THE SECRET WORLD OF OBSESSIVE-COMPULSIVE DISORDER

BY: MICHELLE P. HEATHERTON

“Michelle, will you please check your boots before you come into my room?” Ashley asks me as I approach the doorway to her bedroom. “I know it’s really weird and everything, but it would just make me feel better if you’d check ‘em.”

"Alright," I answer. "I'll check my boots, but what am I supposed to be looking for?"

"Fleas and ticks and anything that looks like them. If you see a black speck, touch it to see if it moves or jumps."

So, Ashley and I stand in the doorway for several minutes, checking our shoes for black marks. Ashley is very diligent about the entire ritual; she inspects her light-colored slacks, one leg at a time. Then, she lifts up each foot separately and searches for any mark that looks like a flea.

"Okay, I guess we can go in now," she says. "Wait a minute, what's that dark mark on the back of your boot?"

I look down at the side of my left heel, and touch the mark. I can see the anxiety in Ashley's face as she watches me investigate the mark. It doesn't move. Ashley releases her breath.

"Oh, it's just a scuff," I observe.

As we enter her bedroom, Ashley continues to stare at the cream-colored carpet that covers the floor. If she sees a black speck, she steps on it and hopes that it will still be there when she picks up her foot again.

"I'm glad we have light carpets in this house," she says. "I don't know how I would, like, check for fleas and stuff if the carpeting were dark.

"It would drive me crazy," she adds.

Finally, we manage to make our way to the other side of her bedroom. Ashley wants to show me her model horse collection on her dresser.

"You can look at 'em, but don't pick up any of 'em up," she remarks. "It really bothers me if people, like, come into my room and touch my stuff or move things."

Ashley explains that she feels very strange and insecure if people come into her room and disrupt her possessions; she can usually tell if something has been moved out of its proper place. Her mom is the only person who is allowed to move things in her room.

“Is this one Kelso?" I ask, pointing to one of the black horses.

"Yeah, and here's Man O' War."

While I'm admiring her horse collection, Ashley quickly slaps her hand on the quilt of her bed.

"Sorry," she says. "I thought it might be one of those jumping spiders, but it's just a fuzz."

"I hate those jumping spiders, too," I add. "It seems like there's been more of them in the past few years."

"Yeah, I know!" Ashley exclaims. "I even taped the tracks of my windows because lots of 'em were coming into my room and getting on the curtains and rug and stuff."

Sure enough, the tracks of the windows are weatherstripped and filled with scotch tape. The tape has helped somewhat, but it doesn't keep all of the spiders out. Ashley breathes rapidly as she cautiously moves the curtains to check for any jumping spiders. Her chapped, red hands are shaking slightly.

"Do you want me to look for them?"

"No, thanks, I have to do it myself."

It's not that Ashley doesn't trust other people. She just has to be the one to check for the bugs so she can feel less anxious and more comfortable in her room.

Soon Ashley's mom, Karen, informs us that dinner will be ready in about 20 minutes. She has to give Ashley a 20-minute notice because Ashley takes this long to wash and re-wash her hands in the bathroom.

Ashley suffers from obsessive-compulsive disorder.

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Obsessive-compulsive disorder (OCD) is a strange sickness of ritual and doubt that has run wild. It can begin suddenly and is usually seen as a problem as soon as it begins. When the thoughts and rituals are intense, one's work and home life disintegrate.

This is a serious disease, more common than doctors ever thought. According to Cincinnati child psychologist Dr. Cheryl Beach, there may be more than four million people in the United States with this disorder. Over one-third of these are children or adolescents.

For those afflicted with obsessive-compulsive disorder, she adds, senseless thoughts go over and over in their minds. Certain acts are repeated continuously.

In School Psychology Quarterly, Gail Adams describes some of the thoughts and behavioral manifestations of individuals who suffer from OCD. For some, the thoughts are meaningless (just numbers, or a phrase); for others, they are highly-charged ideas (e.g., "I have just killed someone").

Some people are "checkers," Adams says. They check lights, doors, appliances, or repeat peculiar acts over and over again. Others spend hours producing unimportant symmetry. She adds that patients with OCD are usually "washers"; they feel the need to wash over and over again because of the fear of contamination.

