Daily Life with Obsessive Compulsive Disorder

The year was 1988 and I was driving home on the autobahn between Wiesbaden and Stuttgart in Germany. As I drove my thoughts turned to the statistics course I had just taught. Without a doubt, I had made a dismal showing of my teaching skills by teaching the entire course without writing on the blackboard. I had failed my students and myself. Why? Fear of catching AIDS from a blackboard. My irrational thinking told me someone with AIDS had contaminated it. What concerned me even more was that this was not the first time I had been unfair to my students. In a previous course, a student with a cut finger had placed his paper in my briefcase; I became frightened of AIDS contamination and threw the entire briefcase away destroying many hours of student homework. This course, just finished, was my last desperate attempt to fight my illness. My desire to move forward with my life was not to be-I realized this in a moment of lucid insight. And then, in just an instant, I decided to end the pain of my recurring failure and resigned my university position.

The academics of Obsessive Compulsive Disorder (OCD) never interested me, perhaps like a cancer patient who doesn't care about the academics of cancer. Living with OCD is enough. In some ways I am probably like many OCD people, and in other ways, I suspect, there are differences. Surely, we have this in common: not telling others about the disorder and disguising OCD behaviors. Like most OCD persons there are "obsessions," or unwanted thoughts and worries, and there are "compulsions," which are behaviors done to relieve the obsessional tension. In my case the obsession is fear of catching AIDS, and the compulsion is mostly hand washing. The result is: withdrawal from life! Almost everything in my tormented world has to be scrutinized to make sure it is not contaminated by AIDS carrying blood+doorknobs, shopping bags, groceries, and clothing, to name a few. Though I have read about AIDS extensively and have listened to the experts, this fear cannot be shaken for it is highly irrational and does not yield to logic and information. And I deeply worry that I will end up like Howard Hughes who obsessively controlled his environment by never leaving his bed. All his riches, his keen intelligence, and his grand accomplishments couldn't prevent Obsessive Compulsive Disorder from destroying his life.

Consider the following illustration: There are ten million needles in a box but only one is contaminated with AIDS infected blood. A billion dollar reward will be given to anyone willing to be stuck with a randomly drawn needle. Hopefully, my idea presents you with the criteria of "risk and reward," which define so much of life. Taking the risk seems logical if you need the money. In my case, however, even if there are a trillion needles in the box and even if I am utterly destitute, I won't allow myself to be pricked. Why? My AIDS risk/reward criteria fall far outside normal parameters. In other aspects of my life, the balance between risk and reward is within normal limits. For example, I will drive at one hundred miles an hour on German autobahns, climb to high places, and swim in extemely deep water. To sum it up: my OCD-induced AIDS fear is illogical and can't be rationally thought away, for I have tried. To provide insight into my housebound life with OCD let me describe daily life. I live in a house with my wife Joyce and our dog Laurie, where only an occasional friend and almost never a stranger is allowed to enter. The house is as clean and neat as Joyce makes it; my OCD contamination fear prevents me from doing housekeeping. For example, if a piece of paper falls on the floor it lies there. It is a difficult time for Joyce who has a demanding job and a demanding OCD spouse. As I continue to describe my daily life, two words come to mind: worry and fear. All my days are spent within the confines of worry and fear.

My day begins when I awake in the only place where there is freedom from AIDS fear: my bed. Although sleeping my life away would be pleasurable, I arise at 9 A,M. after sleeping ten hours. Every behavior from this point must be orderly; for example, I dress sequentially: socks first, shirt next, then pants, and finally shoes. Anything out of sequence, like putting my shoes on first, will break the ritual, escalate the AIDS contamination fear, and increase obsessional anxiety. Therefore, my shoes and clothing are placed within reach of the bed in an orderly fashion. Standing on the bare floor without wearing shoes to protect my feet is impossible, so I dress myself standing on a clean white towel. Putting my pants on poses a special problem. If by accident a cuff touches the carpet, my sequence is broken and I must get a pair of clean pants. Then the ritual of dressing begins again.

