

Coming to America



People with MS who immigrate to the United States encounter new experiences surrounding their disease.

by Vicky Uhland

Sara Qureshi had finished medical school in Pakistan in 2007 when her sister, Kiran Ali, woke up from a nap one day with double vision. Ali visited an ophthalmologist, who referred her to a neurologist. When the neurologist performed an MRI and concluded that Ali likely had multiple sclerosis, the sisters were dumbfounded. MS is so rare in Pakistan that neither of them knew anyone with the disease. “I was attending the biggest medical school in Pakistan and even I hadn’t seen any cases of MS,” Dr. Qureshi says.

The sisters began questioning the neurologist—who also didn’t know much about MS—about Ali’s prognosis. “The first thing my sister asked was: ‘Can I continue hiking?’ and the neurologist said no,” Dr. Qureshi remembers. “Given the lack of experience with MS in the country, we were not able to get the right kind of counseling that should come with a diagnosis of MS. Access to medications was a major issue too.”

It wasn’t until the sisters traveled to the United Kingdom to consult MS specialists that they learned more about the disease. “And it wasn’t until much later, when I was training in the United States as an MS specialist, that I learned the importance of emphasizing that having MS doesn’t prevent you from following your dreams in life,” Dr. Qureshi says.

MS worldwide

In 2013, the MS International Federation (MSIF) estimated that 2.3 million people worldwide live with MS. The data from MSIF’s Atlas of MS showed that most of them lived in North

America or Europe and that the highest incidences of MS are in these two world regions. The Atlas showed that East Asia and Sub-Saharan Africa had the lowest incidence and prevalence of MS. However, this data is changing, says Nick Rijke, MSIF Interim Deputy CEO. Newer epidemiological studies are showing much higher rates of MS than has previously been the case. This is due to a range of reasons, including better patient record keeping, improved diagnosis and people with and without MS living longer. However, whether or not there is an underlying increase in MS remains less clear. Interestingly, Rijke says, evidence from a number of studies shows that when people migrate from low to high prevalence areas, over time the risk that they and their offspring will develop MS becomes much closer to the risk level of their adopted home country. MSIF will publish the third edition of the Atlas of MS in 2020. It will be very interesting to see how rates of MS in North America and Europe compare to other parts of the world, Rijke says. With funding from the National Multiple Sclerosis Society, a study published in February 2019 in the journal *Neurology* reported that nearly 1 million people are living with MS in the United States.

Society MS Navigator Ileana Martinez—one of two Spanish-speaking MS Navigators—says that in the last two years, she’s seen an uptick in calls from refugees who have emigrated from Venezuela, Honduras, El Salvador and Haiti. “There are also people who are coming in on tourist visas and in other ways, seeking medication and treatment,” Martinez says. “One caller shared that people are willing to sell everything to seek treatment in the U.S.”

María De Los Angeles Chiquito immigrated to the U.S. in search of better support for her disease. Chiquito, who was diagnosed with MS in 2004 in her native Venezuela, came to the U.S. as a political refugee in 2017. “The [MS] treatment is better in the United States. There are more resources, more possibilities,” says Chiquito in an email translated from Spanish. “It was the determining factor for my decision to move from my country.”

But while the U.S. may seem like the promised land to people from countries with limited MS treatment options, new immigrants can face some unique challenges. The confusion and despair of an MS diagnosis cuts across many boundaries, but for immigrants, those feelings can be multiplied. Language and cultural barriers, lack of adequate healthcare or health insurance, financial and transportation issues and isolation can amplify the physical, mental and emotional aspects of MS diagnosis, treatment and support.

Here’s how four immigrants from countries around the world have dealt with those issues.



Sara Qureshi, MD, (left) helped her sister Kiran Ali (right) find treatment for MS in the United Kingdom. MS is rare in Pakistan, their home country. Photo

Courtesy of Sara Qureshi

Sara Qureshi, MD, Pakistan

After her sister's diagnosis, Dr. Qureshi decided to devote the rest of her medical career to neurology and the study of MS. She went to New York for neurology training, followed by a two-year MS Society fellowship in neuroimmunology at the University of Texas Southwestern in Dallas. She then moved to Billings, Montana, and in 2017, achieved her dream of opening an MS Center for Comprehensive Care at the Billings Clinic.

Her experiences in Pakistan convinced her of the need for MS centers that cover all facets of patient care. For instance, she says there are only two MS medications available in Pakistan—Betaseron and Aubagio. If people want a different option, they have to find a source and pay for the medication out-of-pocket, as most people in Pakistan don't have insurance. This can make treatment unattainable for many Pakistanis with MS.

Kiran Ali's experiences after her diagnosis also showed Dr. Qureshi how important counseling and other emotional support is for people with MS.

"The diagnosis of MS in the wrong hands, without counseling, is traumatizing," she says. "I make sure to tell my patients that MS is a spectrum, mild to severe. And I tell them that in the last 10 years, MS has changed tremendously because of disease-modifying therapies. Life

is not over. It's possible to control the disease."

