The Family Who Mistook Illness for Identity

A Triptych of Neurological Narratives

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A Look Inside

Nani was the owner of the first Indian Grocery Store in Boston: Indian Tea and Spices. As a 23-year-old immigrant from the village of Umbhel in Surat, she put all of her effort into making the lives of her three children better than her own. However, once Parkinson's began, it didn't stop. A customer would ask where the Haldi or Turmeric was, and she could tell you the exact placement of the box, its price, and its origin, but when it came to grabbing the spice, the shaking took over. Nani would be serving the cafeteria lunch at my mother's school, and she would not be able to give the extra scoop of mashed potatoes all of the kids desperately begged for or hold the mop that was for cleaning the floors.[1] Eventually, these incidents multiplied, causing her to slowly withdraw from the activities she loved most.

At her house, there was a sense of expected responsibility I housed as a 10-year-old:

"It's okay Nani, I can grab it for you," or "let's get takeout Nani, we don't need to cook."

"Digra, will you get me my pain meds, the shaking is acting up again. I am sorry, we can play mastermind later."

At first, it was a monthly doctor check in, until it was twice a week discussions over a treatment that didn't quite exist. She was a kind soul who lived her whole life putting others in front of herself, but now it was time that she needed to let her loved ones back in. It was interesting that the deficiency of one neurochemical (dopamine) that we take for granted disrupted the communication between most of her brain cells, causing her to have resting tremors for the rest of her life.[2] However, nobody discusses what follows motor symptoms by years: depression.

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[1] Nayna Kaushek, interview by the author, Los Altos, CA, May 10, 2025.

[2] American Association of Neurological Surgeons, "Parkinson's Disease," AANS: American Association of Neurological Surgeons, last modified April 30, 2024, accessed June 2, 2025, https://www.aans.org/patients/conditions-treatments/parkinsons-disease/.

When I walked into the hospice, she immediately shed a smile that I knew was suppressed for too many years. She was too weak to use her muscles to speak, but she had just enough energy to serenade me with her warm smile. In those last couple of days, all she could do was apologize.

“I am sorry, Manē mārā priyanē māpha karō.”

“It’s okay Nani, there is nothing you can do.”

After our 3 minutes of peace, the tremors would start again, but this time too violently for me to keep holding her hand. So I would let go and just wait for the earthquake to pass, while I watched her suffer in silence.

When I think of Nani, I can make no sense of what had occurred in terms of conventional neurology. In some moments, she seemed perfectly preserved, and in others incomprehensibly destroyed. Does everything really get better with time? How could Nani then begin her 30s with subtle tremors, and end her life 4 years ago with severe cognitive impairment and destroyed executive function? I never saw her again after that day at the hospice. But I often wonder how she maintained so resilient when Parkinson's was progressively breaking her down more and more by the day. They say most cases of Parkinson's are thought to result from a combination of genetic susceptibility, environmental exposures, and aging.[3] Nani worked on the farms in Umbel as a kid, exposing her to toxins that could cause Parkinsons-like symptoms.[4] Nani also likely had genetic mutations that furthered her disease development. Yet, age did not quite sit right. How does one reconcile their existence when, from age 30 onward, her disorder has become an uninvited co-author of her every experience? Nonetheless, we don’t

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[3] Johns Hopkins Medicine, "Parkinson's Disease Risk Factors and Causes," Johns Hopkins Medicine: Conditions and Diseases, accessed June 2, 2025, https://www.hopkinsmedicine.org/health/conditions-and-diseases/parkinsons-disease/parkinsons-disease-risk-factors-and-causes.

[4] Kaushek, interview by the author.

choose to remember Nani as the soul whose life and liveliness were slowly taken away from her due to the advance of her disease.

“Remember Digra, that your health and education are the most important parts of your life,” she said a couple of weeks before being transferred to the hospice.

I choose to remember Nani as a courageous, selfless Prēraṇā, who got dealt the deathly hand of cards too soon. It was always a source of regret to me that, due to her passing beyond my control, I was not able to follow her case further to ascertain the actual disease pathology and targeted treatment. Yet one day, I’ll be able to tell a future grandchild that her grandmother was cured—to ease the pain of never knowing, “Why Nani?

The Weight Between Us

She was Sam, the hard worker, the athlete, the humorist. As the oldest child, she knew she had to lead by example, and that example had to be perfect. Sam would wake up in high school at 5 am before any of her classmates just to get ahead of the day’s work, while fitting in an hour run as the sun rose in Los Altos Hills.[5] She was good at hiding the work she put in because, to her, it was shameful to let anyone know the amount of effort she applied to maintain this mask of protection. Being determined clearly presented no problems, even if it meant working to make sure nobody knew that she was secretly starving herself, while forcing herself to work out twice a day. No exceptions.

