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Sorting Through the Piles:

Accumulating Tools, Techniques and Interventions to Support Patients with Hoarding in Palliative Care and End-of-Life

DATE: October 20, 2017 PRESENTED BY: Andrea Lehman, LCSW and Dena Wellington, CSWA

About us and why Hoarding?

- Andrea Lehman, MSW, LCSW – Oncology Social Worker, Community Hematology Oncology
- Dena Wellington, MSW, CSWA – Oncology Social Worker, Oncology Care Model program
- Recent increase in patients presenting with hoarding disorder and impact on care, ethical concerns raised

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Presentation Outline

- Overview of Hoarding
- Treatment of Hoarding in the medical system
- Theoretical Framework
- Interventions
- Ethical concerns/considerations

What is Hoarding Disorder (HD)?

- Relatively new field (only about 25 years old) and not well studied
- Frost and Hartl (1996) first defined hoarding.
- Must meet all 3 criteria:
  - The acquisition of, and failure to discard, a large number of possessions that *appear* to be useless or of limited value
  - Living spaces are sufficiently cluttered so as to preclude activities for which those spaces were designed
  - Significant distress or impairment in functioning caused by the hoarding (most people with hoarding are not distressed by it)
- Studies conducted mostly in developed countries (American and European populations) though with the data available suggests HD is universal

DSM-5 Criteria (300.3 –F42)

A. Persistent difficulty discarding or parting with possessions, regardless of their actual value.

B. This difficulty is due to a perceived need to save the items and to distress associated with discarding them.

C. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If uncluttered – only due to third party intervention.

D. The Hoarding causes clinically significant distress ***or*** impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self or others)

E. The Hoarding is not attributed to another medical condition

F. The Hoarding is not better explained by the symptoms of another mental disorder (e.g. OCD, MDD)

DSM-5 Criteria cont.

Specifiers:

a) With excessive acquisition (80-90% of individuals with HD display excessive acquisition – usually via buying but also by taking free items)

b) With good or fair insight (recognize beliefs and behaviors are problematic)

c) With poor insight (mostly convinced beliefs/behaviors are not problematic despite evidence to the contrary)

d) With absent insight/delusional beliefs (completely believe not problematic)

Associated Features

- Indecisiveness
- Perfectionism
- Avoidance
- Procrastination
- Difficulty planning and organizing tasks
- Distractibility
- Some live in cluttered spaces, but must distinguish the difference between HD and squalor. Hoarding relates to volume of possessions, not condition of home.

DSM-V and Tolin (2011)

Demographics:

Prevalence:

- In US - 2%-6% of the population (approximately 16 million Americans) across the lifespan
- Impacts both genders - Women seek tx more often than men though epidemiological studies indicate men have a higher prevalence.
- Average age of voluntary tx is 50 (hoarding prevalence 3x higher in older adults (55-94 y.o) vs. younger adults (34-44y.o).

DSM-V, Tolin (2011), and Muroff, et al (2011)

Demographics Cont.

- Saving begins in childhood/adolescence (average age of onset is 11-20 – mean age of 13) – functional impairment in mid-20's and clinically significant impairment by mid-30's.
- Once onset, course tends to be chronic and worsens over time
- Single (prefer relationships with "things")
- Varying education levels
- Family hx of hoarding (possible genetic vulnerability on chromosome 14) – 50% report having a family member who hoards
- Often difficult family relationships

DSM-V, Tolin (2011), and Muroff, et al (2011)

DSM classification

- Considered an anxiety disorder, not an addiction disorder
- No research supporting the theory that trauma causes hoarding, though people often report stressful and traumatic life events preceding hoarding onset (up to 55%) (Tolin, 2011)
- Evidence linking hoarding to loss
- 92% of patients with hoarding also have an Axis I or Axis II diagnosis (Tolin, 2011) and 75% having a comorbid mood or anxiety disorder (DSM-5)

Co-morbidity rates

MDD – 50.7%
ADHD – 27.8%
GAD – 24.4%
Social Phobia – 23.5%
OCD – 17%
Specific Phobia – 14.3%
Kleptomania – 9.9%
PTSD – 6.9%
Gambling – 5.7%
Dysthymia – 4.6%
Substance Abuse – 1.8%
Bipolar – 1.4%
Eating D.O. – 1.4%

