



Published in final edited form as:

*Am J Geriatr Psychiatry*. 2015 April ; 23(4): 416–422. doi:10.1016/j.jagp.2014.05.009.

## Hoarding Disorder in Older Adulthood

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### Abstract

**Objectives:** Hoarding disorder (HD) is a chronic condition associated with moderate to severe impairment in health and functioning. HD has been primarily studied in midlife adults, and there is limited research on HD in late life.

**Methods:** In this review, we summarize research on the presentation and characteristics of HD and hoarding symptoms in older adults, including evidence for associated impairment in daily functioning, physical health, and cognitive function. Finally, we review the evidence available for intervention outcomes for treating HD in older adults.

**Results:** Geriatric HD is characterized by severe functional impairment, medical and psychiatric comorbidities, and cognitive dysfunction.

**Conclusions:** There is a lack of randomized controlled trials investigating evidence-based treatments for geriatric HD.

### Keywords

Older adults; geriatric; compulsive hoarding; OCD

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Significant health, safety, and functional consequences have been found in older adults meeting criteria for hoarding disorder (HD),<sup>1</sup> compulsive hoarding,<sup>2</sup> and hoarding symptoms.<sup>3</sup> Although HD and hoarding symptoms have been studied in midlife adults, little is known about the presentation of hoarding in late life. The following article will review the characteristics, consequences, and treatment outcomes of HD in late life. Because HD has only recently been codified,<sup>4</sup> much of the literature discussed will involve compulsive hoarding or hoarding symptoms. Although not ideal, the utility of such literature should not be discounted as it presents the first insights into the possible presentation of HD in older adults. Where appropriate, we will refer to each study sample (HD, compulsive hoarding, hoarding behaviors, or hoarding symptoms) as defined by the authors.

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The authors have no disclosures to report.

Similar to anxiety or depressive symptoms, hoarding symptoms in humans had been conceived as presenting along a continuum from collecting certain objects to pathological self-neglect.<sup>5</sup> Hoarding behaviors have been described in various disorders such as obsessive-compulsive disorder (OCD), schizophrenia, organic mental disorders, depression, and anorexia nervosa.<sup>6</sup> Hoarding behaviors have also been observed in the absence of other psychiatric or physical causes, as in the case of what has previously been called compulsive hoarding<sup>7,8</sup> and is now the diagnostic category of HD in the *Diagnostic and Statistical Manual, 5<sup>th</sup> edition* (DSM-5).<sup>4</sup> The DSM-5 criteria for HD are as follows:

- (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 (e.g., 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 (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
- (F) The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in 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).

Research on compulsive hoarding suggests four etiological factors for hoarding symptoms that might also play a role in HD: executive functioning deficits related to decision-making, categorization, and organization; excessive emotional attachment to possessions; a tendency towards behavioral avoidance; and faulty beliefs about the nature of possessions.<sup>9</sup> A more recent model of hoarding behavior proposes a cognitive-behavioral framework based on vulnerability factors such as genetic predisposition, core beliefs about one's identity and adequacy, and cognitive dysfunction,<sup>10</sup> although more empirically valid research is needed to corroborate any proposed models of HD.

There is initial evidence supporting the presence of both genetic vulnerabilities and cognitive dysfunction in patients with hoarding symptoms. A study of hoarding symptoms in twins judged genetic factors to account for 50% of the variance of severity of reported hoarding symptoms<sup>11</sup> and older adults with clinically significant hoarding symptoms have been found to have deficits in attention focusing, decision-making, and organizing.<sup>12</sup> Case studies of patients who presented with hoarding behaviors after developing brain lesions implicate the anterior ventromedial prefrontal and cingulate cortices as potential areas of interest in hoarding symptoms.<sup>13</sup> Finally, a positron emission tomography study found that

individuals with symptoms of compulsive hoarding show a pattern of abnormally low activity in the anterior cingulate cortex,<sup>14</sup> suggesting that HD may be related to deficits in functioning of certain brain areas. These results must be interpreted with caution, however. The hoarding symptoms studied were not necessarily indicative of HD but may be solely indicative of patients who develop hoarding behaviors as a result of other psychiatric disorders or brain trauma.

