Hoarding disorder in adults: Epidemiology, clinical features, assessment, and diagnosis

AUTHORS: David Mataix-Cols, PhD, Lorena Fernández de la Cruz, PhD
SECTION EDITOR: Murray B Stein, MD, MPH
DEPUTY EDITOR: Michael Friedman, MD

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INTRODUCTION

Individuals with hoarding disorder experience persistent difficulty discarding or parting with possessions, regardless of their value, due to a perceived need to save these items and distress associated with discarding them. Possessions thus congest and clutter their living areas, compromising use of these spaces, interfere with the individual's daily life and cause clinically significant distress.

Hoarding disorder is included in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR) [1], replacing its conceptualization in prior Diagnostic and Statistical Manual of Mental Disorders (DSM) as a form of obsessive-compulsive disorder (OCD) [2]. Hoarding disorder was also included as a separate condition in the 11th edition of the International Classification of Diseases (ICD-11) [3].

The epidemiology, pathogenesis, clinical manifestations, course, assessment, and diagnosis of hoarding disorder are described here. The treatment of hoarding disorder in adults is described separately. The epidemiology, pathogenesis, clinical manifestations, course, assessment, diagnosis, and treatment of OCD in adults are also described separately. (See "Hoarding disorder in adults: Treatment" and "Obsessive-compulsive disorder in adults: Epidemiology, clinical features, and diagnosis" and "Management of obsessive-compulsive disorder in adults" and "Obsessive-compulsive disorder in adults: Psychotherapy".)

OVERVIEW

In DSM-IV, “extreme” hoarding was described as a manifestation of obsessive-compulsive disorder (OCD), leading to the widespread conceptualization of hoarding as a symptom dimension of OCD. Research, however, has found that most individuals who show hoarding behavior do not endorse other symptoms of OCD and has further delineated the differences between the two constructs. This culminated in the inclusion of hoarding disorder in DSM-5 and ICD-11, separate from OCD [4,5]. As a recently specified mental disorder, there is less research on its presentation, course, causes, or treatment compared with many other disorders.

EPIDEMIOLOGY

Community surveys, primarily in Europe and the United States, have estimated the point prevalence of clinically significant hoarding to be approximately 2 to 6 percent among adults [6] and 2 percent among adolescents [7]. A study in England that used strict DSM-5 criteria found a prevalence of 1.5 percent [8]. A meta-analysis of 11 prevalence studies including at least 1000 participants estimated that the prevalence of hoarding disorder in adults is approximately 2.5 percent [9].

Although individuals with hoarding disorder tend to be older adults when they present to clinical services, a meta-analysis including 25 studies concluded that the mean age of onset of hoarding symptoms was 16.7 years old [10]. Individuals with hoarding disorder also tend to be more frequently unemployed and more often unmarried, separated, or divorced compared with individuals from the general community [8].

Epidemiologic data from non-Western countries is scarce, but a clinical study comparing the clinical features of individuals with a DSM-5 diagnosis from the United Kingdom, Spain, Japan, and Brazil found that the phenomenology of hoarding disorder was similar across the studied cultures [11].

Comorbidities — The most common comorbid mental disorders found among individuals with hoarding have been [6,8,12-14]:

- Generalized anxiety disorder (31 to 37 percent)
- Major depressive disorder (26 to 31 percent)
- Obsessive-compulsive disorder (15 to 20 percent)
- Panic disorder (17 percent)
- Social anxiety disorder (14 percent)

- Posttraumatic stress disorder (14 percent)

Symptoms typical of attention-deficit/hyperactivity disorder, particularly inattention, are also commonly reported [14,15]. In our and others' clinical experience, comorbidities, rather than the hoarding, are often the main reason for clinical consultation [16].

PATHOGENESIS

Genetic and environmental factors — Although controlled family studies have not been carried out, patient reports have suggested that hoarding runs in families [17]. A handful of twin studies conducted in large, population-based adult twin samples have consistently suggested that this familiality is largely attributable to additive genetic factors (with heritabilities ranging between 36 and 50 percent), with the remaining variance attributable to nonshared environmental factors and measurement error [18-21].

