Unraveling mystery of obsessive-compulsive disorder: A personal journey

I didn't realize at the time that my fear and doubt were pathological.

I was living on the second story of a beautiful condo building, and taking two flights of stairs every day to my underground parking garage. Most mornings, I would gather my belongings and my infant daughter to head out for the day. As any reasonable person would do, I locked the door behind me. Yet, the nagging doubt would always creep in. This distrust in my senses made me question whether my eyes correctly perceived the latch in the locked position. Subservient to my mind, I was forced to verify by unlocking and locking the door not once, but five times. Then, I would schlep down two flights of stairs, lugging my precious daughter.

As I approached my car bathed in the fluorescent garage glow I'd wonder, "did I actually lock the door upstairs?" With doubt overpowering me, the fear of something dreadful happening would hold me in its grasp. Even if I was running late, I would stop in my tracks, baby carrier weighing heavily on one arm, diaper bag and purse in the other, and walk wearily back upstairs to check the lock in a sequence of five again.

This daily ordeal, among other irrational behaviors I suffered, was physically and emotionally exhausting, yet it wouldn't subside until I realized that life didn't need to be this way. In retrospect, I can't believe I endured this constant state of fear.

This account is one firsthand example of bona fide Obsessive Compulsive Disorder. Further, this isn't a fabrication, but just one of several real-life OCD behaviors that controlled the life of one of the co-authors of this article, Kavin Senapathy, for years until she sought treatment.

The general public throws around specific medical terminology either for conditions they have or their friends or family or other acquaintances have. Some of these are simply euphemisms – when someone has the 'stomach flu' it's usually a form of enteritis completely unrelated to the flu, which is shorthand for the respiratory virus influenza.

Similarly, when someone seems unnaturally ordered or organized, he or she may say 'It's just my OCD.' But OCD–Obsessive Compulsive Disorder–is a precise diagnostic term for a spectrum of thoughts and behaviors which can mildly affect individuals or so severely impact their lives that working or having social contact can be unbearable. Indeed, Kavin, who was recently diagnosed with the disorder, gently corrects those who use phrases like "I'm a little OCD," or "he's such a neat freak; it's so OCD." Her friends are accustomed to her jumping into conversations with anecdotes, explaining, "I actually have true OCD. Here's the difference between your organized nature and actual OCD…" The problem is getting her to stop talking!

As its name suggests, OCD is an anxiety disorder characterized by "obsessions," which are disturbing thoughts or images persistent in a sufferer's mind. The sufferer performs a repetitive action or thought (the "compulsions") to neutralize or make the obsessive thoughts disappear. Because the compulsion only

alleviates the disturbing thought temporarily, this cycle of obsession-followed-by-compulsion is not easily ended. Unlike someone with non-pathological cleanliness or organization traits, a true OCD sufferer incorporates specific patterns into his behavior. Further, although being clean and organized are stereotypical OCD behaviors, many OCD sufferers aren't overly-concerned with cleanliness.

Kavin was formally diagnosed with OCD in spring 2014. Throughout this article, she recounts details about her symptoms, diagnosis, encounters with common misconceptions and ongoing treatment. Because she is able to clearly recognize many of her symptoms as OCD behaviors (termed patient "insight,") Kavin regularly shares her experiences with the hope of spreading awareness and reducing stigma associated with the disorder. While the success of medication and treatment can vary, she has experienced a vast improvement of her OCD with a combination of SSRI medication and Cognitive Behavioral Therapy (CBT.)

New research

The newly-revised Diagnostic and Statistical Manual-V (DSM-V), the bible for psychiatry, lists specific criteria that must be met for a diagnosis of OCD to be considered. The newest revision of the DSM has been facing the most vocal resistance of any previous edition, for reasons such as former diagnoses being eliminated or significantly revised, to new diagnostic terms being added for behaviors that many psychiatrists, psychologists, and therapists feel are a part of normal behavior.

