

# How much do you worry that you might possibly have OCD?

Presented by **Jim Hatton**, Ph.D., M.F.T., for **DBSA San Diego** on Monday, 5 October 2009

Thank you all for coming tonight, and thanks to the DBSA for asking me to join you. My name is Jim, and I'd like to talk a bit about OCD tonight – what it is, what it isn't, where it comes from and what we know about what to do about it.

**First, a note about my biography.** My host has told me that she's worried that people will think I'm a nut, and I'll let you draw your own conclusions about that. My bio for tonight was clearly written in jest. In fact, each line of my bio is either a twist on our profession, on my subject tonight, or is an homage to a previous humorist. However, OCD is a serious subject, and though I'll try to give it serious consideration tonight, I'm a firm believer that you can have a light heart about serious subjects without diminishing their importance. Also, I think that far too many of us in the mental health field, especially in the academic parts of it, take ourselves far too seriously. We as providers would do the consuming public a service by reminding ourselves that *you* all, living with these issues on a daily basis, are the true experts, while we are merely the professionals.

No, I'm not really an avatar, but I really do have a nickname (that seems to be a lost tradition in the current generations of names). And I actually do have credentials. I've been in the mental health field for about eighteen years, almost all of it treating people with OCD. Before that I was on the faculty here at UCSD for about thirteen years in the field of Neuroscience, studying the ways that the brain functions to run our lives and direct our behaviors. And, as we'll discuss tonight, how it might *misdirect* our behaviors.

So our topic of the evening is OCD, or Obsessive Compulsive Disorder. **OCD** is an anxiety disorder characterized by the presence of frightening or disturbing thoughts or images, often of harm coming to one's self or others (obsessions), or repetitive or stylized behaviors (compulsions), or both. Both situations are usually recognized by the individual as irrational (except sometimes in children), and are usually ego-dystonic. (In fact, people are often so scared or ashamed of having these thoughts that they don't admit them to their doctors, and suffer in silence for an average of nine years before getting treatment.)

**Let me define** each of these three letters in the acronym, as they are all important, both in themselves and in terms of determining a diagnosis. **Obsessions** are intrusive thoughts or images, things that you don't want in your mind, that are repulsive, disgusting, anxiety-producing or guilt-producing. They are fears of things you know to be irrational or exaggerated, and are not based on things that have really happened. They are NOT things that you like thinking about but just tend to over-do (people might say "I'm obsessed with chocolate" or "I'm obsessed about baseball", but these are common misuses of the term). Examples of obsessions are "What if that's contaminated?" (*The Cat in the Hat*); "What if I'm really gay?" (or "What if I'm really straight?"); "What if I accidentally kill someone?"; "What if I offend God?"; "I might sit on a baby"; "I might leave the door open, and then I will be robbed" (*As Good As It Gets*); "My mother might get cancer"; "What if I lose something?" (*Monk*); "I might not have heard/read/understood that correctly." Obsessions can also be intrusive nonsense words, music or other non-threatening thoughts.

**These thoughts create anxiety** or uncertainty, and these feelings are hard to tolerate, so they usually demand that something be done to reduce those feelings. People tend to do

something that reduces the distress immediately, even if it seems irrational. This is what we call a **compulsion** or a **ritual**. They are behavioral that are done specifically to reduce the distress from an obsession (people might say “I’m a compulsive note-taker” when they really mean that they are good at it, or “He’s compulsive about keeping his teeth clean”, when he does that because he really believes in a very clean mouth, not because it reduces fear. These are also misuse of he terms). Examples of compulsions are ritualized washing, checking, counting, ordering, repeating, talking or asking, hoarding or thinking (mental rituals – these are different from obsessing).

The flow chart looks like this:



So people have an intrusive thought, it creates anxiety, they do a compulsion to try to relieve the anxiety, and leads to quick relief. The problem is that the relief is always temporary, lasting from a few seconds to a few hours, and then the ritual needs to be repeated again. In this way you can draw an analogy to an addiction, where the withdrawal (like the obsession) creates the distress (like the anxiety), and the person goes for instant relief by turning to the drug (the compulsion), but will need to keep turning to it again and again until they find a way to get through the withdrawals an other way. From this analogy you can see that the person with OCD will feel as if his or her compulsions are *required* and not a choice. And in treatment, we often talk about fighting the OCD in order to regain your life’s choices.