Dr. Qureshi says another difference between MS care in the U.S. versus Pakistan is that disability is more of a stigma in Southeast Asia. Her sister Ali, who stabilized in 2011 after developing weakness in her left leg, balance issues, fatigue, heat sensitivity and some pain, felt discriminated against in her job because of her disabilities.

In the U.S., Dr. Qureshi says she rarely sees Asian immigrants with MS, even when she worked in areas of the country with large immigrant populations. But she believes Asian-Americans who do have the disease might not have many issues with accessing care and support. "Many Asians in the U.S. are highly educated and skilled—those are the people who get the visas," Dr. Qureshi says.



Khadra Abdi was diagnosed after immigrating to Yemen, then to the U.S. from Somalia. Photo

Courtesy of Khadra Abdi

Khadra Abdi, Somalia

Like many rural Somalis, Khadra Abdi isn't sure when she was born. She was never issued a birth certificate, so she didn't know what to put on government forms after she immigrated to the U.S. Her father told her she was born in the winter of 1958, but he didn't know the exact date, so she decided her birthday would be Jan. 1, 1958.

In 1991, Abdi and one of her daughters fled war-torn Somalia and spent the next decade with family in Yemen. In 2002, Abdi was able to join her son and another daughter in Fairfax,

Virginia. But Abdi's joy at the reunion was short-lived. In 2004, she began having frequent headaches, tingling in her left hand and leg, double vision and sleeplessness. After an MRI, CT scan and spinal tap, she was diagnosed with MS.

Abdi, who speaks English with a heavy accent, says she hasn't had an issue communicating with her doctors or understanding her disease. Paying for treatment also hasn't been much of a problem.

Abdi became a citizen in 2007, and now has Medicaid, Social Security Disability Income, food stamps and subsidized housing. She also received a pharmaceutical company grant for assistance with her MS medication for one year when she didn't have insurance.

But paying for other necessities is a problem. Abdi says she was assigned a case worker who helped her find jobs, but as her MS progressed, she became unable to work. Consequently, she can't afford a car, which is an issue when she has to walk more than a half-mile to get to the bus line, especially while carrying heavy items such as groceries.

Abdi lives with her son, but he works nights at a local hotel. She feels isolated, relying on a few friends or taxis to get around—including to meetings for an MS support group in a nearby city. But at \$20 in taxi fare per round trip, she wonders how long she can afford to attend the support group. Her lack of transportation also keeps her from going to physical therapy, and she worries her left-leg heaviness will progress.

Until recently, Abdi didn't know any other Somalis with MS. But a young Somali man moved into her apartment building and has MS-like symptoms. "He's from the same tribe as me, and I told him he has MS and should go to the doctor," she says. But because MS is virtually unknown in Somalia and disability carries a stigma there, she thinks he doesn't believe her.

Still, Abdi feels fortunate. Had she been diagnosed with MS in Somalia, "I would have had no treatment," she says.



Ana Guerrero has experienced the pros and cons of living with MS in Mexico vs. the U.S. Photo

Courtesy of Ana Guerrero

Ana Guerrero, Mexico

Ana Guerrero was working as a veterinarian in Mexico City when she decided she needed a change. So in 2016, at age 29, she got a visa to work in rural Holyoke, Colorado, as a caretaker on a pig farm. "I thought it would be an adventure," she says.

But it turned out to be more adventurous than she had imagined.

In 2017, Guerrero began experiencing tingling in her arms, hands and legs. She visited a doctor, who found a spinal lesion but told her it wasn't a big deal. But Guerrero's brother, who lives in Mexico City, was diagnosed with MS when he was 18, so she knew the symptoms. She made the four-hour drive to Denver for an MRI, which showed she had MS.

"I went home, called my mom in Mexico and cried," Guerrero says. "I feel so lonely in this small town in Colorado where I don't have any friends." Guerrero does have a boyfriend, but he lives 30 minutes away. "Sometimes I come home from work and feel so anxious that I cry like a little baby," she says. "I tried an MS support group on Facebook, but there was lots of depression and it made me feel bad."

Guerrero is grateful she can talk to her brother about their disease and their treatments. She's learned there are pluses and minuses to living with MS in the U.S. versus Mexico. "Here, the diagnosis is so fast," she says. "In Mexico, you first have to go to family doctor, then a specialty doctor. And then the doctor does tests and sends them to the USA [for a

neurologist's opinion].”

But the intricacies of health insurance and medical payments are much more difficult in the U.S., Guerrero says. She has health insurance from her job, but was shocked that it doesn't cover all of her treatment. “I had to pay \$4,000 for my diagnosis,” she says. “It's very scary when you receive the mail and it says: ‘You need to pay, you need to pay.’”