Frost (2011)

Health Risks related to Hoarding

- Obesity
- Chronic/Severe medical conditions
- Increased risk of falls/death
- Food Contamination/malnutrition
- Mental Health

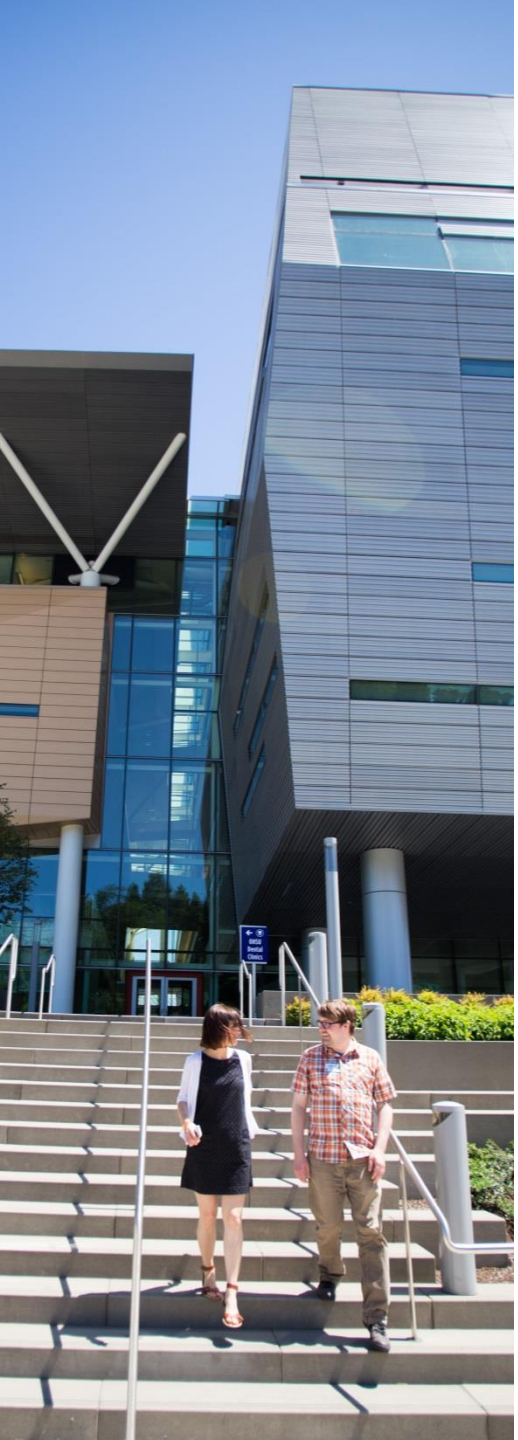
Functional Problems related to Hoarding

- Missed work (if working)
- Relationship challenges/limited social support
- Unstable housing situations/evictions
- Transportation barriers
- Unsafe/toxic housing conditions
- Removal of elderly parent or child from home
- Difficulty with executive functioning
- Limited engagement with care providers

Tolin et all (2008)

Mental Health Treatment Model

- CBT with Paroxetine or Venlafaxine to address the 3 manifestations of hoarding: Saving, Acquisition, and Clutter/Disorganization
- Goal isn't to throw things away, but rather to learn to think about stuff/possessions differently
- Harm reduction model – eliminate risks/hazards 1st
- Self-help groups – Buried in Treasures
- Iceberg Analogy – Increase trauma if done quickly



HD Treatment model Vs. Medical Model

The clinically appropriate treatment model for hoarding disorder and the typical medical model conflict greatly when someone with hoarding disorder is needing increased levels of care/supportive services (i.e. palliative care/hospice). Time is now very precious and the barriers to care can be numerous.

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In the context of palliative care, how do you treat a person with hoarding without re-traumatizing?

Theories used with Hoarding

- Harm Reduction
- Motivational Interviewing
- Trauma Informed Care

Harm Reduction

- Acknowledge long standing issues
- Increase Safety
- Reduce negative consequences
- Returns control to the patient
- “Meets people where they’re at.”

