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Stigma Is Toughest Foe in an Epilepsy Fight

By ALIYAH BARUCHIN

FREETOWN, Sierra Leone — On a sweltering morning on a red-earth lane a few blocks from the largest mosque in this West African capital, Jeneba Kabba stands up.

A tall, striking woman with a serious manner, Mrs. Kabba has been sitting under an awning in the outdoor classroom of a vocational training program for people with [epilepsy](#). Every weekday, some 20 Sierra Leoneans, from teenagers to adults in middle age, gather here to learn skills like tailoring, weaving, tie-dyeing and soap-making, as well as reading — skills that, in this society, will give them a chance to earn a living. Mrs. Kabba, 30, a graduate of the program, is now a tutor.

Her composure belies what she has survived. As a teenager she was taken to a traditional healer, who boiled herbs and made her inhale the fumes from a steam tent for hours. The treatment was supposed to drive out the demons thought to cause epilepsy; she nearly fainted and could have been burned.

But worse was yet to come: She was forced to drink a two-liter bottle of [kerosene](#). “Mi ches don cook,” she says in the Krio language, her voice faltering even now: “My chest started to boil.” Only a panicked trip to the hospital saved her life.

Mrs. Kabba not only survived, but has been [seizure](#)-free for 10 years with the help of phenobarbital, one of the oldest anti-epileptic drugs and virtually the only one available here. And in a country where people with epilepsy are often considered uneducable, unemployable and unmarriageable, Mrs. Kabba teaches, is happily married and has a child.

Now, recalling the personal and professional distance that she has traveled, she rises to her feet. “People used to think I was crazy,” Mrs. Kabba says, her voice shaking. “Now they’re seeking me out; I’m the one that they want. Now, when I teach here, unless I tell you that I have epilepsy, you wouldn’t know. I’m proud of myself.”

Among Sierra Leoneans with epilepsy, Mrs. Kabba and her students are the lucky few, their successes due to the efforts of two tiny groups of advocates.

The Epilepsy Association of Sierra Leone opened this vocational training program 11 years ago, near the end of a devastating decade-long civil war. Now it has been joined by Dr. Radcliffe Durodami Lisk, a Sierra Leonean neurologist trained in Britain, who returned to Freetown last year to open the Epilepsy Project, offering clinics in the city and “upline,” in the remote eastern and southern provinces. In this nation of six million people, Dr. Lisk is the only neurologist.

The vocational program replaces the opportunities that its students have lost, one after another: Their schools have asked them to leave; their employers have fired them for having had a seizure in the workplace; their spouses and families often shun them for fear that they are contagious, or possessed.

And they live here, in one of Africa's poorest countries, where scarce health care resources and the stigma surrounding epilepsy add up to a "treatment gap" of more than 90 percent — meaning that fewer than 10 percent of the estimated 60,000 to 100,000 Sierra Leoneans with epilepsy are getting the treatment they need.

Looking at the array of public-health problems facing many African societies, it is easy to wonder how a disease like epilepsy even makes its way onto the radar. "There is growing appreciation for the importance of noncommunicable chronic diseases in these regions," said Dr. Gretchen Birbeck, a global epilepsy expert who directs a clinic outside Lusaka, the capital of Zambia. "But the focus where it counts — policy and money — is still on [H.I.V./AIDS](#), tuberculosis and [malaria](#)."

Yet epilepsy affects 50 million people worldwide, and according to the World Health Organization, nearly 90 percent of people with epilepsy live in developing countries. In Sierra Leone, Dr. Lisk said, "certain situations increase our prevalence: [infectious diseases](#), childhood asphyxias, injuries from the rebel war, [head trauma](#)."

Epilepsy treatment gaps are driven largely by low income and rural location, making sub-Saharan Africa a treatment-gap hot spot. Treatment in Sierra Leone is not expensive; Dr. Lisk's patients pay about \$2 a month for phenobarbital, which gives more than 60 percent of users significant seizure control. The costs of untreated epilepsy, on the other hand, are enormous, especially in lost productivity.

"People with epilepsy here become disproportionately disadvantaged in the job market," said Max Bangura, founder of the Epilepsy Association of Sierra Leone and its vocational program. "With this training, people now know our students as excellent tailors; they are useful in their communities."

While Dr. Lisk and Mr. Bangura fight a shortage of resources, they say their most intractable problem is still the intense stigma surrounding epilepsy, which often acts as a bar to treatment. "The first hurdle is whether or not the family believes that this is an illness that can be treated," Dr. Lisk said.

