Hoarding disorder: Current understanding and treatment considerations

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ROGERS Behavioral Health

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Disclosures

Brandon DeJong, PhD, and **David Jacobi, PhD,** have each declared that they do not, nor does their family have, any financial relationship in any amount occurring in the last 12 months with a commercial interest whose products or services are discussed in the presentation. Drs. DeJong and Jacobi each declared that they do not have any relevant non-financial relationships. Additionally, all planners involved do not have any financial relationships.

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Learning objectives

Upon completion of the instructional program, participants should be able to:

1. Describe one hoarding-related belief and behavior.
2. Identify at least two strategies to enhance motivation for treatment.

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What we'll cover in this webinar

An overview of hoarding disorder
- Diagnosis and assessment
- Hoarding-related beliefs and behaviors
- Associated features

The cognitive model of treatment of hoarding disorder
- Goals of treatment
- Motivation and insight
- Specific treatment interventions

Clinical application: Case example
- Assessment
- Treatment plan
- Treatment intervention

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A note about diversity…

There is low representation of ethnic and racial minorities in research related to OCD. (Williams, Debreaux & Jahn 2016)

Other issues:

- *Treatment programs* – under representation of minorities in specialized programs for OCD/anxiety
- *Prevalence* – prevalence of OCD in African American population is similar to general population
- *Recruitment for research* – efforts to recruit for research by using less technical descriptors, use of African American therapists to conduct the evaluations and advertising in traditionally African American institutions

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A note about diversity…

- *Barriers to treatment* – may include cost, transportation, stigma, fear of therapy (or of the therapist), lack of awareness of anxiety symptoms and proven treatments for anxiety, lack of providers trained to treat OCD, cultural beliefs barring involvement in mental health treatment
- *Symptom dimensions* – misdiagnosis (more likely to be diagnosed as psychotic) and not receive appropriate care.
- *Comorbidity* – majority of those with OCD have co-occurring disorders (mood, anxiety, substance use) which can complicate diagnosis and treatment

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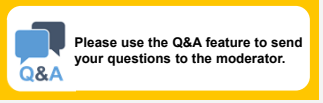
An overview of hoarding disorder



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Why was Hoarding Disorder added to DSM-5?

- Substantial scientific literature on this disorder
- Clinically significant hoarding is prevalent (2-5% of the population) and can be severe, with resulting legal problems
- Most hoarders (up to 80%) do not meet diagnostic criteria for OCD and do not endorse other clinically significant OCD symptoms
- Important differences between hoarding and OCD across a number of validators, including poorer response to SRIs and ERP (Mataix-Cols, Frost, Pertusa, et al., 2010)

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DSM-5 criteria: Hoarding Disorder

- Persistent difficulty discarding or parting with possessions, regardless of their actual value.
- This difficulty is due to a perceived need to save the items and to distress associated with discarding them.
- The 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).
- The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).
- The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
- The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in OCD, decreased energy in MDD, delusions in psychotic disorders, cognitive deficits in major neurocognitive disorder, restricted interests in ASD).

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DSM-5 criteria: Hoarding Disorder

Specifiers:

With excessive acquisition

- If difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is not adequate space.

Insight

- Good or fair insight
- Poor insight
- With absent insight / delusional beliefs

Associated features:

- Indecisiveness
- Perfectionism
- Procrastination
- Difficulty planning and organizing tasks
- Distractibility

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Hoarding Disorder: Research challenges

Research has been difficult to collect for all ages of hoarding

- Experts estimate only 5% of hoarding cases are being treated
- Usually referred by family members or agencies attempting to deliver services
- Hoarding is not perceived as a significant problem by most hoarders in treatment
- Females much more likely to present to treatment despite fact that it affects both men and women and there is some research to suggest that more men may be affected than women (*DSM-5*).
- Hoarding almost 3x more prevalent in older adults (55-94 years) than younger adults (34-44 years; *DSM-5*).

