

# Hoarding

Setting Up For Success:  
working with people struggling with  
“too much stuff”

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## Topics we will cover

- Terminology
- Hoarding definition & diagnosis
- Clutter, Collecting, Squalor
- Comorbidities
- Etiology
- Screening/Measurements
- Treatment



## topics continued

- Effects on Housing
- Cleanouts & challenges
- Multidisciplinary Approach
- What Works - Eviction Prevention
  - Being proactive
  - Inspections & follow-up
  - Reasonable Accommodation/Stipulated Agreements

**Imagine a prized possession ... something that you treasure or value**



## Why do people keep things?

Three types of value:

- **Instrumental** (practical value)
  - “I use this now... or, I might need it later...”
- **Sentimental** (emotional meaning attached)
  - “This reminds me of when...”
- **Intrinsic** (no practical or emotional meaning, but simply “I just like the way it looks”)

These are the same reasons we ALL save things

## Intentional vs Unwanted Saving

### Intentional Saving

purpose/use, sentimental, presents an opportunity, provides comfort

### Unwanted Saving

responsibility and fear of waste (material scrupulosity), sense of guilt, maximum use of object, moral sense of duty to a possession

Again, people with HD give the same reasons that we all give about saving.

## Appropriate Terminology

### Use Strengths Based Language

- Person Centered
- Person First Language

### Mirror their language

- Excessive saving
- Acquiring
- Collecting
- Clutter
- Pack rat
- Clutterbug
- Treasure seeker
- Hoarding



## What is Hoarding?

- Prevent rooms from being used for normal activities
- Often there is excessive acquisition of items
- Trouble and emotional distress when discarding
- difficulty with organization
- causes impairment in social, interpersonal and/or occupational functioning



## What is Hoarding Disorder?

DSM-5 includes Hoarding Disorder as a stand alone diagnosis.

- Persistent difficulty discarding items
- 
- distress associated with discarding
- 
- possessions that congest and clutter active living areas and substantially compromise their intended use
- 
- impairment in social, occupational, or other important areas of functioning

Frequent Specifiers: Excessive acquiring and poor insight

## What does it look like

### **Excessive Acquisition:**

- Buying items
- Stealing things
- Collecting free things (junk mail, handouts/flyers, “free” tables and curbside collecting)
- Compulsive or impulsive shopping

### **Clutter/Disorganization:**

- Piles of possessions
- Pathways
- Churning items (moving from pile to pile or surface to surface)

### **Inability to Discard:**

- Significant distress triggered by thinking of discarding items

## **Collecting**

- New possessions become part of a larger set of items already owned
- Sense of pride in sharing collections
- Display does not impede activity of living and functionality of rooms in home
- Usually well organized and/or stored carefully

## **Clutter**

- Possessions are disorganized and may accumulate around living areas
- No major difficulty with excessive acquisition
- No major difficulty with discarding items
- Can carry on normal activities in home

## Squalor

- No intentional saving of items
- No intentional acquiring of items
- Home in disrepair, unclean, strong odors, rotting food, animal feces
- State of home often does not usually cause distress (cognitive impairment (dementia, head injury, developmental disability, serious mental illness))
- Intervention looks very different

There could be overlap in severe cases but hoarding and squalor are not the same!













## **Prevalence and Onset of Hoarding Disorder**

### **Prevalence**

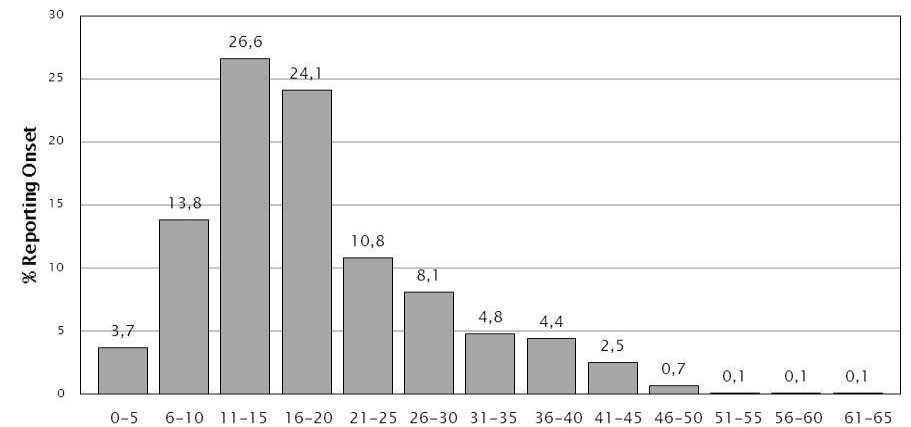
- Meta-analysis of 11 prevalence studies with at least 1000 participants = 2.5%
- No differences by gender

