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MIND

I Had Alice in Wonderland Syndrome

By Helene Stapinski June 23, 2014 4:57 pm

A few months ago, my 10-year-old daughter, Paulina, was suffering from a bad headache right before bedtime. She went to lie down and I sat beside her, stroking her head. After a few minutes, she looked up at me and said, “Everything in the room looks really small.”

And I suddenly remembered: When I was young, I too would “see things far away,” as I once described it to my mother — as if everything in the room were at the wrong end of a telescope. The episodes could last anywhere from a few minutes to an hour, but they eventually faded as I grew older.

I asked Paulina if this was the first time she had experienced such a thing. She shook her head and said it happened every now and then. When I was a little girl, I told her, it would happen to me when I had a fever or was nervous. I told her not to worry and that it would go away on its own.

Soon she fell asleep, and I ran straight to my computer. Within minutes, I discovered that there was an actual name for what turns out to be a very rare affliction — Alice in Wonderland syndrome.

Episodes usually include micropsia (objects appear small) or macropsia (objects appear large). Some sufferers perceive their own body parts to be larger or smaller. For me, and Paulina, furniture a few feet away seemed small enough to fit inside a dollhouse.

Dr. John Todd, a British psychiatrist, gave the disorder its name in a 1955 paper, noting that the misperceptions resemble Lewis Carroll’s descriptions of what happened to Alice. It’s also known as Todd’s syndrome.

Having had it myself, I had a sense it wasn't dangerous. But I wanted to know more. I contacted several neurologists whose work with the syndrome I found online and learned more about its possible triggers: infections, migraine, stress and drugs, particularly some cough medicines.

Epilepsy and stroke were sometimes linked as well, the researchers said. Some even believe that Lewis Carroll, who described his migraines in his journal, may have suffered from it.

Alice in Wonderland Syndrome is not an optical problem or a hallucination. Instead, it is most likely caused by a change in a portion of the brain, likely the parietal lobe, that processes perceptions of the environment. Some specialists consider it a type of aura, a sensory warning preceding a migraine. And the doctors confirmed that it usually goes away by adulthood.

Several neurologists have done M.R.I.s on patients with the condition, though once the bout has passed, there's usually no sign of unusual brain activity. Dr. Sheena Aurora, a Stanford neurologist and migraine specialist, was the first to scan the brain of someone — a 12-year-old girl — in the middle of an episode.

According to Dr. Aurora's 2008 report, electrical activity caused abnormal blood flow in the parts of the brain that control vision and process texture, shape and size. "The brain of someone with Alice in Wonderland syndrome is just a little bit different from those with other auras," she said.

Dr. Aurora hopes to develop a database of patients with other doctors so they can study the condition and other migraine-related auras. Out of the 25,000 patients she has worked with, I was only the third person she had ever spoken to with the syndrome.

She asked for a family tree denoting which relatives had experienced it, so she could perform genetic testing to search for a link. "Sometimes," she said, "one single case can change the way we understand things."

I soon discovered my 14-year-old son, Dean, had had episodes for years — though he had never mentioned it to me until I brought it up. He recently began suffering from migraines.

I learned that my mother experienced the syndrome as a girl; her symptoms

were so bad that sometimes she couldn't walk. My sister, a migraine sufferer, had experienced it as a child, as had my brother, who remembered having it during a bout of mononucleosis, which is sometimes caused by Epstein-Barr virus, another known syndrome trigger.

My first cousin Jamie said she had it into her 20s, at a time of great stress in her life. Dr. Aurora was fascinated to learn of so many people in one family being affected; the condition is considered so rare that there have been few studies of it.

Dr. Grant Liu, a pediatric neuro-opthalmologist at the Children's Hospital of Philadelphia, said his research into the syndrome shows that even small changes to the brain can yield dramatic effects. When those areas involved in determining size, shape and distance malfunction, he said, "the resulting visual experience can be extraordinary."

Dr. Liu recently examined and interviewed 48 patients, all of them who had the syndrome as children between 1993 and 2013. Thirty-three percent of the cases were traced to some sort of infection, 6 percent to migraine and another 6 percent to head trauma. In about half of the cases, however, no cause was found.

A quarter of the subjects with no migraine history eventually developed migraines, Dr. Liu also found. In addition, 40 percent were still experiencing symptoms. Dr. Liu said it took time for family members of those studied to admit that they too had the syndrome, which leads him to believe that it may be more widespread than people think.

"A lot of family members didn't own up to it on the first go-round," said Dr. Liu. "They were almost too embarrassed. People want to be told that they're not crazy."

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