The difficulty with the DSM criteria for disorders is that they are built around (barely to robustly) observable symptoms of behavior, and often aren't linked with quantitative measures of physiopsychology, neuroscience, or genetics. Often, diagnoses can be worked backwards from a DSM diagnosis to familial history (a proxy for genetic inheritance, at least anecdotally) or other experiential event(s) which are taken to be evidence and 'proof-positive' of the life path that led to the issue. Sometimes, these correlations are tenuous and self-reinforcing (for example, if an individual is diagnosed with a psychological condition from the DSM, there's almost no lack of life events or family connections which can be (and are) pinned to the diagnosis to give it gravity and justify where it came from).

The issue, of course, is that everyone has exposures to life events which could be similarly distressing, but not everyone would fit the same DSM condition. It's often suggested that these differences are genetics – why do some soldiers who return home suffer from PTSD and some don't? Why do some teens suffer adverse events from bullying and some don't? When it comes to OCD, it was long-thought that people who came from strict families had higher instances of OCD, but this is not the case. OCD, like all psychological conditions, is neurobiological.

In retrospect, Kavin recalls having OCD symptoms since late childhood, but the severity of these symptoms skyrocketed with with the birth of her first child. Prior to becoming a mother, she didn't realize that many of her bothersome thought patterns and behavior were attributable to OCD. Yet even with an ostensibly triggering life change, it's difficult to determine how much of her disorder is due to genetics, stressful events, and other factors.

According to the International OCD Foundation, roughly 1 percent of adults suffer with OCD in the general

population; This equates to over 10 million people in the United States alone. For something so prevalent, it seemingly must not only be genetic but also highly-conserved (passed on with relatively high frequency). Why would something potentially so devastating be still so common? It seems that there is adaptive success related to OCD – meaning that a higher proportion of respondents in certain career paths tend to respond that they have traits suggestive of OCD than the 3 percent average. These careers include doctors, lawyers, engineers, some clerical workers, and so on; Work in which a focus on precision, working memory, and error detection is absolutely critical for success. And this seems to also be one of the principal hallmarks of the disorder.

With this seemingly high level of heritability, parents who are highly self-aware, and have been proactive about seeking treatment for their OCD may worry about passing the disorder to their children. Nevertheless, while 25 percent of OCD sufferers have an immediate family member with the disorder, it is difficult to predict whether a parent will pass OCD to her offspring.

An international consortium of researchers known as the Obsessive-Compulsive Cognitions Working Group has come up with a list of six dysfunctional beliefs associated with OCD. BeyondOCD.org describes them as follows:

1. Inflated responsibility: a belief that one has the ability to cause and/or is responsible for preventing negative outcomes;
2. Over-importance of thoughts (also known as thought-action fusion): the belief that having a bad thought can influence the probability of the occurrence of a negative event or that having a bad thought (e.g., about doing something) is morally equivalent to actually doing it;
3. Control of thoughts: A belief that it is both essential and possible to have total control over one's own thoughts;
4. Overestimation of threat: a belief that negative events are very probable and that they will be particularly bad;
5. Perfectionism: a belief that one cannot make mistakes and that imperfection is unacceptable; and
6. Intolerance for uncertainty: a belief that it is essential and possible to know, without a doubt, that negative events won't happen.

Error detection

Some of the most persuasive research in the field suggests that OCD is all about 'error detection' gone awry. What does that mean? We are all wired to find errors – this is an adaptive and survival mechanism where if something doesn't appear to be going right, we can use our brain's executive center to course-correct and solve the problems which lead us to think something has gone wrong. In what seems to be a similar feature of our brains' recognition system, we are absolutely adept at pattern-detection and recognition – so much so that we even find patterns where none really exist. Michael Shermer terms this 'patternicity' and it's how our brains try to tie seemingly unrelated events together based on tenuous (and again, often nonexistent) patterns.

Similarly, the orbitofrontal cortex is likely to tell us that there is a spelling error on the restaurant menu, or that our shoe feels a little loose so perhaps the shoelace has come untied (better check). Or that the stove might have been left on (better check that, too). And you can see how subtle this cognitive hijack becomes. It is adaptive behavior (that's kept our species alive) gone haywire. Stephen Whiteside, a psychologist at the Mayo Clinic has said that OCD activities done in 'typical levels' can be very helpful. "It would make sense that people with these kind of [checking, washing, organizing] traits can be highly successful."