(Postlewaite 2019)

# Onset

- Self reported onset: age 12-13 (reported by older adults in tx)
- Chronic condition, slow and steady rise in severity of hoarding
- may have a surge in severity following a loss or trauma
- “Treatment seeking”: average age 50

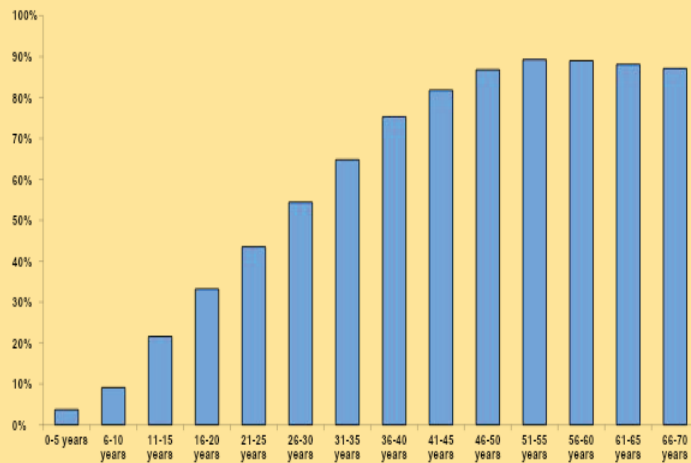
(Tolin et al., 2010; Frost et al., 2011; Ayers et al., 2013; Samuels et al., 2008)



Age of onset of hoarding symptoms

Steketee et al. 2012

## % of Respondents with Moderate to Severe Hoarding



Tolin DF, et al. *Depress Anxiety*. 2010.

## What Causes Hoarding Disorder?

**It's Complicated**

Marnie

[https://www.youtube.com/watch?v=u7oUwO\\_llpI](https://www.youtube.com/watch?v=u7oUwO_llpI)

## Cognitive Dysfunctions

- **Executive Functioning** (difficulty in forming strategies and planning, poor organization, impaired problem solving)
- **Working Memory and ADHD symptoms** (problems with focus and attention)
- **Visual Information Processing** (visual memory, problems with categorization)

(Ayers 2013; Hartl 2005; McMillan 2013; Mackin 2016; Sumner 2016)

## Emotional Dysregulation

### **Sensitivity to Anxiety**

(Cole et al 2003; Medley et al. 2013; Shaw et al. 2015)

### **Negative Urgency and Impulsivity**

(rash and regrettable acts when aroused)

(Phung et al. 2013; Timpano et al. 2014/2016)

### **Distress Intolerance** (Timpano 2014/2016, Shaw et al. 2015;

Shaw and Timpano 2016)



## Psychological Factors

### Hoarding Beliefs

- Need to keep possessions in view
- Emotional attachment to items
- Fear of making the wrong decisions/perfectionism
- Low confidence in memory and fear of forgetting
- Responsibility for items, others and the environment

### Negative Self-Perception

- poor self esteem, diminished self-worth, shame, self criticism
- Intolerance of uncomfortable emotions, distress and uncertainty

(Frost/Hartl 1996; Kyrios 2017; Frost 2007; Chou 2017; Ayers 2014; Oglesby 2013; Mathes 2017; Shaw 2015, Frost 2018)

## Environmental Factors

- Lack of familial warmth
- Trauma (cumulative)
- General life stress
- Interpersonal Stress

(Landau 2011; Timpano 2011, Chou 2018)

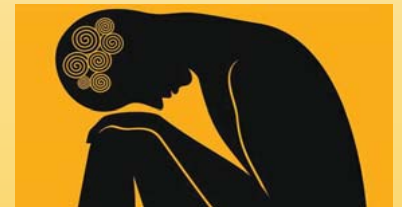
# Genetic Factors

## Twin Studies 35-50%

- Canadian Twin Registry (Taylor et al., 2010)
- UK Twin Registry (Iervolino et al., 2009; 2011)
- Swedish Twin Registry (Ivanov et al., 2013; 2017)
- Netherlands Twin Registry (Mathews et al., 2014)

# Psychiatric Comorbidity

- Major Depression: 52%
- Attention Deficit Disorder 27.8%
- Anxiety Diagnoses: 24.4%
- Social Phobia 23.5%
- Obsessive Compulsive Disorder 17%
- Specific Phobia 14.3%
- Kleptomania 9.9%
- PTSD 6.9%