According to the cognitive–behavioral model of HD, these vulnerability factors contribute to cognitive appraisals about one’s possessions, leading to positive and negative emotional responses, and, ultimately, the hoarding behaviors. Hoarding behaviors are positively reinforced when the individual feels secure in having objects or information that they feel they need as well as negatively reinforced when the individual is able to avoid the unpleasant emotions that accompany discarding or not acquiring desired objects.<sup>10</sup>

## CHARACTERISTICS OF HD IN OLDER ADULTHOOD

### Prevalence of HD in Late Life

Prevalence rates of HD should be interpreted cautiously as the DSM-5 HD criteria are relatively new and so studies prior to 2013 did not have the advantage of utilizing formal criteria. Community epidemiological reports estimate prevalence rates of clinically significant hoarding symptoms from 2%<sup>11</sup> to 5.3%<sup>15</sup> in non-geriatric populations. Results are mixed with respect to an increase in hoarding symptoms with age. One study reported that hoarding symptoms were three times more likely to occur in older adults than in younger adults.<sup>15</sup> Higher rates are also seen in late-life medical samples compared with communitydwelling populations. Among elderly patients aged 61 to 97 years, 25% of senior daycare participants and 15% of nursing home residents exhibited hoarding-related symptoms.<sup>16</sup> Other studies have not found the same association between hoarding behaviors and age using mixed aged samples.<sup>17–19</sup> Other factors, however, may be contributing to the inconsistent findings—including nonclinical samples (general European community populations in both the Mueller et al.<sup>18</sup> and Fullana et al.<sup>17</sup> studies) and differences in the measurement of hoarding symptoms. It may be the case that actual hoarding rates do not increase with age; instead, the consequences of hoarding become more challenging with age due to accumulation of objects over time or because increases in physical and mental illnesses may impair the ability to discard or organize possessions. A second possibility is that adults normalize their hoarding symptoms as they age, which would be difficult to detect with the self-report measures commonly used for comparing hoarding symptoms across the life span. Finally, all of the studies looking at hoarding prevalence have been limited to hoarding symptoms that could have resulted from multiple physical and psychiatric disorders in addition to HD. There is no clear evidence of the prevalence of HD in community or inpatient facilities as no previous studies have utilized rigorous inclusion criteria in determining the rates of HD in their sample.

### Onset, Course, and Associated Conditions of Late-Life Hoarding

Studies examining mixed samples of young, middle-aged, and older adults have found that hoarding symptoms first appear in childhood and adolescence and onset after age 40 is rare,

<sup>20,21</sup> although no studies have specifically looked at individuals meeting criteria for HD. Further, there is a lack of consensus about the course of compulsive hoarding symptoms. Using an Internet sample of self-reported compulsive hoarders, Tolin and colleagues<sup>21</sup> found that hoarding symptoms started in childhood/adolescence, increased for one to two decades after symptoms emerged, and then remained at a high level of severity steadily into older adulthood. Although the study used a large sample size (N = 1,153) of mixed ages (mean age: 49 years), the unfortunate use of an Internet self-reported sample lessens the generalizability of the results. In contrast, Ayers and colleagues<sup>2</sup> utilized clinician-administered assessments for determining both hoarding severity and the progression of hoarding symptoms and required that participants meet the compulsive hoarding criteria outlined by Frost and Hartl.<sup>9</sup> Participants (N = 18; aged 60–87 years) reported increasing severity of hoarding symptoms in each successive decade of their lives.<sup>2</sup> Mild symptom levels were reported in young adulthood, followed by an increase to moderate levels in midlife, and the most severe symptom levels were reported in late life, suggesting a linear progression of hoarding symptoms in compulsive hoarders from youth to old age.<sup>2</sup> Finally, a recent study of patients meeting the proposed DSM-5 criteria for HD found that older adults did not report higher severity of symptoms than did middle-aged adults,<sup>1</sup> although the results may be confounded by the normalization of hoarding symptoms as patients age.

