

Hoarding disorder Cutting through the clutter

JESSICA R. GRISHAM MA, PhD
PETER A. BALDWIN BA(Hons)

With a prevalence of 2 to 6%, hoarding disorder is common and causes significant impairment to patients and their families. Evidence-based tools are available for diagnosing and assessing the severity of hoarding disorder. Cognitive behavioural therapy is the primary evidence-based treatment.

In hoarding disorder (HD), an individual acquires and saves so many possessions that rooms become unusable for their intended purpose, resulting in marked distress and/or impairment to the individual.¹ HD was previously considered part of obsessive-compulsive disorder but is now recognised as a distinct condition. Unlike most psychological disorders, the burden of HD extends beyond the individual and their family to local communities and public health services. As public awareness of hoarding increases and the population ages, GPs will likely encounter patients with HD in their practices. The information in this article will help GPs better understand HD and play an integral role in an HD treatment team.

KEY POINTS

- Hoarding disorder (HD) is characterised by extreme attachment to possessions and difficulties with discarding, which render living areas unusable and cause the individual significant impairment and distress.
- GPs are likely to be the first point of contact for individuals and families affected by hoarding; they should distinguish HD from conditions such as dementia and consider common comorbidities such as anxiety and mood disorders.
- Patients who request treatment should be referred to a mental health specialist.
- Cognitive behavioural therapy is the primary evidence-based treatment for HD; self-help resources may also assist patients and families.
- GPs can play a key role in managing pharmacotherapy, where indicated.

Impact of hoarding disorder

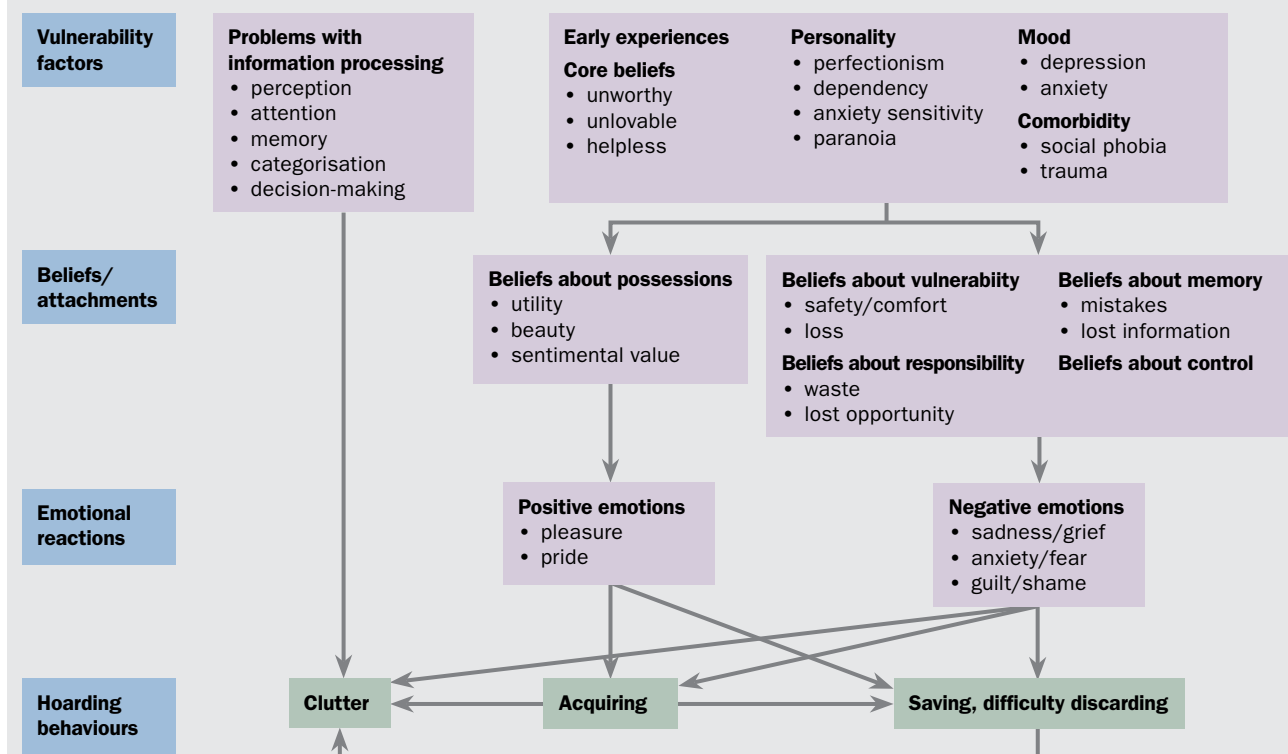
At a population level, hoarding difficulties are common, even more so in older adults. The prevalence of clinically significant hoarding is estimated at 2.3 to 6%.²⁻⁴ Prevalence appears to increase with age, with one study finding that the prevalence of hoarding difficulties in individuals aged over 54 years was three times that observed in individuals aged 34 to 44 years.⁵ Understanding and facilitating treatment of HD will be highly relevant to Australian GPs as our aged population grows in the coming years.

