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Hoarding Disorder FAQ's


The Hoarding Project

MN Fall Supervisors Conference - 9.16.15

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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.

The logo for The Hoarding Project features a stylized grey 'C' shape on the left. To its right, the words 'The Hoarding Project' are stacked vertically in a bold, sans-serif font.

**+ Background on
Hoarding Disorder**

+ Hoarding Disorder is ...

- A mental health disorder that has
- Public safety implications.
- Effective treatment addresses both public safety and mental health.

+ 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?

Research projects that

- About 2-5% of the population hoard, which is about 15 million people in the U.S., on the high end (Jarvolino et al., 2009; Samuels et al., 2008)
- Older people hoard more than younger people (Samuels, et al. 2008)
- People with lower income hoard more than people with higher income (Samuels, et al. 2008)
- Gender differences?



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

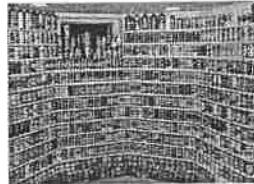
Clutter: possessions are disorganized and may be accumulated around living areas

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



Collecting: existing and new possessions that are 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



+ FAQ: 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 (Frost et al., 2011)
 - 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)

+ Hoarding and Older Adults

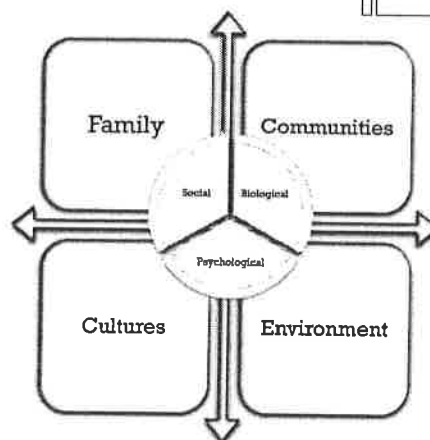
- Symptoms severity increased with each decade of life (Ayers et al., 2010)
- 25% of elderly community-dwelling day care residents and 15% of nursing home residents displayed hoarding symptoms (Marr & Cohen-Masfield, 2003)
- Increased dysfunction in several domains of executive functioning
 - Mental 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 causes hoarding?

The BIOPSYCHOSOCIAL Model of Hoarding Disorder states that:

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!



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Is there a family link to hoarding, and when does it start?



- **Family history** (Pertusa, et al., 2008; Samuels, et al., 2007)
 - More likely to have 1st degree relatives with hoarding (12%) or with hoarding symptoms (49%) (Winsberg, Cassic, & Koran, 1999)
 - Social learning (Polin, 2011)
- **Genetic link** (Iervolino et al., 2009; Lochner et al., 2008; Samuels, Shugert et al., 2007)
- **Course and progression: behaviors begin during childhood or adolescence** (Frost & Gross, 1993; Grisham et al., 2006; Pinto, Elsen, Mancebo, et al., 2007; Samuels et al., 2002; Winsberg et al., 1999)



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What is the link between Hoarding and the Brain?



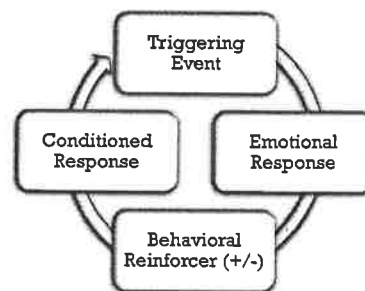
- **Brain functioning differences – Occipital and frontal lobes** (Saxena et al., 2004)
 - Abnormalities in areas associated with: executive functioning, impulse control, and processing of reward value
- **Maladaptive Cognitive Processes** (Grisham, Brown, Savage, Steketee, & Barlow, 2007; Grisham, Norberg, Williams, Certoma, & Kadib, 2010; Hartl, Duffany, Allen, Steketee, & Frost, 2008; Hartl et al., 2004; Lawrence et al., 2006)
 - Information processing difficulties
 - Over-reliance on visual vs. categorical memory cues
 - Attention: Churning; "Clutter blindness" = failure to recognize extent of clutter in the home (Steketee & Frost, 2014, p.2-3)
 - Over- or undercategorization

+ What about hoarding and dementia?