Frank Dattilio notes, in the Journal of Mental Health Counseling, that these problems have similar themes: you can't trust your ordinary good judgment or your own senses (which see no dirt, or know that the door is locked).

Although you "know" you have done nothing harmful, Dattilio explains, you must go on checking and counting. You can't dismiss the idea of washing or the urge to repeat certain acts, he adds. The thoughts keep coming back, and you doubt yourself.

The disorder is not new. In her book, Obsessive-Compulsive Disorder in Children and Adolescents, Dr. Judith Rapoport states that the first clear accounts go back more than 400 years and are found in the theological literature on scrupulosity. She explains that scrupulosity is the persistent concern with an incident, thought, word, or deed. These thoughts usually cause uneasiness and distress, and the individual feels compelled to perform certain rituals which temporarily relieve her or him of the anxiety.

According to Rapoport, scrupulosity (like obsessive-compulsive disorder) occurs in persons who are healthy, normal, and free of other pathological disorders.

Beach explains that obsessive-compulsive disorder can best be described as a physiological problem that manifests itself psychologically. Researchers have discovered that high levels of serotonin, a hormone chemically related to adrenalin and released from the basal ganglia of the brain, are present in individuals who suffer from OCD. Thus, she says, the brains

of people with obsessive-compulsive disorder have different patterns of brain activity than those who do not have the disorder.

According to Rapoport, doctors and researchers have been studying more and more cases of children and adolescents with OCD in the past 10-15 years. No one seems to know whether the disorder is becoming more prevalent, or if parents and doctors are simply becoming more knowledgeable and open about it. Children, like adults, initially hide their rituals, often disguising hand washing as more frequent voiding, or "scheduling" ritualization for private time, she says.

In his article "Obsessive-Compulsive Disorder: The Secretive Syndrome" (Psychology in the Schools), Harvey Clarizio notes that children have usually been performing rituals for four to six months before their parents become aware of the problem. He adds that teachers and peers are also unaware of the problem at first because of the child's partial control.

Clarizio and Rapoport both agree that parents are often baffled by the seemingly willful control, seeing their child suppress rituals at school or with friends, but "having" to do them at home. The children maintain that they expend enormous amounts of energy "controlling" their behaviors in public and ultimately have to "let go" when at home.

However, as the illness progresses in severity, they explain, the patient is no longer able to resist ritualizing in public.

If obsessive-compulsive disorder is suspected, it is usually easy to ascertain the nature of the compulsive rituals, the degree of interference in the person's life, and the degrees to which resistance is effective.

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Ashley Dunn is a bright, petite 12-year-old girl with blue eyes and shoulder-length auburn hair. On July 27, 1998, she will turn thirteen. She's been suffering from obsessive-compulsive disorder for almost two years. Ashley says that her OCD started in August, 1996, when a couple of fleas jumped on her and bit her while she was sitting on her bed.

For several months before this incident, the Dunn's had been dusting their two calico cats and trying to rid the cats and their basement of fleas. The cats lived mostly in the basement when they weren't outside; however, once in a while, they would walk around in the house or sleep on top of Ashley's bed. When Ashley found the fleas in her bedroom, the Dunn's realized that they would also have to spray the carpets upstairs in order to completely get rid of the pests.

"We also got rid of the quilt that was on Ashley's bed, and I washed all of her sheets several times," Karen Dunn says. "But Ashley still didn't want to sleep in her bed even after the fleas were gone, so we ended up buying a new mattress for her."

"We thought that after the flea crisis was over, and especially after we got Ash the new mattress, things would get back to normal, but they didn't," David Dunn, Ashley's dad adds.

Actually, the Dunn's thought that everything had returned to normal until Christmas of 1996. Like so many other parents in this same situation, they didn't realize that Ashley had been going through compulsive rituals for four months.

Even though she had a new mattress and quilt, Ashley admits that she never got over the idea that fleas and flea eggs were still in her bed. She managed to hide her obsessions and rituals from everyone until December, 1996.

"At first, I just worried about fleas being in my bedroom," Ashley comments. "I would start getting ready for bed earlier at night so I would, like, have time to check the rug and the sheets and everything before I got into bed."

