

Step inside the real world of compulsive hoarders

Recent research has changed the way clinicians treat hoarding as well as refuted popular assumptions about people with excessive clutter.

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If you had opened the front door of Lee Shuer's apartment in the early 2000s, you would have encountered a narrow hallway made even narrower by all kinds of random stuff: unnervingly tall stacks of books and papers, cardboard boxes full of assorted knickknacks, and two hot pink salon hair dryer chairs with glass domes suspended from their arched necks. Sidling down the hallway to the right, you would have reached Shuer's bedroom. The door would have opened just wide enough for you to squeeze inside, where you would have seen mounds of stuff three to four feet high on the floor, bed and every available surface. A typical heap might have contained clothes, a violin case, a big box of Magic Markers, record albums, a trumpet, a framed picture, a package of socks, three dictionaries, two thesauruses and a pillow.

Traveling a little farther down the hallway would have brought you to the common space that Shuer shared with his two roommates—a space that they had come to call "the museum room." In addition to Shuer's extensive collection of vintage Atari video games and related paraphernalia—Pac-Man board games and action figures—the room contained numerous bobble heads and kitsch from 1970s and '80s; nine milk crates stuffed with hundreds of eight-track tapes; furniture that he planned to refurbish; pile of newspapers, magazines and his artwork; and an assemblage of curious salt and pepper shakers—a mouse and slice of cheese, a dog and fire hydrant.

Like many people, Shuer collected things in his youth—baseball cards, coins, cool rocks—but his childhood collections never became unusually large or disorderly. After college he bounced from place to place with few possessions. But when he settled down in an apartment in Northampton, Mass., in 2000 he began collecting much more avidly than in the past. He spent his weekends and spare time visiting Goodwill, the Salvation Army and tag sales in search of his next acquisition—the more intriguing and unusual, the better. Sometimes he would visit a thrift shop on his lunch break rather than eat.

The objects and bric-a-brac that Shuer collected provided a sense of comfort, helping him overcome his social anxiety. He was not confident that he was interesting and likeable—but he knew his collection was. If he offered a guest a cup of coffee in an eccentric mug, for example, he could depend on the mug itself to spark a conversation. Soon enough, Shuer had filled his newfound space with enormous piles of stuff. His roommates were remarkably patient, given the circumstances, but they repeatedly gave Shuer an ultimatum: Clear up this mess or we will throw everything out. Shuer would move some items from the common space into his room and continue collecting. The thought of discarding even a single item caused him too much pain—a mingling of sadness and worry that he might need the object one day.

Today, Shuer, 38, lives with his wife Becca in a three-bedroom house in Easthampton that Shuer describes as 85 percent decluttered. When they first moved into the house in 2006 Shuer brought just about everything from his previous apartments with him. His collection completely filled one of the bedrooms on the second story, so that barely an inch of floor space was visible; it spilled out along the stairways, found resting spots on top of the fridge and kitchen cabinets, crowded the living room and claimed half the basement. Now, their living room needs only a little tidying here and there when guests come over. The stairwell leading to the second story is completely free of mess. The kitchen is for kitchen stuff. And Shuer is making good progress on the basement. Through an innovative series of peer-organized workshops designed to help people with excessive clutter—the Buried in Treasures program—Shuer has learned to catch himself in the act of acquiring something he does not have the space for, to challenge his beliefs about the true value of his possessions, and to gradually get rid of things he does not need without mourning their loss.



Michael Maloney/San Francisco Chronicle/Corbis

A greater understanding of hoarding is leading to new developments in treatment.

Most psychiatrists would diagnose Shuer with compulsive hoarding, which is defined as the excessive accumulation of stuff and the refusal to discard it, resulting in problematic clutter. In addition to interfering with daily activities such as cooking and sleeping, extreme clutter often increases health risks from poor sanitation, makes it more difficult to get out of the house in a fire or other emergency and puts the hoarder in danger of eviction. Compulsive hoarders often have other mental illnesses as well: 50 percent have major depressive disorder and 48 percent have either anxiety or social phobia, according to [various surveys](#). In recent years the general public has become more aware of hoarding than ever before, thanks in part to shows such as A&E's *Hoarders* and TLC's *Hoarding: Buried Alive*. Many researchers and hoarders—who often prefer to call themselves collectors or clutter bugs—argue, however, that such shows focus on extreme examples and that their sensationalism obscures the reality of day-to-day life for most hoarders. Studies published in the last 10 years have changed the way psychologists and psychiatrists think about compulsive hoarding and contradicted a number of popular assumptions about people with extensive clutter.