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Hoarding Disorder: Assessment challenges

Hoarding vs. Mess

- Difference is in the functional impairment
- Messy spaces do not impair life functioning (including access, preparation, and willingness to have guests)
- Hoarding represents more significant concerns and generally unwillingness of host or guests to have visits

Hoarding vs. Collecting

- Normative collecting is more organized and systematic
- Normative collecting does not produce the clutter, distress, or impairment seen in hoarding disorder

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Hoarding Disorder: Assessment challenges

- Have difficulty getting rid of items?
- Have a large amount of clutter in the office, at home, in the car, or in other spaces (i.e. storage units) that makes it difficult to use furniture or appliances or move around easily?
- Often lose important items like money or bills in the clutter?
- Feel overwhelmed by the volume of possessions that have "taken over" the house or workspace?
- Find it difficult to stop taking free items, such as advertising flyers or sugar packets from restaurants?
- Buy things because they are a "bargain" or to "stock up"?
- Avoid inviting family or friends into the home due to shame or embarrassment?
- Refuse to let people into the home to make repairs?

IOCDF.org

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Hoarding Disorder: Assessment challenges

Hoarding and dementia

- More common in early stages of Alzheimer's (perhaps to keep known objects in sight?)
- Hoarding may increase as memory and other faculties are affected
- 20% of people with dementia display some hoarding behaviors
- Most hoarders do not have dementia

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Hoarding Disorder: Assessment rating scales

The International OCD Foundation has several standard rating scales available to download from its website for clinicians to use to make a diagnosis and assess the severity and impact of HD on the client:

Saving Inventory-Revised (SIR)- Twenty-three item measure-can be administered as self-report or clinician administered

Hoarding Rating Scale (HRS)-Five-item self-report scale

Clutter Image Rating (CIR)

https://hoarding.iocdf.org/professionals/clinical-assessment/

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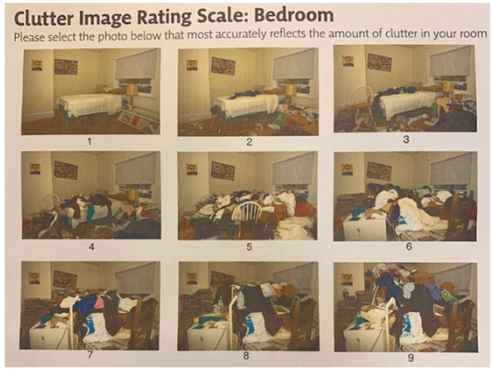
Clutter image rating

Uses 3 series of pictures (Living Room, Kitchen, and Bedroom),

- Client selects the picture that best represents the amount of clutter for each of the rooms of their home by number.
- Instructed to pick the picture that is closest to being accurate, even if it is not exactly right.



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Hoarding disorder: Diagnostic challenges

Hoarding disorder

- Thoughts are not intrusive, or repetitive, or distressing (may actually enjoy acquisition)
- No urge to rid home of clutter
- Distress only at thought of having to discard
- Limited insight

OCD

- Thoughts intrusive and repetitive
- Compulsions present
- Anxiety and distress

(Williams-Behavioral Wellness Clinic
New England OCD Institute, 2021)

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Hoarding Disorder vs hoarding in OCD

No pleasure derived from saving things and the resulting clutter which is typically unwanted and highly distressing.

Not typically interested in the items they save; have few sentimental attachments or beliefs about the value/worth of the items themselves.

Excessive acquisition of items is unusual among those with OCD-based hoarding

Hoarding in OCD tends to relate to symptoms of OCD

- May not touch items that are contaminated so can't discard. Or may collect all items touched due to fear of contaminating others.
- May have issues with decision making
- May avoid discarding due to avoidance of checking different objects or paperwork. Too labor intensive to check all documents

Note: If hoarding symptoms are distinct from OCD symptoms can diagnose both hoarding disorder and OCD

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Comorbidity and hoarding symptoms in African Americans with OCD

- OCD sample overall-87.9% had at least one other comorbid condition
- Mood disorders, anxiety disorders, substance use disorders most common comorbid disorders
- Over half of the participants (56%) had hoarding compulsions
- Those with hoarding compulsions experienced great indecisiveness, pathological slowness and doubting.
- Conclusion: African Americans with OCD tend to have high rates of comorbidity similar to non-hispanic white populations

(Williams, 2017)

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Hoarding Disorder: A global perspective

Nordsletten, Fernandez de la Cruz, Aluco, Alonso, López-Solà, Menchón, et al. (2018) looked at prevalence of hoarding disorder at different sites globally:

- London, England
- Barcelona, Spain
- Fukuoka, Japan
- Rio de Janeiro, Brazil

"Results indicate that the severity and core features of HD, as well as the cognitions and behaviors commonly associated with this condition, are largely stable across cultures"

(pg. 1, Nordsletten et al., 2018)

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Prevalence/phenomenology of hoarding

Actual prevalence?

