6 THE BOY WHO COULDN'T STOP WASHING

Charles, then fourteen, spent three hours or more in the shower each day and took another two hours to get dressed. This strange behavior had been going on for a couple of years.

"I hear you have a new study, Dr. Rapoport," his mother said. "The other hospital didn't know what to do. They stop him from showering *there,* but when he comes home, he just starts up again."

"What does *he* say about all this?" I asked.

"He just tells me he can't help it. He says he just *has* to."

Psychotherapy had not helped, nor had a variety of standard psychiatric drugs, or months of the hospital's behavioral treatment program. Charles kept trying to wash off "something sticky" from his skin. As military dependents, Charles and his family were entitled to care in military hospitals and the doctors had done their best. But they had seen few patients with such a problem before. Most psychiatrists see a handful at best in a lifetime. About the same time, they read about our new study at the National Institute of Mental Health. They were calling from North Dakota.

Now we are flooded with patients much closer to home. At the time, though, I still thought OCD was rare. So Charles and his family came to Bethesda as part of our study in 1976.

Until he had to leave school (or more accurately, couldn't get out of the shower in time to get to school), Charles had been an eager student who loved biology and was interested in plants, genetics, and chemistry. His biology teacher was encouraging him to plan ahead for an out of town college, and to think about becoming a teacher or a doctor. Charles had shown a great ability for observation in the laboratory experiments, and in drawing logical conclusions from these observations.

Now he could not trust his own "good sense" or his senses. There was no such thing any longer as "knowing it was okay" or "seeing for himself" that his hands and body were clean. His mother was desperate; life had become a nightmare of invisible contamination. Charles "knew," he "felt sure" that there was some sticky substance on his skin. He thought of nothing else.

In her futile efforts to help, Charles's mother joined in the rituals. She knew they were crazy. But it was hard for her to see him so miserable if his rituals weren't carried out. So she cleaned everything he might touch with rubbing alcohol. She helped him scour his room over and over again. She kept people out of the house to prevent "contamination" from the street. Charles's father spent more and more time at his job, and came home late to avoid the whole bizarre scene.

I saw how OCD can distort family life, splitting it into warring factions and eliminating ordinary routine. This is familiar now, but at that time, watching a family act out the rituals without understanding was weird. As Charles's mother told me: "He had never been unreasonable before; he really was no different from most boys. So when he cared so much about something, even though I didn't understand it, I felt I had to go along. And he got so upset when I didn't."

Talking with Charles alone was easy and pleasant at first. He was bright and he could be fun. He was hopeful that the study could cure him. But a problem came up almost at once. He was terrified to have an EEG, a brain wave test, because the test involves putting

electrodes on the scalp with a very sticky paste. It is fairly easy to wash off. But, as Charles shouted, *nothing* was easy for him to wash off! Suddenly this poised, bright boy was feeling his horror of stickiness with a bizarre intensity. "Stickiness is terrible. It is some kind of disease, it is like nothing you can understand," he told me. The worst thing he could think of was to touch honey. Once started, Charles couldn't stop. Stickiness was danger, was annihilation.

His condemnation of viscosity was a page that Charles hadn't read from Jean-Paul Sartre's essay on "stickiness," Sartre's personal metaphor for annihilation of the self. Stickiness, Sartre said, is halfway between solid and liquid. It is soft, yielding, and a trap. It clings like a leech and attacks the boundary between oneself and it. "Columns of stickiness falling from my hand," he said, "suggest my own substance is flowing into a pool of stickiness."

Water was different, water was no threat to solidity. Charles always felt the sticky threat on his skin. It meant dread, an insidious attack, the worst feeling he had ever had. Without any provocation he had just spent two years washing. He shrieked that putting something really sticky there would be terrible. "I can feel it," he'd scream at us, "it's really there. I can't stand any more." This was in the heat of the argument. He knew and he didn't know that the stickiness *wasn't* there. We insisted: no EEG, no study. The EEG was done. Charles was up all night washing.