**So the real problem with OCD** is one of being so anxious about something that you can’t tolerate either the fear or the uncertainty, and you have to give in to a safety maneuver. It’s as if OCD is a little terrorist in your head, making you give in to its ransom demands by whispering in your ear “how do you know it’s clean?” or “how do you know you didn’t say the wrong thing?” or “what if you really do need that later?” Your intolerance of this doubt or anxiety will make you give in, against *your* will, and do the checking, washing or reassurance ritual that OCD wants you to stay addicted to. When we get to our discussion of behavioral therapy, we’ll talk about how to fight terrorists.

One final part of the OCD acronym is important, and that’s the “D.” It means disorder, and here it refers to the situation where these symptoms are sufficient to create meaningful distress, or to impair a person’s functioning in one way or another. So if you have an occasional intrusive thought but it doesn’t bother you much, or if you have a certain habit that you do most of the time but it doesn’t get in your way, even if it’s irrational, it probably does *not* mean you have OCD. These days many people will say “I’m OCD about this or that” when they only mean they have a strong preference for something.

There are many, many ways OCD can present, from thoughts about hurting someone, to sexual or religious thoughts that are repulsive, to excessive concerns about right and wrong, order, or saving things, to needing to tell or ask or remember, to washing and cleaning, to avoiding or procrastinating, to hoarding and cluttering, to repeating or doubting or touching things or problems deciding. Most of the time, the thing you *don’t* see (the thoughts) are the most disturbing part of the OCD.

So that's what OCD is; just as important is "**what is OCD not?**" In addition to the colloquial misuses of the terms I already mentioned, the most common misconception is that OCD includes things that are actually **Impulse Control Disorders**. These are things like hair-pulling, skin-picking, gambling, shopping, shoplifting, Internet use, lying, fire-setting, over-exercising and overeating, to name a few. The common thing among all of these is that the person actually *likes* doing the behavior, even if they don't like the consequences of it. They like it so much that they do it so excess, and then later regret that they did it. These are often called "compulsive shopping" or "compulsive lying," etc. But these are not really compulsions; they are more like behavioral addictions. One of these, "compulsive hair pulling" (also called *trichotillomania*), is actually often mistakenly called OCD even by professionals.

Similarly, **addictions** to substances are not OCD. You might hear that someone "compulsively uses amphetamines," but these are addictions, not compulsions. Even when people claim that they are compulsively using something like alcohol to reduce anxiety, they still are talking about an addition and not a compulsion – remember, compulsions are attempts to reduce the anxiety from an obsession.

**Other anxiety disorders** may look like OCD but are distinct from it. For instance, anyone who has an anxiety disorder by definition experiences a high degree of anxiety, and may even say "I had a panic attack" to mean they had a bout of high anxiety. In panic disorder, the anxiety seems to come from out of the blue, and is not related to an intrusive thought or trigger. In Post-Traumatic Stress Disorder people experience stress from thoughts, but these are recollections of bad things that *have* happened to them, not things that have not happened but *might* happen. People with PTSD also have nightmares and flashbacks about things that have happened, something people with OCD don't experience. And Phobias, including Social Phobia, are irrational fears of things or situations, and they might sound like obsessions. But with a phobia, like a fear of spiders, or of public speaking, the fear diminishes the farther away from the source you get. In OCD, the source is your brain, so you can't diminish the fear by backing away because the thought stays with you.

