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:

- **Collecting**: new possessions = part of larger set of items
  - Display does not impede active living areas in home

- **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

- **Hoarding**: possessions become unorganized piles of clutter
  - Prevent rooms from being used for normal activities
  - Motivation to display items: lost
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
  - “Hoardling 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/discardng
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?

- 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.

Pauline Boss
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
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/usable
  
  - **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)
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
Hoardling Task Forces

Q&A
Discussion