The discomfort of going along with our study was worth it for Charles. A month later, he and I took part in a strange, but to us wonderful ceremony. I watched as Charles poured out honey onto a knife, and then grasped the honeyed blade smiling. The ward cheered. He was our first patient to respond dramatically to the new drug Anafranil. (But more about that later.)

I know now that Charles was a typical child with Obsessive-Compulsive Disorder. But at the time, he was one of the most curious cases I had seen.

Because he was one of the first children I ever saw

with OCD, he and I spent hours talking over "why" he couldn't stop washing. He described what he felt—the urgent insistent sense of "I have to" that was inside him. He didn't hear voices telling him to carry out these odd behaviors—"Everybody asks me that, doctor!"—that would be *really* crazy. His eyes were teary when he said: "Please don't say I'm crazy. That's been the worst part, the other kids and even my sisters teasing me and calling me nuts." He knew it *sounded* crazy, but he didn't feel crazy. He just knew he *had* to wash, that's all.

It became easier to talk to Charles when he saw I didn't think he was crazy. The very ease of getting to know each other was deceiving: it all seemed so normal, so simple. So much of my psychiatric training had been geared to interviewing suspicious, angry, isolated, and irrational patients. It took me awhile to realize that for most of this new group of patients, that kind of skill wasn't needed.

On our ward, Charles became the nurses' favorite. He was open, appreciative, and friendly. When we first met Charles, he had only one friend. Rituals left him no time to leave the house. Many of our patients say that one friend stuck by them through years of isolation. I want to meet these friends, but that's another study.

I asked Charles what would happen if he *stopped* washing. He looked perplexed and could come up only with some vague notions that "maybe some sickness would come" or "it could be bad luck." His insights did not really begin to explain how his life could have become so drastically limited by his ritual washing. The psychological explanation about washing might suppose that Charles felt guilty and ashamed about masturbation. I certainly heard sexual wishes, fears, and impulses from other adolescent patients, but not from Charles. That theory isn't enough to explain this disease. Now that we have seen so many patients over many years, we find even more complexity. Symptoms can and usually do change over the years. When patients start before adolescence, they often count,

check, or repeat movements. In adolescence, they wash. After adolescence, they may ruminate. But at some stage, almost 85 percent of our patients have some grooming or washing ritual. A useful explanation of the symptom pattern in OCD must be one that predicts who will get sick, why there is all this washing, and why it comes and goes.

Charles remained free of all symptoms for a year. And then, gradually they returned even though he was taking the medicine regularly. He had developed some tolerance to the drug.

Charles still isn't completely cured. In spite of dramatic improvement with Anafranil, he can hide his ritual activity by performing in the evenings when he's alone. But the pressure to carry out the ritual washing and dressing never completely went away. He still can't go through a door without being compelled to turn around and walk through it again. When taking a shower, he still has his particular soap ritual. He holds the soap for one minute in the water in his right hand, and out of the water for one minute with his left hand, repeating this process over and over for up to an hour. Charles had no response to Anafranil, and only modest improvement with behavior therapy. But he continues to fight these urges, and remains optimistic that help will come.

Charles's rituals and inner calls for symmetry could be a page from an anthropologist's notebook on the rites of a primitive tribe, or a caricature of a nonexistent religious order. *But he had had no teachers for these rituals.* Although he is "typical" of obsessive children and adults, he has never met anyone else who does anything like this. I ask: "Why do you do these things?" He just shakes his head. "I don't know. I really don't know." He means it.

Since Charles, I have met and treated more children and adults with Obsessive-Compulsive Disorder than most psychiatric hospitals see in twenty years. But it was with Charles that I began to respect the illness as a common and terribly destructive affliction. What makes some patients so memorable? With Charles,

perhaps it was his trusting gratitude that I was trying to help. Whatever the reason, I was determined to find out more about his problem.

Darrel was altogether different from Charles. He never understood why other kids in our study cared about washing. He was never compelled to carry out any ritual. The day his problem began, Darrel woke his parents early in the morning; he was in terror. He asked them, begged them, to lock him in his room. He said he was worried that he might go out on the street and kill someone. How? Perhaps push them in front of a car. Or something. They were astonished. Darrel was a quiet boy, who played the piano well and liked school. He had never been a problem child. Darrel had never even needed much discipline and did not have a bad temper.