The mechanisms by which either genetic or environmental factors, or their interaction, confer risk to the development of hoarding disorder remain unknown. Specific genes implicated in hoarding disorder have not yet been identified. The largest genome-wide association study of hoarding symptoms to date, including self-reported data from seven international cohorts (n = 27,537 individuals), could not identify any genome-wide significant single nucleotide polymorphisms associated with hoarding symptoms, but confirmed the heritability of these symptoms (with estimates ranging between 26 and 48 percent). Even larger samples will be needed to identify genes associated with hoarding symptoms and hoarding disorder [22].

Although research has suggested some unique environmental risk factors (eg, traumatic life events), small samples and retrospective self-report methods leave unclear the role of such exposures in the onset or exacerbation of hoarding disorder [18,23]. Anecdotal links between material deprivation and hoarding activity have, meanwhile, received no support in the relevant literature [23].

Future work is warranted to understand how specific genetic and environmental risk factors interact to confer risk to individuals carefully diagnosed as having hoarding disorder. It is likely that these genetic and environmental risk factors will be, at least in part, shared with related conditions such as obsessive-compulsive disorder (OCD) and other related disorders, as suggested in a population-based twin study using self-report measures [24]. The etiological links between hoarding disorder and other neuropsychiatric conditions (eg, anxiety and mood disorders, attention-deficit/hyperactivity disorder) remain to be explored.

Neurobiology — Many of the initial neuropsychological studies recruited OCD patients with hoarding symptoms (with different degrees of severity), whereas others recruited individuals with severe hoarding but predominantly without OCD [25]. The neuropsychological tests employed have been heterogeneous and have tapped into different domains, and few studies employed psychiatric control groups. Findings to date suggest possible impairments in spatial planning, visuospatial learning and memory, sustained attention/working memory, organization, response inhibition, set shifting, probabilistic learning, and reversal learning [25,26].

The neural substrates of hoarding behavior in nonhuman animals are well established, but much less is known about normal and abnormal hoarding behavior in humans. Useful clues come from case studies of brain-damaged patients and of individuals with dementia, particularly of the frontotemporal type.

This research suggests that the ventromedial prefrontal/anterior cingulate cortices, as well as medial temporal regions, may be implicated in hoarding behavior [25]. One theory is that the former cortical regions modulate or suppress subcortically driven predispositions to acquire and collect and adjust these predispositions to environmental context [27]. Damage to these cortical regions may result in dysregulated collecting and hoarding behavior.

The neuroimaging literature of hoarding due to causes other than brain lesions or degenerative disorders (ie, hoarding as a psychiatric symptom) has also implicated the ventromedial prefrontal/anterior cingulate cortices and subcortical limbic structures (eg, amygdala/hippocampus) in hoarding patients. The evidence is preliminary, however, obtained from small samples, and confounded in many cases by the presence of comorbid OCD symptoms [25].

A growing number of studies are documenting differences in brain function, connectivity, and structure between hoarding disorder and other psychiatric disorders, OCD in particular, supporting its classification as a distinct disorder [28-31].

CLINICAL MANIFESTATIONS

The main feature of hoarding disorder is a persistent difficulty with discarding or parting with possessions, regardless of their actual value. The most commonly saved items include newspapers, old clothing, bags, books, and paperwork, but virtually any item can be saved. The nature of items is not limited to worthless possessions, because many individuals acquire and save valuable things too.

Discarding difficulties are generally motivated by the perceived utility or aesthetic value of the items, the strong sentimental attachment to the possessions, the fear of losing important information, or a combination of these factors [32]. The prospect of discarding or parting with possessions usually causes the individual substantial distress, though some individuals, particularly those with poor insight, may not report distress.

The difficulties result in the disorganized accumulation of possessions that congest and clutter active living areas and substantially compromise their intended use. Affected individuals may experience problems functioning amid the clutter – eg, with sleeping or cooking in cluttered bedrooms and kitchens. In mild cases, the impairment may only be apparent to those around the individual. In severe cases, hoarding can put individuals at risk for fire, falling, and sanitation-related health risks.

Attempts by others to discard or clear the possessions typically result in high levels of distress. Other common features of hoarding disorder include indecisiveness, perfectionism, avoidance, procrastination, and distractibility [32]. Characteristic difficulties with planning and organizing can contribute to severe clutter and development of squalor.