We don't have definite numbers – we can only count the people who come forward, *and most do not.*

- 18-30% of those with Hoarding Disorder have OCD
- 40-60% have Social Phobia or GAD
- Isolation is frequent and can lead to depression

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Current conceptualizations of hoarding

Origins

- Family history of hoarding
- Family values (i.e., about waste, sentimentality)
- Information processing problems
  - Difficulty sustaining attention
  - Problems grouping or organizing
  - Considering too many facets of a problem
  - Fear of making a mistake

"When predicting hoarding severity, after controlling for age and mood, recollections of lack of warmth in one's family was a significant predictor of hoarding severity, with hoarding-related cognitions and fears about decision-making being additional unique predictors."

(page 1. Kyrios, Mogan, Moulding, Frost, Yap et al. 2017)

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Current conceptualizations of hoarding

According to Tolin, Frost and Steketee (2014) there are information processing deficits: "*A brain problem, not a house problem.*"

Categorization	Items not where they are used (cotton balls)
Perception	Hoarders don't see items as we do (box to be mailed)
Decision-making	Slow, concern with making ALL "right" decisions
Attention	Similar to ADHD / frequent shifting
Prospective memory	Difficulty remembering/carrying out tasks to do in the future
Complex thinking tasks	3 or more steps

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Current conceptualizations of hoarding

Emotional attachments to / special meaning of possessions:

- Beauty / Aesthetics
- Memory
- Utility/opportunity
- Uniqueness
- Sentimentality
- Comfort
- Safety (physical / emotional)
- Identity / Potential identity
- Control
- Mistakes
- Responsibility/waste
- Completeness
- Validation of worth
- Socialization

(Tolin, Frost, Steketee, 2014)

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Current conceptualizations of hoarding

Behavioral avoidance and significantly strong emotions:

- Hoarders do not want to reduce acquisition
- Positively reinforced
- Hoarders do not want to discard (making mistakes, dealing with others)
- Negatively reinforced

(Tolin, Frost, Steketee, 2014)

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Current conceptualizations of hoarding

Hoarding behaviors:

- Gathering…
  - Actively seek and collect useless items
  - Actively over-seek and collect useful items
- Avoidance …
  - Avoid discarding useless items that naturally accumulate over time
  - So difficult for them they avoid doing it

Hoarded items:

- Could be just about anything…
  - Newspapers, magazines, mail, paperwork
  - Trash, food containers
  - Clothes, toys
  - Broken appliances, lawnmowers
  - Bodily waste, hair, nail clippings
  - Animals

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Elderly populations: Additional hoarding-related problems

- Difficulty moving around living space
- Unable to use furniture
- Hard to prepare food or store food items
- Limited access to hygiene
- Fire hazards
- Risk of falling
- Unsanitary conditions
- Depression
- Anxiety (esp. social anxiety or GAD)
- OCD
- Social skills deficits
- Social isolation
- Organic conditions (e.g., dementia)

(Steketee, Frost, Kim, 2001)

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The cognitive model of treatment of hoarding disorder

Please use the Q&A feature to send your questions to the moderator.

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Hoarding Disorder: Consequences

- What are the typical consequences of hoarding-related behaviors?
  - Decrease in quality and frequency of relationships
  - Isolation
  - Financial/legal problems

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Who gets treatment?

- Who comes forward for treatment?
- How do we hear about them?
- We need to consider effects on the community as well, not just the identified patient.

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Goals of treatment

- Initial focus should be on safety and organization
- Ultimately, we want to use these behaviors from the diagnostic criteria to guide treatment:

  First: the acquisition of and failure to discard a large number of possessions that *appear* to be useless or of limited value.

  Second: "living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed."