### **Hoarding Symptom Prevalence and Onset in Dementia Patients**

Although patients who present with hoarding behaviors as a result of dementia do not meet the DSM-5 criteria for HD, understanding the onset and presentation of hoarding symptoms in dementia patients can serve to help with a differential diagnosis of HD in older adults who may have comorbid dementia. Hoarding behaviors in older adults with dementia are estimated to present in 1.9% of community-dwelling dementia patients<sup>22</sup> and in 22.6% of dementia patients admitted to a geropsychiatric ward.<sup>23</sup>

Studies of geriatric dementia samples have repeatedly demonstrated the emergence of hoarding behaviors in connection to dementia<sup>24,25</sup> and there is evidence that hoarding behaviors are more common in less severely impaired older adults with dementia.<sup>26</sup> These findings are difficult to interpret, however, as the measures of hoarding symptoms are limited to hoarding behaviors (i.e., saving and hiding food and objects) and do not evaluate other criteria of HD such as difficulty discarding. Hoarding behaviors seen in dementia (e.g., collecting or hiding several objects) are more likely to be a manifestation of the cognitive deficits and behavioral symptoms associated with dementia (e.g., repetitive behaviors or inhibition problems) rather than the types of hoarding behaviors typically seen in individuals with HD. It should be noted, however, that individuals with HD may develop dementia in late life, thus adding a confounding element to studies trying to differentiate individuals with HD who developed dementia from individuals with dementia who developed hoarding symptoms.

### **Problems Associated with Late-Life Hoarding**

HD can have serious consequences for older adults, such as increased fall risk, fire hazard, poor hygiene, poor nutrition, and medical problems.<sup>1</sup> Other serious consequences of HD, which have been observed in older adults with compulsive hoarding problems or self-

reported hoarding symptoms, include food contamination, social isolation, and medication mismanagement.<sup>2,27,28</sup> Dust or insect/rodent infestations resulting from hoarding behaviors may exacerbate pre-existing chronic health conditions such as emphysema.<sup>1,29</sup> Some of these risks are similar to those for younger populations, although the results of medication mismanagement, falls, fires, contamination, and so on, are potentially more significant for older adults.

Relatively little is known about the extent of medical problems in older adults with hoarding symptoms or HD. This may be in part due to the difficulty substantiating a medical profile with many older adults with hoarding symptoms who do not receive regular medical care.<sup>30</sup> One study investigating self-reported medical problems in older adults with hoarding disorder found that there are substantially higher rates of self-reported medical conditions (90%) in older adults presenting with compulsive hoarding problems than in older adults without HD (44%).<sup>30</sup> Medical conditions that were the most common for older adults with compulsive hoarding include cardiovascular conditions (hypertension: 61%; stroke: 11%), sleep apnea (22%), and seizures (11%). Hoarding severity was significantly associated with several health conditions, particularly sleep apnea and arthritic and hematological conditions.<sup>30</sup>

There may also be an association between hoarding symptoms and daily functioning. Kim et al.<sup>28</sup> queried caseworkers about hoarding symptoms they had observed in older adults (aged 65–92 years). Caseworkers reported that older adults with hoarding symptoms (as determined by the caseworker) were unable to use basic appliances, essential rooms in the house, and had significant plumbing problems.<sup>28</sup> Over 80% of the patients reported by the caseworkers as having hoarding symptoms experienced substantial impairment in movement through their homes, 70% were unable to use their sofas, over 50% could not prepare food, 45% could not use their refrigerators, 42% could not use their kitchen sinks, 42% could not use their bathtubs, 20% could not use their bathroom sinks, and 10% could not use their toilets. Unfortunately, no actual assessment of hoarding symptoms was conducted in the individuals identified by the caseworkers, and so this study can only serve as an initial exploration of some of the functional difficulties that may be experienced by older adults with HD. However, studies examining activities of daily living in older adults compulsive hoarding<sup>31</sup> or meeting criteria for HD<sup>1</sup> found similar results; older adults with HD or compulsive hoarding have significantly greater impairment than older adults without hoarding symptoms.

Finally, older adults with HD may struggle with eviction and homelessness. Rodriguez and colleagues<sup>32</sup> assessed 115 individuals seeking help for housing problems and found that 22% of the participants met criteria for HD. Of the individuals with HD, nearly one-third were facing imminent eviction and one-fifth had previously been evicted.<sup>32</sup> Whereas midlife adults (ages 40–59) constituted the HD versus non-HD groups similarly (36% and 38%, respectively), 44% of those 60 and older fell in the HD group compared with 9% of non-HD older adult group. Although these results have not yet been replicated, they are suggestive of some of the harsh consequences that may face older adults with HD.