**Other psychiatric diagnoses** have to be eliminated when we're considering diagnosing someone with OCD. For instance, people with severe depressions will often have repetitive thoughts that they don't like, things like "there's nothing worthwhile" or "I shouldn't have done that thing, and now everything will be bad." These are distorted thoughts, things called "morbid ruminations," and are distressing to the individual. But they tend to make the person depressed, not fearful. People who are bipolar can do things over and over again when they're manic but they are anything *but* fearful at that point, and people with OCD can often describe the OCD itself as if they were hearing a voice. But they will tell you the voice is inside their head, while people who are delusional or who are hallucinating will hear a voice outside their head. For the longest time, by the way, the primary misdiagnosis for someone with OCD was actually schizophrenia. This was true as recently as the 1980s. Finally, autistic spectrum disorders like Asperger's Disorder are sometimes confused with OCD because these kids can be preoccupied with one subject to the exclusion of most other interests, but again it's an interest and not a compulsion.

There is one other subset of conditions that might actually constitute rituals, but that we don't consider to be OCD. Those are rituals, like religious ones or political ones, that are **appropriate within a given culture** or situation. Also, sports figures will often perform rituals, even bizarre ones like wearing the same "lucky" socks for every game of the World Series, but these are not to reduce fear as much as they are a superstitious belief in "luck."

One final condition deserves mention, and that is a personality disorder unfortunately named **Obsessive Compulsive Personality Disorder**. I say this is unfortunate because it actually has very little in common with OCD, but many people confuse the two. It is *not* the “mild version” of OCD, it doesn’t result from having OCD over the long term, but it can either occur by itself or together with OCD. Whereas OCD is an anxiety disorder, you might think of OCPD as a disorder of philosophy. People with OCD hate having their symptoms, and generally wish they were more like everyone else. People with OCPD not only like the way they are, but generally believe they are correct in their opinions and approaches and that everyone else ought to be like them. They tend to be rigid, structured, rules-oriented and demanding; they are perfectionistic and controlling. And because they don’t think anything is wrong with their way of doing things, they rarely come in for treatment, although their spouses and kids often wish they would.

**So where does OCD come from** and who gets it? It seems to be mostly genetic, it’s pretty evenly distributed across genders and nationalities, and it affects about 3-4% of the population. It usually starts early, sometimes at birth and sometimes at puberty, but often the symptoms don’t become strong enough to be noticeable until later on. We think it’s related to the function of a neurotransmitter called serotonin (the same one that seems to be related to other anxieties, depression and sleep) because the medicines used to treat it preferentially affect this transmitter. We also know that people with OCD have certain differences in brain metabolic activities as measured by PET scans. For example, most people with OCD have higher activity in their orbito-frontal cortex (the part of the brain above the eyeballs and behind the forehead), and this brain region is responsible for intuitive and creative thoughts, both good and bad. They also have higher activities in the caudate nucleus, a midline brain region responsible for, among other things, filtering out internal and external thoughts and sensory data that you don’t need to pay attention to. So people with OCD have more disturbing thoughts, and less ability to ignore them, than people without OCD. They also tend to be more reactive to internal sensations (which can lead to hypochondriasis) and external sensations (leading to being extra-sensitive to sounds, lights, touch, taste or smell – even to emotions).

We’re also pretty sure that bad parenting, problems with potty training, too much caffeine, low self-esteem and even trauma do *not* cause OCD. People with a family history of OCD are at higher risk, as are people with a family history of depression, tic disorders, other anxiety disorders or impulse control disorders. But these don’t cause OCD either. Rather, they are probably co-inherited. There is some evidence that in about 5% of OCD cases, early bad infections with the Streptococcus virus can result in several things including OCD – this condition is known as PANDAS, or Pediatric Autoimmune Neuropsychiatric Disorders Associated with Strep. In these cases, if you catch the symptoms of OCD at their initial onset, usually during the course of the strep infection, you can resolve the OCD by treating the strep infection with antibiotics. But any later than that, like more than a few days after the infection is gone, and the treatment for those OCD symptoms will be the same as for any other case of OCD.

