

## The Differences Between OCD and Hoarding

A few months ago, I gave a talk in this forum on the basics of Obsessive Compulsive Disorder (OCD). Tonight I'd like to talk about hoarding, currently considered a subtype of OCD, but for reasons we'll discuss, that might not be the case for long.

**OCD** is characterized by the presence of intrusive thoughts, images, nonsense words or music that cause significant distress (these we call Obsessions), or mental or physical behaviors that are stereotyped or repetitive in nature and serve to attempt to reduce the distress from the obsessions (these we call Compulsions or Rituals), or, most commonly, both. Obsessions can be fears about harming, being contaminated by something, doing something bad or wrong in a sexual or religious context, excessive concern about justice or symmetry or knowing something, and many others. Compulsions often (but not always) match the obsession in content, and may be excessively avoiding something or asking for reassurance, washing, praying, checking, counting, rehearsing, asking or telling. In short, any worrisome thing that anyone can think about CAN be an obsession if it's intrusive and distressing, and anything that someone does CAN be a compulsion, if they feel they need to do it in order to reduce distress from a fear.

This is how the current diagnostic manual (the DSM-IV) categorizes OCD. Actually, that manual doesn't go into different types very much, but the lists of subtypes available are all DSM-IV congruent. One of the symptoms currently considered a subtype of OCD is **hoarding**. This is diagnosed by an inability to resist the impulse to acquire something regardless of need, and/or the inability to discard worn out or worthless things. Importantly, there are both hoarding obsessions, like "I might need that later" or "that might have value" or "the environment isn't safe if I throw that away;" and there are hoarding compulsions, like buying things you don't need just because they are on sale, and keeping stacks of material things – clothes, papers, books, trash – that take up your living space. In fact, most of the time the distress caused by hoarding is measured by the impact on your living space. That's not the only way to measure hoarding's impact, but it's a common one.

There are **many reasons** one might display hoarding symptoms that aren't really what we call "compulsive hoarding". One might be too depressed to put things away, or to clean up the place, and it might look like hoarding. One might have another psychiatric problem like psychosis that results in keeping too many things, though it's not because of a fear of losing things or of letting go of value. One might have another neurological problem, like dementia or Prader-Willi syndrome, each of which can result in the seeming irrationality of keeping too much of certain things. Or one might hoard things as a compulsion related to another OCD obsession (like someone who keeps library

books once they've acquired them because the person is afraid they have contaminated them and can't risk returning them to the public). None of these examples is what we mean when we say "compulsive hoarding". The Compulsive Hoarder is someone who looks for things to acquire out of a distorted sense of value of things or fear of not having them, AND/OR fails to discard things, even when they have little or no practical or sentimental value.

The compulsive hoarder can hoard many different **types of things**, always with the concern about what might happen if they don't keep the things, and with a behavior of either excessive acquisition or failure to discard things. The common things are papers, books, clothes, receipts, trash, or random items. Sometimes people hoard only one class of items, like books or refrigerators, but more commonly the person hoards many types of things. Some less common ones include animals (usually cats – many people have heard stories about the lady with 69 cats in her house), digital information (like web pages, old emails or texts of chats), money (the old term for money hoarders was "misers", and it's no coincidence that miser and miserable come from the same root), and time (this might apply to someone who always has to have something to do with them, as they can't stand to "waste time").

So far we've discussed ways that hoarding is **similar** to other forms of OCD. Both start as an irrational, intrusive fear about "what might happen if..." and lead to a behavior designed to reduce that fear, in the case of hoarding, either acquiring or saving or both. Another similarity to OCD is, in many people, an exaggerated sense of **responsibility**. In the case of hoarding, this might be the responsibility to get something to someone else who might be able to use it, or to put something to use yourself, or to save the environment from it, or simply to prevent your family or friends from going without. But there are other features of compulsive hoarding that are leading some people in the field to propose that it needs to become a **separate** diagnostic category. For instance, most people with hoarding problems don't have other forms of OCD (only about 16-25% do have other OCD in addition). And people with OCD don't have hoarding symptoms any more often than normal controls or people with other anxiety problems.

Hoarding has been estimated to be present in anywhere from 2-5 % of the population, and compulsive hoarding accounts for most of that. Since OCD has been estimated at 2.5-4% of the population, that means there are potentially **more hoarders** than total people with OCD! The family histories of people with hoarding tend to be filled with hoarders more than any other form of OCD breeds its similar symptom. So hoarding tends to "breed true" compared to other forms of OCD.