Motivation Interviewing

- Assess readiness to change
- Supports Autonomy; Empowers patient
- Communicates Respect

Trauma Informed Care

- Realizing the prevalence of trauma
- Collaborative
- Empowerment
- Provide corrective emotional experience

How do I identify?

Cues to look/listen for when assessing patients

- Look for acquiring behavior or listen for comments about acquiring belongings
- Look at overall appearance
- Look and listen for signs of no natural supports
- Look at behaviors and listen for comments regarding difficulties with executive functioning
- Listen for statements about “lost” items or the need to clear “space” or “clutter”
- Listen for statements about appliances not working in the home or things not being fixed
- Look and listen for heightened anxiety
- Listen for comments about housing evictions/housing issues
- Inpatient: Listen for concerns from friends/family

Probing Questions

- Have you ever lost important documents? Can you give me an example?
- What does your filing system for important documents look like?
- When was the last time you had someone come to your home to visit or to help with household chores, etc? How do you feel when others are over?
- Have you ever had periods of housing instability in your life? Tell me about it.
- Can you tell me about any items/appliances in your home that may need to be repaired or replaced?
- How do you typically prepare meals?
- What kind of hobbies or activities do you engage in at home?

Clutter Image Rating: Bedroom

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

1

2

3

4

5

6

7

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9

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Assessment focus

Learn information about these topics:

- **Home environment, objects in the home and relation to objects** (Tell me about your _____(item, home, etc))
- **Where the person wants to start** (Are there areas you would like to access or things you would like to do in your home that you can't?)
- **How they have been functioning/organizing** (How have you been able to cook in your home? Was there are a time when you successfully organized your home?)
- **Friends and family involvement** (What does your current support system look like? Have others commented about your home/items in the past or currently?)
- **Health/safety –** (There are some health/safety concerns being expressed by neighbor/provider/property manager. What are your thoughts about these concerns?)
- **Struggles from hoarding –** (Are there ways that the items in your home have prevented you from doing things important to you? Seeing grandchildren, etc?)
- **Intervention Attempts –** (Has any assistance been offered to you in the past to address your clutter?)

Too.Much.Stuff – presentation by Christina Bratiotis, Portland, Oregon 3/14/16;
Muroff, J., Underwood, P., & Steketee, G. (2014)

Now what??

1. Breathe and return to your roots – build rapport and find your social worker ☺

2. Functional Assessment – ADL-Hoarding

3. Assess for housing stability and safety

4. Review treatment plan (anticipate need for caregiver, DME, end of life care, risk of infection, BMT issues)

5. Discuss with treatment team/educate team on working with individuals with hoarding through a trauma informed lens.

6. Informed consent with patient – assess motivation for change or desire for treatment

7. If willing to seek assistance, identify a therapist and local resources (if any)

8. Determine social supports/family member involvement

9. Self-care support (moral distress/ethical concerns)

Communication Strategies

- Divide tasks into small, manageable parts with specifics "Geriatric HD adults may be less able to attend to and process new information" (Yasgur, 2017).
- Build relationship by asking open ended questions
- Be respectful and use non-judgmental language
- Be prepared to repeat yourself often, speak slowly and clearly

Communication Strategies Cont.

- Use the same patient language in referencing items in the home (“treasures”, “things”, “collection”, “untidy”)
- Understand that you will need to continually work on engagement and motivation – especially with changes in treatment or increased needs in home
- Work with patient on completing necessary ROIs to get community and family involvement whenever possible.
- Generously praise even the smallest success

Behavioral Strategies

- Set clear boundaries – limitations, expectations, realistic goals
- Keep things as consistent as possible (staffing, flow, routine)
- Provide instructions both verbally and in writing
- Block extra time in your schedule and allow for care coordination for patient
- Give patients a sense of control
- Provide tools for staff and provide support

Interventions that work?

- Reasonable accommodation letter(s) for housing – protected under ADA
- Referral to ADS/APS or community agencies
- Community Therapists (CBT) or support group
- Transportation
- Placement or Muck-out
- Medication options – paroxetine or venlafaxine
- Support staff in managing challenging patient behaviors and needs
- Educate family/friends on how to be supportive

Special Considerations in Palliative Care/EOL

- Distinguishing the role of PC from PCP/Specialist appointments due to executive functioning impairment
- Assessing for HD in patients during a PC appointment
- Advanced care planning (questions? Surrogate HCP)
- Time
- Acuity of symptoms/symptom burden
- Collaborating with other providers/communication
- Caregiver education/physical safety
- Family member is the individual with HD, not the patient

Patient Example:

Our experiences and lessons learned

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Patient A - Overview

Medical – Patient presented with Stage IV adenocarcinoma of the lung, metastatic to bone. Completed 4 cycles of Carbo/Taxol with disease progression. Received palliative radiation and Zometa. Struggled with pain control and shortness of breath.