In the current edition of psychiatry's standard guidebook—the *Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV)*—hoarding is listed as one of the criteria for obsessive-compulsive disorder (OCD), an anxiety disorder characterized by intrusive, irrational thoughts and ritual behaviors often intended to dispell those thoughts. The *DSM-5*, to be published this May, recognizes hoarding as a disorder in its own right for the first time. Research in the last decade has confirmed that OCD and hoarding are genetically and neurologically distinct. Recent research also emphasizes that hoarders do not exclusively collect junk and are not lazy, disorganized or unclean people, even if their homes are a mess. Neuroimaging studies and case reports have revealed divergent patterns of brain activity and various cognitive peculiarities common to many hoarders: The very act of deciding what to keep and what to throw away causes them great anxiety, for instance, and they form unusually strong emotional attachments to inanimate objects. Traditional therapies for OCD have largely failed to help compulsive hoarders and complete recovery remains rare, but researchers have developed new promising treatments, including the workshop that helped Shuer so much.

Know your stuff

Serious research about compulsive hoarding began relatively recently. Few rigorous hoarding studies existed before the early 1990s, although Freud and other psychologists described particular cases and theorized about why people hoard. A few widely publicized cases, such as that of the Collyer brothers—two reclusive Americans who were found dead in their New York city apartment surrounded by more than 100 tons of stuff—affirmed a misconception of hoarders as eccentric and socially isolated people. In truth, many hoarders live relatively typical lives, hold steady jobs and maintain ties to friends and family, even if their habits create tension. One recent and surprising finding is that compulsive hoarding is much more prevalent than researchers thought. Between five million and 14 million people in the U.S. are compulsive hoarders—at least twice the number of people diagnosed with obsessive-compulsive disorder (OCD). Some researchers contend that these figures are underestimates and that the vast majority of hoarding remains unrecognized and untreated.

Given that the average age of hoarders in published studies is 50, researchers were also surprised to learn that indications of compulsive hoarding sometimes appear early in life, between ages 11 and 15. The drive to collect is common in childhood. By age six, most children have begun a collection of some kind—coins, stamps, seashells, marbles, action figures—but these collections rarely become so unruly that they interfere with a family's daily activities. Some children, however, reveal a proclivity to hoarding in their emotions: They become furious or miserable when faced with losing a particular object, even one that their families did not realize was important to them. Randy Frost of Smith College in Massachusetts—one of the world's leading experts on compulsive hoarding—recalls one young girl who became nearly inconsolable when she learned that her parents were going to ditch the living room couch. In the vast majority of cases, however, compulsive hoarding does not become problematic until adulthood.

[Recent research](#) challenges the notion that hoarders primarily collect and store junk. Hoarders stash a variety of different items, including clothes—old and brand new—bits of glass or pottery, antiques, figurines, magazines, letters, greeting cards, pens, receipts, bills and expired medication. Sometimes hoarders mix incredibly valuable items—such as jewelry or the deed to the house—with piles of genuine junk. Almost anything can become the object of a hoarder's interest and affection. Some collect bits of their own body: fingernails, strands of hair, urine. Others hoard animals. Certain “cat ladies,” such as Irene Vandyke—who, authorities recently discovered, had 67 dead cats in her freezer and more than 100 cats living in crates packed into her home in upstate New York—are likely animal hoarders.