  Third: "significant distress or impairment in functioning caused by the hoarding." (hoarding vs. being a packrat)

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Goals of treatment

- So, taking each into account, we want to help the patient to:
  - Decrease acquisition
  - Increase the ability to discard items
  - Declutter living spaces to regain functionality
  - Tolerate distress associated with the above goals

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Goals of treatment

- The most promising intervention is by Tolin, Frost, and Steketee (*Buried in Treasures*, 2014).
  - Psychoeducation about hoarding
  - Improving decision-making skills (important/meaningful vs. not)
  - Development of an organizational system for possessions
  - Graded exposure to avoided behaviors (making decisions, avoiding acquiring, discarding)
  - Challenging beliefs about possessions

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Goals of treatment: Initial behaviors and cognitions

Feared stimulus	Throwing out a newspaper
Misinterpretation of threat	"Something important is in there."
Anxiety	Anxiety ("What if…")
Avoidant coping	Refuse to discard
Absence of corrective experience	Accumulation of items in home

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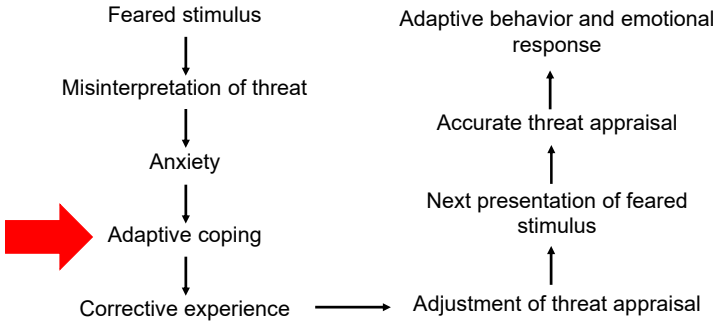
Goals of treatment: Correction of maladaptive coping



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Motivation and insight

"A brain problem, not a house problem."

- Early 90's – use of CBT did not produce good treatment results
- Hoarders typically have a high dropout rate
  - At least 15% drop out of treatment

(Kim, Steketee, & Frost, 2001)

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Motivation and insight

- Dimensions of insight in Hoarding Disorder
  - Anosognosia
  - Overvalued ideation
  - Defensiveness

(Frost, Tolin, and Maltby, 2010)

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Motivation and insight

- Self-referrals account for 3% of hoarders
  - Not accompanied by more significant cognitive impairment
  - Questions about how to “fix” problems (storage space)
- 15% of hoarders acknowledge their behaviors are irrational
- Most hoarders are characterized as having fair, poor, or delusional insight (Kim, Steketee, and Frost, 2001)

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Motivation and insight

- We know that limited insight also contributes to poorer treatment engagement and treatment outcomes (Tolin et al. 2015).
- Individuals with Hoarding Disorder will often deny they have a problem, which can contribute to them resisting interventions, and the degree to which the problem is recognized most likely contributes to readiness to change. (Tolin, 2011)

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Motivation and insight

- Primary component of treatment – increasing recognition of the problem
  - Consistent enough to be in diagnostic criteria
  - Use of measures (e.g. SI-R, ADL-H) – completed by collaterals and patient. Do they match?
  - Conversations with family and friends, though perspectives will differ.

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Motivation and insight

- Significant overlap with Motivational Interviewing
  - "Telling their story" – retrospective analysis of hoarding behaviors and associated interference.
  - Visualization exercises
  - Validation of ambivalence toward decluttering

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Motivation and insight

- Prompting patients to identify goals and reasons for wanting to change
  - Identifying consequences of hoarding and how this may not be in line with one's values

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Insight and symptom measurement

- As hoarders typically have low levels of insight, they are poor historians/reporters.
- Scales have been developed that can get more accurate results by using pictures, as well as being completed by patients and collaterals.

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Insight and symptom measurement

- Saving Inventory-Revised
  - 23-item scale, range 0-92
  - Three subscales: Clutter, Difficulty Discarding, Excessive Acquisition (Tolin, Meunier, Frost & Steketee, 2011)

	Cutoff scores (> indicates HD)	Average HD Score	Average non-HD score
Total	41	62	23.7
Clutter	17	26.9	8.2
Difficulty Discarding	14	19.8	9.2
Excessive Acquisition	19	15.2	6.4

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Insight and symptom measurement

- Hoarding Rating Scale
  - 5-item semi-structured interview, range 0-40
  - Subscales: Clutter, Difficulty Discarding, Acquiring, Distress, Impairment (Tolin et al., 2018)

