

Hoarding disorder: a new obsessive-compulsive related disorder in DSM-5

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Summary

Obsessive-compulsive disorder (OCD) and related disorders have been the subject of significant revisions in the fifth edition of the *Diagnostic and Statistical Manual (DSM-5)*. One of these major changes has been the removal of OCD from the ‘Anxiety Disorders’ section and its instalment in a new and distinct *Obsessive-Compulsive and Related Disorders (OCRDs)* chapter. However, it is the instatement of Hoarding Disorder (HD) as a new OCRD that marks the most significant change. Previously considered a symptom of OCPD, and subsequently linked to OCD, it is now acknowledged that hoarding can emerge independently from any alternative condition. The present paper

provides an updated review of recent investigations supporting the status of HD as an independent nosological entity. Specifically, we will present the new DSM-5 diagnostic criteria and examine the literature pertaining to the psychopathological and phenomenological aspects of the disorder, with particular attention to practical strategies that can help clinicians to recognise and differentiate HD from OCD. Finally, the available assessment and treatment strategies for HD are summarised.

Key words

Hoarding Disorder • Obsessive-Compulsive and Related Disorders • Psychopathology • Epidemiology

Introduction

Obsessive-compulsive disorder (OCD) has been the subject of significant revisions in the fifth edition of the *Diagnostic and Statistical Manual (DSM-5)*. One of these major changes has been the removal of OCD from the ‘Anxiety Disorders’ section and its inclusion in a new and distinct category of *Obsessive-Compulsive and Related Disorders (OCRDs)* – a classification which now also includes body dysmorphic disorder (BDD) (previously in the chapter of Somatoform Disorder), trichotillomania (previously classed among the Impulse Control Disorders and now termed hair-pulling disorder), and two new dis-

orders, excoriation (skin-picking) disorder and hoarding disorder (HD), alongside the residual categories of substance/medication-induced OCRDs, OCRDs due to another medical condition, and other specified OCRDs. All disorders included in this chapter share similarities with OCD, although some appear to have a stronger cognitive component – and thus are closer to OCD – while others mainly consist of body-focused repetitive behaviours (Figure 1). The 11th revision of the *International Classification of Diseases (ICD-11)* will likely contain a similar OCRDs chapter, including HD.

While the introduction of two new disorders in the psychiatric nomenclature is independently noteworthy, it

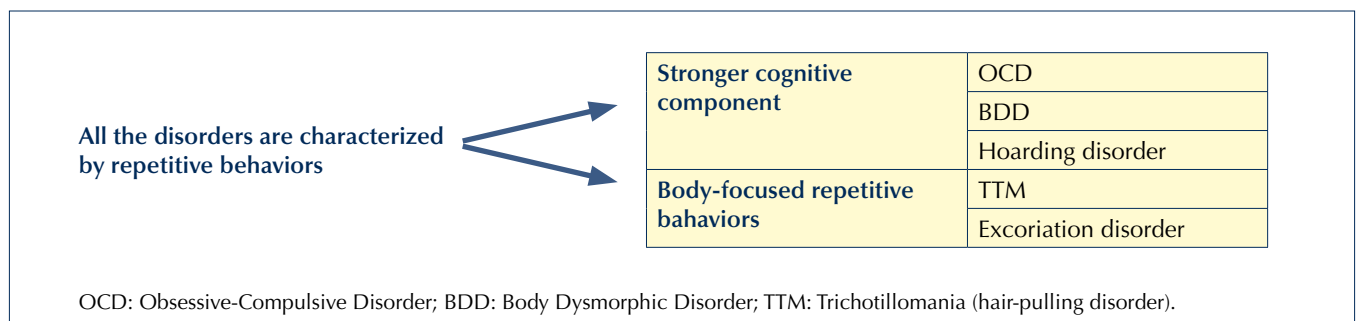


FIGURE 1. Obsessive-compulsive and related disorders (OCRDs).

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is the instatement of HD that marks, perhaps, the most significant change. Previously classified as a symptom of obsessive-compulsive personality disorder (OCPD) in DSM-IV, and only indirectly linked to OCD, it has only been recently acknowledged that hoarding can emerge independent of any alternative condition. Its formalisation as an independent psychiatric condition in DSM-5 and ICD-11 therefore reflects a marked change, and one that has been precipitated over the last decade by an exponential growth in the number and quality of investigations concerned with this behaviour¹.