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Associate Professor Grisham is Associate Professor in the School of Psychology, The University of New South Wales, Sydney. Mr Baldwin is a PhD candidate in the School of Psychology, The University of New South Wales, Sydney, NSW.

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PROMINENT COGNITIVE-BEHAVIOURAL MODEL OF HOARDING DISORDER*



* Adapted from Steketee G, Frost RO. Compulsive hoarding and acquiring: therapist guide. New York: Oxford University Press, USA; 2006.¹³

At the individual level, impairment related to hoarding is broader and more severe than one might expect. Individuals who hoard experience impaired daily living, familial conflict and serious health and safety concerns for both themselves and their community.⁶⁻⁹ These individuals are likely to have other psychological illnesses, particularly depression, and often experience financial hardship, social isolation and significant occupational difficulties.¹⁰⁻¹²

Patients with HD will often have fluctuating insight into their disorder and express ambivalence about treatment. Those who seek treatment often do so under duress from family or local authorities, adding to their reluctance.⁷ For busy GPs, treating an ambivalent patient with chronic HD will likely require ongoing collaboration with psychological and psychiatric specialists. Fortunately, evidence-based tools for assessment, diagnosis and treatment are available, and recovery is certainly possible.

In this article, we describe the typical clinical presentation of patients with HD, discuss common comorbidities and detail

three brief questionnaires GPs could use to assess hoarding symptoms. We then outline the primary psychological and pharmacological treatment approaches, provide recommendations for specialist referral and offer tools for rural GPs.

Presentation

The key clinical features of HD are excessive emotional attachment to possessions and difficulty discarding them. For a diagnosis of HD, the accumulated clutter must be severe enough to prevent the individual using their living areas and cause them significant impairment and distress. The prominent cognitive-behavioural model of hoarding disorder is shown in the flowchart.¹³

Although individuals with HD may self-refer for treatment, they are often strongly encouraged or persuaded to seek treatment by family, friends or other concerned parties. In some cases, individuals with HD refuse treatment for years, finally presenting for help when their hoarding problems have led to housing or interpersonal crises, such as eviction or threat of divorce.

1. DSM-5 DIAGNOSTIC CRITERIA FOR HOARDING DISORDER*

To receive a diagnosis of hoarding disorder an individual must meet all criteria. Specifiers may be used to characterise certain aspects of individual presentation.*

Criteria

- 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 compromise 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 or 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 obsessive-compulsive disorder, 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

1. With excessive acquisition (individual actively acquires items to excess).
2. With good or fair insight (individual mostly recognises hoarding as problematic).
3. With poor insight (individual mostly does not recognise hoarding as problematic).
4. With absent insight/delusional beliefs (individual does not at all recognise hoarding as problematic).