- Hoarding behaviors occur in 15-49% of dementia cases (Tompkins, 2015, p. 16)
- Related to mutation on same chromosome as Alzheimer's-related deficits
- Organic brain illness (e.g. dementia, schizophrenia) or traumatic brain injury will limit effectiveness of standard therapy approaches (e.g. developing insight, changing behaviors)
 - Harm reduction models would be most beneficial

+ What are the Psychological Factors that contribute to hoarding?

- Mental health/emotional distress (Frost & Hartl, 1996)
 - 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



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What are the Social Factors that contribute to hoarding?

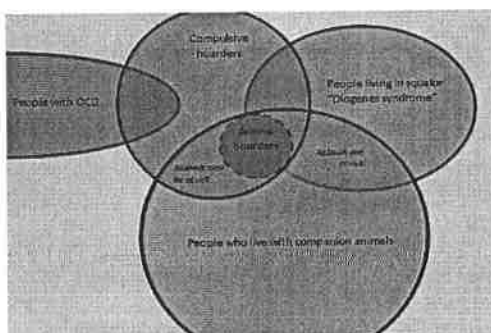
- Major life events/transitions (Grisham, Frost, Steketee, Kim, & Hood, 2000; Kellett, Greenhalgh, Beall, & Ridgway, 2010)
- Higher frequency of lifetime traumatic events (Cromer et al., 2007; Hartl et al., 2005)
- Up to 55% report experiencing a stressful event at onset of symptoms (Grisham et al., 2006)
- Burden on families
 - Positive interpersonal relationships can serve as a protective factor against hoarding severity (Sampson & Harris, 2012)
- Social stigma
- Culture



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What's up with animal hoarding? Is it the same thing as object hoarding?

- There are some similarities between the two, but they differ in several ways.
- Research on animal hoarding is about 20 years behind object hoarding
- Each situation is different
- Presence of squalor does not mean animals are being hoarded



+ Animal Hoarding Defined

From Vet.Tufts.Edu

- The pathological accumulation of animals was first described in [1981]
- Animal hoarding was formally defined in the public health literature in [1999] using the following criteria:
 - Having more than the typical number of companion animals
 - Failing to provide even minimal standards of nutrition, sanitation, shelter, and veterinary care, with this neglect often resulting in illness and death from starvation, spread of infectious disease, and untreated injury or medical condition
 - Denial of the inability to provide this minimum care and the impact of that failure on the animals, the household, and human occupants of the dwelling
 - Persistence, despite this failure, in accumulating and controlling animals

+ Object vs. Animal Hoarding

Similarities

- Acquisition, difficulty discarding, clutter, distress
- Many people who hoard animals also hoard objects
- Co-morbidities

Differences

- Animal hoarding: squalor (100% of homes)
- Gender and age differences
 - AH: More women; later age
- Types of objects:
 - Objects: variety
 - Animals: one species
- Lack of treatment for A.H.
- MAJOR mental health concerns (a mental health professional *must* be involved)

+ At what point is this reportable to the authorities?

Quick answer: If there is a threat of endangerment to the health and safety of:

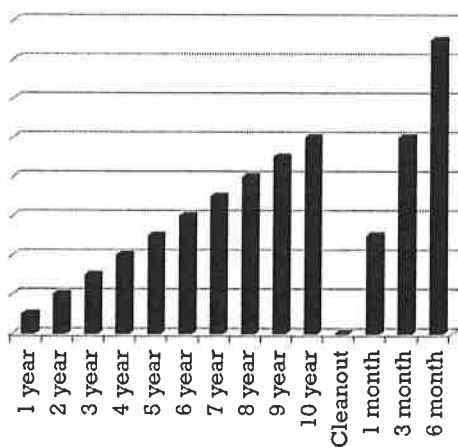
- A child/minor
- Older adult (over 60 with a cognitive, physical, or functional impairment)
- Person with disability or dependency
- Animal

you must report (if you are a mandated reporter)

■ 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

+ Emotional/Psychological Impact of Hoarding Clean-outs on Clients



Clean-outs can do more harm than good.

- Can be traumatizing
- Emotional Flooding
- Even threats can be unhelpful
 - Can ruin relationships and trust

"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

+ FAQ: So if I can't clean out a home that is hoarded, what am I supposed to do? What if there is no time to do therapy?



Quick answer: Safety comes first. Although it would be ideal to address underlying issues first, we can't always do that.