Guerrero says her biggest problem has been MS medications. Her doctor prescribed Ocrevus, but her insurance balked at payment. Between December 2017 and October 2018, she only had one dose of the drug, which is supposed to be given every six months as an infusion. “I don't understand the steps I need to take or where I can go to get help,” she says.

Her brother has fewer financial issues, but also fewer medication options, she says. “And sometimes they run out of the medications.” Because of this, Guerrero worries that she may not be able to leave the U.S. “I would have to start over [with treatment] if I move back to Mexico,” she says.

On the plus side, there's much less stigma associated with MS in the U.S. compared to her home country. “Here, people are more kind about having a disease,” Guerrero says. “In Mexico, they treat you like you are stupid. They say: ‘You can walk if you try.’”

Navigating the foreign world of healthcare

Finding and paying for healthcare can be difficult enough for U.S. citizens. But imagine if you're an immigrant trying to navigate America's complex health insurance system.

“The main questions we answer are how to get health insurance and how to obtain medications and medical services without health insurance,” says Spanish-speaking MS Navigator Jocelyn Cuevas Tellez.

According to Healthcare.gov, “lawfully present immigrants” can buy private insurance through the Affordable Care Act marketplace and qualify for rebates just as a U.S. citizen can. This applies to green card holders, refugees and asylees (including people from Cuba and Haiti), victims of trafficking or other humanitarian issues, and a few other categories.

But in many cases, these immigrants have to wait five years to qualify for Medicaid. The Refugee Center says people who enter the U.S. as refugees may be eligible for Medicaid and CHIP (Child Health Insurance Program) sooner, but it varies from state to state. Also, 29 states plus the District of Columbia provide health coverage to pregnant women and child immigrants without any waiting period.

All of this applies only to documented immigrants, however. Consequently, undocumented immigrants tend to avoid visiting doctors, going to a hospital emergency room only if they have severe MS symptoms. “But when they're released with a diagnosis, they're not able to

see a specialist to start treatment because they have no health insurance,” says MS Navigator Ileana Martinez.

In areas like Texas and California that have large populations of undocumented immigrants, Martinez says community clinics can help connect these immigrants with neurologists and other MS specialists. Similar clinics are available in other states, but people may have to travel some distance to reach them. Tellez says California also has Medicare emergency programs for undocumented people looking for neurologists. Some pharmaceutical companies offer patient-assistance programs that provide free or discounted medications to people in need; however, this may only apply to documented immigrants due to different eligibility criteria, Martinez says.

Tellez says another problem for both documented and undocumented immigrants is a lack of vital information and support about their disease. “Sometimes I feel like clients don’t have a full understanding about what the neurologist is telling them or is expecting from them,” she says. “Things get lost in translation, especially when someone is shy to communicate or look for resources because they don’t speak English or aren’t fluent.”

Tellez says in-person support groups for first-generation immigrants living with MS are rare, unless someone lives in a big city that’s a hub for immigrants from their native country. And unfamiliarity with technology, or lack of access to the internet, can make online resources difficult to access.

National Multiple Sclerosis Society MS Navigators can help immigrants (both documented and undocumented) and others with the financial intricacies of MS treatment, and provide information and resources about the disease. To speak with an MS Navigator, call 1-800-344-4867.

Yarina Ricardo, Cuba

When Yarina Ricardo was diagnosed with MS in her native Cuba in 2013, she had never heard of the disease. “The impact was terrible for my family—and for me, a change of life completely,” she says in an interview translated from Spanish.

Two and a half years later, she and her family immigrated to the U.S. as part of a family reunification program. They initially lived in Miami but moved to Texas when her husband found a job. Ricardo says her husband makes just enough money to cover the family’s living expenses.

And that frightens her because in June 2016, the temporary Medicaid the family was originally granted as refugees expired.

Even though they have green cards (which grant permanent resident status), Ricardo and her family won’t qualify for Medicaid again until they’ve been in the country for five years—which isn’t until October 2020.

"I have been told that in the U.S. people are not discriminated against because of illness or disability," she says. "But I cannot find medical insurance that can cover my needs regarding my illness. I have gone to several places to ask for help and guidance, but it is very difficult to make people understand. I have received very bad treatment."

Ricardo said in Florida, doctors gave her discounted rates. But Texas doctors haven't done the same. She's reaching out to local organizations and agencies for assistance in covering her rent or utilities, which would free up money to pay for her MS treatment.

Ricardo's only symptom currently is optic neuritis, but "I'm terrified of getting worse and not having health insurance," she says.

Despite these worries, Ricardo does see some benefits to living with MS in the U.S. A pharmaceutical company is providing her MS medication free for one year. And she notes that there are many more resources for her disease in her newly adopted country.

Vicky Uhland is a writer and editor in Lafayette, Colorado.

Visit [Café con Leche](#), a telephone-based support group for native Spanish speakers.

MS Navigators can offer help to a variety of non-English speakers. Call an MS Navigator at 1-800-344-4867.

Find [resources in Spanish](#) from the National MS Society.