(Frost et al , 2011 )

## HD/Medical Comorbidity

- Obesity
- Arthritis
- Stroke / Hypertension
- Ulcers
- Fibromyalgia
- Chronic Fatigue
- Kidney Disease
- Diabetes
- Asthma
- Heart Attack
- Depression/Anxiety

Tolin et al. 2008

## Hoarding and Trauma

- Higher trauma **exposure** rate among individuals with hoarding disorder-  
99% of people with HD have been exposed to at least one trauma. (Chou et al, 2018)
- Average number of different types trauma over lifetime = 7 (Chou et al, 2018)
- **Interpersonal trauma** is associated with more severe hoarding symptoms, especially for those with earlier onset. (Chou et al. 2018; Grisham et al. 2006; Landau et al. 2011; Shaw et al. 2016)

## Thoughts about HD and PTSD?

- Childhood Adversity/Interpersonal Traumas  
vs.  
Episodic Trauma (rape, kidnapping, combat, held at gunpoint etc) ?
- The development of HD acts as a kind of “buffer” to prevent the onset of PTSD?

## Attachment Theory

- Secure Attachment to Others– leads to sense of identity
- Insecure Attachment – leads to:
  - Difficulty managing emotion
  - Avoidance of negative emotion
  - Poor impulse control
  - Expectation of unreliable & hurtful behavior from others

(Frost & Gross, 1993)

## **Attachment Theory and HD**

- Insecure attachment to people
- Secure attachment to possessions

Correlation with measures of insecure attachment

Use of possessions for comfort and safety

Anxious attachment is tied to hoarding disorder

Norberg et al, 2018

## **Screening for HD**

## Identifying Hoarding in clinic settings

### Add a few questions to your intake process!

Do you have trouble getting rid of things that other people would get rid of?

Do you have clutter that makes it hard to use rooms and surfaces in your home?

Do you buy items or acquire free things that you don't really need or have space for?

### Red Flags:

problems with neighbors or landlord

isolation, people not visiting

mentioning storage units

## Use these screening tools

- Saving Inventory Revised
- Hoarding Rating Scale
- Clutter Image Rating Scale

# Assessment Tool

## *Clutter Image Rating Scale*

- A visual rating scale using 9 pictures to assess severity of hoarding and gauge the individual's insight
- Volume of clutter may look differently in different homes
- 4 or 5 and greater is a clinically significant indicator of hoarding

### Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.



### Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.



1



2



3



4



5



6



7



8



9

# Interventions



## Why is Help Refused?

- poor insight
- shame
- fear
- have different solution in mind
- feelings of hopelessness
- mistrustful
- overvalued ideation of items
- ambivalence

(Tompkins, 2009)



## What Works?

### **Medications:**

some recent study of these medications but there was no control group so they were not true clinical trials.

Paxil and other SSRI's - mixed data on these

Effexor (34% reduction in symptoms)

Strattera (40% reduction in symptoms)

*(Journal of Psychiatric Research 2016)*

# What Works

### **Cognitive Behavioral Therapy:**

- Meta Analysis for clinician facilitated CBT
- 35% reached clinically significant symptom reduction (individual and group)

*(Tolin et al. 2015)*

### **Buried in Treasures -**

- 16 week evidence based CBT based peer led workshop
- 30% clinically significant symptom reduction

*(Frost et al 2012)*

## **Compassion Focused Therapy**

40 patients who had completed a 26 week course of CBT but were still significantly symptomatic.

Half received another course of CBT and the other half received CFT.

### Results:

Compassion Focussed Tx group: 62% clinically significant symptom reduction

Cognitive Behavioral Tx group: 29% clinically significant symptom reduction

CFT may be promising treatment option, especially for those who are not responding well to CBT.

Chou, 2019

## Treatment options to consider:

Cognitive Behavioral Therapy (Tolin, Frost, Steketee, Matthews etc)  
Compassion Focused Therapy (Chou)  
Cognitive Rehabilitation and Exposure Therapy (Ayers)  
Community Intervention Models (Vancouver BC, Boston, San Francisco)  
Buried In Treasures (Frost, Shuer)  
Attachment Based Therapy  
CBT targeting self-identity (O'Conner)  
Mindfulness  
Motivational Interviewing

## Harm Reduction Approach

- Try to keep people safe and comfortable in their homes
- Focus on moving possessions out of high risk areas (eg. reduce trip hazards, egress, fire...)
- Set up systems and strategies to minimize acquisition and maintain organization
- Provide supportive ongoing monitoring

(Tompkins & Hartl, 2009)

## Tips for Increasing Motivation

- Use open-ended questions
- Use reflective listening statement
- Use summarizing statements
- Affirm client strengths
- Inform and advise only by client request
- Avoid arguing, blame, or taking on the role of expert

## Work on Increasing Motivation

- Importance of the change  
What is motivating you to address this now? Why is this important to you?
- Confidence that change is possible  
From 1-10, how confident are you in being able to make this happen? What would make that number higher?
- Focusing on function  
What would you like to be able to do in your space that you are not able to do now?

