The Only Cure for OCD Is Expensive, Elusive, and Scary

The best treatment for obsessive-compulsive disorder forces sufferers to confront their fears. But for many patients, the treatment is far out of reach.

In exposure therapy, OCD patients obsessed with cleanliness might be encouraged to touch toilets.

Alan George / Getty

OLGA KHAZAN | OCT 27, 2016 | HEALTH

Some days, Molly C.'s brain insists she can't wear her work shirt. She realizes this is irrational; a uniform is required for her job at a hardware store. Nevertheless, she's addled by an eerie feeling—like, "If you wear this shirt, something bad will happen today." Usually she can cope, but a few times she couldn't override it, and she called in sick.

She can't resist picking up litter whenever she spots it; the other day she cleaned up the entire parking lot of her apartment complex. Each night, she must place her phone in an exact spot on the nightstand in order to fall asleep. What's more, she's besieged by troubling thoughts she can't stop dwelling on. (She asked us not to use her last name in order to protect her privacy.)

Molly is a college student, but her symptoms of obsessive-compulsive disorder started when she was 14. Since then, a succession of therapists have failed to help her. They've told her, "I don't really know how to treat this," she said. Or, they talked to her about the possible source of her troubles. "It's nice," she said, "but eventually I'm like, 'Okay, I can just talk to my sister.'"

Though Molly and other sufferers of obsessive-compulsive disorder exhibit a wide array of symptoms, they share a common plight: difficulty finding the right treatment. In the small Ohio town where Molly lives, there are no psychologists who specialize in exposure and response prevention, the specific kind of therapy she and many others with OCD require in order to break their crippling thought cycles.

worst, OCD can compel people to spend hours each day rehearsing an intricate mental dance they feel powerless to end. At an OCD conference in Chicago this July, I met one mother of a young girl who is so afraid of getting dirty, she opens doors with her feet. A 19-year-old college sophomore, profoundly insecure about his appearance, told me he spends an hour and 20 minutes each morning brushing his teeth and washing his face. (Pop-culture often portrays the OCD-afflicted as washing their hands frequently, but excessive cleanliness is just one of the disease's many manifestations.)

Along with medication, exposure and response prevention, or ERP, therapy is the gold-standard treatment for people with OCD. It is radically different from more traditional talk therapy, which excavates patients' childhoods or past relationships for clues to their present-day problems. In ERP, none of that matters. Instead, a person is forced to confront their obsessive thoughts relentlessly. The goal is to make the sufferer so accustomed to their obsessions that they no longer feel tempted to engage in soothing compulsions.

At the conference, Scott Granet, a clinical social-worker who struggles with body dysmorphic disorder, a type of OCD, showed how this can be done. Because of an acute fear of having his hair look rumpled, he avoids hats at all costs. Standing before a room of conference attendees, he took a deep breath and slowly drew a baseball cap over his head. "I don't feel too bad, actually," he said, his voice trembling.

"It gets to the point where you want

Other interventions are more extreme: People obsessed with not offending God might hold a satanic ritual. Those assailed by persistent (and baseless) fears they will molest their siblings might read the incest tome *Flowers in the Attic*.

"When people have [intrusive] thoughts, they're worried that it means something about them or expresses their potential for harm," said Karen Cassiday, a psychologist who practices ERP at the Anxiety Treatment Center of Greater Chicago. ERP teaches people, "these thoughts are meaningless, you need to learn to ignore them."

Many OCD sufferers and their families say finding the right kind of therapy is the most difficult part of overcoming the disease. Because of the dearth of psychologists with experience in ERP, as well as geographic and financial barriers, some studies estimate it takes OCD sufferers 17 years to find proper treatment from the onset of symptoms. Seeking certain forms of talk therapy can make them worse, not better. In the meantime, some experience symptoms so debilitating they are confined to their homes.

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The tough-love story of ERP begins in the 1950s. The psychologist Richard Solomon trained dogs to avoid an electric shock, which was heralded by a bright light, by leaping across a barrier in their cages. Eventually, the light would make the dogs jump the barrier, even if no shock followed. Solomon, in other words, gave the dogs OCD, making them irrationally obsessed with a harmless light.

When Solomon shined the light and prevented the dogs from jumping the

stopped fearing it. Their obsession with the light had gone "extinct," in other words.

In humans, the treatment can be similarly grueling, but effective. Most moderate OCD cases get at least partly better if the patient receives two or three months of ERP. It's a big "if," according to Jeff Szymanski, executive director of the International OCD Foundation. "The treatment works, but no one does it, and no one can find it," Szymanski said.

