

The Mind of a Hoarder Carol Adkisson*

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Opinion

Let's start with some basics; hoarding originally comes from a term that was used to describe animals that stored their food for future use.

Randy O Frost and Tamara L Hartl defined compulsive hoarding with the following [1]:

- The acquisition of, and failure to discard, possessions that appears to be of useless or of limited value.
- Living spaces so cluttered that using the room as intended is impossible.
- Significant distress or impairment to function.

The demographics of an average hoarder

- Hoarding disorder affects people of all ages and demographics.
- Hoarding usually starts around ages 11 to 15, and it tends to get worse with age.
- However, hoarding is more prevalent in older age groups, and the symptoms seem to increase with age.
- Prevalence of approximately 1.5%.
- Affects people of both genders.
- More often unmarried (67%).
- More likely to be impaired by a current physical health condition (52.6%) or co-morbid mental disorder (58%).
- More likely to report lifetime use of mental health services.

The Developmental stages of a hoarder

- Childhood-Difficulty discarding things.
- Teenage to Adulthood -Gradual build up of items.
- 20's to 30's-Saving an excessive number items.
- Middle Age-Symptoms accelerate.
- Elderly-Rooms become unusable.

A study looked at group patients who had 'focal brain lesions' very specific injuries to small areas, in particular those who displayed 'abnormal collecting behavior'.

Using high-resolution, three-dimensional magnetic resonance

imaging they compared the study group with normal images and found that damage to a part of the frontal lobes of the cortex, particularly on the right side, were shared by the individuals with abnormal behavior.

This means that there is a particular spot in the brain that put the brakes on hoarding.

Another study has shown that compulsive hoarders have a unique pattern of brain activity, distinct from that seen non-hoarding OCD patients or normal control subjects. It suggests that hoarding is associated with impaired decision making. When hoarders wrestled with decisions about their personal items MRI scans show much more activity in the areas of the brain that control decision making, attention and controlling emotions.

This area of the brain is known as the 'bilateral anterior ventromedial prefrontal cortex' or VMPFC. The prefrontal cortex is the most 'advanced' area of the brain, only mammals have it and it is most developed in humans.

It seems that, although the regions are missing in the brain lesion patients and over-active in the OCD hoarding patients, in that they share the same functional unit of the central nervous system.

Put simply, this means that hoarders think differently. This may explain why traditional treatments for OCD sufferers with hoarding are less successful for those without hoarding. These findings are at a very early age of discovery.

A 2008 publication has shown that NTRK3 gene may contribute to the genetic susceptibility to hoarding and OCD and has identified this as an area for further research.

A separate 2007 study has shown that there is a region on chromosome 14 linked with compulsive hoarding behavior in families with OCD. Even though these studies are on very small samples, these could be dramatic breakthroughs.

Can be triggered by an emotionally heavy life event.

How much is the risk of becoming a clinical compulsive hoarder is genetic and how much is learned behavior and upbringing is yet uncertain. Genetics, brain functioning and stressful life events are being studied as possible causes.

My experience with the average hoarder:

- Ego syntonic vs ego dystonic (header).
- Don't see themselves with a problem.
- Compulsive hoarding is characterized by difficulty discarding items, often resulting in significant distress and impairment due to excessive accumulation of clutter [2].

Therefore, the act of hoarding is considered ego-syntonic in Hoarding Dystonic and ego-dystonic in OCD.

- Lacking linear thought, speaks in circles.
- Frustrating to work with.
- Family system is burnt out
- Lack of understanding of the consequences of their disorder.
- Limited growth without treatment.