# Hoarding and Housing

## What effects does hoarding have on housing?

- Fire & safety hazards
- Poor hygiene
- Poor nutrition
- Poor health
- Failed inspections
- conflicts with neighbors
- Shame, social isolation
- Eviction
- Homelessness



## Some of the Effects of Hoarding

From a 2018 study in the San Francisco Bay area - (N=323)

8-12% experienced eviction

59% had moderate to severe difficulty moving freely in home

58% had difficulty eating at their table

34% had difficulty preparing food in kitchen

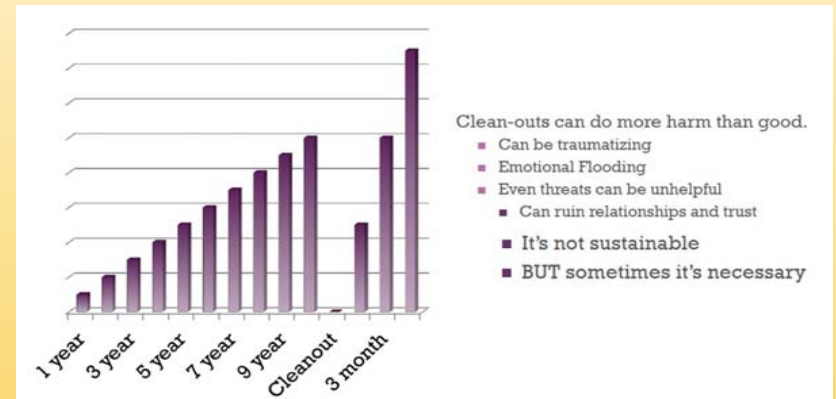
25% could not exit home quickly in an emergency

24% had difficulty sleeping in their bed

Hoarding is a factor in up to 24% of deaths by house fire

Mathews 2018

## Can't we just clean out a hoarded home?



*"One Massachusetts town in our survey of health departments conducted a forced cleanout costing \$16,000 (most of the town's health department budget). Just over a year later, the cluttered home was worse than ever." – Frost & Steketee, 2008*

## Follow These Tips

### DO NOT

- judge decisions or make negative comments
- let the amount of stuff overwhelm you
- minimize the challenge
- declutter behind the person's back
- make decisions for the person
- make arguments or try to persuade
- equate the clutter with the person

## Follow These Tips (working with the person)

### DO:

- Ask permission to touch/move possessions
- Allow client to make all decisions about possessions
- Establish categories before sorting possessions
- Proceed systematically (one area at a time, use boxes)
- Encourage “thinking out loud” during decision-making process
- Only handle it once (OHIO) -Deals with “churning”
- Be creative and flexible in carrying out intervention





## ***What Does Work***

- Lease & House Rules for Renters
  - Quantifiable limits to stacking and pathway width
  - Quantifiable limits to garbage and recycling accumulation
  - No storage of flammable items including newspapers, empty paper bags & empty boxes
  - No stacking of furniture items
  - Egress and ingress access - windows and doors

## ***What Does Work***

- Lease & House Rules (cont.)
  - Doors must open to at least a 90 degree angle
  - Food storage is limited to kitchen spaces
  - No trip hazards (extension cords for example)
  - Unit to be free from accumulation of debris and rubbish
  - Limit storage on balconies
  - Maintenance issues required to be reported immediately

## What *Does* Work

- Be proactive
- Hold annual “Spring Cleaning” free of charge
- Recycling & Shredding receptacles near mailboxes
- Open communication between maintenance, inspectors, management, and resident service coordinators
- Create a pre-inspection checklist to be posted a week prior to inspection
- Incentivize residents for passing inspections
- Gift cards or financial incentives
- Longer time between inspections



## Animal Hoarding

- Accumulation of more animals than a typical pet owner (not a farmer or breeder)
- Failure to provide adequate care of the animals (unsanitary conditions, animals in poor health, no veterinary care, poor nutrition)
- Reluctance to place animals in others' care