Social – Patient is a 56 y.o. male, single, living alone in own home. Patient rents his home and lived in a small town community. Patient has minimal friends and no family, and reports preferring to be isolated and a "hermit". Patient reports that he only has 2 people that her can rely on for assistance. Patient was very active before and enjoyed walking and bike riding in town. Patient obtained STD/LTD through his employer and applied for SSD. Previously worked as a fork lift operator. Finances were initially not a struggle, but became challenging over time.

Emotional – Patient very emotionally withdrawn and exhibited signs of depression. Uncertain if wanted to start an antidepressant, but eventually agreeable. Resistant to any interventions in-home, despite needing them. Patient expressed fear of end of life and increased anxiety with disease progression. End of life wishes were to stay in his home.

Interventions:

- Charitable organization assisted with transportation
- Housing was stable – no communication with owner
- Patient refused ADS assessment for caregiver, despite not being able to perform all ADL needs, due to condition of home
- Friends tried to assist with clean-up, but caused friction between friends and patient.
- Patient refused home health, in-home palliative care, and hospice care due to condition of home.
- Patient hospitalized due to inability to care for self and transferred to in-patient hospice where he died.

Issues Raised:

- End of life care for patients with HD
  (how to honor wishes)

- Limited resources to assist in this situation

- Moral distress in treating patients at end stage of life who refuse placement or assistance

- Trauma of a “muck out” at end stage to get in-home services

- Loss of friendships and isolation for patient

- Guilt/shame experience for patient

Ethical Considerations

- Are we re-traumatizing with our interventions?
- Who is directing care – patient or ourselves based on our own ideals?
- Do you report to APS or not? When does it become a public health concern?
- When does the removal of barriers cause more harm emotionally than good? And who makes this decision?

Limitations of Palliative Care/Hospice Role

- Moral distress
- Home visits vs. not able to do home visits
- HIPAA
- Limited Resources
- Time
- Education on Hoarding

Do's of helping with HD

- Be aware of power relationship and dynamics of power
- Be proactive about asking about the daily life in patients with anxiety and look for clues
- Create clear boundaries and consistent patient experience
- Understand that patients with HD (especially older patients) have impairment in executive functioning related to comprehension/planning, communication, financial skills and transportation (Yasgur, 2017)
- Build goals around the client
- Work on eliminating greatest risk
- Advocate for the patient within the medical team and educate staff
- Self-care

Do Nots of Hoarding Disorder

- Judge
- Abandon
- Push a client too fast
- Re-traumatize
- Not assess for HD in patients with anxiety and clues of HD
- Give up – be creative

Resources

Books:

- The Hoarding Handbook: A guide for human service professionals. (Bratiotis, C., Schmalisch, C.S., & Steketee, G.) 2011. Oxford University Press
- Treatment for Hoarding Disorder: Therapist Guide (treatments that work) and Treatment for Compulsive Hoarding: Workbook (treatments that work). Both by Steketee, G & Frost, R.O (2013).

Websites:

- For Professionals: http://www.hoarders.org/rpr.html
- Family and Caregivers: http://www.hoarders.org/f-c.html
- Boston University School of Social Work (www.bu.edu/ssw/research/hoarding)
- Smith College Department of Psychology (www.science.smith.edu/departments/PSYCH/rfrost)
- Clutterers Anonymous (http://sites.google.com/site/clutterersanonymous

Scales:

- Clutter Image Rating Scale
- UCLA Hoarding Severity Scale or Savings Inventory- Revised
- Hoarding Rating Scale –Interview or Hoarding Interview
- HOMES Multi-disciplinary Hoarding Risk Assessment
- Activities of Daily Living – Hoarding (ADL-H) Scales

Closing Thoughts and Questions?

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Questions?

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