However, the slow yet painstaking symptoms went unacknowledged for months and then years.

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[5] Samina Kaushek, videoconference interview by the author, Los Altos, CA, May 9, 2025.

During the car ride home from the last day of Sam's sophomore year, I was told to tell my mother that Sam could not make it to any family dinner this week. What could be occupying her every single night for the next seven days? What secret was she hiding?

"It is just a really busy time for me, you know, with college? You will understand one day." I convinced myself of the logic behind her response, yet still carried on unsettled.

People with anorexia nervosa may recognize hunger signals, but brain circuits involved in reward processing, interoception (awareness of internal body states), and decision-making often function abnormally, which can lead them to ignore or suppress those signals.[6] This masked dysfunction was increasing Sam's food avoidance, yet nobody knew. Our summer ice cream drives and slurpee Sundays slowly ended. Our pre-school Starbucks runs never happened again. Our Castilleja gossip sessions have reduced in frequency. There was someone—something always on her mind, and I was left simply asking myself why?

It was not until Sam's sophomore summer that she decided she would begin her fitness journey.[7] Was it a journey or a deceiving trap? Nobody knew at the time. February 11th, 2020, marked Sam's favorite time of year: the Super Bowl. On the drive up, I watched as her eyes glimmered—almost with a level of addiction—as she posted "easy 10 miles: bright and early" on her Strava account. At my aunt's house, I examined her as she served herself her "favorite" dishes: mac and cheese, chicken wings—the whole ordeal—yet not once did I ever see her take a bite. Interestingly, anorexia affects the hypothalamus, a brain space that regulates appetite and satiety through neuropeptides or protein-like molecules. In anorexia, their regulation becomes dysregulated, contributing to persistent food restriction and

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[6] Guido K W Frank, "Altered Brain Reward Circuits in Eating Disorders: Chicken or Egg?," National Library of Medicine: Current Psychiatry Reports, last modified October 1, 2014, accessed June 2, 2025, https://pmc.ncbi.nlm.nih.gov/articles/PMC3888645/.

[7] Kaushek, videoconference interview by the author.

hyperactivity.[8] Sam did not lay eyes on the Super Bowl game once; rather, she was too engrossed in the harmful plate lying in front of her.

Just three months later, coupled with hundreds of missed meals, lost friendships, and a sickly amount of workouts, the day came. She was diagnosed with severe anorexia nervosa, and while my family was still in denial, I was nothing but grateful for the diagnosis. Sam became so terrified of exposing what she saw as a "weakness" of hers, to the point where her struggle resulted in inpatient treatment for her eating disorder.

It was December 21st, 2020—almost Christmas time—and my new form of bonding with Sam was bringing Chinese food to her hospital bedside and simply eating with her.

"Please Ariya, couldn't you have brought anything else?" she said.

How come something we used to love to do so dearly had become a punishment for her? How could one starve themselves to the point where their brain reduced in size, and their vitals were nearing death?[9] Sam did not choose to be her anorexia, but it got to a point where she felt that was all she was.[10]

Months passed of therapy, acceptance, and treatment, and I could see the real Sam coming back. She was slowly choosing a life where she was so much more than what she ate or the number of steps she hit that day. But as we have resorted back to our late-night drives, I often think about the fact that her years—my years—of confusion and misery could have all been avoided if we could have found the person in her brain stealing her away, one step sooner.

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[8] Philip Gorwood, Jeanne Duclos, and Jean-Claude Melchior, "New Insights in Anorexia Nervosa," Frontiers in Neuroscience, last modified June 28, 2016, accessed June 2, 2025, https://www.frontiersin.org/journals/neuroscience/articles/10.3389/fnins.2016.00256/full.

[9] Sidney Taiko Sheehan, "Groundbreaking study shows substantial differences in brain structure in people with anorexia," Keck School of Medicine of USC: Newsroom, last modified June 14, 2022, accessed June 2, 2025, https://keck.usc.edu/news/groundbreaking-study-shows-substantial-differences-in-brain-structure-in-people-with-anorexia/.

[10] Kaushek, videoconference interview by the author.

One Last Spot

Raj did not always care about the amount of times he washed his hair a day. He did not always need to tap his foot hundreds of times to feel control in a conversation.[11] Obsessive-compulsive disorder (OCD) is inherently polygenic, meaning it involves hundreds of common genetic variants, each contributing a small effect.[12] The disorder has a significant genetic component. So how is it that the person I shared a womb and a childhood with inherited something that I seemingly did not? Of all the people qualified to observe the condition that shapes my twin brother's life, I contain the unique advantage in understanding the role OCD plays in it.