Religiosity

There is a field called neurotheology, which looks at which regions of the brain are responsible for thoughts about morality, religion, spirituality, and scrupulosity. The ability to 'check' behaviors and have 'thoughts about thoughts' is very complex, and is the space of *metacognition*. It may even be that religious thoughts and feelings, including the joy of spirituality, the anxiety of shame, and other components of the religious spectrum are related to similar brain regions responsible for the error-detection of OCD.

There could be reason to think that these thought and behavior patterns evolved in such a way as to protect the survival of our species; For example, the fact that repetitive religious behaviors gives a certain solace to practitioners could be likened to the faulty causal linkages present in superstitions. But early in our species' development, to be wary of any causal links (however incorrect) would have provided a survival benefit. Some of these would have developed into notions of 'If you hear rustling in the reeds, beware of predators,' termed 'patternicity' by Shermer. These ideas would be selected-for genetically, even if slightly preferentially, and would also be passed-on within families as shared superstitions – some with undoubted utility. These more vigilant and cautious lineages would be preserved.

Our advanced brains' executive function fights this every day as we factor in likelihood to our decision-making (though people are notoriously poor at estimating probabilities to make decisions). This has been such a vestigial carryover that impacts the way our society functions today that medical school even teaches students, "If you hear hoofbeats, think horses – not zebras," to mean that even though we're keyed-in to create causal links, half the time we do it instinctively and incorrectly, and we need to consider the relative likelihood of the decisions that we make.

OCD – Not all about hand washing: Aversion to uncertainty

It’s common to hear people refer to OCD as being related to cleanliness (routine and exaggerated hand washing, for example), and while that can absolutely be included within the symptoms, it’s not necessarily so. That’s one of the ways the brain tries to regain control over uncertainty – through routinizing activities. Closely related to ‘error-detection’ but not intuitively so, is the other hallmark of OCD: an absolute aversion to uncertainty. Along with thinking that a stove may have been left on, for example, is the unwavering and inescapable aversion to the uncertainty about not knowing – ‘need to check.’

Again, this routinized checking behavior is one of the ways to close the loop between error detection and satisfying a need to resolve uncertainty. Indeed, Kavin never experienced typical excessive hand washing or cleaning symptoms. Yet, she spent much of her precious time checking the stove, oven, alarm clock settings, and more. A few other examples of OCD that are observed:

 More than 50% of patients with OCD can experience what is

commonly known as “just right” symptoms. This is characterized by the nagging feeling that a specific action or thing isn’t “quite right.” For example, to alleviate obsessive thoughts of harm coming to her family, Kavin engaged in the lock-checking compulsion described previously. She would have to visually confirm the door was properly locked, and supplement the visual confirmation by touching the lock. Yet, she often doubted that the lock-touching was done “just right,” so she would repeat the ritual until this intangible “rightness” was achieved. Those with “just right” symptoms may also obsess over the placement of objects on the table, the “rightness” of words in an email, the pressing of buttons on an alarm clock, and more. With ongoing Exposure-Response Prevention (ERP) a specific type of Cognitive Behavior Therapy, Kavin’s “just right” symptoms have reduced vastly.

Counting

Some OCD sufferers repeat certain counts, or if they ‘check’, ‘wash’, or other behaviors, they may have to do it a certain number of times. There seems to be some overlap in brain regions with counting or tabulation of numbers and the resolution of uncertainty specific to OCD symptoms.

Counting was one of Kavin’s persistent compulsions. For years, she attempted to alleviate frightening thoughts with the number five. For example, when her first child was an infant, Kavin spent significant time in the middle of the night, counting the rise and fall of the baby’s chest in multiples of five. When the disturbing thought of harm coming to her family intruded on her peace of mind, Kavin felt compelled to touch a wooden or metal object five times. Often, her counting compulsions overlapped with her “just

right" symptoms, with the need to repeat the counting until the act seemed done properly. With continued ERP, Kavin does not perform counting compulsions.