I am never in a hurry to get dressed because the difficulty of making breakfast lies ahead. Ritualistic hand washing begins here. After entering the kitchen, the cleanest counter top is selected. Any visible speck of dirt on a counter top forces me to wash my hands, wash that speck off, and then rewash my hands after washing off the faucet. Only then can my breakfast, which consists of tea and toast, be prepared. Everything, like dressing, must be done in a certain order. First, a loaf of bread is taken from the refrigerator and placed on the counter; then my hands are washed again. Next, a plate is selected from the kitchen cabinet. If this plate has a water spot or speck of food on it, another plate must be taken-a contamination free plate must be found. After selecting the plate my hands are washed, the bread is placed on it, my hands are washed again, and so on. There were days when five plates had been selected before a suitable one was discovered. Think of me sitting eating toast. I touch the plate and, alas, remember that my hands haven't been washed after the plate was placed on the table. The toast and plate must now be put in the sink, and I must start again to look for a clean plate. Here the obsession is believing my food is contaminated with the AIDS (HIV) virus while the compulsion is to keep washing my hands to assuage the obsession: a vicious cycle if there ever is one. And one that requires constant thinking: my mind never rests. Rational thinking says, "Just eat your toast you're not going to catch AIDS from it."

There were days when I did fight through fear and defy rituals. But OCD made me pay a powerful price for confronting it: my fear of catching AIDS dramatically increased and obsessional anxiety rose causing me to feel like a patient sitting in a doctor's office waiting for cancer test results. This anxiety could last for minutes, hours, or even days. Living with rituals became easier than living with defiance anxiety. This day before finishing breakfast, my hands have been washed ten times. Most days are spent home alone with our dog, Laurie. Fortunately, there is a small fenced yard so she can go out herself. Laurie lays on the couch and sleeps or just looks at me watching television. Television is my sedative but it contributes nothing to my mental health. If the phone rings, I let it ring. When I hear a knock at the door, I ignore it unless I know someone is stopping by. Of course, there are practical exceptions, for example, if Joyce has said she will be calling. Still, my ear never touches the receiver; AIDS fears are everywhere.

The highlight of my day occurs when Joyce returns from work. She is the support I need to venture out, if only for an hour. I feel terrible about being unable to pet and play with Laurie, but once Joyce returns we can all take our daily walk. Protecting myself from AIDS is more complicated outside the house. My perceptual skills are acute-a cut finger, a gum wrapper, a piece of tissue, or a cigarette butt can be sighted from a great distance. All these things are associated with AIDS and contamination. As we walk Joyce reassures me and helps me look for pieces of tissue, band-aids, and the like. By now the nature of the OCD mind set should be apparent, but let me finetune this understanding a bit. Let us suppose that I step within three inches of a tissue before seeing it. After this, I will obsess and constantly ask Joyce if I have stepped on it. Her reassurance is desperately needed.

She always gives it to me. Still, I question her again and ask her for more reassurance. I may even walk back to the tissue and retrace my steps at least once, perhaps twice, maybe even ten times. You see, constant reassurance and ritualistic behavior are the only ways obsessional anxiety can be reduced; otherwise, an agonizing relentless anxiety will drive me to bed. Occasionally things are perfect and my walk gives me an opportunity to declare a small victory. Most often, however, OCD defeats me. Usually something has happened, I have stepped too near a band-aid, piece of paper, or beer bottle-a stranger has petted our dog or Laurie has met another dog, so by the time we return home, I am obsessing, and Joyce is anxious and distraught. Then to make matters worse, Joyce has to disinfect my shoes and give Laurie a bath. The evening meal is less difficult for me because Joyce prepares it.

Now there are only obsessions about eating the meal, not making it, and hand washing is not as necessary. Thank God that Joyce is such a good facilitator and does things for me. Without her help I could never have found enough strength to continue my struggle against OCD. Bathing and personal hygiene require the highest level of orderliness. Our house has three bathrooms, mine is private. Even Joyce isn't allowed to use my bathroom. When bathing and showering everything must be arranged in the right order: a special unused soap and a lint free white towel are required. If I notice the tiniest piece of lint after taking a shower, I must shower again and dry off with another towel. There are many evenings when four consecutive showers will be taken before I can climb into bed. Within the OCD morass, a sense of normalcy is found in my sexual relations. Having conjugal relations with Joyce represents a triumph of my will over OCD and shows me that there is a limit to OeD controlled behavior. Of course, our sexual relationship represents love and caring but in a special way it also represents the hope that other things can change. If this limit can be set, then why not others? OeD isn't keeping one's house and dresser drawers in order. It is a complex and debilitating disorder that can thoroughly isolate a functioning child or adult.