Approximately 63 to 90 percent of persons with hoarding disorder engage in excessive acquisition (ie, of items that are not needed or for which there is no space available) [8,12,14,33]. Individuals with hoarding disorder vary in insight that their hoarding beliefs and behaviors are a problem, from full recognition to an absence of awareness.

Animal hoarding — Animal hoarding can be defined as the accumulation of a large number of animals with a failure to provide minimal standards of nutrition, sanitation, and veterinary care, and/or a failure to act on the deteriorating condition of the animals and the environment. It is unclear if animal hoarding is a special manifestation of hoarding disorder, but a study has found that most individuals who hoard animals also hoard inanimate objects [34].

COURSE

Retrospective reports of several hundred cases indicate that hoarding difficulties begin early in life (eg, between ages 11 and 15) and span well into the late stages [35]. A meta-analysis including 25 studies concluded that the mean age of onset of hoarding symptoms was during the late adolescence (mean = 16.7 years old, 95% CI 14.5-18.9) [10].

Symptoms often start interfering with the individual's everyday functioning by the mid-20s [23,36], and cause clinically significant impairment by the mid-30s [36]. Once symptoms begin, the course of hoarding is often chronic with a steady worsening of symptoms over each decade

of life [37]. Few individuals reporting a waxing and waning course [35]. Participants in clinical research studies are usually in their 50s [12,17].

In the absence of sufficient research, the long-term course of hoarding disorder, with or without treatment, is currently unknown.

ASSESSMENT

The diagnosis of hoarding disorder is usually made on the basis of a direct interview with the person with the features of the disorder. Because hoarding may not always be the initial reason for consultation [16], clinicians often need to ask direct questions, such as:

- Do you find it difficult to discard or part with possessions?
- Do you have a large number of possessions that congest and clutter the main rooms in your home?

An affirmative answer to either question can initiate a dialogue that may lead to diagnosis. Validated clinician-rated and self-administered questionnaires can also help with this process. (See 'Assessment instruments' below.)

We often use the Structured Interview for Hoarding Disorder [38] based on DSM-5 criteria to facilitate a diagnostic interview.

A home visit is recommended for the assessment of clutter, impairment, and associated risks. If a home visit is not feasible, the clinician should try to gather additional information from reliable informants, such as a spouse or relative (with the patient's consent). This is particularly important for affected persons with limited insight because they may underestimate the extent and consequences of their difficulties. Informants may help establish whether the current presentation is long-standing or transient, whether third parties have intervened to clear away some of the clutter, and whether there are potential risks that require attention.

Photographs of the patient's home can be useful in helping to document the presence of clinically significant clutter and to track treatment outcomes [39,40], particularly when home visits are not possible or are impractical. Photographs are not a substitute for a thorough psychopathological interview.

The diagnostic interview provides an opportunity to carry out a thorough risk assessment. Attention should be paid to potential fire hazards, the risk of a clutter avalanche, the presence of rodent or insect infestation, or other unsanitary living conditions that pose a risk to health. It

is important to establish whether other vulnerable persons (eg, children and elderly people) live with the person who is hoarding.

Assessment instruments — We prefer the Hoarding Rating Scale, which is available in an interview and self-report version (form 1). The scales consist of five Likert-type ratings ranging from 0 (none) to 8 (extreme) assessing clutter, difficulty discarding, excessive acquisition, distress, and impairment. The Hoarding Rating Scale – Interview has shown high internal consistency and cross-context reliability, correlates strongly with other measures of hoarding, and reliably discriminates hoarding from nonhoarding participants. A cutoff of 14 shows excellent sensitivity and specificity (0.97). The Hoarding Rating Scale – Self-Report correlates strongly (r = 0.92) with the Hoarding Rating Scale – Interview [41,42].

We also find the Clutter Image Rating scale [39] to be useful. The instrument visually depicts various levels of clutter in the person's home; it has excellent psychometric properties. Other clinician and self-administered instruments have been developed to quantify hoarding disorder and response to treatment [39,43,44].

DIAGNOSIS

DSM-5 diagnostic criteria — DSM-5 diagnostic criteria for hoarding disorder are listed below. For a diagnosis of hoarding disorder, all six of the criteria must be met:

- 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 living areas are uncluttered, it is only because of the interventions of third parties (eg, family members, cleaners, authorities).
- 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 and others).
- E. The hoarding is not attributable to another medical condition (eg, brain injury, cerebrovascular disease, Prader-Willi syndrome).