The aim of the present paper is to provide an updated review of the HD literature. Specifically, we will present the new DSM-5 diagnostic criteria and examine the work pertaining to the psychopathological and phenomenological aspects of the disorder, with particular attention paid to those aspects that can help clinicians to recognise and differentiate HD from OCD. In addition, we will also highlight the psychopathological and clinical features that may help distinguishing HD and OCD when both conditions coexist. In the final sections, we will summarise the available evaluation and intervention strategies for HD.

Definition and diagnostic criteria of hoarding disorder

Like most human behaviours, saving and collecting possessions may be viewed along a continuum, with one end representing common and adaptive behaviours (accumulating and storing resources, collecting), which are widespread phenomena in the general population and are evident even during infancy and the other end pertaining to behaviours that are excessive or pathological (excessive acquisition of possessions and failure to discard them). The term 'hoarding,' which first appeared in a paper by Bolman and Katz², refers to the latter extreme of this continuum, though it has been noted that hoarding behaviour may not always be pathological³. Modern recognition of hoarding as a disorder, and the formal definition of this disorder's pathological features, began with Frost and colleagues several decades later^{4,5}. These authors conceived 'compulsive hoarding' (a term no longer in use) as excessive collecting and an extreme inability to discard worthless objects, and proposed an operational definition that would eventually form the basis of the DSM-5 criteria for HD. These early criteria defined 'compulsive hoarding' as: 1. the acquisition of and failure to discard a large number of possessions that seem to be useless or of limited value; 2. living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and 3. significant distress or impairment in functioning caused by the hoarding⁵.

Despite the significant burden caused by hoarding be-

haviours, classification systems did not characterise this activity as an independent clinical entity until the publication of DSM-5. Prior to this, hoarding only appeared in DSM-IV-TR where it was classed as one of the eight symptoms/criteria for the diagnosis of obsessive-compulsive personality disorder (OCPD) (*is unable to discard worn-out or worthless objects even when they have no sentimental value*). However, in the text accompanying these criteria, it was explicitly mentioned that a *diagnosis of OCD should be considered* – instead, or in addition to that, of OCPD – particularly *when hoarding is extreme (e.g., accumulated stacks of worthless objects present a fire hazard and make it difficult for others to walk through the house)*. While DSM-IV-TR did not mention hoarding directly as a symptom of OCD, the manual suggested a link between such symptoms and OCD¹.

In accordance with this nosological approach in DSM-IV-TR, hoarding has been long considered a behaviour/symptom dimension of OCD, a view that has been supported by factor analytic studies highlighting the prominence of hoarding as a distinct symptom dimension of OCD (e.g.,^{6,7}). The inclusion of hoarding items on measures and scales specific to OCD, such as the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) or the Obsessive-Compulsive Inventory-Revised (OCI-R), also served to reinforce an association. For example, the Y-BOCS symptom checklist includes an entry for hoarding/saving obsessions (*worries about throwing away seemingly unimportant things that you might need in the future, urges to pick up and collect useless things*) and hoarding/collecting compulsions (*saving old newspapers, notes, cans, paper towels, wrappers, and empty bottles for fear that if you throw them away you may one day need them; picking up useless objects from the street or from the garbage can*).

However, alongside and in contrast to these developments, several studies began to emerge providing evidence that hoarding may represent a clinical entity distinct from OCD^{1,8-12}. First, several studies emerged (see Table 1) noting that hoarding, as an abnormal or excessive behaviour, can occur in the context of a variety of neurological and psychiatric conditions beyond OCD, including dementia, cerebral lesions, schizophrenia, major depressive disorder, or generalised anxiety disorder¹³⁻²⁰. Then came crucial clinical studies that noted that the majority of individuals presenting with prominent hoarding behaviours were not presenting with other obsessive-compulsive symptoms/dimensions and, ultimately, could not be found to fulfil the criteria for OCD. For example, Frost et al.²¹ found that among 217 individuals with pathological hoarding, only 18% had a comorbid OCD diagnosis, with comorbidity rates for other, ostensibly unrelated disorders ranged considerably higher (e.g. 51% for major depressive disorder, 24% for social phobia, 24%

TABLE I.
Prevalence of hoarding behaviours in illnesses other than OCD.