### Comorbidities with HD in Older Adulthood

Psychiatric comorbidities such as anxiety and depression are common in older adults with compulsive hoarding problems<sup>2</sup> as well as older adults meeting the proposed DSM-5 criteria for HD.<sup>1</sup> In a community sample of older adults with compulsive hoarding, Ayers et al.<sup>2</sup> reported that mood disorders were the most frequent psychiatric comorbidity (28% major depressive disorder [MDD], 22% with dysthymia), followed by anxiety disorders (16% OCD, 11% post-traumatic stress disorder [PTSD], 5% generalized anxiety disorder [GAD], 5% social phobia, 5% agoraphobia, and 5% anxiety not otherwise specified). Similar patterns of comorbidity were observed in a sample of older adults with HD,<sup>1</sup> but with higher rates of occurrence of the comorbid disorders: 51.4% MDD, 23.3% GAD, 23.3% social phobia, 18.1% OCD, 13.8% specific phobia, and 7.1% PTSD. Finally, Reid et al.<sup>33</sup> reported symptoms of depression, OCD, and anxiety uniquely predicted hoarding behaviors among nonclinical older adults. There are not yet any published studies examining the impact of comorbid psychiatric disorders in older adults with HD on treatment outcomes.

### Cognitive Dysfunction in HD in Older Adulthood

Cognitive dysfunction has been discussed as a possible vulnerability for the development of compulsive hoarding<sup>10</sup> and executive functioning problems have been observed in middle-aged adults with compulsive hoarding, including problems with categorization,<sup>34–36</sup> planning and organization,<sup>34,35,37</sup> and shifting set.<sup>36</sup>

Researchers have started to examine the cognitive status of older adults with hoarding symptoms.<sup>38,39</sup> Mackin and colleagues<sup>39</sup> found preliminary evidence that older adults with major depression and suspected hoarding (as determined by therapist) had categorization and problem-solving impairment compared with their non-hoarding peers. It is unclear, however, if the executive functioning impairment found in Mackin et al.<sup>39</sup> would be seen in non-depressed older adults with hoarding symptoms. Because this study did not utilize formalized measures of HD, the results should be interpreted with caution.

To date there has only been one investigation of possible cognitive impairment in older adults as a result of HD. A sample of older adults (N = 42) diagnosed with HD without comorbid mood or anxiety disorders revealed significant differences in multiple subtests of executive functioning on the Wisconsin Card Sort Test compared with a same-aged, demographically matched, non-psychiatric peer group (N = 25).<sup>38</sup> Older adults with HD had a greater number of total errors, indicating problems with set-shifting, conceptual skills, updating information in working memory, and attentional control, than the comparison group. They exhibited a greater number of non-perseverative errors indicating difficulty with categorizing, learning efficiently, maintaining attention, and utilizing feedback. Older adults with HD also displayed impairment in conceptual level responses, reflecting difficulties with insight, abstract thinking, set shifting, and maintaining cognitive set. Moreover, they had difficulty generating hypotheses, selecting strategies, inhibiting incorrect responses, and monitoring performance, as reflected by the lower total number of categories completed. Finally, the larger number of trials required to complete the first category suggests that older participants with HD experience difficulties with strategic planning, flexible thinking, and organized searching. These skill sets likely affect the quality of information retention in

older adults with HD. Future work should examine a full neurocognitive profile that is not limited to executive functioning as well as examine the impact of cognitive functioning on treatment outcome.

## DIAGNOSTIC CHALLENGES AND SPECIALIZED CLINICAL ASSESSMENT

### Treatment

Studies examining the efficacy of medications in midlife compulsive hoarding patients have yielded mixed results,<sup>40</sup> with the exception of a recent report showing that extended-release venlafaxine administered over the course of 12 weeks may have decreased hoarding symptom severity in 24 adults with HD (mean age: 51.8 years, range: 33–61) by up to 36% on clinician-administered measures and up to 32% on self-reports.<sup>41</sup> Unfortunately, age was negatively correlated with improvement in hoarding symptom severity,<sup>41</sup> and so venlafaxine may not prove to be an efficacious treatment option for older adults with HD.