In these first few months, Ashley's OCD seemed to be confined to her bedroom. She was not bothered at school or in public by thoughts of bugs and germs. But then, during Christmas break, 1996, the obsessive-compulsive disorder began to escalate. At this time, her parents began to notice that something was wrong.

"We had some relatives come over our house for the holidays, and Ashley didn't want them to use her bathroom or walk into her room," Karen explains. "She said she didn't want them in there because they might have bugs or germs."

Ashley says that one of the kids at school got lice just before Christmas break and the school passed around an informational flyer that explained how people could prevent themselves from getting lice from infested individuals.

"The flyer said that you would probably get it if someone, like, shared your bathroom and stuff," Ashley adds. "I don't know my relatives that well, and I didn't want to get anything from them, if they happened to have something like that."

Due to lack of space, though, Ashley's relatives ended up using her bathroom despite her protests. To remedy the situation, Ashley cleaned the toilet seat each time before she went to the bathroom; she also kept her towels and washrags hidden in the linen closet so her relatives would not accidentally touch or use them. After they left, Ashley scrubbed up the sinks, the bathtub, the bathroom floor, and vacuumed the carpet, bedspreads, and drapes in her bedroom and in the guest bedroom.

"After Christmas break, I started thinking that germs and bugs could be anywhere--at school, at the mall, outside," Ashley states. "I had to protect myself from 'em, even if I did look weird or crazy."

When Ashley returned to school in January, 1997, she would wash her hands repeatedly in the restroom. She would often excuse herself from class just so she could wash her hands. Eventually, the other kids started to make fun of her. She finally fabricated a story about having a skin ailment in order to account for her constant hand washing. Now, she carries Dial's anti-bacterial hand sanitizer with her so she can clean her hands whenever the compulsion strikes her.

Ashley is additionally preoccupied with the idea of food contamination and food poisoning. She's heard the news reports concerning e-coli and salmonella and is also obsessed with the thought of contracting a tapeworm. She stopped eating red meat altogether and only eats chicken and fish when they're extremely well-done. Fresh fruits and vegetables present a problem, too; they may be contaminated with amoebas and other parasites. Ashley also heard the reports about people eating lettuce and drinking apple juice that had been contaminated with e-coli bacteria.

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Mealtime is an especially problematic occasion in the Dunn household. Ashley refuses to eat out at restaurants; therefore, if the rest of the family wants to eat out for dinner, Ashley ends up staying home and fixing herself a peanut-butter-and-jelly sandwich. She says that it's safe.

On this particular evening, Karen fixes baked barbecue chicken for dinner. As we sit down at the table, Ashley begins to ask her mother several questions about the preparation of the food.

"Mom, is the chicken well-done?" Ashley asks.

"You know it is," Karen answers.

"How long did you cook it?"

"An hour and 15 minutes at 375. There's nothing left to it."

Ashley then shifts her attention to her dad and her 8-year-old sister, Brittany.

"Did you wash your hands, Dad?" she asks.

"You just saw me in the lav, Ash," David replies.

"Yeah, I know, but did you, like, really suds up your hands?"

"Yes, I did--"

"Brittany, don't touch my baked potato!" Ashley says, interrupting her dad.

"I washed my hands real good," Brittany answers as she licks some butter off her finger.

"If you washed your hands, then why are your knuckles still brown?" Ashley asks.

"I don't know," Brittany sighs, shrugging her shoulders. "I'm not lyin'."

Brittany's knuckles do look dirty. Whether or not she actually washed her hands before dinner is anyone's guess. Unlike Ashley, Brittany doesn't seem to worry at all about germs, bugs, or parasites. Brittany's carefree attitude only seems to aggravate Ashley's condition. The two of them are total opposites.

Before Ashley can settle down to eat, she has to look at the floor and the ceiling and check out any dark specks that look like fleas or jumping spiders. After pouring the milk, she has to wash her hands again because she touched the plastic container.

"Come on, Honey, your food's gonna get--"

"I'm comin'," Ashley says, interrupting her mom. "I just have to rinse off all this soap."

Finally, Ashley sits down and takes a small bite of chicken to test if it's well-done.

"Is it done, Michelle?" she whispers.

"It's extremely well-done," I answer, trying to chew through the dry chicken.

"Is the milk okay?"

"Yeah, it's fine."

