

The Impact of Hoarding Disorder on Individuals, Families and Communities

Janet Yeats – janet@thehoardingproject.org

The Hoarding Project –

www.thehoardingproject.org

NAPSA Conference, October 3, 2013

+ Objectives



- Background on Hoarding
- Safety/health issues involved with hoarding
 - Are there any precautions *we* should take for our safety?
- Measurement/Assessment Tools
- What to do when we encounter a homeowner with a hoarding situation:
 - How to talk with them re: hoarding concerns
 - How to offer resources
- Further Considerations

+ History and Background





Background on Hoarding

+ FAQ: What is hoarding disorder?



Quick answer: A new diagnosis with the DSM5, 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



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



Quick Answer:

- **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

+ FAQ's: How many people hoard?

Quick answer: More than you think but we're really not sure yet!

- Estimates range greatly- up to 15 million in the U.S.
- Studies haven't been big enough to give accurate estimates yet



■ Prevalence

- 2-5% of the population (Iervolino et al., 2009; Samuels et al., 2008)

On the high end,

That means that over

342 million people **on the planet**

meet criteria for moderate to severe compulsive hoarding behavior.

That's approximately

15.7 million people in the **United States.**



FAQ's: Are some people more likely to hoard than others?

Quick answer: Research shows that

- **Men** hoard more than **women**
- **Older people** hoard more than **younger people**
- People with **lower income** (Samuels, et al. 2008) hoard more than people with **higher income**



+ FAQ: What causes hoarding?

- Quick answer: lots of things can contribute to hoarding-like biological, psychological, and social factors.

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.





FAQ's: What are the Biological Factors that contribute to hoarding?



- Family history/genetic link
- 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; Tolin & Villavicencio, 2010; Tolin, Villavicencio, Umbach, & Kurtz, 2010; Wincze, Steketee, & Frost, 2007)
 - Attention
 - Memory
 - Categorization
 - Complex thinking
 - Decision-making

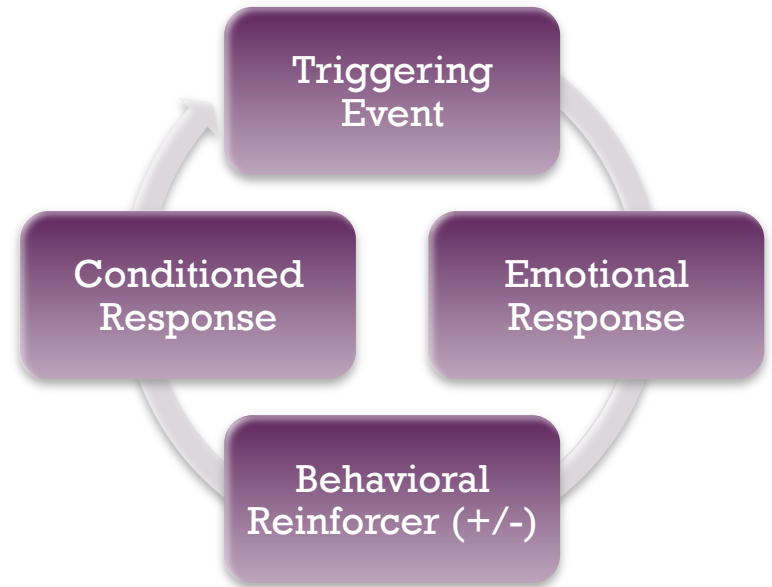




FAQ's: What are the Psychological Factors that contribute to hoarding?



- Mental health/emotional distress
 - Unresolved trauma and loss
- 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





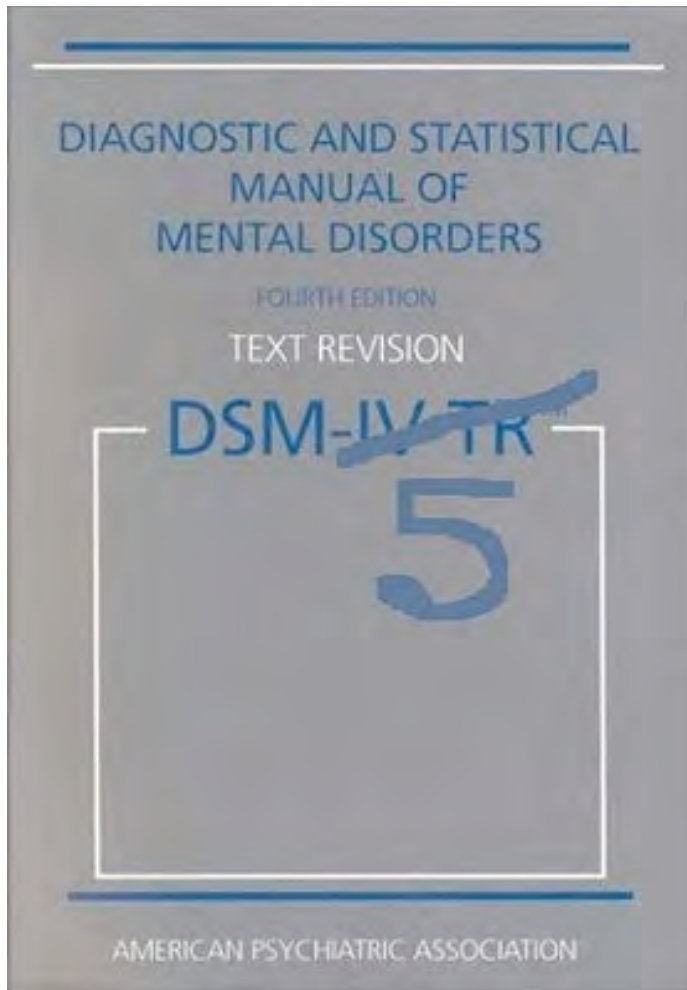
FAQ's: What are the Social Factors that contribute to hoarding?