ERP is a subset of cognitive-behavioral therapy, itself a relatively new form of therapy aimed at changing the patient's ways of thinking, rather than at trying to understand the thoughts themselves. ("People with OCD already put too much importance on random thoughts," Szymanski said.) There is no mandatory number of hours that psychologists must spend training in either cognitive-behavioral therapy or ERP, said Lynn Bufka, a psychologist with the American Psychological Association. Bufka did not know what percentage of psychotherapists provide ERP, but she suspects it's "small."

Between 3 and 7 million Americans suffer from OCD at some point—a substantial number, but still far fewer than the vast multitudes who seek therapy for anxiety and depression. Graduate psychology students might never encounter an OCD patient during their clinical training.

There tend to be long lags between the moment mental-health strategies are proven effective and when they're put into practice, Cassiday said. Older psychologists might have had no ERP training at all. While continuing education is available for psychologists, these courses typically focus on ethics or on special populations, like drug users or refugees. And once a psychologist specializes in a given area, such as depression, she is more

Because the symptoms can be entirely mental, it can take years for either patients or therapists to recognize OCD for what it is. Sharon, a 29-year-old from Brooklyn who asked we use only her first name, has a type of OCD that affects her swallowing, breathing, and sleep. When she was a senior in high school, she became convinced she had to breathe a certain way—not too shallow, not too deep—or she wouldn't be able to fall asleep. She went sleepless for days. Her parents, members of a sheltered, Orthodox Jewish community, didn't understand the disease, but they saw she urgently needed help.

Help is not what Sharon found, however—at least not at first. She saw a child psychologist who told her she had anxiety. A social worker advised her to make her "sleeping area a place of zen." She suggested a family session in which Sharon and her parents would examine their past familial tensions. "I didn't have a perfect childhood," Sharon told me, "but I didn't have anything that I would deem traumatic." Nothing worked.

Sharon quit that therapist, and she eventually did find an ERP practitioner. That therapist charges $300 per 45-minute session.

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In other cases, what stands between OCD patients and the right treatment is wide swaths of land. Access to ERP therapists is compounded by the already profound shortage of psychotherapists in rural areas. More than half of U.S. counties have no mental-health professionals at all.

Sarah Terpstra lives in South Dakota, and she drives three hours for her treatment for her contamination fears. At first, Terpstra went to a local

Her ERP therapist doesn't accept insurance, so Terpstra has been fighting with her insurance company to pay her claims. Still, it's worth it. "Even now, going outside and seeing the garbage everywhere ... I try to avoid it as much as I can," she said. "It gets to the point where you don't want to go outside, you want to just stay inside and not have to face any of it. And then you're not living any life that way."

ERP specialists might feel no need to take insurance, since they are so rare they often have no shortage of clients, Szymanski, of the International OCD Foundation, pointed out. Cassiday, the Chicago psychologist, doesn't accept insurance, explaining that ERP's complexity often extends beyond the bounds of a traditional doctor's appointment. "If someone has rituals, we may need to go into their home," she said.

Shirley Huefner, who came to the conference from Los Angeles, said an intensive inpatient program helped her son overcome his extreme fear of germs. But the treatment was so expensive it contributed to the family's decision to sell their house.

When families finally do obtain it, ERP can be life-changing. Janet Singer's 17-year-old son realized he had OCD when he found himself trapped in strange mental grooves, like envisioning harm coming to his friends or feeling unable to stop counting to 1,000. Singer—a pseudonym under which she's written a blog and book about her family's journey—took her son to a pediatrician, who put him on the antidepressant Prozac and recommended he see a psychologist.

They went to popular therapist in their small town. "That therapist said, 'I treat OCD!' and proceeded to do totally the wrong thing," Singer told me.

Her son assured Singer he was getting better, and he went off to college. But in his second semester, Singer became alarmed at how he sounded when he called home. She told him to go to the school counseling center.

"I can't," he said. "I can't."

"I finally realized he was saying the OCD wouldn't let him leave his room to walk down the path to go to the counseling center," she told me.

Singer flew to visit him, and his condition shocked her. Her son would sit in a chair for eight hours at a time and go days without eating. He was obsessed with the feeling that harm would come to those he loved. If he avoided eating, he was convinced, he could keep it from coming true.

At that point, a year and a half after her son first exhibited symptoms, Singer placed him in a residential treatment program at a psychiatric facility she asked me not to name. When I called the facility, a recording told me there was a three-month waiting list for its inpatient OCD treatment program. Over the course of nine weeks, Singer's son slowly recovered through ERP that cost $400 to $500 weekly, as Singer recalls, after insurance. Though he's not completely free of OCD, he's now living independently and working in his chosen field. He even has a steady girlfriend.

"It was the best money we ever spent," Singer said.

ABOUT THE AUTHOR

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