Was he mad at anyone? "You don't understand," he said (a phrase I have heard almost every day since I began studying this disease), "I just am not sure, I think I *might* do this. Or electrocute someone." His parents tried to distract him. They were wasting their energy. *He couldn't get the thought out of his mind.*

Darrel's parents did what he asked. They locked his door. A few hours later, they brought him downstairs for breakfast. He was crying. And asking the strange question: "How do I *know* if I am going to kill someone?" All the "right" answers didn't work—"You are a good boy, you are gentle, you would stop yourself, you would never hurt anyone," and so forth. Darrel listened patiently to these useless phrases. They provided only a few seconds' pause before he started up again. "But how do I know if . . ." "How can I tell?"

I met Darrel while he was still on very high doses of haloperidol, a strong tranquilizing drug that is used for schizophrenic patients, and after he had been on a ward for violent patients for several months. He walked stiffly, and spoke in a monotone. But he could describe his curious state of both knowing and not knowing his innocence. He kept on asking, "How can I be sure if I killed anyone?"

This sort of philosophical discussion took up most of the time I spent with Darrel. In fact this was all he would talk about. "Knowing" was the subject. Darrel could not believe his memory, his eyes, his thoughts. In one way or another, every patient with OCD wants to know how to know.

7 THE DOUBTING DISEASE

A major feature, and a strange one, of Obsessive-Compulsive Disorder is the inability to be reassured by the senses. Obsessives have lost their ability to "know" certain simple things that we all take for granted, things that we all constantly check for by some mechanism of which we are unaware, except when it doesn't work. This mechanism is not working for these patients at a level that astonishes me, for they are asking "How do you know" about things that we find ourselves hard put to explain: Is the grass really green? Are my eyes blue? "Why," I say, "we just *know,* that's all."

Obsessive-compulsive patients literally come to doubt their own senses, at least in a selective way. The younger children get demoralized, bewildered, that their parents don't help them, can't help them, and struggle with their families who can't understand why they "just don't stop" their rituals. "When you write your book," they tell me, "be sure to explain that *WE JUST CAN'T STOP.*"

Then there is the content of the rituals. Compulsives (our term for patients who mostly ritualize) and obsessives (those who mostly ruminate) rarely have rituals or thoughts about neutral questions or behaviors (although this can happen; some of these curious "neutral" obsessions are described later in this book). What are their rituals about? There are several possible ways to list the symptoms of OCD. Everyone agrees that the most common preoccupations are dirt (washing, germs, touching), checking for safety or closed spaces (closets, doors, drawers, appliances, light switches), and thoughts, often thoughts about unacceptable violent, sexual, or blasphemous behavior ("I have killed someone," "I am a lesbian"). These thoughts are virtually never acted upon. But in all these preoccupations, a basic function is out of control.

Our patients all believe that their thoughts are odd or crazy; they are embarrassed by their habits and teased by their friends. They keep their ideas and actions secret; indeed some become brilliant actors at hiding their thoughts or rituals. (Thought: Can such a disease prepare one for a stage career? I wonder if there are actors who suffer secretly from OCD?)

When it gets bad, the patients hide. Avoidance of others and of situations that set off these odd patterns is a major complication of OCD. Even the most neutral compulsion—straightening drawers, or counting to 32—is embarrassing because these too have the inner compelling force that marks the disease. The most trivial gesture looks peculiar when it is repeated over and over and over again.

My patients' secretiveness takes the most inventive forms. I have learned some of their tricks. Marion, now 26, used to pray briefly before hopping into bed when she was 12. Her grandmother, who slept in the next room, heard the noise from the bedsprings and assumed her granddaughter had finished praying. After her grandmother began to snore, Marion crept out of bed and prayed for three more hours.

During our study at the NIMH, two boys with severe washing rituals would shower for five minutes on the hospital ward to avoid suspicion. Then they sneaked off to a ward under renovation elsewhere in the hos-