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Neurologists Look at Causes of Baffling Brain Condition
By Maggie Freleng

Diane Rabinowitz sits in her Los Angeles living room in front of a bookshelf brimming with self-help books and memoirs. She has a blonde bob, thick glasses and a chunky sweater. She’s a science teacher and a single parent. As she tells the story of her last seven years, she looks tired but slightly on edge. Every few minutes her son Tariq walks through the room, dragging his baggy jeans, on his way to the kitchen to grab some food with dirt-covered hands. He keeps to the shadows, listening, like a child. But Tariq is not a child. He’s 24. The deep cut on his lip and burn scars on his body reflect the inner struggle he’s dealt with his whole life.

“At first we thought he was rebellious,” said Rabinowitz. “Headstrong. He had always been a little headstrong, so it was just a little more of it. And he was a teenager, so we couldn’t really be sure.”

But then his behavior became bizarre. He seemed paranoid. He told her that all the teachers at school were staring at him and that at 11:15 a.m. everyone would cough.

One day Rabinowitz got a call from the police.

“They said, ‘We think you should come home and see your son. Did you know he was burned?’ And I said, ‘No, I didn’t know’...That’s when I realized something was wrong.”

Tariq was diagnosed a couple of years ago with schizophrenia, a chronic brain disorder that affects the way people think and act. Tariq is one of the at least 7 million of people in the U.S. who suffer from severe mental illness like schizophrenia. He became increasingly withdrawn, isolated, and angry. As his condition worsened, he would often talk or yell at people who were not there, and he became so consumed with his own thoughts that he lost the ability to care for himself, not bathing and failing out of school.

Even though he now has a diagnosis and prescription, Tariq often refuses to take his medicine because he truly believes there is nothing wrong with him. And when he doesn’t, things can get really bad. Rabinowitz says he has spent a lot of time homeless and in jail.

“For a long time, I was really afraid of him,” she said. “I was afraid he was going to hurt me or steal things. There was one time the house was broken into, and I’m pretty sure he was in on it. I had to call the police several times. One time he threatened me. One time he knocked me down.”
Although people with schizophrenia are usually not violent, according to the National Institute of Mental Health, their delusions and hallucinations make them unpredictable. Making matters worse, more than half believe that their delusions and hallucinations are completely real.

Tariq is not in denial. He suffers from a neurological condition known as anosognosia -- the inability to recognize one’s own illness. It’s very common in people with schizophrenia.

“Anosognosia is the classic term of lack of knowledge of disease,” said Philip Gerretsen, a psychiatrist with a Ph.D. in neuroscience. Gerretsen does his research at the Centre for Addiction and Mental Health in Toronto. Anosognosia actually translates as “lack of insight” or “lack of awareness.”

Doctors have been aware for centuries that some people are blind to their own ailments, but the person who coined the term was the French neurologist Joseph Babinski.

In the early 1900s, Babinski treated two partially paralyzed patients, each of whom was unable to move her left arm. When asked to do so, one woman acted as if the question had not been asked; the other insisted that she had done it. Babinski called this lack of awareness anosognosia. Experts now recognize it in conditions as diverse as Alzheimer’s disease, brain injury and anorexia. Anosognosia explains the syndrome in which people with anorexia perceive their bodies as normal when in fact they are malnourished and skeletal.

Experts don’t know for sure what causes anosognosia, especially when there is no visible damage to the brain, but they have noticed that it involves an imbalance between the two halves of the brain.

Our brains are divided into twin lobes called hemispheres. Gerretsen said the setup is like a twin propeller plane.

“If you think of each propeller as representing one of the brain’s hemispheres, the two work in tandem, or work together to help the plane fly in the proper way,” he said. In a healthy brain, everything is moving along in the right direction, both propellers working succinctly.

But, “In anosognosia, one of the brain hemispheres is underactive and it veers the brain or the plane in the wrong direction.”

Experts hypothesize that anosognosia occurs when the left hemisphere is working harder than the right. To test that theory, Gerretsen and colleagues recently asked people with schizophrenia to lie in brain-scanning machines while answering a list of questions. Things like: Do you have
schizophrenia? Are you mentally well? Is the devil’s voice real? Do you need treatment? My antipsychotics are poison.

And indeed, Gerretsen’s team found that the people who had most trouble distinguishing thoughts from reality tended to have asymmetrical activity in their brains, with the left hemisphere in overdrive.

Gerretsen speculates that a factor in this phenomenon is the brain chemical dopamine. Often called the happiness hormone, dopamine pulses through the brain when people fall in love or eat a satisfying meal. But dopamine also assigns levels of importance to our experiences, Gerretsen explains, and when dopamine goes haywire, as in a brain with anosognosia, neutral occurrences, such as the glance of a stranger, can take on too much significance.