Intrusive thoughts

Really this refers to the 'obsessive' part of the term obsessive-compulsive disorder; Intrusive thoughts often cause different levels of anxiety and discomfort in the OCD sufferer. Ruminations can revolve around thinking those the sufferer knows could be sick or injured, that a conversation didn't go 'quite right' and needs to be resolved, that an activity wasn't done 'the way it should have been', and so forth. Notice that there is a great overlap with some of these thought processes and the error-detection short-circuit described above, as well as with an aversion to 'not knowing' (uncertainty).

Many of these themes above which trip the OCD sufferer's error circuitry are things that could make him or her better at managing things in life – for example, the friend who calls you back to resolve a discussion you had could be better at orchestrating relationships than another friend who is unfazed by how your last contentious conversation went. Or someone who does particularly well at finding errors in spreadsheets, computer code, or editorial type. So again, these behaviors seem to be adaptive but taken to a potentially severe extreme. Kavin is often commended for her organized nature, and for always being "on top of things." She often wonders how much of her personality is intertwined with her OCD.

Excessive reassurance seeking

Also known as ERS, this behavior is common among OCD sufferers. ERS is essentially a form of checking behavior or compulsion, wherein an OCD sufferer frequently checks in or questions family members or friends to help reassure themselves, assuage obsessive thoughts, and reduce general uncertainty. Like other OCD compulsions, the repetitive nature of ERS leads to an ongoing vicious cycle.

ERS is one reason that family members can need to play a part in an OCD sufferer's treatment. Kavin recalls seeking reassurance incessantly from her spouse, primarily during the period of severe OCD symptoms following the birth of her child. For example, to alleviate disturbing thoughts of her spouse having a car accident, she would insist that he send a text message upon arrival to his workplace daily. Believing this was a harmless indulgence, he complied.

Similarly, Kavin would frequently ask her husband whether he remembered to turn off the stove, whether he thought their daughter was healthy, and would remind him countless times a day to "be careful." Most of the time, he obliged and answered the questions. Offering reassurance may seem like a compassionate and loving act. After all, who doesn't want to help alleviate loved ones' anxiety and stress? Nevertheless, complying with ERS behaviors is enabling, and helps perpetuate the OCD cycle.

As part of treatment, Kavin's behavioral therapist, also a psychiatrist, provided strategies to avoid seeking reassurance. Further, he advised that her husband either refrain from answering the questions, or using canned responses like, "I think you know the answer." In addition, Kavin's spouse was advised not to respond to obvious ERS type text messages. While this type of process can be challenging, and even cause strife within family relationships, she believes that a combination of good communication and an

understanding spouse helped tremendously. While her ERS behaviors have reduced drastically, she still finds herself slipping on occasion, especially during stressful periods. Indeed, because there is no cure for OCD, sufferers must use tools garnered in therapy to keep symptoms manageable.

Severe OCD

Here are a few brief case example of actual OCD patients' behaviors:

- A new book by David Adam about his battle with OCD and inescapable fears of disease and the compulsions that it drove.
- Jacob Billsborough, an artist in Ireland with OCD reports "I plan my whole life around my OCD tendencies and sometimes when I'm not in the mood for that anxiety I just avoid going outside my apartment. It can be exhausting." And perhaps the 2-3% rate of OCD reported in Ireland isn't a real anomaly, but just better diagnosis or diagnostic sensitivity there compared with elsewhere.
- Similar to Kavin, this mother in the UK felt compelled to 'check' her daughter's breathing 15 times per hour to make sure she was still healthy and living.
- A young male whose OCD went undiagnosed even within his own home – he was not eating, and would sit in a specific chair because it was "safe." When he went off to college, he wouldn't go into certain buildings on his college campus.
- And of course, Howard Hughes, for whom the Howard Hughes Medical Institute is named was also famously-afflicted with OCD – so much so that in his last years of life he was so disturbed by his psyche that he thought any social contact – at all – would contaminate or infect him, so he lived in a hotel room with several doctors onhand and would see no visitors. When Hughes and his wife moved to Las Vegas, he reserved the top two floors of the Desert Inn hotel. He then refused to leave because of his thought patterns, and so bought the hotel for twice its valuation price. He began communicating with his wife by notes rather than face-to-face because of his phobias (likely of contamination). He even "wrote a staff manual on how to open a can of peaches–including directions for removing the label, scrubbing the can down until it was bare metal, washing it again and pouring the contents into a bowl without touching the can to the bowl." For four months he wouldn't leave his room and would urinate in jars to avoid the idea of having to leave. Again, it seems from the outside and objectively to be so out-of-the-ordinary that '*you'd* never do that' – but for someone with the disorder, the overwhelming sense of dread to *not think or act* in certain ways is absolutely intolerable.
- Some spectacularly famous cases are here.