Illness	Prevalence of Hoarding Behaviours	Authors
Moderate to severe Dementia	22.6% 15-25%	Hwang et al., 1998 ¹³ Marx et al., 2003 ¹⁴
Prader-Willi syndrome Velocardiofacial syndrome	37-58% 11%	Dykens et al., 1996 ¹⁵ Gothelf et al., 2004 ¹⁶
Schizophrenia	5% 40%	Stein et al., 1997 ¹⁷ Wustmann et al., 2005 ¹⁸
Social Phobia	15%	Tolin et al., 2011 ¹⁹
GAD	29%	Tolin et al., 2011 ¹⁹
Compulsive buying	62%	Mueller et al., 2009 ²⁰

for generalized anxiety disorder). Additional findings of interest concerning the distinction of hoarding and OCD have included: 1) insights on the phenomenological differences between hoarding and 'classical' obsessive-compulsive symptoms⁹⁻¹¹, 2) a lack of or modest correlation between hoarding and other OCD dimensions^{9,22}, 3) distinctions in the neural bases for hoarding and OCD²³⁻²⁵, and 4) differences between OCD and hoarding patients with regard to symptomatology, clinical course and anti-obsessional treatment response²⁶⁻³⁰. Taken together, this body of evidence strongly supported a formal move to distinguish hoarding from OCD, with the introduction of HD as a distinct clinical entity in DSM-5. The decision to title this entity 'hoarding disorder', rather than 'compulsive hoarding' as was initially suggested in the literature was due to further underline its autonomy from OCD and to avoid confusion between the two disorders. Still, despite these distinctions, HD has retained some link to OCD, with both conditions being contained in the DSM's OCDs chapter.

The DSM-5 diagnostic criteria for HD are reproduced in Table II. As shown there, the cardinal feature of HD is a persistent difficulty discarding or parting with possessions (criterion A). Though very similar to Frost's original criteria, the DSM version does not specify that items must be 'useless' or of 'limited value', with research suggesting that the most commonly saved items are useful items such as newspapers, books, bags, clothing and the like⁹. In the context of HD, difficulties discarding such items must be due to the perceived usefulness or aesthetic value of the items (intrinsic value – items are valuable or may become in handy in the future), a strong sentimental attachment to the possessions (emotional value), the wish to avoid creating waste, or a combination of these factors³¹.

Also essential for the diagnosis is that the person feels distressed when confronted with the idea of discarding or parting with the possessions (criterion B). As detailed in

subsequent sections, this criterion is particularly essential for differentiating OCD-related hoarding (hoarding secondary to obsessions in OCD), where attachment to the possessions is not typically present, from true HD.

The excessive collecting results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use (criterion C). Consequences of severe hoarding may be, for example, the inability to cook in the kitchen, sleep in a proper and clean bed, or even move from one room to the other; severe HD poses a broad range of health risks both for patients and their family members, including risk of fire, falling, poor sanitation and even being trapped by a 'clutter avalanche'³¹⁻³³.

The hoarding causes significant distress or impairment in social, occupational, or other areas of functioning (criterion D). Quality of life of patients and family members is severely affected, and family relationships are often considerably strained³³⁻³⁵. Often, the person with HD does not fully recognise the consequences of their hoarding behaviours, and another family member is the help seeker who asks for the intervention of a mental health provider.

A proper diagnosis of HD requires a differential diagnosis; cluttered living spaces should not assumed to be a manifestation of HD, as they may result from multiple conditions (see Table I) such as brain injury, cerebrovascular disease, Prader-Willi syndrome (see criterion E), or be the product (or secondary manifestation) of symptoms of other mental disorders such as typical obsessive-compulsive symptoms in OCD, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficit in major neurocognitive disorders, or restricted interests in autism spectrum disorder (criterion F). HD should also be differentiated from normative collecting. Table III (from Nordsletten et al.³⁶ & Mataix-Cols³¹) provides some clinical criteria that might

TABLE II.
DSM-5 diagnostic criteria for hoarding disorder.

A. Persistent difficulty discarding or parting with possessions, regardless of their actual value
B. This difficulty is due to both a perceived need to save the items and distress at the thought of discarding them
C. The difficulty in 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, or 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, or the Prader-Willi syndrome)
F. The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessive in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficit in major neurocognitive disorder, or restricted interests in autism spectrum disorder)
Specify if: <i>With excessive acquisition:</i> if difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space.
Specify: <i>With good or fair insight:</i> the individual recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic. <i>With poor insight:</i> the individual is mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary. <i>With absent insight/delusional beliefs:</i> the individual is completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.

be helpful in distinguishing common and non-pathological collecting behaviour from HD.

Sometimes, a diagnosis of HD can also be suggested in cases of severe domestic squalor, which tends to be more frequent in old people. Squalor is frequently associated to cases of object acquisition/accumulation due to 'organic' pathology. Cases of 'organic' hoarding may be differentiated from HD on the basis of some phenomenological differences that are summarised in Table IV (from Snowden et al. ³⁷).