Types of hoarders

- Clinical compulsive hoarding- which is the most common type.
- Clinical compulsive hoarding tends to run in families. Several studies have shown that approximately 50% of hoarders report a first degree relative, e.g. a parent, sibling or offspring who hoards. Some of the latest research into compulsive hoarding has been into genetic factors [3,4].
- Compulsive hoarding, also known as hoarding disorder, is a pattern of behavior that is characterized by excessive acquisition and an inability or unwillingness to discard large quantities of objects that cover the living areas of the home and cause significant distress or impairment.
- OCD or 'perfectionist' hoarding.
- Perfectionists are heavily represented among hoarders.
- Hoarders may have perfectionist tendencies in a few areas of life but not in others.
- Animal hoarding.
- This is very rare, although these are the cases that reach the newspapers.
- When most people hear about animal hoarding, they recall shocking news stories about the "crazy cat lady."
- The term "animal hoarding" refers to the compulsive need to collect and own animals for the sake of caring for them that result in accidental or unintentional neglect or abuse.

- Most animal hoarders fall victim to their good intentions and end up emotionally overwhelmed, socially isolated, and alienated from family and friends. The problem causes immense suffering for both animals and people.

Specific problem Areas

Animal hoarders have problems with acquiring animals and handling, managing, and getting rid of them. They have every intention of caring for the animals, but their difficulties with organization, attention, and focus contribute to their living spaces becoming very messy with animal waste and clutter [5].

Hoarders have a hard time letting go of their objects or animals because they have a terrible time making even simple decisions; for example, "Is this dog my favorite or should I adopt him out?" They also may have subtle memory problems and feel that they cannot trust their recall, so they keep things to preserve memories.

Strong emotional attachments

Hoarders also have an intense emotional attachment to their animals. They avoid the pain of letting go of things that seem very special, even when clutter prevents comfortable living.

They imagine the wonderful way in which they will heal love, and nurture their pets, while overlooking the terrible effects of having too many of them.

Newspaper and magazine hoarding

Drive is not towards personal growth: To make them totally up to date with current affairs or their career, but involves fear of missing something that might have a detrimental affect on their lives, such as new rules and laws they may get into trouble for not observing [6].

Another aspect of written work hoarding has been guilt: people afraid that they have inadvertently written something about themselves in newspapers and magazines that carry stories that triggered this guilt (often sexual) [7].

Hoarding levels

The National Study Group on Compulsive Disorganization created a Clutter Hoarding Scale as a guideline for professional organizers making their first few contacts with clients:

- **Hoarding Level One:** Clutter is not excessive, all doors and stairways are accessible, there are no odors, and the home is considered safe and sanitary.
- **Hoarding Level Two:** Clutter inhabits 2 or more rooms, light odors, overflowing garbage cans, light mildew in kitchens and bathrooms, one exit is blocked, some pet dander or pet waste puddles, and limited evidence of housekeeping.
- **Hoarding Level Three:** One bedroom or bathroom is unusable, Excessive dust, heavily soiled food preparation areas, strong odors throughout the home, excessive amount of pets, and visible clutter outdoors.
- **Hoarding Level Four:** Sewer backup, hazardous electrical wiring, flea infestation, rotting food on counters, lice on

bedding, and pet damage to home.

- **Hoarding Level Five:** Rodent infestation, kitchen and bathroom unusable due to clutter, human and animal feces, and disconnected electrical and/or water service.

Diagnostic criteria for hoarding:

1. Persistent difficulty or parting with possessions, regardless of their actual value.
2. This difficulty is due to a perceived need to save the items and to distress associated with discarding them.
3. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (eg. Family members, cleaners, authorities).
4. The hoarding causes clinically significant distress or impairment in social, occupational or other important areas of functioning including (including maintaining a safe environment for self and others).
5. The hoarding is not attributable to another medical condition (eg. brain injury, cerebrovascular disease, Pracer-Willis syndrome).
6. The hoarding is not better explained by the symptoms of another mental disorder (eg. Obsessions in obsessive-compulsive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Risk Factors

- **Personality:** Many people who have hoarding disorder have a temperament that includes indecisiveness.
- **Family history:** There is a strong association between having a family member who has hoarding disorder and having the disorder yourself.
- **Stressful life events:** Some people develop hoarding disorder after experiencing a stressful life event that they had difficulty coping with, such as the death of a loved one, divorce, eviction or losing possessions in a fire.