*(Patronek, Lear & Nathanson 2006)*

## **Special Considerations for Hoarding of Animals**

- Proactive Measures:
  - Set limits on lease and house rules for how many pets are allowed per household
  - Service and companion animals must each be designated to address a separate component of a disability.
- If you discover a resident hoarding animals:
  - Proceed with lease violation process
  - Use Reasonable Accommodation/Stipulated Agreement if necessary
  - Engage with Animal Control Services and Humane Society

## **Special Considerations for Older Adults**

- Physical Limitations (mobility, gait, vision, lifting, hearing, turning, reaching)
- Possible Cognitive Limitations
- Fall Risks and Trip Hazards
- Accommodations (extra help with moving and hauling items, verbal and written reminders, rapport building)

## What *Does* Work: Multidisciplinary Approach

- Mental Health Provider - group and/or individual tx
- Case Management
- Housing Provider
  - Management
  - Resident Services Coordinator
    - Identify the scope and availability of the RSC to be able to work 1:1 with the resident
    - Goal setting, skill building, weekly/monthly home visits
- Adult Protective Services
- Social Service Agency
- Cleaning Services
- Professional Organizers
- Court System & Legal Aid
- Fire Department
- Family, Friends and other Community Resources



## Conducting Inspections in a Trauma Informed Way

- Ask if it's ok to come in
- Explain your process before and during the inspection
- Take pictures
- Don't engage in arguments with the resident
- Ask questions rather than make assumptions
- Compliment areas that pass inspection, artwork, and pictures
- Thank them for allowing you into their home.
- Be consistent in the inspection tool you use.
  
- **Recommended: Uniform Inspection Checklist (developed by Marnie Matthews, LICSW; [marniematthewslicsw@gmail.com](mailto:marniematthewslicsw@gmail.com))**



## Reasonable Accommodation

- Reasonable Accommodation = the removal of a barrier to equal access
- Does not mean that the health and safety violations can continue indefinitely
- In a hoarding situation, it usually = more time and clear plan
- Housing providers can offer a reasonable accommodation without the resident requesting one
- A request for Reasonable Accommodation can be received verbally or in writing.



## Reasonable Accommodation

- should include:
  - Specific details, focus on health and safety issues as a priority
  - Specific timelines and re-inspection dates (more frequent inspections)
  - Maintaining cleaned/de-cluttered areas
  - Requirement of reporting maintenance needs immediately
  - Be truly reasonable for both management & resident

## Reasonable Accommodation

- Meet with the resident to review the RA
  - Encourage them to have a friend, family member or other advocate present; if appropriate
  - Review the areas of concern individually and explain how each of them violates their lease/house rules
  - Have pictures available to give visual cues of corrections needed - Clutter Image Rating Scale for example

## Stipulated Agreements

Stipulated Agreement = a written agreement between the two parties in a Housing Court Case. Holds same power as a court order.  
(Happens at the time of eviction hearing)

## Adding Treatment to a Stipulated Agreement

Depending upon availability, participation in one or more of these can be added to a stipulated agreement:

- Individual Counseling/Therapy
- Case Management
- Support Groups
- Clutterers Anonymous
- Skill Development Groups (eg. organizing)
- Buried in Treasures Workshop

## Resources

Multnomah County Hoarding Task Force  
<https://multco.us/ads/hoarding>

Individual & Group Therapy for hoarding in Portland

Pacific Psychology and Comprehensive Health Clinic  
503-352-2400

NW Anxiety Institute 503-542-7635

Anxiety and Panic Treatment Center 971- 645-0033

Clutterers Anonymous: (866) 402-6685 or clutterersanonymous.org

Local Support Group at OHSU

- OCD Group with focus on hoarding
- 1<sup>st</sup> & 3<sup>rd</sup> Thursday evenings

## more resources...

Clean Up Help Critical Care BioRecovery: (503) 698-4415

Pegasus Social Services: (503) 252-8499

ServiceMaster of Portland: (503) 483-4036

Supportive Services: (503) 305-4923

National Association of Professional Organizers: [napooregon.com](http://napooregon.com)

### Self-Help books:

*Buried in Treasures* by Tolin, Frost, and Steketee

*Digging Out: Helping Your Loved Ones Manage Clutter, Hoarding, & Compulsive Acquiring* by Michael A. Tompkins and Tamara L. Harti

## Multnomah County Hoarding Task Force Trainers and speciality areas

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