- Interpersonal relationships
 - The better family connections (in past and present), the less hoarding (Sampson & Harris)
- Social support
 - The more support experienced from family, the less hoarding (Sampson & Harris)
- Major life events/transitions
 - Unresolved trauma and loss contributes to hoarding (Sampson & Harris)
- Social stigma
 - “Hoarding is weird”
 - Stigma can contribute to depression, anxiety, etc.
- Culture
 - Western, consumer cultures = hoarding is present
 - Not sure about other, non-consumer-driven cultures
 - Consider context (e.g. refugee families, etc)



+ FAQ: Is hoarding really just OCD?



- **Quick answer:** Not necessarily
 - Only about 30-40% of people who hoard actually show other symptoms of OCD
 - It's also associated with lots of other mental health issues:
 - Depression- <53%
 - Anxiety- <24%
 - ADHD- <20%
 - Impulsivity-
 - Personality Disorders- <29%
 - Organic Brain Illness- <31%



FAQ: Hoarding must be some sort of coping mechanism, right?



Quick answer: It depends.

Trauma has been related to hoarding in the research

- **Traumatic life events** (Cromer, Schmidt, & Murphy, 2007; Hartl, Duggany, Allen, Steketee, and Frost, 2005)
 - 76%: endorsed a history of a traumatic life event (Breslau et al., 1998)
 - 55%: stressful life event around onset of hoarding (Grisham, et al., 2006)
 - Relational traumas

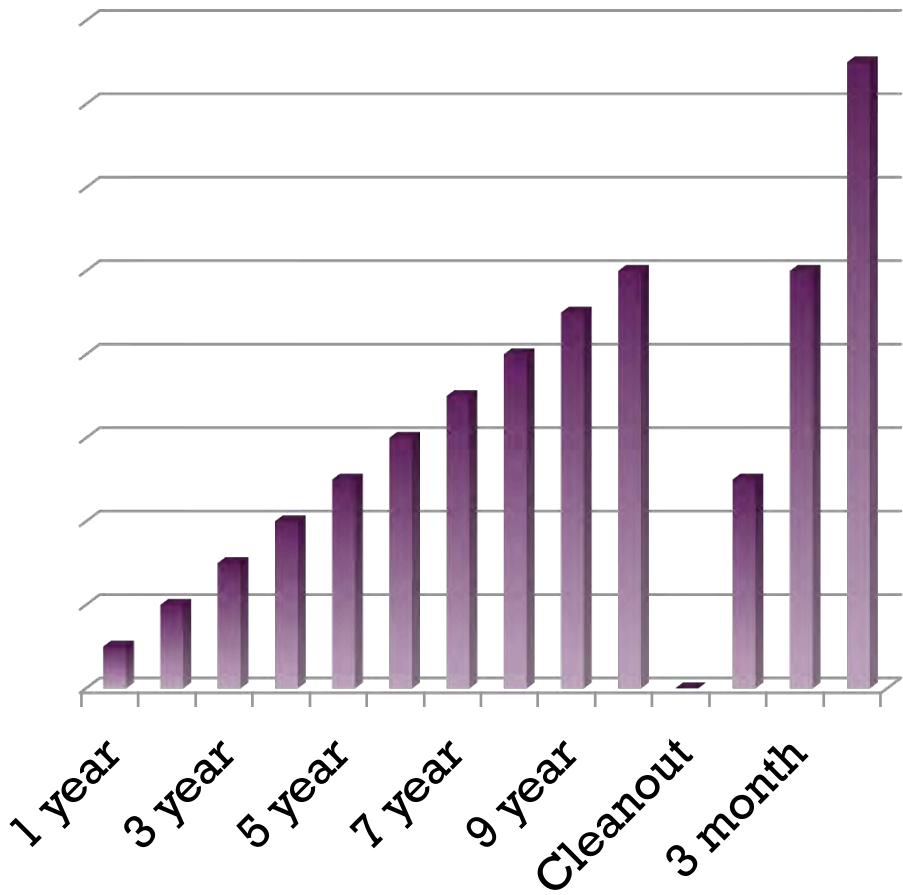
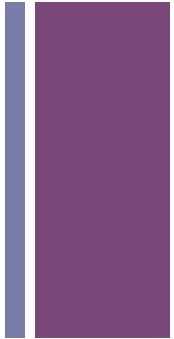
But it can also be considered a reinforced behavior that occurs over time because of difficulties with:

