January 2023

ELDER CARE

A Resource for Interprofessional Providers

Hoarding Disorder

Lisa O'Neill, DBH, MPH, University of Arizona Center on Aging Teri Kennedy, PhD, MSW, University of Kansas Schools of Nursing, Medicine, and Social Welfare, The University of Kansas Medical Center

Hoarding disorder is a mental health condition in which a person feels a strong need to accumulate and save an excessive number of items, regardless actual value. Significant distress is associated with attempts to discard possessions. This cycle of accumulation and failure to discard compromises the intended use of living areas and can be associated with functional impairments and elevated safety risks.

In 2013, hoarding disorder was included in the DSM-5 as a stand-alone diagnosis. See Table 1 for a summary of diagnostic criteria.

Hoarding Disorder and Older Adults

Hoarding disorder affects approximately 5% of the U.S. population, roughly 17 million people. The average age of onset is between 11-18. Without intervention, the hoarding behaviors will continue throughout the person's lifetime and their continued accumulation of items leads to housing and relationship issues. It is estimated that up to 84% of those with hoarding disorder have a first degree family member who exhibits hoarding behaviors, possibly reflecting a genetic predisposition. Prevalence is similar for all genders, and the average age of patients in treatment is 50 years old. Hoarding disorder occurs in all cultures and socioeconomic levels.

Depending on its severity, hoarding can present serious health and safety risks for older adults. These include higher rates of falls, infections, and respiratory problems; limited ability to move around in, or access parts of the home; and a higher risk of fire with decreased ability to escape if fire occurs. Adult protective service agencies can intervene when individuals demonstrating hoarding behaviors lack decision-making capacity.

Clinical Presentation

Patients are often unaware of the severity of their behavior or situation. If they are aware, they may not

Table 1. Summary of DSM-5 Diagnostic Criteria

- Persistent difficulty and significant distress associated with discarding possessions, regardless of value
- Accumulation of possessions that clutter living areas and substantially compromises their intended use
- Significant distress or impairment in social, occupational, or other areas of function, including safety
- Hoarding behaviors are not attributable to another medical condition (e.g., brain injury, stroke)
- Hoarding behaviors are not better explained by another mental health disorder

believe they need treatment and thus don't want others to know about their hoarding behavior. As a result, if clinicians do not ask patients (or their families) questions about home safety, general living environment, or emotional well-being, they may not become aware of the hoarding behaviors. It is important to be alert for clues, such as a patient's reluctance (or refusal) to accept home health services following hospitalization. Home health personnel are often the first to detect hoarding, before it is apparent to office-based clinicians. Patients or their families may also make comments about possessions or collections, or complaints about pest infestations, or may delay getting home repairs (out of concern their hoarding behaviors will be detected).

Assessment

Several tools are available to assess the presence and severity of hoarding behaviors (Table 2). Be sure to include at least one or two questions in every clinical visit that can help indicate if the patient might have mental health issues related to hoarding behaviors and/or an unsafe living environment.

Health care professionals are often the first to begin a dialogue about a hoarding situation and possible interventions. Motivational interviewing is recommended to avoid aggressive or judgmental language.

TIPS ABOUT HOARDING DISORDER IN OLDER ADULTS

- Use standard assessment instruments (Table 2) to determine the presence and severity of hoarding.
- Involve community agencies to help individuals with hoarding behaviors and environments, with a focus on safety.
- Refer patients to counselors who have experience with and/or education related to Hoarding Disorder.
- Identify and treat existing mental and physical health conditions.