Perhaps the most noticeable difference between hoarding and OCD is that hoarders often describe the ritual or compulsion of acquiring things as **pleasurable**, sometimes even "a thrill." You would be hard-pressed to find someone with contamination fears

saying that they love washing their hands over and over. This is what we call an “ego-syntonic” symptom, one that goes along with who you feel you are. Most OCD symptoms are ego-dystonic, going against your sense of self. In fact, many hoarders do not experience their symptoms as distressing until they can’t complete their ritual (they can’t acquire what they want, or they have to throw something out), or when another person, like family or the police/fire/code enforcers, make a complaint about the hoarded things.

It’s likely that hoarding has a **later age** of onset than other forms of OCD, with OCD tending to first occur sometime around either puberty or in ones early 20s, and hoarding beginning in the 30s. But the more we look, the more we find antecedents to hoarding early in life, like kids who save every leaf or pencil shaving. It might be that we’ve only noticed hoarding later, because it early on there is usually someone else to take control of throwing things out (like a parent), and it takes time to acquire enough stuff to present problems. So it’s not clear yet that there really is a discrete age-of-onset difference.

However, there are clear differences in the **brain regions** affected between hoarding and OCD when studied with brain-mapping techniques. PET scans, which are useful for measuring cell metabolism in the brain (but only in large groups of people, not for individual diagnostics) show that both the orbito-frontal cortex and the caudate nucleus are over-active in the brains of people with OCD. The orbito-frontal cortex, if you remember, is responsible for creative thought and scary thoughts, so this being over-active means more scary thoughts in the brains of people with OCD. The caudate nucleus is responsible for, among other things, filtering out the sensations and perceptions that you don’t need to pay attention to, like the weight of your clothes, or the smell of the air. Over-activity here means your gate is stuck open, and all those thoughts come in unfiltered. In hoarders, by contrast, those two areas are effectively normal, while another area called the anterior cingulate cortex is UNDER-active compared to both controls and to people with other forms of OCD. So brain scans of people with OCD and hoarding don’t look anything alike.

UNDER-active anterior cingulate cortex. What does that mean for a hoarder? It’s likely that this area of the brain mediates certain **cognitive skills**, like organization, prioritizing, decision-making and attention, all of which are difficult for hoarders. Also, part of this cortex mediates **memory for fear extinction**, meaning that hoarders don’t have the same ability to habituate to fears. That might explain why the hoarding obsessions persist past traditional therapy treatment in hoarders long after they would in people with OCD. I’ll say more about that in a bit.

So, much more than is true for OCD, hoarding presents as a problem with **executive functioning**. Decisions about which things to throw out and how much one needs are

difficult; prioritizing which things need to be done first, and what is less important, is hard. Organizing is painful, often because of a fear of forgetting that one HAS certain things leads many hoarders to want to keep things in plain view, leading to the associated problem called **clutter**. Not all hoarders are clutterers (some people have neat stacks of boxes full of their prizes), and not all clutterers are hoarders (people with ADHD are often too distracted to keep their place neat). How many hoarders find that if someone “puts something away for you”, it not only leads to a fear that you won’t remember it, but it actually makes it seem harder to find that thing? And they call it helping, huh? That “need to remember” can also be about other things than just remembering that you have something. It can be represented by taking pictures of bills so that you remember that you sent them out, or keeping mementos like straw wrappers so that you remember an occasion, or keeping information so that you remember “important tidbits.” In fact, most people who hoard information have a need to know or a need to remember.

**Procrastination and perfectionism** are certainly present in other forms of OCD. But in hoarding it becomes a staggering problem. Hoarders often put off tasks because they are too overwhelming, just like the rest of us. But they also put off tasks because of the sense that they will never be able to do it “right,” or because they can’t do “A” until “B” is done, and that one of them depends on “C”. In fact, a lot of the hoarding problem stems from procrastination, in a way. People collect things because they will “get around to fixing them some day” or because “they will be useful later, when I find a good home for them” or because “I have to have ALL of the similar objects collected before taking them to the intended recipient (like Goodwill)”. Meanwhile, the objects pile up, just waiting. And waiting. The pathways between these piles of objects are what I call the “**Someday Aisles (I’lls)**, making play on “aisle” meaning pathway and “I’ll get around to it.” Many hoarders try so hard to do certain things perfectly, and hoarding ends up being the result of failed perfectionism.