- F. The hoarding is not better explained by the symptoms of another mental disorder (eg, obsessions in obsessive-compulsive disorder [OCD], decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Specifiers — Specifiers for hoarding disorder in DSM-5 include the presence of excessive acquisition and the assessment of the patient's insight. (See 'Clinical manifestations' above.)

- **Excessive acquisition –** If difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space.

- **Patient's degree of insight into the illness –** Indicate whether hoarding beliefs and behaviors are currently characterized by one of the following:

  - Good or fair insight – The individual recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic.

  - Poor insight – The individual is mostly convinced that hoarding-related beliefs and behaviors are not problematic, despite evidence to the contrary.

  - Absent insight/delusional beliefs – The individual is completely convinced that hoarding-related beliefs and behaviors are not problematic, despite evidence to the contrary.

Differential diagnosis — A diagnosis of hoarding disorder can be made only after other medical conditions and mental disorders that can lead to the excessive accumulation of possessions have been ruled out. Hoarding must also be distinguished from healthy collecting.

- **Other medical conditions** – Hoarding disorder is not diagnosed if the symptoms are judged to be a direct consequence of another medical condition, such as traumatic brain injury, surgical resection for the treatment of a tumor or seizure control, cerebrovascular disease, infections of the central nervous system (eg, herpes simplex encephalitis), or neurogenetic conditions such as Prader-Willi syndrome [4]. (See "Prader-Willi syndrome: Management".)

  Damage to the anterior ventromedial prefrontal and cingulate cortices has been associated with the excessive accumulation of objects [25,27]. In these individuals, the hoarding behavior is not present prior to the onset of the brain damage and appears shortly after the brain damage occurs [27]. Some of these individuals appear to have little

interest in the accumulated items and are able to discard them easily or do not care if others discard them, whereas others appear to be very reluctant to discard anything [25].

- **Neurodevelopmental disorders** – Hoarding disorder is not diagnosed if the accumulation of objects is judged to be a direct consequence of a neurodevelopmental disorder, such as autism spectrum disorder or intellectual disability. Individuals with autism spectrum disorder, for example, may excessively acquire or retain possessions that correspond to a particular sensory preoccupation or "special interest."

- **Neurocognitive disorders** – Hoarding disorder is not diagnosed if the accumulation of objects is judged to be a direct consequence of a degenerative disorder, such as neurocognitive disorder associated with frontotemporal lobar degeneration or Alzheimer's disease. Onset of the accumulating behavior is typically gradual and follows onset of the neurocognitive disorder. The accumulating behavior may be accompanied with self-neglect and severe domestic squalor (where there is trash, rotten food, or excrement), alongside other neuropsychiatric symptoms, such as disinhibition, gambling, rituals/stereotypies, tics, and self-injurious behaviors [45].

- **Obsessive-compulsive disorder** – A patient with OCD may present with hoarding symptoms. He or she would not be diagnosed with a hoarding disorder if the symptoms are judged to be a direct consequence of typical obsessions or compulsions, such as fears of contamination or harm, or symmetry obsessions [46].

  As examples, patients may not want to discard objects they have touched due to a fear of contaminating other people. They may also present with superstitious thoughts associated with discarding (eg, fear of catastrophic consequences if items are discarded or are not discarded in ritualistic ways) or have fears of being prosecuted if they accidentally discard items containing personal information. The accumulation of objects can be the result of persistently avoiding onerous rituals (eg, not discarding in order to avoid endless washing or checking rituals) [4,6].

  Symmetry obsessions and compulsions are the most commonly associated with this form of hoarding. As an example, patients may not discard in order to avoid feelings of incompleteness or in an attempt to document and preserve all life experiences [46].

  In OCD, hoarding behavior is generally unwanted and highly distressing, and the individual experiences no pleasure or reward from it. Excessive acquisition is usually not present; if excessive acquisition is present, items are acquired because of a specific obsession (eg, the need to buy items that have been accidentally touched in order to avoid contaminating other people), not because of a genuine desire to possess the items. These

individuals are also more likely to accumulate bizarre items, such as trash, feces, urine, nails, hair, used diapers, or rotten food [17]. Accumulation of such items is very unusual in hoarding disorder.

