# Hoarding Disorder in Older Persons Western Illinois Area Agency on Aging September 13, 2018 Moline, IL

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- Disclosures: None
- I will not discuss off label use and/or investigational use of medications in my presentation.

#### **Hoarding Disorder Prior to DSM-5**

- Hoarding mentioned in DSM-IV only in context of Obsessive-Compulsive Personality Disorder (OCPD)
- ...Is unable to discard worn-out or worthless objects even when they have no sentimental value (retained in DSM-5)
- DSM-IV text suggested that serious hoarding should be considered a form of OCD (Obsessive Compulsive Disorder)

#### OCD/OCPD: Did Not Account for All Cases

- Most cases do not meet criteria for OCD/OCPD
- hoarding affects 2-6% of population
- In OCD studies, hoarders have poor outcome
- data challenged specific relationship between OCD/OCPD
- Research demonstrated distinctiveness from OCD
- Not as common as cleaning or checking
- clinicians often fail to ask about hoarding
- hoarding appears in about 20% of OCD patients
- excessive saving behavior runs in families

# Obsessive Compulsive & Related Disorders (OCRD)

- Obsessive Compulsive Disorder
- Body Dysmorphic Disorder
- Hoarding Disorder
- Trichotillomania (hair-pulling disorder)
- Excoriation (skin-picking disorder)
- Substance/medication-induced OCRD
- OCRD due to another medical condition
- Other specified/unspecified OCRD

#### Why Does Classification Matter?

- May enhance treatment options for OCRDs that are largely ignored
- Facilitate development of possible medication treatments
- Increase accessibility to insurance
- Influence research agencies to fund

# Hoarding Disorder

Hoarding affects 2%-6% of adult population

- May affect 2% of adolescents
- Prevalence increases with advancing age
- Only psychiatric disorder that worsens with age, except for dementia
- Equal gender distribution
- Associated with worse physical health
- Chronic and progressive

## • Let's start with the instructive case: the Collyer Brothers, Harlem, 1940s

- Homer and Langley Collyer lived in isolation in their Harlem brownstone inherited from their mother
- Obsessive collectors, they set booby traps to ensure intruders.
- Their house became a maze of boxes, tunnels, junk, and trash.
- Both died in March 1947 surrounded by 140 tons of trash
- Langley was crushed to death after setting off a trap to while bringing Homer food.
- Homer died 12 days later from starvation.

# Compulsive Hoarding Criteria

- Specify if:
- With excessive acquisition: if difficulty discarding is accompanied by excessive acquisition of items that are not needed or for which there is no available space.
- Specify if:
- Good or fair insight: Recognizes that hoarding-related beliefs and behaviors (difficulty discarding, clutter, or excessive acquisition) are problematic.
- *Poor insight*: Mostly convinced that hoarding-related beliefs are not problematic despite evidence to the contrary.
- Delusional: Completely convinced that hoarding-related beliefs and behaviors are not problematic despite evidence to the contrary.

#### Compulsive Hoarding Criteria (continued)

- 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)
- Not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi Syndrome)
- Hoarding symptoms not better explained by symptoms of another mental disorder, (e.g., hoarding obsessions in OCD, decreased energy in major depressive d/o, delusions in schizophrenia or another psychotic d/o, delusions, cognitive deficits in major neurocognitive d/o restricted interests in autism spectrum d/o)

# Compulsive Hoarding: Current Working Definition

 The acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value

#### Acquiring

- Many people acquire/save large numbers of items, but it doesn't interfere with their lives
- Those with hoarding problems buy and keep a large number of "just in case" items; often have many duplicates because they couldn't find ones they already have
- Acquisition of free things excessive
- Often used to justify acquisition
- Kleptomania occurs in 10%
- 10-15% of people who hoard do not report excessive acquisition

## Living Spaces Cluttered

- Often only pathways through rooms
- Many are unable to sleep in their bed, sit on sofa, cook, eat at the table
- Safety issues created, e.g., won't let repair person into house, falling over items, poor air circulation (e.g., mold develops).

## Living Spaces Cluttered

- Clutter obstructs use of space
- Often only pathways through rooms
- Many are unable to sleep in their bed, sit on sofa, cook, eat at table
- Safety issues created, e.g., won't let repair person into house, falling over items

# Crazy Busy

- Involved in many activities
- Little time at home
- When home, too tired to do anything
- Constantly running from one event to another
- Grab-n-go, Drop-n-Go
- Surface clutter
  - Courtesy of Becky Esker, CPO, "Get Organized! LLC"

#### Distress or Impairment

- Inability to use space as intended
- Emotional reactions to other people moving or touching possessions
- Restrictions on socializing in the home
- Conflict with family members
- Problems with neighbors, social service agencies, landlords, or city officials
- Limited access for fire/rescue
- Obstructed exits in emergencies