* Refer to Diagnostic and statistical manual of mental disorders 5th ed for more information.¹

The level of insight varies among individuals with HD, and those with low levels of insight can be challenging to assess and treat.¹⁴ A related issue is that some individuals lack motivation to undergo treatment or express fear that they will be forced to discard their highly treasured items. It is important to note, however, that levels of insight and motivation are variable within this population and may also fluctuate over time. Some individuals are very aware of their hoarding-related problems and are eager to obtain treatment, whereas others possess a high level of insight but are reluctant to seek treatment because they are ashamed of the state of their home.

Diagnosis

When an individual with apparent HD presents for treatment, the GP should evaluate the individual's reasons for saving to distinguish hoarding behaviour from nonpathological collecting or a build-up of possessions secondary to a physical or mental disorder, such as dementia or schizophrenia.

People with hoarding problems typically report either instrumental or sentimental reasons for their excessive acquisition and saving, or both, as follows.

- Instrumental reasons reflect resistance to discard items that may be needed for an unrealistic or unidentified future purpose (e.g. 'maybe my niece could use these broken laundry pegs in an art project' or 'someone I know may travel to Vietnam one day and this [outdated travel brochure] will come in handy').
- Sentimental reasons for saving include beliefs that one's possessions are closely aligned with one's identity or beliefs that possessions have human-like qualities (e.g. 'I feel very guilty for discarding this old doll, as if I am throwing away part of myself'). Individuals with HD often describe strong emotional attachment to their possessions and feelings of intense anxiety or sadness in anticipation of parting with them.

In addition to extreme or maladaptive beliefs about the meaning and utility of possessions, a significant portion of those with HD demonstrate mild cognitive difficulties in sustained attention, as well as impairment in categorising belongings and making decisions about them.¹⁵⁻¹⁷

HD now comprises its own diagnostic category in the 2013 edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, which provides six diagnostic criteria (Box 1).¹ Interview and self-report measures may be used to assess the diagnostic criteria of HD and to determine severity.

The Saving Inventory-Revised is the most commonly used self-report measure for hoarding.¹⁸ It comprises 23 items that assess excessive acquisition of purchased and free items, saving and discarding behaviours, and excessive clutter in adults (available online at [http://www.ocfoundation.org/uploadedfiles/hoarding/resources/si-r\(modifiedformat\).pdf](http://www.ocfoundation.org/uploadedfiles/hoarding/resources/si-r(modifiedformat).pdf)).

However, in the context of a brief evaluation one of the most practical measures is the Clutter Image Rating.¹⁹ This is a pictorial index of the extent of clutter within kitchens, living rooms and bedrooms. For each room, the patient simply selects the picture that most closely matches their actual room (Figure).

Another time-efficient option is the use of a very brief semistructured interview: the Hoarding Rating Scale – Interview (HRS-I). The HRS-I contains five items that assess clutter, difficulty discarding, excessive acquisition and the extent of distress and impairment caused by hoarding (Box 2). More information about the HRS-I and associated scoring is available