ELDER CARE

Table 2. Assessment Instruments for Hoarding

- Hoarding Rating Scale (HRS) Brief interview, 5 questions, to access compulsive hoarding http://www.philadelphiahoarding.org/resources/Hoarding%20Rating%20Scale%20Assessment%20Tool.pdf
- Clutter Image Rating (CIR) Assesses severity of hoarding through nine photographs of three living spaces http://www.hoardingconnectioncc.org/Hoarding cir.pdf
- Activities of Daily Living for Hoarding (ADL-H) Measures extent to which hoarding interferes with daily functioning https://www.networkjhsa.org/wp-content/uploads/2020/11/ADL-H.pdf
- Saving Inventory-Revised (SIR) Measures excessive acquisition, difficulty discarding, and clutter http://www.philadelphiahoarding.org/resources/Saving%20Inventory%20-%20Revised.pdf
- HOMES Multidisciplinary Hoarding Risk Assessment Measures health, obstacles, mental health, endangerment, structure, and safety. https://www.masshousing.com/-/media/Files/Community-Services/Hoarding/Tools/HOMES Risk Assessment.ashx

Treatment Options

Refer patients to counselors who have experience with and/ or education related to hoarding disorder. They will be able to customize cognitive behavioral therapy to include education, goal setting, and exposure activities focused on reducing acquiring behavior. Other aspects of treatment will include a focus on sorting, discarding, organizing, decisionmaking, problem solving, and new behavior maintenance.

Treatment should also address any co-occurring mental health conditions, such as depressive disorders, generalized anxiety disorder, social phobias, obsessive compulsive disorder, attention-deficit hyperactivity disorder, post-traumatic stress disorder, and substance use disorders.

Structured, facilitated community-based workshops and support groups have also shown some success in helping patients to modify their hoarding behaviors. Professional organizers and in-home coaches can also be helpful if they have experience with hoarding environments.

Medications used to treat existing mental health and physical conditions may not directly impact hoarding behaviors, but will improve overall quality of life and function.

Interprofessional Approaches to Hoarding

Given the complexity, time, and resources required to address hoarding, and its intersection with public health and safety, hoarding is often best addressed with an interprofessional and interagency approach, such as a task force. Hoarding disorder task forces usually follow one of three models: education, care coordination, or intervention. Depending on the task force's mission and funding, some will provide public education, community resource information, case management, and family support. Task forces may include representatives from housing, public and environmental health, behavioral health, primary care, child and adult protective services, fire and police, legal and fiduciary services, and animal welfare. Some home health agencies offer home safety assessments that may provide first-hand information about hoarding behaviors.

It is important to note that forced clean-outs are not an ideal solution as they cause serious anxiety for individuals with hoarding disorder. Studies have shown the person typically re-acquires items quickly to ease their anxiety or depression, and often within 6-18 months they will have reacquired the same or a greater number of possessions.

References and Resources

David J, Crone C, Norberg M. A critical review of cognitive behavioral therapy for hoarding disorder: How can we improve outcomes? Clin Psychol Psychother. 2022; 29(2), 469-488. https://doi.org/10.1002/cpp.2660

Levy H, Worden B, Gilliam C, D'Urso C, Steketee G, Frost R, Tolin D. Changes in savings cognition mediate hoarding symptom change in cognitive-behavioral therapy for hoarding disorder. *JODRD*. 2017; 14, 112-118. https://doi.org/10.1016/j.jiocrd.2017.06.008

Samson, G. Behavioral and cognitive psychotherapy. In Steketee G, Frost R, eds. Treatment for hoarding disorder: Therapist guide (2nd ed.) Oxford University Press. 2015; 635-636. https://doi.org/10.1017/S1352465815000296

Interprofessional care improves the outcomes of older adults with complex health problems

Editors: Mindy Fain, MD; Jane Mohler, NP-c, MPH, PhD; and Barry D. Weiss, MD
Interprofessional Associate Editors: Tracy Carroll, PT, CHT, MPH; David Coon, PhD; Marilyn Gilbert, MS, CHES;
Jeannie Lee, PharmD, BCPS; Marisa Menchola, PhD; Francisco Moreno, MD; Linnea Nagel, PA-C, MPAS; Lisa O'Neill, DBH, MPH; Floribella Redondo; Laura Vitkus, MPH
The University of Arizona, PO Box 245069, Tucson, AZ 85724-5069 | (520) 626-5800 | http://aging.arizona.edu

Supported by: Donald W. Reynolds Foundation, Arizona Geriatrics Workforce Enhancement Program and the University of Arizona Center on Aging