Hoarding Disorder 101

The reality vs. what you see on reality TV

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Agenda

- Description, diagnostic criteria, and prevalence of Hoarding Disorder (HD)
- Etiology & function of HD
- Differential diagnosis and comorbidities
- Assessment tools
- Interventions
- Broaching the topic of HD with clients
- Creating HD-specific services at Jefferson Center
- Further resources & reading

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- Dr. Christiana Bratiotis
  - Associate Professor, PhD Program Chair in the School of Social Work at The University of British Columbia in Vancouver, Canada

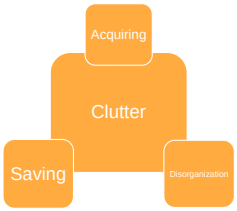
What is Hoarding Disorder?

- Persistent difficulty discarding or parting with possessions because of a perceived need to save them.
  - "discarding" vs. "letting go"
- The person experiences distress at the thought of getting rid of the items.
- Excessive accumulation of items, regardless of actual value, occurs.

Diagnostic Criteria

A. Difficulty discarding/parting with objects
B. Difficulty discarding due to urges to save
C. Symptoms result in accumulation of possessions that clutter living areas
D. Distress or interference
E. Not better accounted for by medical condition
F. Not better accounted for by other mental illnesses

Diagnostic Specifiers: With excessive acquisition, level of insight

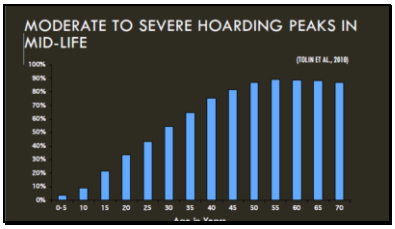


Animal Hoarding

- Accumulation of many animals
- Failure to provide minimal standards of nutrition, sanitation, and veterinary care
- Failure to act on the deteriorating condition of the animals
- Failure to act on the deteriorating condition of the environment
- Major differences between animal hoarding and object hoarding
  - Extent of unsanitary conditions
  - Poor insight in animal hoarding

Hoarding Disorder by the numbers

- Prevalence is approx. 5% in the U.S.
  - (Samuels et al., 2008)
- Average age symptoms appear is 16.7
  - (Zaboski et al., 2019)
- Moderate to severe hoarding peaks in later life (age 50-55)
  - (Tolin et al., 2010)



What people with Hoarding Disorder save

- The same types of things people without HD save
  - Magazines, newspapers, other reading materials
  - Clothes
  - Dishes
  - Containers
- Disorganizations leads to items of different value being mixed in together

Why People Hoard

- Complex interplay of:
  - Evolutionary
  - Biology
  - Neurobiology
  - Genetics
  - Thoughts
  - Emotions
  - Life experiences
    - (Mathews et al., 2007; Timpano et al., 2011)
- Resist reductionist tendencies - no single causal factor

Cultural Considerations

- Most research done in Western, industrialized countries & urban communities
- Available data suggests HD has consistent clinical features cross-culturally
- In cultures with a high value placed on thrift & saving possessions, basis of diagnosis should be the presence of distress and functional impairment
- Men and women generally experience the same key features of HD
  - Women tend to have more excessive acquisition (especially buying)

Why people save/acquire items

- Sentimental-emotional attachment
- Instrumental-useful
- Intrinsic-beautiful

- Values
  - Frugal
  - Creative
  - Resourceful

Differential Diagnosis: Rule out diagnoses

- Medical conditions
  - Brain injury, cerebrovascular disease, Prader-Willi syndrome
- Other mental disorders
  - Obsessions in OCD
  - Decreased energy in MDD
  - Delusions in psychotic disorders
  - Cognitive deficits in major neurocognitive disorder
  - Restricted interests in autism spectrum disorder
- Collections
  - Systematic, organized fashion
  - Doesn't impair function

Comorbid mental health concerns

- Major Depressive Disorder: 50.7%
- Generalized Anxiety Disorder: 24.4%
- Social Anxiety Disorder: 23.5%

- ADHD: 27.8%
- PTSD: 6.9%

- Any Anxiety Disorder: 53.5%
- Any anxiety or mood disorder (other than OCD): 76.5%
  - (Frost, Steketee, & Tolin, 2011)

Screening & Assessing

Hoarding Rating Scale (HRS)

0	1	2	3	4	5	6	7	8
None/not at all		Mild		Moderate		Severe		Extreme

1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?
2. To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?
3. Do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?
4. To what extent do you experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?
5. To what extent do you experience impairment in your life (daily routine, job/school, social activities, family activities, financial difficulties) because of clutter, difficulty discarding, or problems with buying or acquiring things?

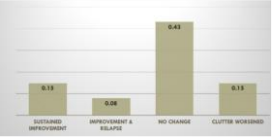
(Tolin, Frost, & Steketee, 2010; Tolin et al., 2018)

Options for Intervention

- Supportive, step-by-step reduction of clutter
  - Bibliotherapy
  - Community-led interventions
  - Behavioral coach, in-home
  - Mental health treatment
    - Individual treatment
    - Group treatment
    - Medication
  - Harm reduction strategies
- Supported clean-out
- Clean out without control/presence
- Eviction/condemnation of the home

Think minimum effective dose!

