UPDATE ON HOARDING DISORDER

MAINE OCCUPATIONAL THERAPY ASSOCIATION: APRIL 7, 2018

PREVIOUSLY PRESENTED AT: AOTA MENTAL HEALTH SPECIALTY CONFERENCE: SEPTEMBER 16, 2017

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LEARNING OBJECTIVES:

At the conclusion of this session participants will be able to:

1. Define *hoarding disorder*
2. Describe the occupational performance problems experienced by individuals with hoarding disorder
3. Identify two strategies for effective intervention with individuals with hoarding disorder
• Who has had experience with/exposure to a hoarded home?
• Who has not?
• Who has seen any of the hoarding reality shows?
• What do you most want to know?
Shalom House Inc., sponsors a workshop with Dr. Randy Frost

Portland Hoarding Task Force is convened by Eric Grainger, MSW of Shalom House, Inc.

2012

Task Force reviews available services

Volunteer pilot program using 2 Task Force members initiated

2012

8 OT students for 10-week fieldwork placement using the 1:1 pilot model for in-home assist

2013
HOARDING DISORDER: DEFINITION

Previously thought to be a rare “side effect” of OCD, *hoarding disorder* is now a distinct diagnosis in DSM-5 with the following criteria:

- 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 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, or the authorities)
- The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining an environment safe for oneself or others)
- The hoarding is not attributable to another medical condition
- The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, etc.)
- Specifiers: with excessive acquisition; with good or fair insight; with poor insight; with absent insight/delusional beliefs

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HOARDING DISORDER: PREVALENCE

• Estimates of the prevalence of hoarding disorder in the U.S. range from two to five percent of the adult population (Muroff, Bratiotis, & Steketee, 2011), although anecdotal accounts from mental health service providers suggest the prevalence could actually be at least double that number (E. Grainger, personal communication, December 5, 2014).

• Onset is usually during childhood/adolescence, with a chronic, progressive course (Grisham, Frost, Steketee, Kim, & Hood, 2006)

• Typical co-morbidities include depression, ADHD, serious medical conditions, and obesity (Frost et al., 2011; Tolin et al., 2008)
Research indicates that people with hoarding disorder often experience cognitive challenges with information processing and behavioral avoidance (Frost & Hartl, 1996); inattention (Tolin & Villavicencio, 2011); and working memory, sequencing, concentration, mental control, set shifting, inhibition, and cognitive flexibility (Ayers et al., 2013). Additionally, evidence supports a correlation between decreased executive function and severity of hoarding symptoms (Ayers, Dozier, Wetherell, Twamley, & Schiehser, 2016; Ayres et al, 2012).
HOARDING DISORDER: RISKS AND CONSEQUENCES

• Eviction
• Health problems/falls
• Can’t use home as intended
• Pests/squalor
• Decreased function
• Stigma and Isolation

(Chater et al., 2013)
<table>
<thead>
<tr>
<th>Acquiring</th>
<th>Goat path</th>
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<tbody>
<tr>
<td>Discarding</td>
<td>Cave in</td>
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<td>Decluttering</td>
<td>Storage units</td>
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<td>Forced clean out</td>
<td>Eviction</td>
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<td>Safety day</td>
<td>“Finder/Keeper”</td>
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<td>Squalor</td>
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<td>Clutter blindness</td>
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**Match the person’s language**
THREE TYPES OF HOARDING:

1. Inanimate Objects
2. Animals
3. Data
THE THREE MOST COMMONLY HOARDED ITEMS?

1. Clothing
2. Papers
3. Organizational supplies: bins, containers, etc.

ASSESSMENT

- Saving Inventory-Revised (Frost, R., Steketee, G., & Grisham, J. (in press). Measurement of compulsive hoarding: Saving Inventory-Revised.)
  - Series of 23 questions leading to subscale scores in: clutter, difficulty discarding/saving, and acquisition that determine a focus for intervention:
    - How much control do you have over your urges to acquire possessions?
    - How much of your home is difficult to walk through because of clutter?
    - How much does clutter in your home interfere with your social, work, or everyday functioning?
      Think about things that you don’t do because of clutter.
    - How upset or distressed do you feel about your acquiring habits?
    - How frequently does clutter in your home prevent you from inviting people to visit?
ASSESSMENT

• Activities of Daily Living in Hoarding scale (ADL-H) (Frost et al., 2013)

  • Uses likert scale scoring to specifically assess activities of daily living that are compromised by hoarding: the ability to move/exit quickly, find important items, appropriate use of appliances, plumbing (both kitchen and bath), furniture, and rooms

  • 3 scales: Activities of Daily Living; Living Conditions; Safety Issues
Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.

1 2 3

4 5 6

7 8 9

(Stekete & Frost, 2013)
ASSESSMENT

• Transtheoretical model/stages of change
• OT:
  • COPM
  • KAWA
  • MOHO assessments of habits/roles/routines
INTERVENTION MODELS

- CBT: individual and group; office and home based
- Wellness Recovery Action Plan (WRAP) for Reducing Clutter
- Support groups
- Clutterer’s Anonymous (online)
- Peer-led:
  - Buried in Treasures workshops/groups
  - Clutter buddies
- In home support: therapists/case managers/volunteers
INTERVENTION

- Work in home is most effective; can be parallel with CBT and other office-based approaches but little changes unless support is provided in the cluttered environment.
- Takes a long time.
- Safety first.
- The person with hoarding disorder is in charge of the process.
- Collaborate on a decision-making process to follow: 3-second rule/3-bag system, etc.
- Collaborate with primary therapist around specific strategies and working past resistance.
- Forced clean outs traumatize people and typically do not change hoarding behavior.
OT AND HOARDING DISORDER