Genetic basis

There is some evidence of heritability as the occurrence of OCD within families is slightly higher than the average reported in the population. But again, all of these statistics assume the reporting is (fairly) accurate, which often isn't the case – especially with mental conditions, where stigma is still *de rigeuer*. Genetics appear to only be partly responsible. The International OCD Foundation suggests that "Perhaps an illness or even ordinary life stresses that may induce the activity of genes associated with the symptoms of OCD," elaborating a tantalizing link with epigenetics.

PANDAS

A specific type of hypothesized post-infection class of OCD-like symptoms, it stands for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections. It has been observed in a number of cases, and in fact, the disorder was characterized by the clinical appearance of symptoms in children following infection with strep. The jury is still out on the prevalence and robustness of the scientific data, but there are well-documented cases of symptomology looking a lot like severe OCD with very sudden onset. The suggested mechanism here is that antibodies which target certain fragments of the streptococcus bacterial antigen also cause damage to certain brain regions. Some rapid remission has been reported in some children, spontaneously resolving; and other cases have seemed to persist.

Drug therapies

Some drugs in the selective serotonin reuptake inhibitor (SSRI) class have been approved for use in treating OCD, typically at higher doses at which the drugs are used for generalized anxiety disorder (GAD), major depressive disorder (MDD), and other conditions they are approved to treat. There are currently no good workable theories why this should be the case, and it's likely that OCD sufferers can experience some relief from their symptoms on SSRIs as a halo effect – that the drug isn't directly targeting all the neurotransmitters or brain regions which are involved, but in a broad way they're helping to align some brain functions.

There are some new pharmaceutical treatments currently being investigated for OCD to more specifically target some hypothesized pathways through which OCD is thought to function.

Cognitive therapy

There is good reason to suspect that psychotherapy is effective for OCD sufferers, and has a similar magnitude of effect as the drug treatments. The best outcomes seem to be with an adjunct combination of drug therapy along with psychotherapy. There are several different methods to treat OCD in 'talk therapy', including cognitive behavioral therapy (CBT), and many involve some form of 'exposure and response prevention' (ERP) where the uncomfortable thoughts or feelings (even physical symptoms) are elicited to occur, and then the therapist coaches the patient to prevent him or herself from engaging in the compulsive actions or ruminative thoughts that have been learned to defuse the anxious feelings.

A combination of sertraline (an SSRI) and CBT have helped Kavin alleviate her OCD symptoms considerably. In a systematic manner characteristic of proper CBT, her therapist helped her resist performing compulsive behaviors. She is thankful to have found such an effective therapist, and creditshis work for improving her quality of life. Yet not all OCD sufferers are as fortunate as Kavin; there areoften roadblocks to treatment success. Indeed, OCD sufferers sometimes don't recognize that theirbehaviors are irrational, or avoid seeking treatment due to stigma or fear. Additionally, while CBT andcertain medications are the only evidence-based treatments for OCD, sufferers often end up participatingin inappropriate, non science-based treatments like hypnotherapy, homeopathy, and dietary changes.This is why it's imperative to find a reputable service-provider with experience treating OCD sufferers.

Because we are a combination of our genetics and our life experiences, we each fall into an overall range of behaviors (and even then, we have a range of behaviors in different circumstances). Why we approach circumstances the way we do is partly mediated by our genetics, and certain aspects of the human condition like OCD appear to be a part of humanity because when it's not so severe that is disruptive, it has allowed us to perhaps be more fastidious, detect more errors, and strive for more certain outcomes than if those genetic combinations never existed.

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Additional Resources:

- Brain breakthrough: Genome-wide association studies herald advances in treating mental disorders
- What role will genetics play in a biology-based approach to psychiatry?