Cleanouts don't work without other interventions



(Kim, Steketee, & Frost, 2001)

Treatment: Specialized CBT for Hoarding

- Assessment and case formulation
- Enhance motivation
- Reduce acquiring
- Train skills: organizing, problem solving, cognitive rehabilitation
- Practice sorting and discarding unwanted items – "exposure"
- Cognitive therapy to challenge beliefs
- Maintain gains, prevent relapse
  - (Steketee & Frost, 2007; 2014)

Community support is critical

- Need for support from housing, social services, hauling services, healthcare, family, peers, and mental health treatment
- Hoarding can impact the entire community around the individual (family, neighbors, law enforcement, etc.), so support is needed from all areas.

How to talk to someone about their clutter

- Use respectful, non-stigmatizing language. Leave the judgment at the door.
- See if the person brings up the topic of clutter first. Match their language.
- Avoid touching objects (if in the home) or making suggestions about what they should do with it.
- Focus on safety and legal compliance (if needed); avoid focusing too much on getting rid of things.
- Avoid persuading or arguing.
- Don't shield the person from negative consequences of their clutter.
- Use encouraging language about efforts that have been made.
- Offer liberal praise for progress made
  - If client is significantly depressed, don't overdo the praise or the person won't believe it. Be more modest in your compliments.

How to talk to someone about HD treatment

- Familiarize yourself with the programs and resources in your area, as well as the clinical interventions available.
- Normalize it: *A lot of the clients I work with wish there was someone who could help them go through and organize their things. Is that something that would interest you?*
- Let them know there are programs that can help, ask if they'd be interested in connecting with those specific resources.
- Reinforce that the programs will only take items the person has agreed to let go of (if intervention is voluntary).

If Safety is a Concern

- Calmly and objectively state the concern
  - *I'm concerned that there isn't a clear path to the door in case EMS would need to come out. Have you thought about that, as well?*
- If the person has capacity and the welfare of others is not at risk, ask for permission to connect with resources
  - *I'd like to make a referral to someone who could help clear a path. Would that be alright?*
- Refer to APS, CPS, or welfare checks as appropriate for concerns around capacity, self-neglect, or negative impact to other vulnerable individuals in the home.

Hoarding Disorder Services at Jefferson Center

Timeline of addressing need

- 2017: Jefferson County Aging Well creates hoarding task force
- March 2019: Seniors' Resource Center announces funding from DRCOG to assist with clutter clean up through partnership with Clutter Truckers
- January 2020: At JCMH, group and individual treatment for HD begins, primarily utilizing "Buried in Treasures" group curriculum.
- December 2020: DRCOG approves funding request to expand hoarding treatment, new Senior Reach clinician hired at JCMH
- May 2021: Next50 approves funding for a care manager position at JCMH to staff referral line and provide additional support for group facilitation and individual coaching

Services offered

JCMH

- January 2020
  - Individual therapy
  - Buried in Treasures workshop
- January 2021
  - Alumni of Buried in Treasures group
- Summer 2022
  - "Supporting Treasures" for loved ones
- Clinical consultations
- Community webinars & trainings

Seniors' Resource Center

- Deep Cleanings
  - Offered through Chores program
  - 3 hours per visit
  - Up to 3 visits per year
- Excessive Clutter Cleanouts
  - Partnership with Clutter Trucker
  - Service hours can be spread out over time as needed

Clients Served in FY22

JCMH

- FY22
  - Individual therapy: 8 clients, 69 therapy sessions
    - 60% increase from FY21
  - Buried in Treasures workshop: 23 clients, 477 group sessions
    - 92% increase from FY21
  - Clinical consultations: 5-10 (estimated)

Seniors' Resource Center

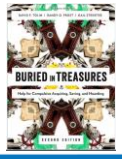
- Clutter Removal clients: 152
- Clutter Removal hours: 1,896
- Total of $82,431 spent on clutter removal

Funding

- Billable services
  - Hoarding Disorder recognized as a standalone diagnosis in the DSM-V in 2013. Bill skills training and development, individual therapy, and group therapy.
- Area Agency on Aging
  - Provides funding to do outreach visits prior to a client engaging in services.
  - Reimburses for services provided by unlicensed clinicians and interns when client has Medicare or private insurance.
- Next50 Initiative
  - Provides funding for a care manager to staff the referral line and engage client in services. Care manager connects clients to additional resources, co-facilitates the Buried in Treasures groups.

Buried in Treasures workshops

- 15 weeks
- Peers work through the book "Buried in Treasures" and support each other in doing the assessments and exercises



Where to learn more: Books

- Stuff: Compulsive Hoarding and the Meaning of Things by Gai Steketee & Randy Frost
- Treatment for Hoarding Disorder: Workbook and Therapist Guide (Treatments that Work) by Gail Steketee and Randy Frost
- The Hoarding Handbook: A Guide for Human Service Professionals by Christiana Bratiotis, Cristina Sorrentino Schmalisch, and Gail Steketee
- Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding by David Tolin, Randy Frost, & Gail Steketee
- Decluttering at the Speed of Life: Winning Your Never-Ending Battle with Stuff by Dana White
- Digging Out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring by Michael A. Tompkins and Tamara L. Hartl

Additional Resources

- International OCD Foundation
  - Resources for:
    - Individuals with lived experience
    - Family members & supporters
    - Mental health professionals
    - Researchers
  - "Find help" resource finder
  - Annual Hoarding Disorder Conference
  - Hoarding.iocdf.org

International OCD Foundation

Questions?

Jefferson Center
With you in mind

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