There was not one specific day when he woke up and was hit with the impact of his OCD. Perhaps during his childhood, his cortico-striato-thalamo-cortical loop—responsible for decision-making and habit formation—was already disrupted, but the imbalance didn't lead to repetitive thoughts and behaviors until later in life.[13]

There was a period of time when he had an obsession with applying sunscreen. To be quite frank, it caused me to question whether I was the incautious one in the family. Day in, day out, that Neutrogena Ultra Sheer SPF 70 bottle never caught a break.

"This is why I never get burnt, Ariya. It's just because I'm safer than you," he would say.

"Well, does that really have to mean applying sunscreen 3 times a day, you can't possibly be that frantic?"

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[11] Rajan Kaushek, interview by the author, Menlo Park, CA, May 9, 2025.

[12] Behrang Mahjani, "Genetics of obsessive-compulsive disorder," Cambridge University Press: Psychological Medicine, last modified May 25, 2021, accessed June 2, 2025, https://www.cambridge.org/core/journals/psychological-medicine/article/genetics-of-obsessivecompulsive-disorder/DD321BD5C262228FA9D419347A12E4B7.

[13] Jessica Calzà et al., "Altered Cortico–Striatal Functional Connectivity During Resting State in Obsessive–Compulsive Disorder," Frontiers in Psychiatry, last modified May 10, 2019, accessed June 2, 2025, https://pmc.ncbi.nlm.nih.gov/articles/PMC6524661/.

There was a compulsive reinforcement within Raj, putting on sunscreen reinforced the cycle via negative feedback loops.[14] These patterns continued to manifest themselves in dissimilar ways.

“Make sure you lock the doors when I am not here!” my mom would say before leaving for her work trips.

Maybe Raj took that too seriously, or was just trying to be the man of the house, but he would re-check the doors repeatedly to ensure they were locked. I could tell he was catastrophizing his intrusive thoughts, believing it was his personal responsibility to prevent any possible harm.[15]

But his OCD wasn’t just something he lived with; it was something he had to own.

“Bro, chill it is just a car,” his friends would say when he would get mad after they stained his Lexus with cheeto dust.[16] I saw him first hand, trying to hide the side of himself, telling him cleanliness was the only answer, yet it followed him everywhere.

There was a time when Raj and I were coincidentally math partners, when I got to perceive the way he went about learning. He could not sit with the fact that there was an incorrect answer on the page. Erase, erase, restart.

“Raj, it’s fine, let me get a new paper,” I exclaimed.

He had no problem funneling me out and resorting to his old repetitive habits. I drive with him every day. I run with him every day. I eat with him every day. But living with him every day is hard—knowing that, by pure chance, a genetic predisposition has permanently reinforced a maladaptive neural pathway in his brain. Out of the hundreds of genes and countless environmental interactions, what

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[14] Tiago V. Maia, Rebecca E. Cooney, and Bradley S. Peterson, "The Neural Bases of Obsessive-Compulsive Disorder in Children and Adults," Cambridge University Press: Development and Psychopathology, last modified April 19, 2011, accessed June 2, 2025, https://pmc.ncbi.nlm.nih.gov/articles/PMC3079445/.

[15] Rajan Kaushek, interview by the author, Menlo Park, CA, May 9, 2025.

[16] Kaushek, interview by the author.

caused that one genetic variation that now condemns him to live a life where there will always be one spot left?[17]

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[17] Mahjani, "Genetics of obsessive-compulsive," Cambridge University Press: Psychological Medicine.

Roundtable Introduction:

In my creative piece, I aimed to create a triptych of neurological narratives that examine three distinct neurological conditions through the lens of intimate personal experience. Drawing significant inspiration from Oliver Sacks's empathetic and scientifically rigorous approach in *The Man Who Mistook His Wife for a Hat*, my work explores Parkinson's disease, anorexia nervosa, and obsessive-compulsive disorder (OCD) through the lives of my own family members. This collection intentionally bridges the medical world and the personal, similar to Sacks's approach, while incorporating current understandings of neurological disorders as complex biopsychosocial phenomena rather than simply biological malfunctions. Each narrative was constructed to blend scientific insight with emotional content, creating what Arthur Kleinman (Harvard Anthropologist and Psychiatrist) would call "illness narratives" that capture not just the biomedical aspects of disease but the lived experience of disorder[18]. By focusing on family members rather than patients themselves, I wanted to explore the dimension of illness—how neurological conditions reshape not just individual lives, but entire family systems.

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[18] Bareiss W. (2022). The practice of qualitative inquiry in illness narrative scholarship. *Qualitative research in medicine & healthcare*, *6*(2), 10898. https://doi.org/10.4081/qrmh.2022.10898

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