#### Chronic Disorganization

- Lots of organizing books
- Lots of organizing products
- Remnants of failed systems
- Organizing seminar groupies
- Right-brainer living in left-brainer world
- Lack organizational skills
  - Courtesy of Becky Esker, CPO, "Get Organized! LLC"

# Compulsive Hoarding: Brain Imaging

- "Brain-imaging research shows that people with compulsive hoarding have distinct abnormalities in brain function compared to people with non-hoarding OCD and those with no psychiatric problems..."
- Jack Samuels, PhD, Dept. of Psychiatry & Behavioral Sciences, Johns Hopkins U School of Medicine

## Compulsive Hoarding:

## **Brain Imaging**

- Compared to non-hoarders, hoarders have different levels of activity in certain regions of the brain
- These regions are known to affect decision-making, attention, organization, and emotion regulation
- Brain lesions (TBI, aneurysms, tumors, etc) in certain regions are known to affect judgment and decision-making abilities

# Brain Abnormalities: Possible Causes

- Genetics
- 50 to 85% of hoarders report a first-degree family member with similar characteristics
- Genetic markers associated with hoarding behavior have been found
- Stroke
- Surgery
- Injuries
- Infections
- Environmental events (e.g. family trauma)

# Does Hoarding have an Evolutionary or Historical Root?

- Many animals hoard (e.g., honeybees, rodents, crows, etc.)
- Hoarding may reflect a naturally selected urge to stockpile resources for times of scarcity
- Is hoarding a reflection of hard times (e.g., great depression of the 1930s)?

## Onset of Compulsive Hoarding

- May have had lifelong tendencies, but not problematic until mid to late life
- May surface because of physical/cognitive decline
- Social or geographic isolation makes it easier to hide
- Onset often preceded by loss (death, divorce)
- Presence of spouse, partner, housemate may have kept it under control
- Less pressure to conform to expectations of others

# Assessing Hoarding

- Do your possessions get in the way of:
- Preparing food?
- Using kitchen table, chairs, sink?
- Moving around kitchen?
- Using toilet, tub, or shower?
- Sitting in living/family room?
- Sleeping in bedroom?

# Impact on Family & Others

- Attempts to help hoarder met with resistance; rarely produces long-term change
- Common situation is adult child clearing the home without permission
- Hoarder feels betrayal, anger, anxiety, grief
- Family often shocked by intensity of reactions

# Hoarding and the Elderly

Significant public health problem

- hoarding is only psychiatric disorder that worsens in severity and prevalence with age (except dementia)
- Compromises food preparation, personal hygiene, sanitation, air quality
- Increases danger of falling, fire
- Homes can be declared "uninhabitable" and demolished

## Hoarders Have Deficits in Several Areas

- Information processing deficits
- Emotional attachments to possessions
- Behavioral avoidance
- Erroneous beliefs about the value and usefulness of possessions (overvalued ideation)

# Information Processing Deficits

- Decision-making problems
- Not just what to keep or throw away
- Any kind, i.e., what to order at a restaurant, what clothes to wear
- Unable to combine like objects into categories for filing and/or storage
- Each item viewed as unique, irreplaceable
- Items examined and put back in pile
- Result: pile of unrelated objects, important and unimportant, that get "churned"

# Information Processing Deficits

- Difficulty with memory
- Lack confidence in ability to remember
- Out of sight means they may not remember they have it
- Rely on visual cues
- Believe it is important to remember everything
- Focus of attention is on cost of discarding, no consideration of cost of saving

#### Emotional Attachments to Possessions

- Excessive sentimental attachments to seemingly meaningless objects
- Reminders of important past events
- Person feels objects are a part of them
- May have replaced relationships with objects
- Throwing things away is losing a part of themselves
- Often can't decide what value their possessions truly have

## Behavioral Avoidance

- Related to decision-making problems
- Better to avoid decisions rather than risk making a bad one
- Avoids changing behavior and risking anxiety
- May reflect passive-aggressive personality style

#### Erroneous Beliefs About Nature of Possessions

- Belief in existence and importance of perfection
- Elaborate sense of responsibility for proper use
- Cannot discard if item has some potential use, no matter how unlikely
- Even if they may not need item, can think of someone who might
- No concrete plan to get item to that person

## More Erroneous Beliefs

- Must be prepared for every contingency
- Need for control over possessions
- Get upset by thought of others touching, using, or discarding their things
- Often will not let others into their home
- What they expect of themselves
- Should be able to read and remember everything

#### Barriers to Treatment

- Depression
- Other OCD symptoms
- Distractibility (?ADD)
- Anger
- Lack of support
- Cost
- Feeling overwhelmed

#### Treatment Goals

- Create living space
- Increase appropriate use of space
- Improve decision-making skills
- Organize possessions to be more accessible
- Discard unneeded possessions
- Prevent future hoarding
- Find alternatives to compulsive shopping and/or acquiring