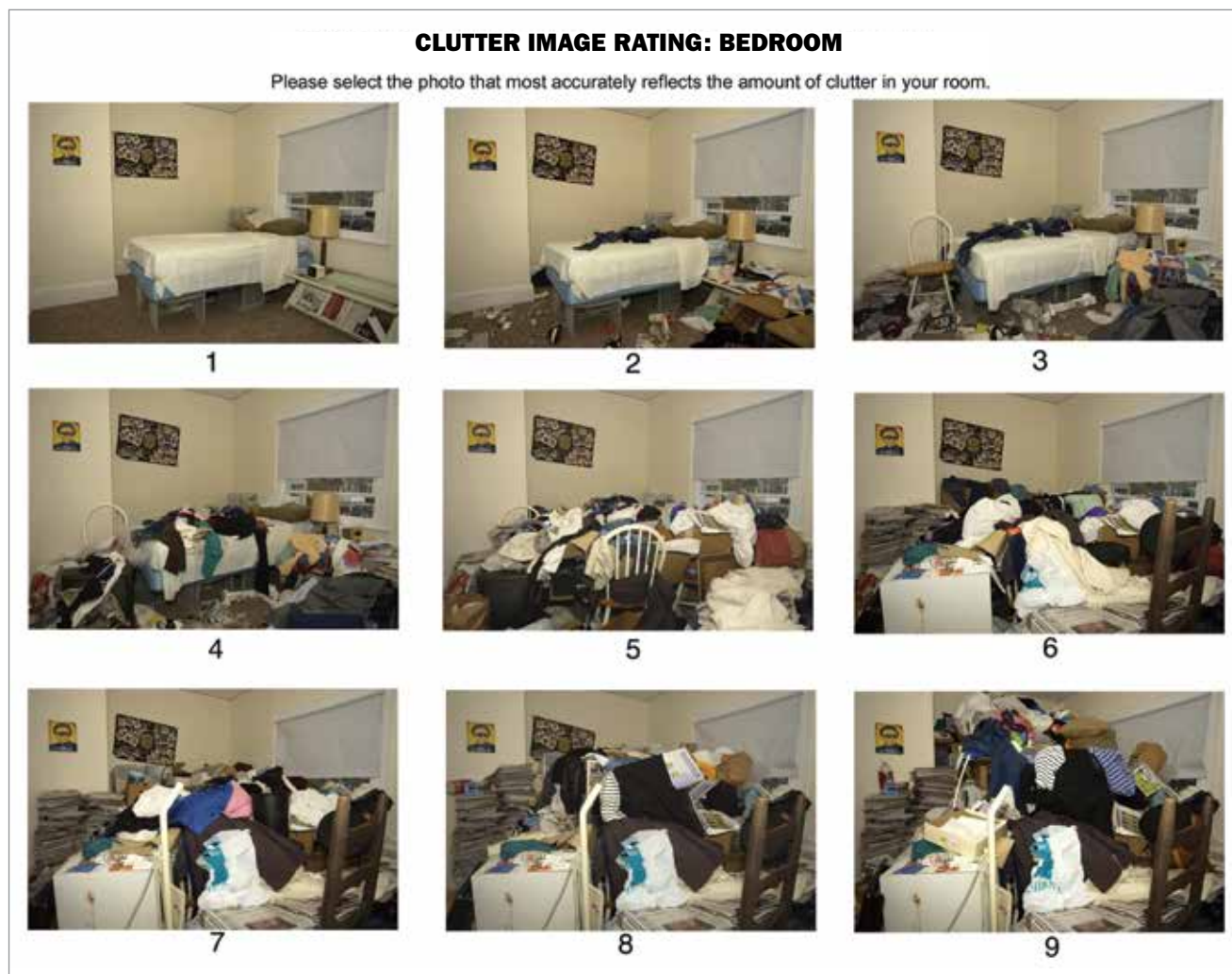


Figure. The Clutter Image Rating index for the bedroom. The patient is asked to select the picture that most closely matches their actual room. A score of 4 or more is considered significant clutter that requires clinical attention. There are similar indices for the kitchen and living room.^{13,19} Reproduced with permission from Oxford University Press (<https://global.oup.com/academic>).

at the website of the International OCD Foundation (<http://www.ocfoundation.org/uploadedfiles/hoarding/resources/hoarding%20rating%20scale%20with%20interpret.pdf>).

Common comorbidities

HD is often accompanied by other disorders or problems that require assessment for treatment planning or referral. It is associated with high rates of comorbid anxiety and mood disorders, including social phobia, generalised anxiety disorder and major depression.^{10,12,19} A comorbid diagnosis or symptoms of attention deficit hyperactivity disorder (ADHD) are also common in patients with hoarding.^{10,14,20} In addition, people with hoarding problems often report a history of trauma and high rates of personality disorders.^{19,21} Finally, individuals with

hoarding problems may also present with complex medical histories and physical disorders that may influence presentation and treatment outcome.⁹ Depending on whether hoarding is the primary presenting difficulty, individuals may require referral for treatment of anxiety, mood disturbances or other psychological or physical difficulties before beginning treatment for HD.