	Healthy Controls	Hoarding Disorder
Clutter	0.09	5.52
Difficulty Discarding	0.09	6.25
Acquiring	0.11	4.48
Distress	0.05	5.65
Impairment	0.02	5.84
Total	0.36	27.73

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Insight and symptom measurement

- Clutter Image Rating
  - 9 items per room
  - Ratings > 4 indicate levels of clutter requiring clinical attention (Frost, Steketee & Tolin, 2008)
- Activities of Daily Living – Hoarding
  - 15 items related to ADLs (range 1-5, higher scores indicate greater impairment)
  - HD – 2.2; HD and OCD – 1.95; OCD – 1.19, Controls – 1.15

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Treatment interventions

- It will be critical to involve collaterals, as well as the measures just reviewed.
- Broadly, interventions involve leveraging exposure-based activities in order to help:
  - Reduce Acquisition
  - Increase Discarding
  - Increase Motivation

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Treatment interventions

- Most promising intervention is by Tolin, Frost and Steketee (2014)
  - Psychoeducation about hoarding
  - Graded exposure to avoidance/safety behaviors (making decisions, avoiding acquiring, discarding items)
  - Improving decision-making skills (important/meaningful vs. not) and restructuring beliefs about possessions
  - Development of an organizational system for possessions

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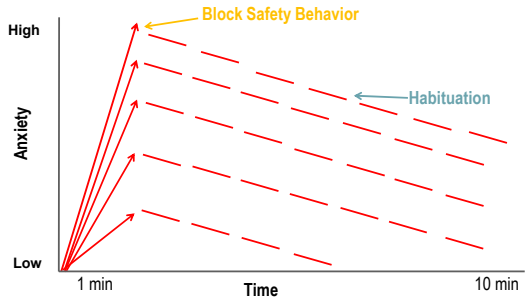
Treatment interventions: Exposure

With repeated exposure, patient's peak anxiety levels will begin to gradually decrease (*between-trial habituation*)



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Treatment interventions

- Reducing acquisition:
  - Normalizing the reinforcement from acquiring new things
  - Tracking acquisition behaviors
  - Understanding the acquisition process
  - Changing thoughts about acquiring
  - Tolerating the desire to acquire
  - Developing alternative sources of enjoyment/ways to cope

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Treatment interventions

- Increasing discarding:
  - "Work your practice muscle daily"
  - Target activities and times which support discarding and work around deficits
  - Create problem-solving strategies
  - Create strategies for organizing/categorizing (Esp. paper)
  - Regular upkeep
  - Rewarding oneself

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Treatment interventions

- Increasing discarding
  - "Do I keep it or let it go?"
  - Consistent follow-through
  - Tolerating Distress
  - Behavioral experiments: Testing out letting go

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Clinical application: Case example

Please use the Q&A feature to send your questions to the moderator.

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Case example: Betty

Demographics:

- 66-year old Caucasian female
- Home in rural Wisconsin
- Ph.D. in Rhetoric
- Husband passed away 2 years prior to this intervention
- 2 children – son and daughter, strained relationship with both – 3 grandchildren

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Case example: Betty

Assessments:

- Connected to a local clinic through a study using the intervention from *Buried in Treasures* (3 months)
  - Weekly therapist-led support and education group about hoarding
  - Clinician work with participants in their homes
- Completion of a retrospective interview, SI-R, HRS, CI-R, and ADL-H, depression, and normative functioning

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Case example: Betty

Assessments:

- Retrospective interview
  - Involvement of adult children
  - Recent loss of husband
  - Decline in physical functioning
  - Beliefs about possessions
  - Acquisition behaviors

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Case example: Betty

Assessments:

- Retrospective interview
- SI-R: 63
- HRS: 24
- CI-R: 4, 8 (different locations)
- ADL-H: 2
- Additional assessments to rule out neurocognitive issues and depression

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Case example: Betty

Treatment plan – *what to take into consideration?*

- Strained relationships (children, neighbors)
- Social isolation
- Financial difficulties (paying for storage units, fixed income)
- Not familiar with treatment
- Physical capacity
- Location of home in a rural area

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Case example: Betty

Treatment plan – *what form does her hoarding behavior take?*

- Saving items from children
- Information (newspapers, magazines)
- Driving in the community on trash days
- Ordering items online