## How Families/Others Can Help

- Education about the behavior
- Find professional help
- Be patient! Change is very difficult
- Reward progress, no matter how small
- Show kindness and compassion
- Hoarding is rarely malicious
- Focus on individual's positive qualities
- Spend time doing enjoyable activities

## Avoid Common Traps

- Do not try to accelerate by doing work for hoarder
- Pay attention to your comments
- Not helpful to remark on how slow it's going
- Control urge to move immediately to other areas once one area is clear
- Notice what has been accomplished

#### What Happens in Treatment?

- Psychoeducation can give hope
- Behavioral assessment to assess level of clutter and thoughts/behaviors that maintain hoarding
- Behavioral plan made by client & therapist
- Target areas established
- Therapist never touches items without explicit permission

## Behavioral Treatment Data

- Superior to wait list control (44% vs. 0% much or very much improved)
- wait list subjects later offered treatment and 71% improved
- 37% of eligible subjects declined to participate
- For 62%, gains were maintained at a 1-year F/U

# That would be the ideal way to treat, but...

#### What Happens When...

- Hoarders are living in dangerous conditions (structural problems, fire hazard, insect infestations, animal waste, etc)?
- Involved in legal issues (child protective services, need assisted living, facing eviction)?
- Are physically unable to clean out?
- Others become involved in disposal of items?

## Legal Definitions vs DSM

- DSM not meant to have force of law
- Definitions used by judicial system may conflict with scientific requirements
- Having a DSM diagnosis may not exempt from punishment or other legal restrictions on behavior

#### Be Prepared

- Situation will be very stressful for hoarder
- Hoarder may harbor strong negative feelings toward those involved in process
- Try to find therapist who can help with "crisis management"
- Tell hoarder what needs to happen, how it will occur, and consequences of non-compliance
- Allow hoarder to participate in saving a few truly important items

## Treatment (continued)

- Simple categorical systems to help client process items
- Churning discouraged items should be placed into final category
- Clients will want to save more items at first
- Identify, challenge, replace thoughts contributing to hoarding
- Discuss relapse prevention

## A Word of Warning

- Once home is decluttered, problem is not solved
- Hoarder needs to learn previously discussed skills or cluttering will recur
- Therapist can help individual mend relationships and learn skills

## Treatments: Medication

- Paroxetine (Paxil) produced improvement in hoarding and non-hoarding OCD patients (2007)
- SSRIs may help with depression, but not hoarding
- Previous studies found hoarding/saving in OCD associated with poor response to medications
- No RCTs for hoarding disorder
- Open-label trial results mixed
- \*\*\*Bottom line: cannot depend on medication to treat hoarding disorder

Source: Black et al., 1998; Nordsletten & Mataix-Cols, 2015

## Does Medication Help?

- No FDA-approved medications
- No RCTs for hoarding disorder
- Open-label trial results mixed
- Hoarding associated with poor treatment response in OCD patients
- SSRIs may help with associated depression and anxiety
- \*\*\*Bottom line: Cannot depend on medication to treat hoarding

#### Treatment: Behavioral Treatments

- Therapist guided
- Compulsive Hoarding and Acquiring in "Treatments That Work" series (Steketee and Frost, Oxford University Press)
- Treatment designed to take about 6 months
- Therapist guide
- Client workbook
- Teaches organizational skills
- Includes relapse prevention

# For More Information and Self-Help Resources

- Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding (Tolin, Frost, Steketee)
- Written in self-help format
- Can be used by friends, family members, and therapists to help clients
- On the Web: <u>hoarding.iocdf.org</u>
- Also: <u>adaa.org</u>

## Area Resources for Hoarding

Google: Professional Organizers, Quad Cities, Iowa and Illinois

# • Animal Hoarding: Definition\*

## \*Hoarding Animals Research Consortium

- More than typical number of companion animals
- Unable to provide even minimal standards of nutrition, sanitation, shelter, and veterinary care, often resulting in illness, starvation, and death

# Animal Hoarding (continued)

- Denial of the inability to provide this minimum care and the impact of that failure on the animals, the household, and the human occupants of the home
- Differs from other kinds of animal cruelty (person believes they are rescuing/saving animals)
- More studies needed

# Responses to Animal Hoarding

- When animal hoarder is unwilling to accept help:
- may face animal cruelty charges
- fire department may cite for fire code violation
- health department may find housing code violations
- zoning official may cite for keeping excessive number of animals

## HSUS Recommendations

- Removing animals:
- temporary solution
- recidivism rate nearly 100%
- need long-term plan that involves
- psychotherapy/medication intervention
- animal control
- social service agencies
- health and housing agencies
- family and others involved in hoarder's life

# ■ HSUS Recommendations (continued)

- Mandatory psychological evaluation and treatment
- Restrict ownership to 2 animals
- Lengthy probation period
- hoarder must agree to periodic unannounced visits
- jail time where animal suffering is extreme (consider mental health of hoarder)

THE END