

Hoarding Disorder: Mental Health Concern or Self Neglect?

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Who We Are

- 501(c)(3) public charity
- Mission: To promote an effective, ethical, and sustainable response to hoarding in communities, through research, education and prevention, and collaborative approaches to treatment.



What is hoarding disorder?



Quick answer: With the DSM5 hoarding disorder is a diagnosis, the common definition has 4 parts:

1. Excessive acquisition of stuff*
2. Difficulty discarding possessions
3. Living spaces that can't be used for their intended purposes because of clutter
4. Causing significant distress or impairment (Frost & Hartl, 1996)



*Not universal in all people who hoard

How many people hoard and are some people more likely to hoard than others?

Quick answer: Research shows that

- About 2-5% of the population hoard, which is about 15 million people in the U.S., on the high end (Iervolino et al., 2009; Samuels et al., 2008)
- Older people hoard more than younger people
- People with lower income hoard more than people with higher income (Samuels, et al. 2008)
- No gender differences in prevalence rates (Timpano, et al., 2011)



Hoarding and Older Adults

- Symptoms severity increased with each decade of life (Ayers et al., 2010)
- 25% of elderly community-dwelling day care residents and 15% of nursing home residents displayed hoarding symptoms (Marx & Cohen-Masfield, 2003)
- Increased dysfunction in several domains of executive functioning
 - Mental control, working memory, inhibition, and set shifting (Ayers et al., 2013)
- Major consequences for older adults:
 - Increased risk of falls, fire hazards, food contamination, social isolation, and medication mismanagement (e.g. Ayers et al., 2010; Frost & Gross, 1993; Kim, Steketee, & Frost, 2001)
 - Increased risk of medical conditions (e.g. Ayers et al., 2013; Timpano et al., 2011; Tolin et al., 2008)



What's the difference between clutter, collecting, and hoarding?

Clutter: possessions are disorganized and may be accumulated around living areas

- No major difficulty with excessive acquisition AND no major difficulty discarding items
- Can carry on normal activities in home



Collecting: new possessions = part of larger set of items

- Display does not impede active living areas in home



Hoarding: possessions become unorganized piles of clutter

- Prevent rooms from being used for normal activities
- Motivation to display items: lost

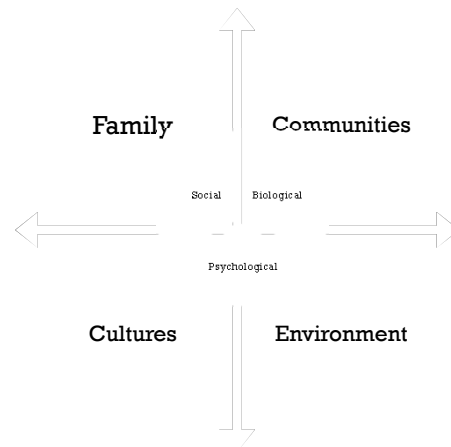


What causes hoarding?

The BIOPSYCHOSOCIAL Model of Compulsive Hoarding states that:

Compulsive hoarding behavior arises from a variety of external and internal variables that are biological, psychological, and social in nature.

We can't talk about one of these pieces without talking about the others!



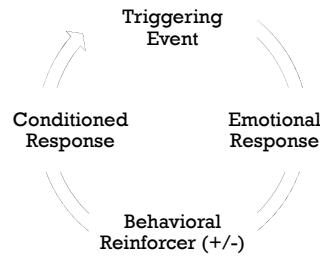
What are the Biological Factors that contribute to hoarding?

- Family history/genetic link (Pertusa, et al., 2008; Samuels, et al., 2007; Winsberg, Cassic, & Koran, 1999)
- Course and progression: behaviors begin during childhood or adolescence (Frost & Gross, 1993; Grisham et al., 2006; Pinto, Eisen, Mancebo, et al., 2007; Samuels et al., 2002; Winsberg et al., 1999)
- Brain functioning differences
 - Occipital and frontal lobes (Saxena et al., 2004).
 - These are the parts of the brain that are responsible for visual things and executive functioning (see below)
- Information-processing (cognitive) deficits (Grisham, Brown, Savage, Steketee, & Barlow, 2007; Grisham, Norberg, Williams, Certoma, & Kadib, 2010; Hartl, Duffany, Allen, Steketee, & Frost, 2005; Hartl et al., 2004; Lawrence et al., 2006)
 - Attention
 - Memory
 - Categorization
 - Complex thinking
 - Decision-making



What are the Psychological Factors that contribute to hoarding?

- **Mental health/emotional distress** (Frost & Hartl, 1996)
 - Poor coping/self-care
 - Co-morbid mental health conditions
 - Unresolved trauma and loss (Sampson & Harris)
- **People who hoard have specific beliefs about and attachment to their possessions** (Frost & Hartl, 1996)
 - Feelings toward object
 - Memory-related concerns
 - Desire for control
 - Responsibility and waste
 - Aesthetics
- **Hoarding behaviors can be reinforced over time** (Frost & Hartl, 1996)
 - Acquiring things makes us feel good, so we want to do more of it
 - Getting rid of things makes us anxious, so we want to do less of it



What are the Social Factors that contribute to hoarding?