We note that boys and girls tend to get OCD at about the same rate, but girls tend to get it a bit earlier. It can occur at birth, and we can recognize someone at 6 months throwing a temper tantrum if they can’t line up their blocks in a certain order, or later if they are picked up and not put back down in the same place. For some people the symptoms come on gradually, and for others the onset is abrupt. In a few cases the onset can be later in life, especially after a traumatic event, but these are pretty rare, with most cases beginning by the early 20’s. For the longest time, we thought that hoarding was the exception to this rule, with symptoms coming on usually in the thirties, but it seems now that even these tendencies begin early, and are only

noticeable when the accumulation of things gets significant enough to outstrip one's living space.

Although there are mild, moderate, and severe cases of OCD, the incidence of all types of OCD tends to be distributed across all types of people, in all professions, with one notable exception. People with OCD tend to be very bright people, even if their symptoms might inhibit their performance in school or on the job. This probably comes from the fact that the overactive parts of the brain are the same parts that produce creative and insightful thoughts. It's one of the things I enjoy most about my work, and that's that I get to work with very bright people. In fact, there are three levels of cognitive awareness. The first is just behaving, or taking action. Most people are at this stage most of the time. If after they do something you ask them "what were you thinking when you did that," they would likely answer "I dunno." And they really don't, because they weren't thinking. The second level is thinking, and most of us do that when we're in school, or when we're puzzled, or when we're anxious about something like our taxes. But people with OCD get to a third level, and that is thinking about their thinking. They evaluate things like "why am I thinking this?" and "what does it mean about me?" and "why can't I stop my mind?" For those of you with OCD, it might be odd for you to know that most other people only rarely do that kind of thinking.

Now, the big question is really "**what can we do about it?**" I have to disclose before I get into this question that I'm an evidence-based therapist and scientist. That means that I believe in things for which there is evidence, and I tend to shy away from things for which there isn't any. Many things have been tried in the pursuit of treatment for OCD, and if you look on the internet or listen to folklore you'll come across things that have worked for one person or another. These are called "case studies," and do not stand the scrutiny of evidence because they are usually not repeatable, or don't extend to other people very often. For instance, the Salem witches were drown, and there's a good chance that one of the witches were observed by the tattletale town girls doing an OCD ritual with their little dolls. Drowning did stop the symptoms, but I guess we wouldn't call it an effective treatment. More seriously, electroconvulsive therapy (ECT), lobotomy, anti-psychotic drugs, psychedelic drugs, biofeedback, neurofeedback, herbs, dietary changes, exercise regimens, scolding, exorcism, yoga, meditation, acupuncture, prayer, amino acids, vitamins and all manner of talk-type therapies have been tried, and some have helped certain individuals. In fact many have helped people feel better in general, or even reduced their baseline anxiety, but only three things have been shown to be more effective than placebo for large number of people in reducing the primary symptoms of OCD, those being obsessions and compulsions. Those three things are SSRI-type medications, brain surgery, and a certain type of Cognitive-Behavioral Therapy called Exposure and Response Prevention.

First we'll talk about **medications** for OCD. The SSRI's are a class of antidepressant and anti-anxiety medications that act primarily on the neurotransmitter serotonin. In fact, SSRI stands for Serotonin-Selective Reuptake Inhibitor, suggesting that they block the reuptake mechanism that removes the serotonin from the active site after its done it's job. In the brain, nerve cells (or neurons) are separated from one another by a gap called the synaptic cleft. In order for these two nerve cells to communicate, the signal from the sending neuron gets changed from an electrical signal into a chemical one at the pre-synaptic terminal, and that chemical messenger, which in this case is serotonin, floats across the cleft and sticks to the post-synaptic neuron where it translates the signal back into an electrical impulse. Are you all getting this? Because you'll have a short quiz next period. Okay, back to our story. Once the serotonin is done with that delivery, it un-sticks itself, and normally either gets chewed up by enzymes as it floats around, or it gets recycled by the sending cell by the serotonin reuptake mechanism. If an

SSRI-type medication blocks this reuptake, then the serotonin can float around in the active cleft longer, and potentially double its work output by sticking to the post-synaptic cell again and delivering another message. So these medications don't increase the serotonin in your brain, they must make the serotonin you have work harder. Or that's the theory.