Ashley mashes up her baked potato and peas to see if any bugs are in them. Throughout dinner, she is constantly looking down at the floor or up at the ceiling. It takes her an excruciatingly long time to eat her food.

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How has obsessive-compulsive disorder affected Ashley's life and the lives of the people around her?

"Well, I'm still getting all A's in school, but it takes me, like, a real long time to finish my homework because I get distracted with all of the checking and hand washing," Ashley admits.

She adds that sometimes she can be doing fine all day until she sees a jumping spider or another pest. Then, she'll feel very nervous and "itchy" like bugs are crawling on her. Obviously, her concentration is adversely affected by all of this.

In addition to being a good student, Ashley used to participate in softball and soccer. Now, she finds it very difficult just to go outside for any extended period of time.

"Last year was the worst," she recalls. "I couldn't stand to go outside and play softball in gym class because of the bugs."

This year, Ashley's able to stand in the grass for a while, but she has to keep checking her socks and shoes for bugs. It makes her feel a little better when she checks herself instead of pretending that something doesn't bother her.

"I also have to, like, keep my mouth closed real tight when I bend over to pick up the ball so fleas or other things won't jump in," she continues. "You can get a tapeworm if a flea gets in your mouth and you swallow it, or if you eat rare beef, pork, or fish. I read that in a medical dictionary."

Ashley hopes to go to medical school and become a doctor or researcher someday so she can discover cures for diseases; she would also like to permanently eradicate many kinds of germs and pests.

She realizes that she will somehow have to get her OCD under control in order to accomplish things in her life. Ashley despises the condition and hates the compulsive thoughts and feelings that force her to perform the senseless rituals.

"I just want people to understand that these rituals are *not* things that I *want* to do." Ashley states emphatically.

She hates the rituals, but she has to perform them; otherwise, she can't stand the anxiety. Ashley doesn't look for things to worry about.

"The thoughts just come into my head ...it's hard to explain...it's like an end-of-the-world feeling," she says. "I can't ever feel comfortable."

Karen and David Dunn have experienced all the pain, frustration, stress, and guilt that parents feel when their child suffers from this disorder. When they first realized that Ashley had a serious problem, they began to wonder if they had caused it in some way. They were also extremely upset because they couldn't seem to help their daughter. "No one knows except a parent what it feels like to see your precious child suffering and you can't do anything about it," Karen says, rubbing her forehead. "We blamed ourselves at first."

However, when the Dunn's talked to Dr. Cheryl Beach, she told them that obsessive-compulsive disorder is caused by high levels of serotonin in the brain. It really has nothing to do with a child's upbringing or home environment.

Ashley began seeing Beach, a child psychologist specializing in the treatment of obsessive-compulsive disorder, during the summer of 1997.

"Obsessive-compulsive disorder is such an insidious condition," Beach states. "At times, it can be triggered by, what some people may call, a traumatic event."

She adds, however, that an individual's brain chemistry has to be conducive for allowing the effects of the trauma to *become* OCD. On the other hand, she explains, OCD may appear suddenly without any particular event triggering it; certain obsessive thoughts just begin to occur to the person afflicted with the condition.

Dr. Jill Bley, a Cincinnati psychologist conducting research in the area of obsessive-compulsive disorder, agrees that the onset of the condition seems to be different in everyone.

"For some people, a tornado is a traumatic event. Others can perceive an army of ants coming into their homes as a traumatic event," Bley says. "Then, you have the people who think they ran over someone while driving, for no apparent reason."

Bley emphasizes also that this disorder is not something that patients can control; they can only learn how to deal with it.

Beach explains that the most effective current treatment techniques for the disorder are: behavioral therapy, group therapy, pharmacologic interventions, inpatient hospitalization (only in extreme cases), and combined treatment methods. Clomipramine (CMI), fluoxetine, and fluvoxamine are the three main drugs that are prescribed to treat obsessive-compulsive disorder, Beach says. These drugs work by inhibiting the release of serotonin in the brain, she adds.

"The drugs, especially clomipramine, significantly reduce OCD symptoms in about half the patients I've seen," Beach observes. "But they do have many side effects."