- **Interpersonal relationships** (Sampson, 2012; Sampson & Harris; Sampson, Yeats, & Harris, 2012)
- **Social support** (Sampson & Harris)
- **Major life events/transitions** (Grisham, Frost, Steketee, Kim, & Hood, 2000; Kellett, Greenhalgh, Beall, & Ridgway, 2010)
- **Social stigma**
- **Culture**



Are there other mental health issues related to hoarding?



- Yes, hoarding disorder must be considered a co-occurring disorder and is associated with another mental health diagnosis 92% of the time
 - 57% major depressive disorder
 - 29% social phobia
 - 28% generalized anxiety disorder (Frost et al., 2006)
 - 30-40%: OCD (e.g. Samuels et al., 2007)
 - 31%: Organic Brain Illness
 - 30%: Personality Disorders (Mataix-Cols, et al., 2000)
 - 20%: ADHD (e.g. Sheppard et al., 2010)
 - Dementia (Hwang et al., 1999)
 - Eating Disorders (Frankenburg, 1984)
 - Substance abuse (Samuels et al., 2008)



Is it safe to go into a hoarded home?

- There are definitely concerns you must be aware of before entering a hoarded home.

Common safety risks:

- Fire hazard
- Blocked exits
- Risk of falls/items falling
- Lack of routine home maintenance
- Structural damage to building
- Risk of eviction and homelessness



What are the Safety & Health risks associated with hoarding?

Safety

- Fire hazard
- Blocked exits
- Risk of falls/items falling
- Lack of routine home maintenance
- Structural damage to building from increased weight and volume of clutter
- Risk of eviction and homelessness

Health

- Impaired functioning
 - Poor hygiene and grooming, nutrition
 - Inattention to medical needs
 - Inadequate financial management
 - Difficulty cleaning around clutter
 - Sleeping on floor instead of bed
- Mental Health
- Increased Health Problems
 - Molds, bacteria, dust, dirt
 - Asthma, allergies, headaches
 - Rodent/insect infestation
 - Animal/human feces/remains (hanta virus, tapeworm, psittacosis, cat scratch disease)



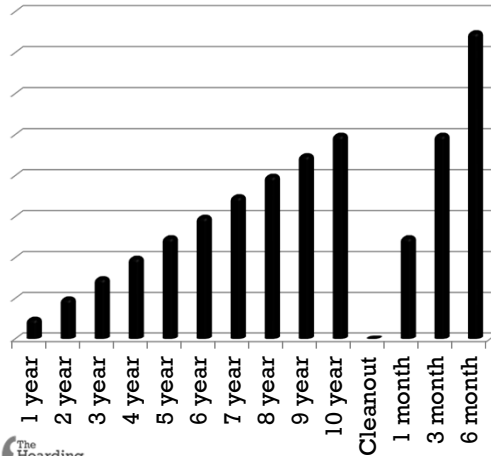
Hoarding: A Community Concern



- By the time hoarding cases come to public attention, they likely:
 - Require intensive, lengthy, costly, strategic and complex responses
 - Require coordinated, collaborative efforts from many different public and private systems
- Education and research are lacking
 - Current responses are:
 - Ineffective
 - Inappropriate
 - Expensive
 - Unethical



Mandatory Cleanouts/Abatements



Forced Cleanouts are not effective or ethical

- It can do more harm than good.
- Can be traumatizing

"In all three instances of going in and cleaning these places up, within weeks of relocating the individual back into a clean environment, the individual passed away...it was such a dramatic change for them because we didn't realize the impact of the sociological change." (Brace, 2007)

- It's not sustainable
- BUT sometimes it's necessary

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At what point is this reportable to the authorities?

A vulnerable adult is defined by law as:

- a person 60 years of age or older who lacks the functional, physical, or mental ability to care for him or herself;
- an adult with a developmental disability per [71A.10.020](#);
- an adult with a legal guardian per [11.88 RCW](#);
- an adult living in a long-term care facility (an adult family home, boarding home or nursing home);
- an adult living in their own or family's home receiving services from an agency or contracted individual provider; or
- an adult self-directing their care per law ([74.39.050 RCW](#))

■ Building codes differ from city to city and county to county, but general safety concerns include:

■ Health

- Ex: cannot use bathtub/shower/toilet; cannot prepare food/use refrigerator/sink; presence of feces or urine; insects/rodents; mold

■ Obstacles

- Ex: Cannot move freely/safely; inability for EMT to enter/gain access; unstable piles/avalanche risk; egresses/exits, vents blocked/unusable

■ Structure

- Flammable items by heat source; Storage of hazardous waste/material; Caving walls; Electrical wires/cords exposed; No heat/electricity; No running water/plumbing problems

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What is Self-Neglect?