Medications in the **SSRI** class include Prozac, Paxil, Zoloft, Luvox, Celexa, Lexapro and their generics. An older medication called Anafranil is actually a member of the tricyclic class of antidepressants, but it works primarily on serotonin too, and is used to treat OCD as well. Two hybrid medications also used are Effexor and Cymbalta. Each of these are used at lower doses for depression or certain types of anxiety problems. But to treat OCD, they all need to be used at 2-3 times the dose needed to treat depression. In addition, you need to be on them for a long time to know whether they will work or not. In this case a long time means several weeks from the time to get up to the therapeutic dose; in fact we say that you can't know that a medication is *not* working until you've been at the target dose for twelve weeks. So it's really a long haul to try a medication for OCD. Some of these medications can be combined with others, but some combinations are not okay in general. And of course, they all have possible side effects. The trick is to find a medication or a cocktail of them where you can tolerate the side effects and it benefits your OCD. A good benefit on medications along might be 50-70% reduction in your OCD symptoms. All of these are about equally effective across a large number of people, but everyone seems to have a "best medicine" for them, and everyone's response to any given medicine will be different.

Medications in other classes can be added to these primary ones. Anti-anxiety medications like Xanax and Klonopin can help to reduce short-term anxiety, but tend to be addictive if used for the longer term. Anti-psychotics, especially the ones called "atypicals," can be added not to suggest that you're actually psychotic, but because they take the edge off the unpleasant thoughts, and because they often make the SSRI's work better. And sometimes mood stabilizers, stimulants or anti-depressants from other classes might be added to further treat a coexisting mood disorder.

Speaking of coexisting disorders, it's certainly possible to have OCD in addition to another problem that deserves treatment. These are called co-morbid disorders, and there are a few that are more common when someone already has OCD than are others. Depression, for instance, occurs in as many as 70% of OCD sufferers over their lifetime. When we're talking about the SSRI's, the same medication can often be used to treat both problems, if they're used at the right dosage. Generalized anxiety, other anxiety disorders, tic disorders, Attention Deficit/Hyperactivity Disorder and Impulse Control Disorders frequently are co-morbid with OCD. Bipolar disorder is more common among OCD sufferers than in the general public, but isn't necessarily one of the more common ones to co-occur with OCD.

Yes, I mentioned **brain surgery** earlier. It's generally reserved for people with very severe cases of OCD, and is only available for people who have had a good trial with at least four SSRI's and have failed to improve on them, and who have also had a good trial with CBT, which we'll talk about shortly. The two types of surgeries are called anterior cingulotomy, where a cut is made in the front part of the cingulate gyrus, and capsulotomy, where a cut is made in the internal capsule. The first is a bit more generalized, and the second is a bit more specific. In each case, the cut is designed to interrupt the circuit that conducts the excessive fear message before it gets to the ineffective gating mechanism. These surgeries are effective for about 30-50% of people who get them, but *any* brain surgery is a very serious consideration, and comes with many potential side effects. So of course we want to make sure that we've tried everything else before choosing this option.

Before we get to **cognitive-behavioral therapy (or CBT)** for OCD, let me mention that I'm a cognitive-behavioral therapist by training, so I might be a little biased in favor of this type of treatment. And I don't own any stock in drug companies. Okay, so much for disclosures. First, a bit about CBT in general. There are many different types of talk-based therapies, and most of them don't help treat OCD. CBT refers to a group of therapy techniques that are based upon research findings, are testable and teachable, and specifically focus on helping a person change either his thinking (that's the "cognitive" part) or his actions (that's the "behavioral" part). But there are lots of different types of CBT also, and most of *them* don't really help with OCD either. For example, one type of CBT that many people in this room might know is the cognitive therapy for depression, designed by Albert Ellis and Aaron Beck, and made popular by David Burns in his book *Feeling Good*. This is the therapy that involves thought records and daily mood logs and the "Ten Cognitive Distortions." While this approach is wonderful for treating depression, it doesn't do much for the symptoms of OCD. Relaxation training is considered CBT also, as is Systematic Desensitization, EMDR, Modeling, classical conditioning, operant conditioning and a whole slew of other very useful techniques. But when you have obsessions and compulsions, the one form of CBT you want to use for those symptoms is called Exposure and Response Prevention. Any other form of CBT just won't do. And when I speak about OCD, I might slip and call this treatment either behavior therapy, or CBT, but I really mean ERP.