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Case example: Betty

Treatment plan

- Psychoeducation about the treatment model
- Explanation of treatment intervention, and what to expect
- Development of a model of behavior unique to her
  - What does she see as the reasoning for her behavior?
  - What feelings or beliefs are associated with acquiring, saving, and clutter?
  - Vulnerabilities linked to feelings, thoughts, and behaviors
- Use of personal values to motivate participation in treatment

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Case example: Betty

Treatment intervention – a word on communication:

- Matching language ("Collection" "Stuff")
- Respectful language
  - Avoiding judgmental expressions ("junk," "trash," or nonverbal expressions such as grimacing or eye-rolling)
- Initial focus should be on safety and organization
- Avoid telling the client what they should focus on/do
- Avoid touching the client's possessions
- Noticing and commenting on strengths/progress

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Case example: Betty

Treatment intervention

- Weekly home visits and hoarding support group attendance using *Buried in Treasures* for 3 months
- Data collection – how and why do you get items?
- Education on the connection between thoughts, emotions, and acquiring behaviors
- Development of alternative sources of enjoyment

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Case example: Betty

Treatment intervention – idiographic conceptualization:

- *Meaning of possessions*
  - Connection to children, utility, waste
- *Vulnerabilities*
  - Perfectionism, distractibility, categorization, poor insight
- *Feelings*
  - Identity, sentimentality, responsibility
- *Negative reinforcement*
  - Reduced distress ("Getting it wrong")

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Case example: Betty

Treatment intervention – idiographic conceptualization

- *Values* ("I care about…")
  - Family connection
  - Education
  - Honesty
- *Goals* ("I want to do…")
  - See her grandchildren; reconnect with children
  - Have a safe home
  - Appreciate art
  - Be able to sleep in her bed

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Case example: Betty

Treatment intervention

- Changing thought process about acquiring (rules, pros/cons)
- Exposure to acquisition triggers ("non-shopping trips") as well as sorting tasks; use of hierarchy

Situation	Urge to acquire (1-10)
Researching new hobbies online	3
Driving past the bookstore	4
Going to the bookstore	6
Holding magazines/newspapers without buying them	8
Walking/driving on trash day	9

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Case example: Betty

Treatment intervention

- Develop a system of organization and practice sorting
  - Keep or discard?
  - How can I categorize this?
  - Where should I put it?
- Practice problem-solving

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Case example: Betty

Treatment intervention

- Be aware of the "bad guys"
- Maintenance and relapse prevention
  - Organizing schedule and sticking to the created rules
  - "Broken windows theory"
  - Increasing contact with others

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Case Example - Betty

Outcomes:

- SI-R: 63 → 42 (particularly Discarding and Acquiring scales)
- HRS: 24 → 16
- CI-R: 4, 8 (different locations) → 2, 6 (esp. due to family help)
- ADL-H: 2 → 1.2
- Spending significantly more time with family, able to visit with grandchildren (greater feeling of safety in home), lowered sense of shame/frustration, putting up art, sleeping in her bed

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Time for questions and answers…

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Where to get additional information…

ABCT ASSOCIATION for BEHAVIORAL and COGNITIVE THERAPIES

Association of Behavioral and Cognitive Therapy
https://www.abct.org/

International OCD Foundation

International OCD Foundation
https://hoarding.iocdf.org/

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About the presenters….

David Jacobi, PhD

Dr. Jacobi is a licensed clinical psychologist who serves as the clinical director for Rogers Behavioral Health in Sheboygan. He has an extensive practice background in the treatment of anxiety disorders in the United States and Canada and has conducted research related to OCD and anxiety. Dr. Jacobi has presented to numerous clinical and academic audiences at the local, regional, and national levels. He is a member of the International OCD Foundation and has served as one of the trainers for its Behavior Therapy Training Institute, an intensive training course in cognitive behavioral therapy for mental health professionals.

Brandon DeJong, PhD

Dr. DeJong is a licensed clinical psychologist and clinical supervisor at Rogers Behavioral Health in Hinsdale. He has been treating anxiety disorders with exposure and response prevention (ERP) for over a decade and has significant personal experience tailoring interventions to the individualized, unique presentations of his patients. Dr. DeJong is a member of the American Psychological Association

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