Stigma here is based on two myths: that epilepsy is contagious and that it is caused by demonic possession. Dr. Lisk is quick to point out that beliefs about possession traverse societal boundaries. "You think it relates to level of education, of literacy, but somehow it doesn't," he said. "Sometimes it's the most educated people who will tell you that it's demonic. They say it's in the Bible." (Some biblical references to possession have long been thought to describe people with epilepsy.)

As a result, discrimination against people with epilepsy here is blatant and unabashed, and it begins in elementary school. "The school authorities often ask the students with epilepsy to leave," Mr. Bangura said. "There is the notion that epilepsy is contagious; so when somebody has an attack during school, the

perception is that if somebody happens to step on the spittle of an affected student, that would be one way of contracting the disease.”

Nearly half of Sierra Leonean children with epilepsy drop out of school once their condition is discovered. Teachers are often unwilling to help a child having a seizure in class.

“Wherever the kid fell, they circle it and tell people to stay away from it, because that spot is a bad spot,” said Lima Kanu, a graduate of the vocational training program who is now in charge of tailoring instruction.

A young woman in the program tells of being thrown out of school after having a seizure in class. Accepted into a new school, she stayed for three years but ultimately left. “It was *my* decision,” she says. “I was ashamed.”

And in some cases, parents keep their children out of school. “They know the shame epilepsy might mean to their family, so they prefer that their children not go,” Mr. Bangura said.

The situation is no better in the workplace, even for professionals. One woman in the vocational training program lost her civil service job in the country’s Ministry of Works the first time she had a seizure at the office.

Against this backdrop, anticonvulsive medications become a shield against discrimination, since they can prevent a person’s epilepsy from becoming known.

“People who would never have touched these students now come and say, ‘Please, can you do this handiwork for me?’ ” said Assanatu Blessing Turay, an administrator at the vocational training program. “Now they interact.”

Finding medication is often a battle. “When you have epilepsy and you go to the hospital here, they say, ‘We don’t have medicine for that,’ so people are forced to go to traditional healers,” Mr. Bangura said. These patients are often at risk of burns or other injuries, as Mrs. Kabba was; some male healers sexually abuse teenage girls with epilepsy, claiming that sex is a way to drive out demons.

But Dr. Lisk’s clinics are starting to make a difference. “A lot of the doctors — and it’s not only in this country, but generally — they really don’t know how to deal with epilepsy,” he said. “They’re happy that there’s somewhere patients can be referred now.”

Another problem is getting patients to stay on their medication. “People expect instant response,” Dr. Lisk said. “If you give the medication and two or three weeks later they have a seizure, they think, ‘No, it’s not working.’ And then it’s the ‘I told you so’ from the relatives — and they stop.”

As with everything in Sierra Leone, cost is a deciding factor. Dr. Lisk’s program makes phenobarbital available for about \$2 a month regardless of how many times a day a patient takes it. Even so, Mr. Bangura said, many patients say they cannot afford it.

In the developed world, epilepsy care involves brain imaging. Sierra Leone has one electroencephalogram machine (thanks in part to Medical Assistance Sierra Leone, a British charity), one CT scanner and no M.R.I. machines. More complex epilepsy treatments like [neurosurgery](#) are unheard of.

Yet Dr. Birbeck, in Zambia, said such high technology was “not needed to have a public health impact on epilepsy” and added, “You have to have a different approach.”

That, she says, includes the priorities that she and Dr. Lisk have set in their own programs: raising awareness that epilepsy is a medical condition that can be treated; having a functioning health care system with facilities patients can reach; training health workers in epilepsy care; and offering anticonvulsive medicine at low or no cost.

Mr. Bangura and Dr. Lisk aim to expand their efforts. The Epilepsy Association wants to open 10 more vocational training programs; Dr. Lisk is trying to integrate epilepsy care into Sierra Leone’s health care system.

“We hold almost all of our clinics within Ministry of Health facilities, and we also train the staff,” he said. “Because we have one eye on the future: These are the people who have to be able to take over.”

But he added: “We need to have enough trained personnel — more than one neurologist, epilepsy nurses, trained community health officers. We need to do what we are doing 10 times over.”

And ultimately, all efforts come back to dispelling the stigma that still clings to epilepsy here.

“Epilepsy is just a sickness,” said Mrs. Kabba, the vocational tutor. “If your child got a sickness, you wouldn’t just let them down. Look after them. Take great care of them.”