According to Beach and Bley, patients most commonly experience confusion, short-term memory problems, and impaired attention. Some other adverse effects are dry mouth, weight gain, constipation, and blurred vision.

Ashley took clomipramine for a couple of months because her OCD was increasing in severity last summer. The drug did help with her compulsive behavior; however, the side effects from the medication were beginning to interfere with her activities. She was unable to concentrate and felt lethargic most of the time. She also had trouble with dry mouth and blurred vision and experienced some nausea. Because of these problems, Ashley's parents decided to take her off the drug.

"You have to determine which is the lesser of the two evils," Karen sighs. "I just never liked the idea of my 12-year-old daughter taking a prescription drug on a regular basis. And when she started having those side effects, well, that made up my mind."

"But then when she didn't take the CMI anymore, the obsessions and rituals started all over again," David adds.

After Ashley stopped taking the drug last fall, she and her parents decided to take a systematic approach to behavioral therapy. Of course, Ashley has also been trying to control her compulsions and is working hard to reason things out when she starts to feel obsessive about something.

Beach and Bley explain that behavioral treatment for obsessive-compulsive disorder in childhood is very new compared with the relatively recent but far more extensive behavioral work with adults.

Despite the success of behavior modification with other childhood disorders in the past 20 years, childhood OCD received little behavioral attention due to its perceived rarity, they suggest. However, a higher than expected prevalence rate in the general population has directed new attention to behavioral treatment.

According to Beach, behavioral therapies showing varying degrees of effectiveness with obsessive-compulsive disorder include: systematically exposing the patient to the feared thing/person, thought stopping (the patient attempts to "stop" the thought), keeping a daily log of OCD behaviors, and monitoring by a parent or guardian.

However, behavioral therapies do not cure the patient of OCD; they simply help the patient learn how to deal with, and hopefully reduce, the rituals, explains Beach. The only thing that can really cure OCD is a change in the brain chemicals.

Ashley and her parents report that they've had some success-with these behavioral therapies.

"I've been keeping a log of rituals that I go through every day, and I try to spend less time on things like washing my hands and inspecting the rug for bugs," Ashley says.

"Then her father and I look at her log to see if she's improving," Karen adds. "Just a little bit of improvement gives me a lot of hope."

"I know I'm far from being normal, but I have cut down on the hand-washing, and I don't ask Mom the same questions over and over as much as I used to," Ashley states.

Beach also emphasizes the importance of openly discussing the disorder with relatives, teachers, and friends. The secrecy, shame, and guilt that usually surround OCD only contribute to the stress and anxiety of the situation.

David Dunn admits that it was very difficult for him to talk to others about Ashley's obsessive-compulsive disorder.

"Of course, I was being selfish and worrying that people--my family mainly--would think that Ash was having problems because I was a bad parent," David explains. "In this day and age, most people seem to be blaming the parents for everything that goes wrong with their kids."

So, David read extensively about the disorder and shared that information with others who didn't understand or believe it.

"Sure, it's difficult to explain all of this," he says, "but we really have no other choice because we love Ash tremendously."

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Ashley wants people to understand that she is not performing compulsive rituals to get attention. She says that she does not obsessively worry about germs, bugs, and parasites because she's self-centered, self-absorbed, or has nothing better to do. Obsessive-compulsive disorder is not enjoyable; it's pure hell.

"I know that normal people can't really understand, like, why I do these things," Ashley remarks. "But I just think that people shouldn't be so mean just because they think I do weird things. I know I do weird things, and I'm trying to stop it."

Ashley's condition is improving slowly, but it is improving. She only washes her hands for 15-20 minutes now instead of 30 minutes. At night, she only stays in the bathroom for 45 minutes, as opposed to the previous hour-and-a-half.

When she's outside, Ashley tries not to look at her shoes and socks more than five times. Most importantly, she's trying not to ask her mother as many questions concerning the food preparation and cleanliness.

"I know that Mom washes her hands a lot and always cooks the food really well," Ashley admits, swallowing hard to hold back her tears. "It really hurts me when I think about what I've put Mom through. I know I've upset Dad and Brittany, too, and I've apologized to them a lot.

"But I think Mom's been affected the most by all of this because we're so close," she adds. "I'm just really sorry. Every night I ask God to help me get better so my family doesn't have to suffer anymore."