Treatment of hoarding disorder

Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) is the primary evidence-based treatment for hoarding.²² CBT for hoarding is a relatively new treatment protocol that continues to increase in breadth and effectiveness. Broadly, CBT for hoarding involves training

2. HOARDING RATING SCALE-INTERVIEW*

The patient is asked to respond to each question using a rating scale of 0 to 8, where 0 = no problem and 8 = extreme, very often (daily). Clinically significant hoarding is indicated by a score of 4 or more on questions 1 and 2, and a score of 4 or more on either question 4 or question 5.

1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?
2. To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?
3. To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?
4. To what extent do you experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?
5. To what extent do you experience impairment in your life (daily routine, job/school, social activities, family activities, financial difficulties) because of clutter, difficulty discarding, or problems with buying or acquiring things?

* Adapted from Tolin et al. *Psych Res* 2008; 160: 200-211.⁹

3. WEBSITES AND SELF-HELP RESOURCES FOR HOARDING

- International OCD Foundation Hoarding Site: <https://hoarding.iocdf.org>
Information and practical resources for professionals and anyone affected by hoarding
- Compulsive Hoarding Community: <https://groups.yahoo.com/neo/groups/h-c/info>
A Yahoo! community that uses cognitive behavioural therapy-based discussions and activities to provide support and help for individuals who hoard. Membership is limited, but a waitlist is available.
- Tolin D, Frost RO, Steketee G. *Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding*. 2nd ed. Oxford: Oxford University Press; 2013. Information and evidence-based cognitive and behavioural strategies to address both hoarding behaviours and the difficult thoughts and feelings that accompany them.
- Frost RO, Steketee G. *Stuff: Compulsive Hoarding and the Meaning of Things*. Boston: Houghton Mifflin Harcourt; 2010. Hoarding researchers present a series of patient cases in a warm and informative style.

in organisational and problem-solving skills, combined with exposure and cognitive strategies to help identify and address unhelpful thoughts and behaviours that maintain the patient's hoarding problems.²³ Throughout CBT, therapists also use motivational interviewing techniques to address the fluctuations in insight and desire for change that are common among individuals with hoarding.²⁴

As clients practice sorting and discarding their items, clinicians use various methods to facilitate decision-making and allow clients to challenge their beliefs about the feared consequences of discarding or nonacquiring. A list of challenging questions may be used, such as 'Do I have a plan to use this? Have I used this in the past year? How many do I already have?' Clients may also engage in behavioural experiments in which they test the validity of their predictions about the catastrophic consequences of discarding. For example, an individual with many disorganised stacks of newspapers cluttering his home reports a strong fear that if he discards any of his newspapers, he will be unable to otherwise obtain the information they contain. A behavioural experiment for this client might involve asking him to attempt to find information on a specific topic of interest in two ways: first, by hunting through his own newspaper stacks; and second, by using an alternative method such as searching the Internet or looking through reference books at his local library. The patient would then review with the therapist which of the two approaches was the easier and faster way to obtain the desired information.

Finally, treatment may address excessive acquisition through encouraging clients to visit contexts where they typically buy or otherwise collect items and allowing them to practice resisting the urge to acquire. These 'nonacquiring' exposures are typically done in a hierarchical fashion, beginning with easier locations (e.g. walking by a shop window) and proceeding to more difficult situations and exercises (e.g. touching items in a favourite shop without purchasing them).

