had launched international programs in Kenya, Tanzania, South Africa, Mozambique, and Rwanda in 2002. Later, ICAP would expand to Thailand, Cameroon, Côte d'Ivoire, Ethiopia, Lesotho, Nigeria, Swaziland, Uganda, and Zambia.

ICAP became one of the first centers to approach AIDS care by focusing on the whole family, not just the infected individual. ICAP was also one of the first to put pregnant women at the center of programs, providing mothers with antiretroviral treatment and pills that reduced the transmission rate to their unborn children. There's no way to measure the number of lives saved, but ICAP currently is providing care to more than 560,000 people, including life-sustaining antiretroviral therapy to more than 260,000 individuals, according to Paul Olson, a public affairs officer at the Mailman School.

El-Sadr says she believes ICAP will continue to expand. Global AIDS-related deaths have stabilized but she wants to see the day that HIV infections sharply decline. She's witnessed the transformation of communities where rail-thin people with HIV were dying on cots, to places where HIV-infected people are living productive lives. Medications have cut in half the number of mother-to-child HIV transmissions. "Using the word miraculous," El-Sadr says, "is not an overstatement."

No Time to Sleep

El-Sadr saunters into her office, clutching files and a legal pad. At her desk is a half-eaten bag of potato chips and a Diet Coke — her lunch on this and many other busy days. A red and black Egyptian scarf flows from her shoulders, over a nondescript all-black outfit. Black patent leather cowboy boots peek out from under a flowing skirt. She's wearing her wavy, jet black hair as she always does, set high in a ponytail.

Colleagues call her a workaholic; so does her 14-year-old daughter Olivia Yasmeen, who quips, "We'll go on vacation and she'll bring her laptop to the beach."

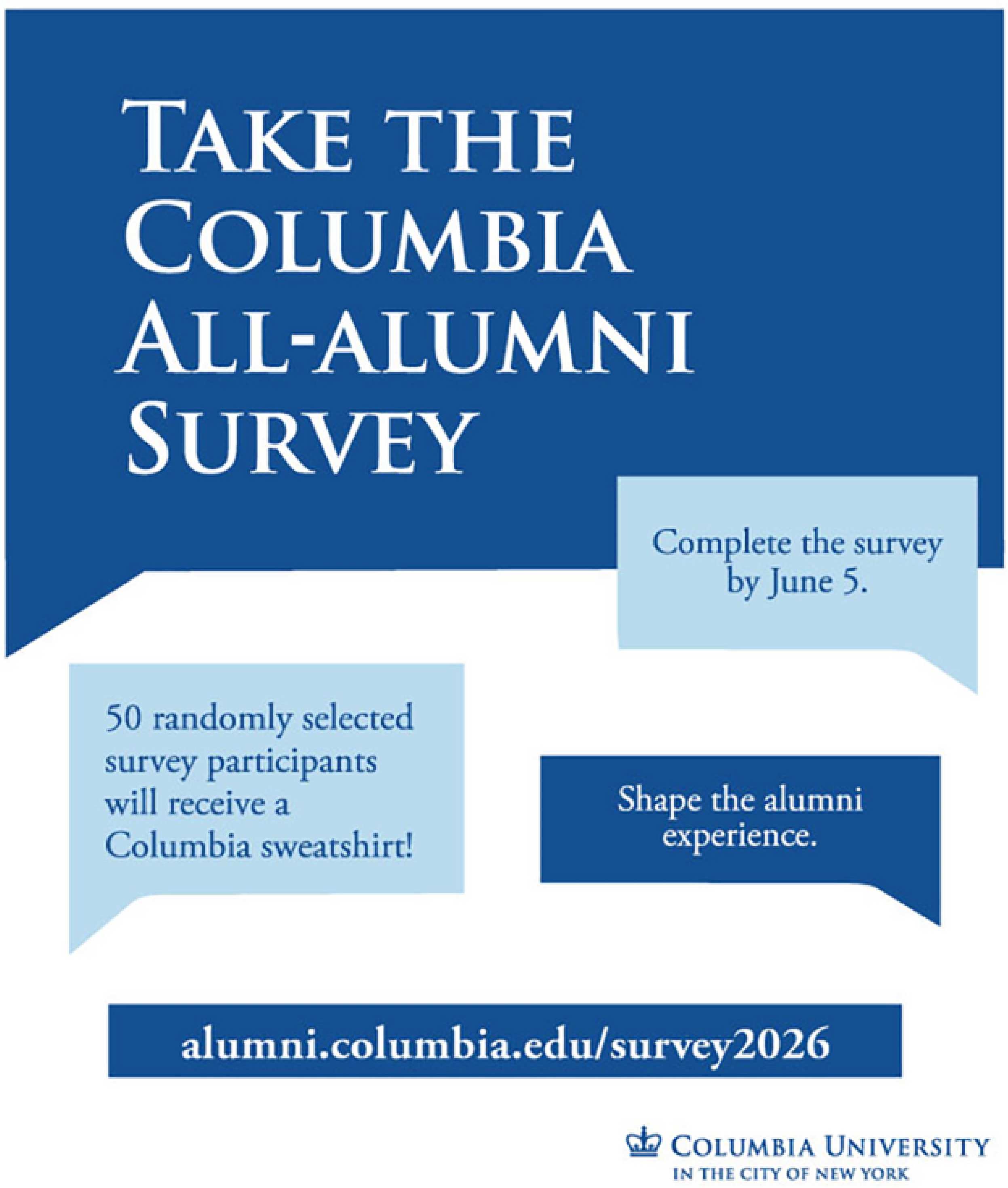
El-Sadr admits she doesn't take time for herself. She sleeps an average of five hours a night, gave up running two miles a day, which she enjoyed, and doesn't have time to cook dinner on weekdays. In any given month she's away from home about half the time, attending conferences and meetings all over the world.

When she is in town, she and her daughter make a point of eating dinner together every night. From their apartment near Columbia's Morningside Heights Campus, they'll head to their favorite restaurants on Broadway: Le Monde, Deluxe, Community. If they stay at home, supper is microwaved frozen pasta. But every Sunday night, her younger brother, Hany, also a doctor practicing in Manhattan, comes over for dinner and the three feast on homemade tabouli, chicken tagine, rice with lentils.

By 6 a.m. Monday, El-Sadr is back on the job, working from her laptop at home, then heading to her office at Mailman or the HIV clinic at Harlem Hospital, where patients greet her like an old friend. She's known some of them for 20 years, back when it was unclear whether antiretroviral drugs would prolong their lives. She says she often tells her patients, "we are growing old together." One such patient, a 50-year-old grandmother, reminisced with El-Sadr the other day about how far she had come. When she first met El-Sadr, she was a high school dropout who was addicted to crack cocaine. Now she has a G.E.D., is sober, and works full-time — as an HIV counselor. "She tells me she can't believe it's been that many years," El-Sadr says. "I sometimes can't believe it either."

Read more from ***Cindy Rodriguez***

Guide to school abbreviations



Take the Columbia All-Alumni Survey

Complete the survey by June 5.

50 randomly selected survey participants will receive a Columbia sweatshirt!

Shape the alumni experience.

alumni.columbia.edu/survey2026

Columbia University
in the City of New York

All categories >

Read more from ***Cindy Rodriguez***