Both hoarding disorder and OCD may be diagnosed when severe hoarding appears concurrently with other typical symptoms of OCD but is judged to be independent of these symptoms [4].

- **Schizophrenia and other psychotic disorders** – Hoarding disorder is not diagnosed if the accumulation of objects is judged to be secondary to specific hallucinations or delusions, or a failure to discard useless items or waste due to the presence of negative symptoms in schizophrenia spectrum and other psychotic disorders [4,6].

  Individuals with schizophrenia who are prone to hoarding tend to be older, have spent longer time in institutions, and have less severe positive symptoms but more severe negative and cognitive symptoms. When hoarding presents in schizophrenia, the clinical picture continues to be dominated by the symptoms of schizophrenia, which will assist the clinician with the differential diagnosis [47].

- **Major depressive episode** – Hoarding disorder is not diagnosed if the accumulation of objects is judged to be a direct consequence of psychomotor retardation, fatigue, or loss of energy during a major depressive episode.

- **Healthy collecting** – Pathological hoarding must be distinguished from normative or healthy collecting [48]. This is particularly relevant because quite a few individuals meeting criteria for hoarding disorder define themselves as "collectors," as they perceive this term as being somewhat less pejorative [48]. Normative collecting is a common activity that is both benign and pleasurable. Most children and up to 30 percent of adults collect items at some point [49]. Collectors report the acquisition of, attachment to, and reluctance to discard objects, but they do not have the disorganized clutter, distress, and impairment that is characteristic of hoarding disorder. In contrast to hoarding, the process of collecting is highly structured and planned, very selective (ie, confined to a narrow range of items), pleasurable, and often a social activity. Most collectors, even those who might be considered eccentric, are unlikely to meet the diagnostic criteria for hoarding disorder [48,49].

SOCIETY GUIDELINE LINKS

Links to society and government-sponsored guidelines from selected countries and regions around the world are provided separately. (See "Society guideline links: Obsessive-compulsive disorder and related disorders".)

SUMMARY

- **Overview** – "Extreme" hoarding has been conceptualized as a manifestation of obsessive-compulsive disorder (OCD), leading to the widespread conceptualization of hoarding as a symptom dimension of OCD. However, research has delineated the differences between the two constructs and has found that most individuals who show hoarding behavior do not endorse other symptoms of OCD. (See 'Overview' above.)

- **Pathogenesis** – The mechanisms by which either genetic or environmental factors, or their interaction, confer risk to the development of hoarding disorder remain unknown. Specific genes implicated in hoarding disorder have not yet been identified. Neuropsychological testing has found possible impairments in various domains including spatial planning, visuospatial learning and memory, working memory, organization and response inhibition. (See 'Pathogenesis' above.)

- **Clinical manifestations** – Approximately 63 to 90 percent of persons with hoarding disorder engage in excessive acquisition. Individuals with hoarding disorder experience persistent difficulty discarding or parting with possessions, regardless of their value. Possessions typically congest and clutter their living areas, compromising use of these spaces, sometimes creating risks of harm (eg, fire, injury, sanitation-related illness, interfere with the individual's daily living and cause clinically significant distress). (See 'Clinical manifestations' above.)

- **Course** – Retrospective reports of several hundred cases indicate that hoarding symptoms may first emerge between ages 11 to 15. Symptoms often start interfering with the individual's everyday functioning by the mid-20s and cause clinically significant impairment by the mid-30s. Once symptoms begin, the course of hoarding is often chronic with a steady worsening of symptoms over each decade of life. Few individuals reporting a waxing and waning course. (See 'Course' above.)

- **Assessment** – The diagnosis of hoarding disorder is usually made on the basis of a direct interview with the person with the features of the disorder. Because hoarding may not always be the initial reason for consultation, clinicians often need to ask direct questions, such as (see 'Assessment' above):

- Do you find it difficult to discard or part with possessions?
- Do you have a large number of possessions that congest and clutter the main rooms in your home?

- **Differential diagnosis** – The differential diagnosis of hoarding disorder includes medical conditions (eg, traumatic brain injury, cerebrovascular disease, central nervous system infections, and Prader-Willi syndrome), neurodegenerative and neurocognitive disorders, OCD, schizophrenia, and major depression. (See 'Differential diagnosis' above.)

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