<https://www.dshs.wa.gov/altsa/home-and-community-services/self-neglect>

- WA State DSHS Website:
 - “A general term used to describe a vulnerable adult living in a way that puts his or her health, safety, or well-being at risk”
 - Person’s own failure to maintain health and safety
- Signs include:
 - Sudden decline in physical appearance
 - Untreated injuries or health problems
 - Unsafe living conditions
- *Diogenes Syndrome*: Behavioral disorder characterized by domestic squalor, extreme self-neglect, hoarding, and a lack of shame regarding one’s living conditions



The Challenges...

- When to intervene?
- Does the individual have the mental capacity to make an informed choice about how they are living?
- Balancing choice, control, independence, and well-being
- Some adults will refuse help
 - Interventions can be offered, but person must accept help



What to do to help

- Stay alert to any changes that might indicate a problem with an aging customer. Is mail or newspapers piling up? Is there a significant, negative change in his or her behavior that concerns you? Stay alert for signs a person may be in trouble.
- If you become concerned, knock on the door. Law enforcement and social service agencies cannot be everywhere. Your help is needed.
- If the person does not answer the door and you are concerned for their safety, call 911 and ask for a welfare check.
- Get help from Adult Protective Services if you are concerned an adult may be self-neglecting.

<https://www.dshs.wa.gov/altsa/home-and-community-services/self-neglect>



What can be done by Adult Protective Services (APS)?

- APS is a voluntary investigative agency
- With an individual's consent, APS will do everything possible to ensure safety and well-being once case has been reported and investigated
- APS *cannot* remove a person from home against his or her will or force them to get help
- APS can intervene without the consent of vulnerable adult only if:
 - all other avenues have been exhausted,
 - if person has found to be incompetent by the courts, and
 - a court order has been granted to appoint a legal guardian to make decisions on his or her behalf



Mental Health & Public Safety

- Care providers need to balance protecting individual rights and autonomy while effectively responding to public health and safety imperatives (Saltz, 2010)
 1. Thorough mental and physical health assessment, including mental capacity
 2. Development of positive and trusting relationship with patient
 3. Providing mental health treatment for co-occurring diagnoses even if treatment doesn't improve hoarding
 4. Reducing risk by emphasizing increasing safety rather than eliminating hoarding behavior
 5. Working with appropriate community agencies to improve communication and develop coordinated response

If the client has:	Goal of intervention:
High risk/high capacity	Accept client's right to self-determination
High risk/low capacity	Intervention required up to and including legal (guardianship, conservatorship, etc.)
High risk/moderate capacity	Reduce resistance; reduce risk; increase capacity



Harm Reduction

- Set of practical strategies that reduce the negative consequences of a particular health issue (Harm Reduction Coalition, 2010)
- Goal: not to eliminate behavior itself but to minimize negative, unwanted consequences that accompany behavior
- Does not require the individual to have “insight” into reasons for hoarding
 - Only recognize the potential for harm to them, others, or neighbors and to agree to minimize the risk
 - Doesn't prevent new items from coming in or increase discarding
- Helpful for individual with cognitive impairments or for people who are unwilling to seek treatment



Harm Reduction Goals (Tompkins & Hartl, 2009)

- Safety
 - Moving flammable materials away from heat sources
 - Clearing walkways of trip hazards
 - Clearing enough room around doors and window
- Health
 - Clearing access to bathroom and washing facilities
 - Ensuring proper food storage
 - Addressing appropriate trash and waste disposal
 - Eliminating pest infestations
- Comfort
 - Addressing heating and cooling problems
 - Designating and clearing appropriate places to sleep and eat
 - Making space to conduct daily tasks



Resources

What resources are available?

Quick answer: There are several different resources that are available to people who hoard, their families, and people who work with them.

Non-profit agencies:

- The Hoarding Project (local)
- International OCD Foundation
- Mental Health Association of San Francisco
- Institute of Challenging Disorganization
- Children of Hoarders

Support Groups

- The Hoarding Project (local)
- Children of Hoarders
- Bay Area Resources
- Clutterers Anonymous



Important Local Resources, Info

The Hoarding Project
www.thehoardingproject.org

Local Task Forces

- King/Pierce: Monthly meetings
 - 3rd Tuesday morning of each month
 - Wataskforce@thehoardingproject.org
- Snohomish Hoarding Task Force



King/Pierce County
Hoarding Task Force



Reading Resources

- **Stuff: Compulsive Hoarding and the Meaning of Things (2010)**, Frost & Steketee
- **Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding (2007)** Tolin, Frost, & Steketee
- **Digging out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring (2009)**, Tompkins & Hartl
- **The Hoarding Handbook: A Guide for Human Service Professionals (2011)**, Bratisotis, Sorrentino Schmalisch, & Steketee
- **Ambiguous Loss: Learning to Live with Unresolved Grief (2000)**, Boss
- **Motivational Interviewing: Preparing People for Change, 2nd ed. (2002)**, Miller & Rollnick



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Q & A



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