1. History/vulnerabilities
2. Information-processing deficits
3. Beliefs about possessions
4. Emotions
5. Reinforcement

Cognitive Behavioral Model of Compulsive Hoarding
(Frost & Hartl, 1995)



FAQ: Can't I just clean out my loved one's home?



Quick answer: Not if you can avoid it.

- It can do more harm than good.
 - Can be traumatizing
 - 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
 - Higher relapse rate among forced clean out
 - You'll just have to do it again later
- Sometimes it's necessary though
 - Involve the homeowner as much as possible for lasting change



FAQ: Does therapy work come before, during, or after work on the hoarding problems?

Quick answer: It depends. Oftentimes, we can do them simultaneously when safety and coping skills are in place.

Rule of thumb:

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





Why a theory of grief and loss for hoarding?

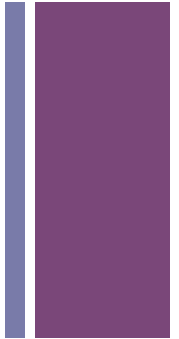


- **Presence of loss in stories**
 - Family members AND people who hoard
- **Current approaches for dealing with hoarding do not reflect an understanding of the role of grief and loss in hoarding behavior**
- **Behavioral treatment alone has not been effective**
 - Systemic approach
 - We are more than just our behaviors
- **Not “typical” losses**
 - Need a unique framework for working with unresolved losses





Ambiguous Loss - What is it?



Pauline Boss

- University of Minnesota
 - Native American women
 - Wives of MIA/POW pilots in Vietnam war
 - Families living with dementia.

- A loss that is unclear, cannot be fixed, can be physical or psychological.

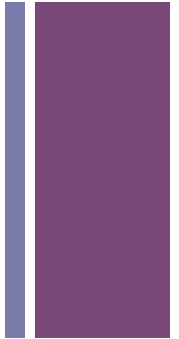
- No official verification of loss since final decisions have not been made.

- Complicates grief with no resolution due to relationship, not individual weakness.

- The interaction between ordinary and ambiguous losses.



Two Types of Ambiguous Loss



Type 1: Leaving without Goodbye

- Physical absence with psychological presence
- Catastrophic: disappearance, lost without a trace, missing in action
- Common: divorce, adoption, immigration

Type 2: Goodbye without Leaving

- Psychological absence with physical presence
 - Catastrophic: dementia, depression, hoarding
 - Common: loss of a dream, loss of way of life
 - **For family members of people who hoard, this seems to be the type of loss experienced**



Systemic Effects of Ambiguous Loss



- Stress: not because of weakness in the individual or family but because the situation of ambiguity is so difficult.
- “The ambiguity is the culprit.” (Boss, 3/17/12)
- Relationships are immobilized:
 - Decision-making is put off and confused.
 - Coping is blocked and grief is frozen.
 - Conflict is created within families.
 - Security/safety is questioned.

+ Ambiguous Loss: Effects on Individuals

Depression,
anxiety, guilt, shame

Neglect or lack of
self-care

Somatic Illnesses

Ineffective coping
(gambling, hoarding)

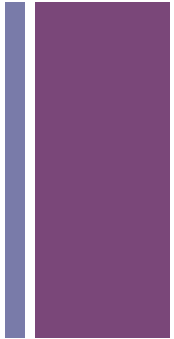
Abuse: substance and
other

Distress and
traumatization
(the brain and dreaming)

PTSD



+ Ambiguous Loss + Hoarding



Family Members

- Loss of relationships, future opportunities, sense of home *due to the hoarding behavior* (Sampson, in press)
- Understanding -> compassion -> support

Person who Hoards

- Experiences of unresolved A.L. throughout life
 - Not necessarily related to hoarding
- Loss of relationships, etc *due to hoarding behavior*
- Understanding -> begin to work towards resolution -> increase in healthy coping

Need for integration of grief and loss theory into our understanding and work with compulsive hoarding





FAQ: 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



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



■ **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

- 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)



FAQ: 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

+ Further Consideration:

Safety Day

Collaboration

Hoarding Task Forces

Q&A

Discussion