Clinical trials examining psychotherapy outcomes for older adults with HD are limited because most have focused on midlife compulsive hoarding samples.<sup>42,43</sup> Published treatment outcome research for using cognitive behavioral therapy (CBT) to treat late-life hoarding problems is limited to case studies and open trials featuring older adults with compulsive hoarding.<sup>44–46</sup> Case studies highlight the complexities of treating late-life compulsive hoarding, but should be interpreted with caution because they do not account for patient differences in neurocognitive status, insight, medical status, motivation, and therapist differences in competency or adherence to treatment protocols.

Although there have been no randomized controlled trials examining the effectiveness of CBT for HD (or compulsive hoarding) in older adults, two studies<sup>29,47</sup> have made preliminary investigations of the efficacy of Steketee and Frost's<sup>10</sup> CBT protocol for compulsive hoarding in older adults, and one study<sup>48</sup> has investigated a cognitive rehabilitation and exposure therapy for HD in older adults.

Turner et al.<sup>29</sup> examined a case series of 11 older adults (mean age: 72.3 years, range: 56–87) with compulsive hoarding problems. Treatment consisted of weekly home visits that included motivational interviewing, and an emphasis on problem-solving, decision-making, and cognitive restructuring skills. Six patients completed treatment in an average of 35 sessions.<sup>29</sup> Participants reported a significant improvement in the extent of clutter using the Clutter Image Rating,<sup>49</sup> a set of nine photos of the kitchen, living room, and bedroom in varying stages of clutter levels.<sup>29</sup> These results are promising, although they are limited by the lack of formal criteria used for diagnosing compulsive hoarding as well as the small sample size. This study points at potential feasibility and acceptability problems, as approximately half of the participants did not complete treatment and the high number of sessions required by the intervention may exceed what would be covered by most U.S. health insurance companies.

Ayers and colleagues<sup>47</sup> conducted an open trial of CBT for compulsive hoarding with a sample of 12 participants (mean age: 73.7 years). Although they found statistically significant reduction in symptom severity scores (14%–20% reduction on the Savings

Inventory-Revised [SI-R]<sup>50</sup> and UCLA Hoarding Severity Scale [UHSS]<sup>51</sup>), participants' severity of hoarding symptoms remained clinically significant.<sup>47</sup> There was also no change in anxiety, disability, and amount of clutter both following completion of treatment and 6 months after completion of treatment.<sup>47</sup> Out of the 12 participants, two participants showed an increase in hoarding symptoms following the 6-month intervention and only three participants were classified as treatment responders. Although Ayers and colleagues<sup>47</sup> used a more thorough set of inclusion criteria than did Turner et al.,<sup>29</sup> their study was still limited by a small number of participants, utilization of one therapist, and the lack of a control condition.

The most promising results have come from an open trial featuring cognitive rehabilitation and exposure to discarding and acquiring in 11 older adults (mean age: 66 years) meeting the proposed DSM-5 criteria for HD.<sup>48</sup> This intervention combined compensatory cognitive training with exposure-based treatment. The compensatory cognitive training was designed to address deficits in executive functioning and included specific skills in calendar use, task completion, problem solving, thinking flexibility, and planning. Instead of emphasizing traditional cognitive behavioral skills such as cognitive restructuring, the manual primarily focused on the compensatory cognitive training skills and exposure exercises. Hoarding symptoms improved an average of 36% on the SI-R and 41% on the UHSS, and patients had subclinical hoarding levels following the intervention.<sup>48</sup> Eight of the 11 participants were classified as treatment responders and three were classified as partial responders.<sup>48</sup> Although these results are promising, they also highlight the need for a larger and more systematic study (e.g., a randomized controlled trial) of the efficacy of interventions for late life HD. Further, that study utilized only licensed clinical psychologists and a treatment-seeking sample, therefore the results may not translate to an elder service agency setting. Finally, the older adults utilized by Ayers et al.<sup>48</sup> represented a relatively younger sample of older adults and their results may not generalize to more elderly samples of older adults.

## CONCLUSION AND FUTURE IMPLICATIONS

Hoarding disorder in late life is characterized by severe functional impairment, medical and psychiatric comorbidities, and cognitive dysfunction. There are currently no published randomized controlled trials investigating late-life hoarding treatments. Future studies should examine the efficacy of such interventions using randomized controlled trials with the eventual goal of bringing treatments to community settings with a focus on functional outcomes.

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