A recent meta-analysis examined 10 studies of CBT delivered to adults with hoarding symptoms, across both individual and group therapies. The authors found large, clinically significant improvements in all primary hoarding symptom dimensions: clutter, acquiring and difficulty discarding, with discarding the most improved symptom.²⁵

Pharmacotherapy

Previously, hoarding was considered to be resistant to pharmacotherapy.²⁶ However, recent research using hoarding-specific measures of treatment outcome is more promising. In one patient sample, treatment with venlafaxine (extended release) for individuals with a primary HD diagnosis led to symptom improvement comparable with the effects of CBT.²⁷ The additive effects of combination CBT and pharmacotherapy are unclear, as is the long-term maintenance of functioning in individuals receiving pharmacotherapy alone.

GPs should also be mindful of contributing to the common comorbidity of obesity in patients with HD and also of potential cardiovascular risk when prescribing serotonin and

noradrenaline reuptake inhibitors.²⁸ Medical professionals considering pharmacotherapy should interpret the encouraging but preliminary evidence for venlafaxine (extended release) alongside the more substantial empirical support for CBT, especially in individuals without comorbid depression or anxiety.

Specialist referral

Patients who present with hoarding and request treatment should be referred to a mental health specialist, such as a psychiatrist or clinical psychologist. GPs should collaborate with these specialists to determine whether pharmacotherapy is indicated, based on a comprehensive mental health assessment.

At-home assessment and treatment may be helpful in some circumstances. Therapist-facilitated discarding in the home may boost symptom improvement.²⁵ However, CBT without home visits is still effective.²⁶ When considering referral, GPs could ask specialists whether they provide home-based therapy for hoarding, and consider these services for less mobile patients, patients with poor insight or patients facing immediate health and safety risks.

Hoarding patients are likely to suffer financial difficulties, and thus access to Medicare-eligible specialist services via a GP Mental Health Treatment Plan may encourage treatment uptake. GPs should bear in mind that Medicare Better Access screening tools (currently the Kessler Psychological Distress Scale, K10) assess for general anxiety and depression, which are often, but not always, present with hoarding.^{10,11} For patients who present with hoarding but do not report high K10 scores, a GP Mental Health Treatment Plan may follow specialist assessment.

Rural practice

Although CBT delivered by a mental health specialist or trained therapist is ideal, rural GPs often face limited access to specialist services. Early evidence supports self-help approaches, both online and in groups, based on the self-help manual *Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding*.^{29,30} This manual also provides useful information for loved ones, carers and community professionals dealing with hoarding.

Conclusion

Given the prevalence and social burden associated with HD, GPs are likely to be the first point of contact for many individuals and families affected by hoarding. When individuals with HD do present to their GP, they often come on the insistence of others after many years of hoarding. The chronic course of the illness, combined with poor insight and concomitant physical and mental illnesses, will likely require a team approach to treatment.

Clinically, HD is characterised by extreme attachment to possessions and difficulties with discarding. For an HD diagnosis, the resultant clutter must render living areas no longer

usable for their intended purpose, and the individual must show significant impairment and distress as a result. GPs should also consider whether the hoarding is better accounted for by organic illness, such as dementia. Once a diagnosis is made, GPs should use the recommended questionnaires and clinical judgement to establish the severity of hoarding and decide on appropriate specialist referral.

CBT is the primary evidence-based treatment for HD, so referral to a CBT practitioner is advised. CBT will help establish and maintain an individual's motivation for change, while engaging the patient in cognitive and behavioural strategies to reduce acquiring and facilitate discarding. Self-help resources are available and will assist both patients and their families (Box 3).

In addition to specialist services, GPs can play a key role in managing pharmacotherapy (where indicated) and treating physical illnesses that may be more common in patients with HD, such as hypertension, diabetes and cancer. Lifestyle interventions for obesity-related illness in patients with HD should consider their possible unique circumstances, such as financial hardship or a lack of food preparation and storage facilities. With their GP's help, many individuals will recover from HD and reclaim a life once lost among the clutter. MT

References

A list of references is included in the website version (www.medicinetoday.com.au) and the iPad app version of this article.

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