

#### **Hoarding Disorder: Mental Health and Public Safety**

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## **Objectives**

- Recognize effective diagnosis and treatment strategies of hoarding disorder.
- Describe alternative options to treatment other than a forced cleanout.
- Apply evidence-based treatment strategies to address issues of safety in hoarding disorder.
- Develop collaborative networks in your area to form a community response to hoarding disorder.



### 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.



Background on Hoarding Disorder: Inside the Mind of a Person Who Hoards

# What is hoarding disorder?



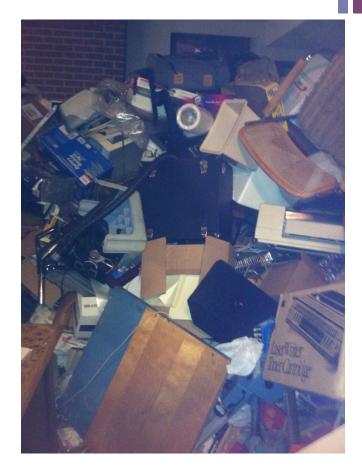
Quick answer: With the DSM5 hoarding disorder is a diagnosis, the common definition has 4 parts:

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

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

#### 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)
- Likely this number is small qualitative experience says 20-25%.
- 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)



### + Co-morbid Diagnoses



- Hoarding Disorder is also associated with lots of other mental health issues:
  - 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)

### + FAQ: 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!



# **FAQ's:** 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



# FAQ's: 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



# **FAQ's:** 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, Beail, & Ridgway, 2010)
- Social stigma
- Culture



### FAQ: What's up with animal hoarding? Is it the same thing as object hoarding? Similarities:

- Quick answer: There are some similarities between the two, but they differ in several ways.
- Research on animal hoarding is about 20 years behind object hoarding
- Know that people who hoard animals began with the best intentions, they did not intend to harm animals.

- - 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)

# 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?

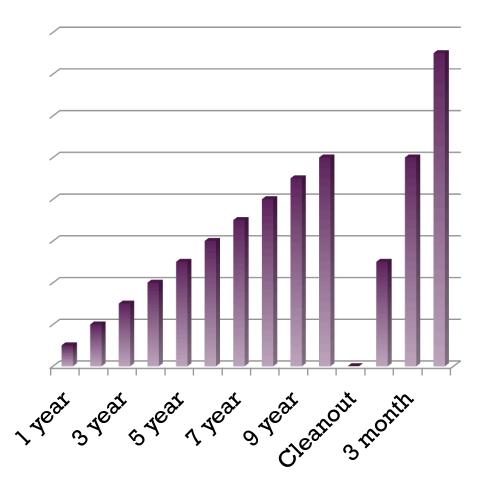
#### Safety

- 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)

# 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

# Mental Health + Public Safety: Implications of Diagnosis

- Communities: Neighborhoods, Multi-family housing
  - Fair Housing And Equal Opportunity
- Professionals: Code
  Enforcement, Fire, Law
  enforcement
  - Need for collaborative care



# FAIR HOUSING IS THE LAW!

Diagnosis and Assessment of Hoarding Disorder

# + 300.03 Hoarding Disorder

- a. "persistent difficulty discarding or parting with possessions, regardless of their actual value"
- b. Difficulty due to a perceived need to save items and to distress associated with discarding them
- c. Difficulty discarding possessions results in 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 (e.g. family members, cleaners, authorities)
- d. Hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others)
- e. Not due to medical condition (e.g. brain injury, cerebrovascular disease)
- f. Not due to another mental health condition (e.g. OCD, major depressive disorder, schizophrenia, neurocognitive disorders, autism)

#### Specify if:

- a. With excessive acquisition
- b. Insight (good, poor, delusional)

### 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









### + Assessment: ASK!

- First and foremost, ASK!
- Make sure to incorporate some form of question that can help indicate a problem at home with clutter, excessive acquisition, or difficulty discarding.
- Examples:
  - Are any areas of your home difficult to walk through because of clutter?
  - Are you unable to use any parts of your home for their intended purposes? For example, cooking, using furniture, washing dishes, sleeping in bed, etc?
  - Do you find the act of throwing away or donating things very upsetting?
  - Do you have strong urges to buy or collect free things for which you have no immediate use?
  - Have you ever been in an argument with a loved one because of the clutter in your home?

### + Assessment Tools

#### In office:

- Structured Interview for Hoarding Disorder (Pertusa & Mataix-Cols, 2010)
- Hoarding Rating Scale (Tolin, Frost, Steketee, 2010)
- Activities of Daily Living for Hoarding
- Saving Inventory-Revised (Frost, Steketee, & Grisham, 2004)

- Home Visit:
  - ICD Clutter—Hoarding Scale
  - Clutter Image Ratings
  - HOMES

# 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

# +

### **Treatment and Strategies**

## 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?

Safety comes first. Although it would be ideal to address underlying psychological 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

# Motivational Interviewing

- Motivational interviewing strategies (Miller & Rollnick, 2002)
  - Avoid persuasion and arguing
  - Encourage progress, state remaining problem in enough detail so client can understand requirement, and ask for specific change

- Highlight strengths: "I can see how much you care about your cat."
- Praise change efforts liberally: "You've worked really hard today, well done!"

# Safety Day: Coordinated and Systematic Response to Mandatory Clean-outs

- Diffuse Physiological Arousal
  - Emotional Flooding
- Psychological First Aid
  - Recognize and respond to symptoms of psychological crisis
- Support resilience:
  - Promote Safety
  - Calm & Comfort
  - Connectedness
  - Self-Empowerment
  - Prevention Strategies
  - Self-Care

- Harm reduction approach to mandatory clean outs
- Critical Incident Stress Management
  - Preparatory Phase
    - Informed consent
    - Decision Making
    - Teaching Stress management techniques
  - Critical Phase
    - Stress management
    - Coordinate clean-out efforts
  - Recovery Phase
    - Process clean-out
    - Transition to mental health care

## Collaborative Work with Related Professionals

- Research indicates that individual treatment approaches have limited success. (Saxena, Brody, Maidment & Baxter 2007; Tolin, Frost & Steketee 2007)
- Multidisciplinary approaches attend to the complex nature of hoarding. (Koenig, et al 2010)
- Why work collaboratively?
  - Ethical right thing to do
  - Effective bio-psychosocial problems
  - Resource-conserving integrated care less expensive
  - Clinician and professional-friendly supportive in a situation which has small "successes"

Identify stakeholders impacted by compulsive hoarding.

- Mental Health Professionals
- Professional Organizers
- Housing
- Public Health and Safety
- Protective Services
- Animal Control
- Legal System
- Medical Professionals

## **Tips for Hoarding Work**

- Assessment
  - Identify all significant factors, including any co-occurring disorders (by mental health professional
  - Prioritize treatment with all factors considered in collaboration with team
    - Safety first
    - Skill building second
    - Deeper processing third
- Work collaboratively as resources allow
  - Once physical space is "safe", de-cluttering does not need to be prioritized as main focus of treatment
    - Working with organizer as adjunct to therapy can be helpful
- Remain singularly focused within one session (even week or month)
  - Cognitive deficits may limit client's ability to "multi-task within session"

# • 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 (local)
- MN Hoarding Task Force
- Institute of Challenging Disorganization
- Children of Hoarders

Support Groups

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

**Q & A** 



## The Hoarding Project www.thehoardingproject.org

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## **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, 2<sup>nd</sup> ed. (2002), Miller & Rollnick