When I describe **ERP** to people who have never heard of it, this sounds like your worst nightmare. Exposure means facing your obsessive fear on purpose, and response prevention (or ritual prevention) means not doing your safety maneuver. Things like touching the dirty doorknob and not washing your hands; fearing that you've left the front door unlocked and going to bed anyway without checking; fearing that you might act out on an impulse to stab your mother and walking behind her with a knife anyway; and throwing away something likely to be trash when you're not really sure whether you'll need it anyway. Sounds hard, huh? In fact, for some of you who have seen behavior therapy on TV, it often looks like just doing gross or disgusting things, or taking severe risks. Well, it's not really like that. Remember the idea of the terrorist in your head? We want to find ways to fight him, and that means to tolerate the uncertainty without giving in to the demand to be sure. Building up tolerance is really what ERP is all about, and when you build up anything, you start out small and work your way up. Like when you build up muscles, you might start out lifting light weights, and build up to heavier ones as you get stronger.

The way ordinary mortals actually do ERP is by building up a **hierarchy**, a list of exposure and response prevention pairs in rank order from least anxiety to most anxiety. These are scored using a SUDs scale, or Subjective Units of Distress according to how anxious each thing makes *you*. Once you have a list of these made, you start by choosing one item and rehearsing it the same way every day for a week until it gets boring. For instance, if your lowest item, like saying the word "knife" and not mentally reassuring yourself that you won't do anything bad with it, only creeps you out at a level of 10-20, then each day you say that out loud, tolerating it until it goes away by itself. By the end of the week the item doesn't bother you any more, and we say that it has extinguished, or that you've habituated to it. Then you move up to the next item. Each time, it's as if you're telling the terrorist "go ahead, do your worst, I'm not giving in to your demands" and finding that the terrorist was really just bullying you with threats. Each thing you master makes you stronger and more tolerant of doubt, and because the benefits generalize to other things, you normally don't have to face each and every possible scary scenario in order to be less fearful.

Now in fighting terrorism (or playing a game or a sport, for that matter), you have two different approaches, those being **offensive** and **defensive**. The defensive way to approach OCD is to

wait until you are triggered and then figure out how to defend yourself. This is what leads most people into choosing rituals, and you can't win a game or a war only by being defensive. You need to do the ERP therapy to have an offensive approach, to intentionally trigger the fear so that you're going after the terrorist himself. So therapeutic exposures are not done when you accidentally get triggered; they are not substitutes for rituals. They are done to invite a measured amount of anxiety so that you can learn to tolerate it. Remember, exposures are meant to temporarily increase your anxiety. It's just the opposite of what most people do naturally. You will still be accidentally triggered in your normal life, and then you'll have to do whatever you can to deal with it – before you get to higher items on the hierarchy, you will probably have to continue to give in to those rituals. Later on, you can learn a defensive approach for OCD that sounds like “whatever the urge is – to wash, to avoid, to check or to repeat – do the opposite.”

Studies show that both **SSRIs and ERP treatments for OCD** make the majority of people better, and when you look at their brains using a PET scan, you see that the same reductions in brain metabolism occur in both treatments. So both treatments do the same thing, and in fact they facilitate each other. The difference seems to be that the benefit from ERP, since it's about learning something, are permanent, while the benefits from medicine last as long as you take it. We usually advocate trying ERP first for kids and adolescents, and a combination of ERP and medications for adults. But again, everyone is different. But when ERP is done well, and when it works, people get their choices back, they aren't dominated by fear any more, and the “real them” comes back. Once they are in shape, they probably have to remain in shape by continuing to do a reduced level of exposures forever, but your gains can be maintained just like your health or your fitness can be maintained.