“They have these strong beliefs that they are being, say, followed by the mafia or someone is persecuting them. And in those contexts, dopamine seems to be assigning a higher level of meaning to these thoughts than it otherwise should be,” he said.

Anosognosia may have protective value, Gerretsen believes. “I see it as a normal mental operation of the brain,” he said. “It has survival advantages, so that a person doesn't hyperfocus on an injury or illness that they have on a 24/7 basis. So in the short run, anosognosia can be quite adaptive and promote survival, but in the long run it might be more detrimental. So at that point it becomes maladaptive and might lead to longer-term issues for the individual.”

Gerretsen emphasized that this idea is highly speculative, and that further research is required. But in the meantime, hundreds of thousands of people like Diane Rabinowitz are left seeking help for loved ones who insist that they don’t need it.

Anosognosia is one of the main reasons that people with schizophrenia refuse treatment, and often wind up homeless or in prison. The Treatment Advocacy Center, an advocacy organization based in Virginia, estimates that about one third of the homeless population and 16 percent of the prison population are people with untreated severe mental illness.

“Most are people resisting treatment, getting hurt, getting in trouble, being victimized, spending too much money. That’s kind of the norm, unfortunately,” said Rabinowitz.

But trying to convince Tariq to take his medication and that his paranoid thoughts weren’t real only led to arguments.

“There is help here in L.A. He just won’t go for it,” she said. “Sometimes you can pick up and fight, and sometimes you’ve got to lay it down.”
But Rabinowitz has been working with therapists trained in a new approach. Psychologist Dr. Xavier Amador has developed a method to help families communicate, even when one member is divorced from reality. This approach teaches “the three A’s”: apologize, acknowledge your fallibility, agree to disagree.

Amador is the author of many books, including one on Rabinowitz’s bookshelf entitled, “I Am Not Sick, I Don’t Need Help!” He’s also the founder of the LEAP Institute in New York, which stands for: Listen, Empathize, Agree and Partner.

“There’s really no reason to keep throwing gasoline on the fire of this conflict of: You’re sick. No I’m not. No, you're really mentally ill, you need treatment. No, you’re the one who's sick; I don’t need treatment,” he said.

Trying to force a person with anosognosia to see things the way they really are only deepens the rift, he said. “These are individuals who don’t have the ability to see the difference... I wouldn’t want treatment for an illness I don’t believe I have.”

Instead, Dr. Amador encourages caretakers to acknowledge the sick person’s version of events, and to make suggestions, not proclamations. It sounds something like this:

“I’ve been thinking. I could be wrong, and I’m sorry if this is disappointing, but I think you should try this medication because you are so terrified all the time about the surveillance you’ve been telling me about. I hope we can agree to disagree, but since you’ve asked me several times I think you ought to try it, just for two months.”

The goal is to find common ground. Dr. Amador said that removing conflict helps build a trusting relationship. Once that relationship has been re-established, it’s more likely the person will take advice and make better, autonomous decisions. For example, the most severely mentally ill who refuse medication can be ordered by the court system to undergo treatment—medication, therapy, or both.

“And you might think, ‘Hey, why would you want to use LEAP on that person?’” Amador asked. “Because it’s not solved. [Court-ordered treatment] is a lifesaving compress in some instances, but sooner or later the compress comes off.”

When the court order ends, if the person does not have insight into their illness it might be back to square one. So even for people who are already on medication, LEAP can be beneficial.

When Rabinowitz tried Dr. Amador’s approach, things began to improve for her and Tariq.
“We’re living somewhat in peace,” she said. “I learned that yelling doesn’t do any good. Now I say, ‘Hey, would you like to take your meds?’ Or I’ll ask him, did he take his meds? And there must be a different way it’s coming out, because he doesn’t view it as an irritant.”

Tariq has been taking Haldol, an antipsychotic that slows his racing thoughts. He appears lethargic and has trouble piecing together sentences. While certain anti-psychotics like Haldol have been reported to produce these symptoms, it is unclear whether it is the medication or his illness producing them in this instance.

Although Tariq doesn’t really know why he’s on medication, it does seem to help. He is living back home, has cleaned his room, and no longer chooses to sleep in the bathroom – a decision that can most likely be explained buy the unpredictability of the illness. Rabinowitz said she is less afraid of him now and has not had to call the police in a while. Tariq even decided to sit down and join our conversation. When I asked him about going back to school, he cracked a huge smile and said yes, he wants to.

“Maybe even do some kind of sports stuff or some type of hobby class,” he said.

Although Rabinowitz and Tariq still have a long road ahead, things are getting better.