One of the big reasons that people keep things is out of a distorted notion of **value**. What do we mean by value? Well, in it’s simplest form, it means the worth something has. But who gets to determine the worth? I’ll give you an example of this quandary. If I’m out wandering in the desert, dying of thirst, and I come across a \$5 bill and a glass of water, the bill will have no value to me. But the glass of water certainly will! But if I’m walking in downtown La Jolla and I come across the same two, I’ll pass on the glass and pick up the bill. Of course, in La Jolla, \$5 has almost no value either, but you get my meaning. And before anyone here says “just pick up both,” we’re talking about relative value in this example. In terms of absolute value, let’s go back to the desert example and replace the \$5 bill with a piano. If you keep it, it will cost you so much in energy to move it as to have negative value to you.

People with hoarding issues often think that **EVERYTHING has value**, and that there is **NO negative value** in keeping things. A broken refrigerator has value, if it's fixed. A trailer step has value, if you ever happen to acquire a trailer that just happens to be missing a step. This reminds me of my High School physics class. This was back before the Flood, of course, but we talked about the difference between **Potential Energy** and **Kinetic Energy**. Potential Energy was the energy stored up in something at rest, like a ball on the shelf – it got changed into Kinetic Energy if it fell off the shelf and plummeted to the floor. Kinetic Energy is the energy of action. Potential energy required something to happen in order to be useful, and that usually meant putting more energy into the system. Using that model, we can think of Potential Value and Kinetic Value. Broken things have Potential Value, but in order to transform that into Kinetic Value, more value (as in effort, money, time) needs to be put into the system. Twenty-five broken refrigerators in the house might need an awful lot of value added back in before they have any Kinetic Value, the value of action. So in that respect, yes they have value, but at what cost?

So if a hoarder says “this has value,” you might have to ask “to whom?” Or you might have to ask “if you add what kind of value to it first?” Value is not a property that objects have **intrinsically** to them; rather, value is a construct, individual to each of us, based on our perception of the object. In order to keep things, hoarders often have to have under-valued how much value they will have to add to the object to make it worthwhile, or they have under-valued the cost of keeping it. To throw something out, they often have to learn that their **sense of value** is as distorted as the sense of hearing is in someone who hears voices that aren't there.

What is the **cost** of excessively keeping things? The cost of storage is one cost that can easily be translated into dollars. I just learned about someone paying several thousand dollars a month in **storage unit** fees for a loved one's hoarded stuff. The loss of **space** is a huge one. Often there are no unused horizontal surfaces in a hoarder's home. The loss of **time** is also huge, with time spent on acquiring, churning (moving things from one “I'll deal with it later” pile to another), sorting and thinking about their stuff. The loss of **relationships** is another cost – often the people living with the hoarder are negatively impacted by the loss of space and the loss of the hoarder's time, but also by the shame at having people over to the house that many hoarders feel. This is sometimes called **CHAOS**, or “can't have anyone over syndrome.” So the costs are significant.

The **treatments** for OCD are really only two things, medications called SSRI-type antidepressants, and a specific type of cognitive behavioral therapy called Exposure and Response Prevention. In OCD each of these is up to 50-75% effective; the two together can be up to 80-90% effective. When they are applied to hoarding, even when adding a form of cognitive therapy to enhance executive functioning skills, the highest success rate in treatment over a large group has been about 30%. So the best that we currently

have to treat hoarding is still not very good. And the same medications used to treat OCD also seem to be less effective at treating hoarding, although the results in the literature are mixed. This might be due to the problem of reduced learning of fear extinction caused by under-activity of the cingulate cortex, meaning that the worries don't go away as easily with repeated exposure like they do for OCD. But clinically, it seems like the hoarders who do the best in recovery are the ones who learn the "de-cluttering rules" (like someone else can be your hands but you have to make all the decisions) and who then pair up with a "clutter-buddy," someone who can keep you motivated and focused on the task. Obviously, this approach needs to be better studied.

We have work ahead of us in terms of treating hoarding, and when the DSM-V comes out some time next year, there's a good chance that Compulsive Hoarding Disorder will be listed as a separate diagnostic category, as a cousin of OCD like Hypochondriasis and Body Dysmorphic Disorder are, but no longer under the symptom umbrella of OCD.