Psychologists no longer regard hoarding as a subset of obsessive-compulsive disorder (OCD). Although some symptoms of hoarding and OCD overlap, and the disorders can co-occur, they differ in a number of important ways. First, most hoarders do not perceive thoughts about hoarding as intrusive or unpleasant whereas many people with OCD regard their obsessions as unwelcome interruptions in their usual stream of thoughts. Some hoarders experience no distress at all until a friend or family member intervenes and insists that they get rid of their stuff, although others acknowledge that the clutter is a problem on their own. And, whereas the

severity of OCD symptoms fluctuates over time, hoarding tends to get progressively worse. Hoarding and OCD seem to be genetically distinct too. The evidence suggests that hoarding is inherited as a recessive trait, whereas the compulsive checking and organizing common in OCD are dominant.

Researchers have also discovered a number of psychological peculiarities that characterize compulsive hoarding. Everyone endows otherwise ordinary objects with special meaning—the ticket stub from one's first concert, the dependable duffel bag or backpack that has been to several continents. Hoarders tend to see meaning and value in far more items—and a much wider variety of items—than most people. Their emotional investment in those items is much larger than usual, as well.

Some hoarders imbue the inanimate with a kind of sensibility or sentience. Frost and his colleagues describe, for example, a woman who bought half-a-dozen puppets from a TV shopping channel because no one else was bidding on them and she worried that the puppets' feelings would be hurt. Even though she recognized this as an irrational thought, she could not disperse her concern for the puppets. In another case study a young boy stopped eating for a while, fearing that chewing hurt his food. For other hoarders, piles of possessions provide a sense of comfort and security. Some hoarders will keep anything with someone's handwriting or name on it, suggesting that they have a strong tendency to link a person's identity to an object.

The act of deciding which of their belongings to keep and which to throw out makes many hoarders incredibly anxious: they worry that they will make the wrong choice and fear discarding or wasting anything that could prove useful one day. To avoid that anxiety, they often do nothing, allowing stuff to pile up. Hoarders also refuse to throw something out because they anticipate the grief that will follow their loss.

Hoarders tend to organize the world spatially and visually, rather than categorically. Instead of putting a new electricity bill in a designated folder, for example, a hoarder might slip the bill on top of a particular pile of stuff, committing to memory a visual map of its location. In this way, many hoarders can look at their piles of stuff and know exactly what they contain—although the larger and more jumbled the heaps become, the more difficult it is to keep track of individual items. Many compulsive hoarders have difficulty categorizing their possessions—believing that each item is too unique to lump with others—even though they have no trouble classifying objects they do not own.

Research by David Tolin, a clinical psychologist at the Institute of Living in Connecticut, and his colleagues has begun to elucidate some of the neural circuitry underlying compulsive hoarding. In one such study 43 compulsive hoarders, 31 people with OCD and 33 healthy individuals showed up at the lab with their junk mail and newspapers in hand. Inside brain scanners the participants watched a computer screen on which appeared pictures of either their mail and newspapers or paper documents that belonged to someone else. The volunteers had six seconds to make a decision by pressing one of two buttons—keep the item or throw it away. They were under the impression that if they chose the latter the experimenters would shred the paper.

Compared with other participants, hoarders reported more anxiety, sadness and indecisiveness during the experiment. The scanners revealed unique patterns of electrical activity in two particular regions of hoarders' brains: the anterior cingulate cortex (ACC) and insula. Among many other functions, the ACC and insula are important for monitoring errors, assessing risk and processing fear and other unpleasant emotions. When hoarders made decisions about items that did not belong to them, they had unusually low activity in the ACC and insula. When choosing whether to discard their own possessions, however, they showed unusually high activity in these regions. Tolin and his colleagues interpret these patterns of brain activity as corroborating what hoarders report: When faced with the choice of keeping or discarding a belonging, hoarders experience an inflated sense of risk and excessive fear of making the wrong decision.

New treatments

Because hoarding was considered a subset of OCD, clinicians initially tried the same treatments for both disorders. These attempts mostly failed. Certain antidepressants, in particular selective serotonin reuptake inhibitors (SSRIs), often help people with OCD but have limited success in treating compulsive hoarding. Cognitive behavioral therapy (CBT), which involves recognizing and changing maladaptive thoughts, emotions and behaviors, works well for a range of mood and anxiety disorders. The variety of CBT typically used for OCD helps only 30 to 40 percent of compulsive hoarders, however.