Comorbidity: Many people with hoarding disorder also experience other mental health disorders, such as:

- Depression
- Anxiety disorders
- Obsessive-compulsive disorder (OCD)
- Attention-deficit/hyperactivity disorder (ADHD)

As someone who grew up with a Stage Five hoarder, I have always had a natural curiosity to understand “What creates a hoarder” and is it treatable. As a clinician I have evolved into a therapist with many specialties that interweaves trauma and it’s affects on the human and consequently also on the human brain. I created my non profit “The Trauma and Healing Foundation” for the purpose of treating trauma and its affects, one of those affects

is the collection of items and the emotional attachment that to most others makes very little sense [8].

I too, was traumatized as a child; I went through horrific abuse that caused pain, hurt, fear of abandonment as well as many other overwhelming feelings. However, as an adult I am not a hoarder. Some children of hoarders become hoarders similar to their parents, and other’s like me, would sooner throw something away then become similar to how I grew up.

I became more curious and began to realize as I treated hoarders in my office, that they are almost virtually impossible to treat. Although they don’t meet the criteria of addiction, they do seem to mimic each other in the ism. That is the addictive personality of someone who grew up in a dysfunctional family home [9]. The addiction can manifest in so many different ways, including substance use, or relationship addiction, gambling, food and also hoarding, just as an example.

My mother is one of the many hoarders that grew up in the depression era, and many parents that grew up in that era; appear to have a genetic predisposition to their children also meeting some criteria of hoarding disorder. If you think about it, what the parent teaches, the child learns is normal and thus the family pattern of hoarding continues generation after generation.

As I studied hoarders, I learned that there are five stages of hoarding, described above. This spectrum is important to understand to assess the client and specifically the stage can affect the suggestions of unique treatment.

That being said I looked at the current research and realized that the brain of a hoarder is indeed different. Many of those changes are listed above and referenced below. That made sense to me. If I ask a question of a hoarding client, there appears to be no linear thought, instead a stream of consciousness that has nothing to do with the actual question originally asked. It is a type of paranoia that if they answer the question incorrectly they could be trapped, with no way out, the biggest fear “they could be wrong in answering the question”. It appears the prefrontal cortex of the hoarding brain, what I call the secretary of the brain is damaged and the executive functioning is minimal, if at all available to the hoarder. Further there is a gene NTRK3 that may be a contributing factor to the genetic predisposition of a generational hoarding family.

Why some members of a family meet full criteria for hoarding and some just a few criteria could be based on the under activated and over activated areas of the brain. I am not a doctor, it is more of a hypothesis I have developed through working with family systems that are struggling with this disorder.

Many times the hoarder does not seek out therapy. Instead that person becomes the identified patient that is brought to the therapist’s office for the therapist to fix. As a clinician I tell them, good news, this person doesn’t have a problem, you all do. I begin to explain the hoarding mind and how circular the thinking process is, the dysfunctional family system and codependency. I teach the family that without a united front, much like in an addiction, this family will not heal. Yes the hoarder is the one that may be the predicating factor to bring the family in the

office, however family systems therapists understand it is the entire family system that needs help for the treatment to be most effective. I use many techniques for treatment including 12 step recovery, transformational training and cognitive behavior therapy. If the family is truly a united front, the shift will begin to happen. If not, I would say the family isn't ready to admit their own culpability in their family member's problems [10].

In conclusion, yes a hoarding mind is different; there are often many levels of trauma that they experienced as a child and beyond. As they begin to isolate themselves there is less and less people around them that are willing to help their family member and the hoarder progresses from Stage One to Stage Five, on a spectrum that is at times difficult to delineate. This is a progressive disease, and if not stopped, it is possible for Code Compliance, Adult Protective Services and many other agencies to become involved. Will that change the mind of a hoarder, no? If the original trauma is not treated, the hoarder will go on to re-ward until they pass. Which isn't an appealing end? Just like the addict the family will always play a role in the healing or the lack of healing, as they say in recovery, when the family becomes sick and tired of becoming sick and tired, you are now at the beginning of the actual hope for healing to begin.

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