- Development of “Friendly Visitor” volunteer program: pilot
- OT Practice article: case study based on my volunteer experience (Spear, 2014)
- Placement of MOT level I students as Friendly visitors
- Qualitative research study on “Friendly Visitor” volunteer program (Noyes, van Houten & Wilkins, in press)
OT PRACTICE (2014): CASE STUDY

- Marge, middle aged woman with whom I volunteered for 1 ½ years
- Severe occupational imbalance related to hoarding behaviors
- Eviction notices; storage units
- MOHO:
  - Roles/identity: no longer a worker but “a person who hoards things”
  - Habits: yard sales, support groups
  - Routines: typical day structured around hoarding activities, acquiring or planning to acquire
  - Rituals: symbolism and meaning of holiday and family-related objects
VOLUNTEER PROGRAM: THE BEGINNING

• Required of students before beginning:
  • Attend Eric’s “Hoarding 101” presentation
  • Shalom’s employee orientation (confidentiality, background check, policies, etc.)
  • Complete assigned readings (coursework)
  • Meet with Eric to get background information on the person’s preferences and experience with best ways to provide support

• Clients and students were matched based on personalities and preferences

• Volunteers provided at least 2 hours/week of direct, on-site, hands-on support with decluttering for 10 weeks

• On and off site supervision throughout the fieldwork placement
VOLUNTEER PROGRAM: 2013-2017

• 6-8 OT student ‘volunteers’ every spring

• The experience evolved to include:
  • Monthly group supervision
  • Use of occupational therapy ‘Kawa’ assessment tool
  • Collaborating with person on summary and plan at end

• Occasional other volunteers; many potential volunteers from public rejected

• Qualitative research project initiated to gather information from individuals and volunteers regarding their experience of the program, to inform program development
QUALITATIVE RESEARCH ON THE VOLUNTEER PROGRAM

• Qualitative research study to address the question:

"What are the perceptions of the participants in a volunteer program that addresses hoarding behaviors?"

• Individual interviews of 9 participants in the ‘Friendly Visitor’ program
  • 6 volunteers and 3 people who received volunteers--“clients”

• Gathered feedback from participants in the program to understand strengths and challenges of this intervention
  • Provided program evaluation data to shape volunteer program going forward
  • Offered guidance for selecting and supervising volunteers
## RESEARCH FINDINGS: THEMES AND SUBTHEMES

<table>
<thead>
<tr>
<th>Importance of Relationship</th>
<th>Demands of decluttering</th>
<th>Strategies for decluttering</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hopes and expectations</td>
<td>• Physical</td>
<td>• Consistency, frequency, duration</td>
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<td>• Process</td>
<td>• Emotional</td>
<td>• Having a plan and a system</td>
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<td>• Outcomes</td>
<td>• Cognitive</td>
<td>• Making decisions and attending to the task</td>
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<td>• Accountability</td>
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**RELATIONSHIP: PROCESS**

“**I worked very hard to not be judgmental in any way, and to not show it, if I was surprised by something or taken aback...asking questions instead of requiring something to go some way or making statements instead...just getting a sense of who she was and I tried not asking everything about the hoarding situation...in those times I think the work went better...we were doing this while we were having good conversation.”** – Jeffrey

“**They were so respectful and they were only hands on when I asked them to be hands on... I never felt they were being judgmental to me and there was always the respect. Because there’s nothing worse than opening the door and it’s like ‘oh my god how do you live like this?’ I haven’t seen anybody show their emotion; they may think it but they haven’t shown it.”** – Cindy
DEMANDS OF DECLUTTERING: EMOTIONAL

• The notion of progress was tied to the emotional demands of decluttering
• Clients and volunteers varied in their definition of the concept
  • Clients:
    • Goal oriented/accomplishment focused
  • Volunteers:
    • Struggled with defining and understanding progress as related to decluttering
    • Identified a need for more supervision in order to gauge progress in realistic terms
    • Eli specifically reframed his thinking about what progress meant with his client:

  “When you do accomplish it, it feels so good, you get a really good feeling about yourself.”
  — Cindy

  “I believe in harm reduction… maybe if I hadn’t been there over the last nine months… her situation would be worse than it is right now.” — Eli
STRATEGIES: MAKING DECISIONS AND ATTENDING TO THE TASK

• The stress and turmoil that comes with making discarding decisions was evident:
  
  “It’s easy to just sit there and think and think and overthink and get so paralyzed by the thinking that you can’t really put action in there.” – Cindy
  
  “I get so stuck I can’t think. When I’m overwhelmed I can’t think. It’s when I do the circle dance.” – Marie

• Leveraging the strength of the relationship, volunteers were able to help curb the stress and bring the client back to the task
  
  • Reminder of the client’s goal
  
  • Gentle redirection when the client began neglecting the discard and donate piles
  
  “Is this getting you closer to your goal or moving you further away from your goal?” was helpful to “[bring] her back to the task and [keep] her there.” – Sally
  
  “Everything was becoming a ‘keep,’ I would try to redirect to ‘that looks like we can maybe donate that?’” – Eli
WHAT’S NEXT?

• Continue to investigate the distinct value of OT intervention for people with hoarding disorder: cognition, sensory processing
• Continue to evolve MOT student FW experience
• What else?
RESOURCES

- Clutterer’s Anonymous: https://clutterersanonymous.org/
- WRAP for Reducing Clutter: http://www.mutual-support.com/wrap_for_reducing_clutter
REFERENCES


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