In the mid 1990s, Frost and Gail Steketee of Boston University—another leading expert on hoarding—began developing a form of CBT tailored for compulsive hoarding, eventually publishing a treatment manual for therapists in 2007. Steketee and Frost recommend, for example, asking patients to write a list of pragmatic questions that they might ask themselves when deciding whether to buy something

—Can I afford this? Do I have the space for this object? Do I really need it?—and to keep the list with them. Whenever they get the urge to buy or otherwise acquire something, patients are supposed to bring out the list and answer the questions in order to make smarter decisions.

Tolerance-building exercises gradually teach patients to resist the urge to acquire. At first, patients simply drive by a store they would like to visit without stopping to go inside. Then they learn to walk right past the store. In the final stage they enter the store, pick up an item that they really want to buy, put it down and leave. Similar exercises teach hoarders to discard items they already have and do not need. Helping hoarders declutter their homes bit by bit is far more effective than hiring a cleaning service to remove everything in one shot: the sudden and dramatic loss can enrage hoarders or plunge them into depression; some go into hoarding hyperdrive to replace what was taken from them.

In one test of hoarding-specific CBT, 18 volunteer hoarders immediately began a course of treatment, completing 26 one-hour-long sessions over several months; another 19 volunteers had to wait 12 weeks before beginning the same treatment program. In those first 12 weeks volunteers receiving hoarding-specific CBT improved far more than wait-list participants on measures of clutter and difficulty discarding items, indicating that the treatment was working and that improvements were not just an effect of time. At the conclusion of the study, after all 37 participants had completed their treatment, 26 (70 percent) had improved in some way and therapists concluded that nine patients (24 percent) were "very much improved."

Some of Tolin's [neuroimaging studies](#) suggest that hoarding-specific CBT changes the brain activity of compulsive hoarders. In one small study six compulsive hoarders completed 16 weekly 90-minute CBT sessions. Before treatment, activity in the cingulate cortex and insula was unusually high when hoarders had to make choices about their possessions, as observed in earlier studies. When their treatment was complete, the activity in these regions was much lower, sometimes approaching levels seen in healthy participants, although their habits had not changed much. Tolin thinks that even if therapy changes brain activity relatively quickly, significant changes in behavior require more time.



To increase awareness about hoarding-specific CBT, Steketee, Frost and Tolin and co-authored a book entitled *Buried in Treasures*. The book has become the basis for peer-organized support groups for people with problematic clutter—especially for those who cannot afford one-on-one therapy. In typical Buried in Treasures workshops, which are free, between eight and 12 participants complete many of the same exercises and homework assignments central to hoarding-specific CBT over a period of 20 weeks, guided by a peer "facilitator." In various trials of the Buried in Treasures workshops, symptoms of hoarding declined by between 22 and 27 percent and, in one study, an inspector judged more than 70 percent of participants as "much" or "very much" improved after visiting their homes. Buried in Treasures workshops, which originated in Massachusetts, are now active in San Francisco and Miami and will soon begin in New York City.

In 2007, not long after moving into his Easthamptom home, Shuer met Frost through colleagues and volunteered to run a series of Buried in Treasures workshops. In the process, Shuer began to change his self-image and his habits. "Over time my self-esteem and identity shifted," he says. "I learned that I didn't need those props anymore to have a social life. I don't feel a sense of loss or pain anymore when I give something up." He is now the director of Mutual Support Services, a component of the mental health and social services organization ServiceNet, and he continues to sort through his colossal collection, getting rid of what he does not really need and cannot accommodate in his home. A recent photograph that he provided depicts a charming and neat living room: no boxes of knickknacks or piles of magazines and concert flyers; nothing draped on the beige couches; one stray pillow and some cat toys on the carpet; and a single bookshelf with framed pictures, vases and figurines carefully arranged.

"I have learned to limit myself," Shuer says. "I'm not saying that I can never get anything again. If I find a cool book, I now know that I have to make space for it on the bookshelf. I have more free time and a much happier partner who really appreciates it. She loves me but she definitely did not love living with all that stuff."