Rule of thumb:

1. Safety first.
2. Skills second.
 - Emotional regulation (self-soothing)
 - Self-awareness/mindfulness
 - Organization, categorization, etc
3. Therapy and everything else can follow.
 - Grief, loss, and trauma
 - Hoarding work: acquisition/discarding

+ Treatment and Strategies for Mental Health Professionals



Treatment Planning for Hoarding Disorder

- Combining strategies from across fields can help to most holistically treat this mental health and public safety issue
- Integrated treatment approach (modeled after treatment for co-occurring disorders)
 - Prioritize treatment goals for primary diagnoses
- CBT most Evidenced Based Practice
 - Integrated treatment for hoarding will include different types of interventions to support specific treatment goals
 - Examples:
 - Distress re: discarding items: Exposure treatments (CBT)
 - Organization skills: Executive skills building (ADHD treatment)
- Medication for Hoarding Disorder?



Common treatment goals for Hoarding Disorder

- | | |
|---|---|
| ■ Increase understanding of hoarding behavior. | ■ Reduce compulsive buying or acquiring and replace these behaviors with other pleasurable activities |
| ■ Create living space | ■ Evaluate beliefs about possessions |
| ■ Increase appropriate use of space | ■ Reduce clutter level in home environment |
| ■ Organize possessions to make them more accessible | ■ Learn problem-solving skills |
| ■ Improve decision-making skills | ■ Prevent future hoarding |

+ 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

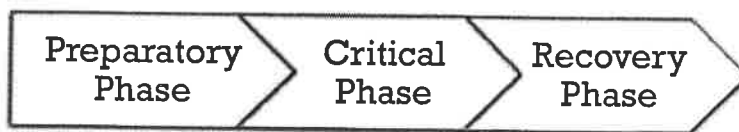
+ Harm Reduction Goals (Tompkins & Hartl, 2009)

- 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

+ Safety Day: Coordinated & Systematic Response to Forced Clean-outs for Hoarded Homes (Level 3)

- Safety Day is a *harm reduction* approach to mandatory clean outs.
- Why harm reduction approach? (Tompkins, 2014, p. 50)
 - Goal of harm reduction is to manage symptoms to decrease risk.
 - Goal of treatment is to eliminate or minimize symptoms to decrease stress and impairment.
- Diffuse Physiological Arousal
 - Emotional Flooding
- Apply Psychological First Aid
 - Recognize and respond to symptoms of psychological crisis
 - Support resilience:
 - Promote Safety
 - Calm & Comfort
 - Connectedness
 - Self-Empowerment
 - Prevention Strategies
 - Self-Care

+ Critical Incident Stress Management (CISM) Treatment Phases for Hoarded Homes (Levels 4 and 5)



- Preparatory Phase
 - Obtain informed consent
 - Process decision-making
 - Teach stress management techniques
- Critical Phase
 - Implement stress management techniques/Psychological First Aid
 - Coordinate clean-out efforts
- Recovery Phase
 - Review clean-out
 - Coordinate transition to long-term mental health treatment

+ What resources are available?

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
- International OCD Foundation
- Mental Health Association of San Francisco
- Institute of Challenging Disorganization
- Children of Hoarders

Support Groups

- The Hoarding Project
- Children of Hoarders
- Clutterers Anonymous

+ Reading Resources

- **Treatment for Hoarding Disorder Workbook (2014)**, Frost & Steketee.
- **Clinician's Guide to Severe Hoarding: A Harm Reduction Approach (2014)**, Tompkins
- **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 & Hardt
- **The Hoarding Handbook: A Guide for Human Service Professionals (2011)**, Brattonis, Sorrentino Schmalisch, & Steketee
- **Loss, Trauma and Resilience (2006)**, Boss
- **Motivational Interviewing: Preparing People for Change, 2nd ed. (2002)**, Miller & Rollnick
- **Narrative Means to a Therapeutic End (1990)**, White & Epston
- **Dirty Secret (2010)**, Jessie Sholl
- **Coming Clean (2014)**, Kimberly Rae Miller



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Q & A



The Hoarding Project

www.thehoardingproject.org

Contact information:

Janet Yeats
janet@thehoardingproject.org

Jennifer Sampson
jennifer@thehoardingproject.org

Max Zubatsky
zubatskyjm@slu.edu

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