DSM-5 considers two specifiers for HD: presence of excessive acquisition and degree of insight (Table II). The first applies when 'the difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space'; the vast majority of patients with HD present with excessive acquisition ^{38 39} and this subtype has been associated with more severe hoarding, earlier onset and higher comorbidity rates ³⁸. Failure to address excessive acquisition in treatment has been linked to treatment failure ³⁷. An insight specifier is also provided, which may be used to characterise an HD patient's level of insight into their behaviour and its consequences. This insight specifier is clinically relevant because treatment strategies depend on whether or not (and to which degree) the individual recognises that hoarding-related

beliefs and behaviours (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic: in cases of poor insight, for example, motivational interviewing techniques may be recommended before cognitive-behavioural therapy ⁴⁰.

HD and OCD

As noted in prior sections, hoarding has traditionally been considered a symptom or symptom dimension of OCD. This association is not without reason, as a proportion of OCD patients (ranging from 18 to 40%) have been found to display hoarding symptoms ⁴¹⁻⁴⁴. However, while present in a proportion of cases, only a minority of these OCD patients (approximately 5%) presents this dimension as the most prominent clinical manifestation.

Several phenomenological differences exist between hoarding symptoms that emerge as part of OCD and hoarding that fulfils the criteria for HD. For example: 1) HD-related thoughts are, in contrast to traditional obsessions, not usually experienced as intrusive, repetitive, and distressing; additionally, HD-related thoughts are associated with pleasure and reward in most cases, and are frequently unrelated to other prototypical OCD themes (while compulsions are usually linked to obsessions in

TABLE III.
Differences between normative collecting and Hoarding Disorder^{31 36}.

	Normative collecting	Hoarding Disorder
Object content	Very focused; objects are bound by a cohesive theme, with a narrow range of object categories	Unfocused; objects lack a cohesive theme, and the accumulation contains a large number of different object categories
Acquisition process	Structured; planning, searching for items, and organising the collected items	Unstructured; lack of advance planning, focused searching and organisation
Excessive acquisition	Possible, but less common; primarily bought items acquired	Very common; estimates consistently >80%, with both free and bought items acquired
Level of organization	High; rooms are functional, and collected items are arranged, stored, or displayed in an orderly fashion	Low; the functionality of rooms is compromised by the presence of disorganised clutter
Presence of distress	Rare; for the majority of collectors, the activity is pleasurable, although for a minority, collecting may result in distress due to factors other than clutter (e.g. finances)	Required for the diagnosis; distress is often a consequence of the presence of excessive clutter, forced discarding, or inability to acquire
Social impairment	Minimal; collectors have high rates of marriage, and the majority report forming and engaging in social relationships as part of their collecting behaviour	Often severe; hoarding disorder is consistently associated with low rates of marriage and with high rates of relationship conflict and social withdrawal
Occupational interference	Rare; scores on objective measures indicate that collectors do not have clinically significant impairment at work	Common; occupational impairment increases with hoarding severity; high levels of work-based impairment have been reported

some ways); 2) in HD, symptoms are perceived as ego-syntonic, unlike hoarding thoughts in OCD, which are generally egodystonic; 3) in HD, distress comes from clutter, while it comes from intrusiveness in traditional OCD; and 4) in traditional OCD, the thoughts lead to urges to get rid of them and/or perform a ritual to relieve them, while this is not common in HD^{9 31 45 46}. Additionally, the drive for keeping items is different in HD and in OCD-related hoarding; in HD, the hoarding of items is the result of 1) a fear that the items will be needed in the future (intrinsic value) or 2) a strong emotional attachment to the possessions. Crucially, individuals with HD have a genuine desire to possess their items. Such characteristics stand in strong contrast to the views and experiences of OCD individuals who engage in hoarding behaviour (Table V).

Hoarding should be viewed as a symptom of OCD only when it is clearly secondary to typical obsessions, and the relationship between these obsessional thoughts and the resulting behaviour (i.e., hoarding) is the same as that between traditional obsessions and compulsions. To fit with this definition, the hoarding should either relieve obsessional doubts (like a checking compulsion; hoarding as preventive of something bad happening); prevent harm from aggressive obsessions (e.g., *something bad will happen if things get thrown away*) or contamination fears (like preventive or washing compulsions; e.g., *I will*

contaminate the others because I spread contamination through items); or relieve feelings of incompleteness or not-just-right experiences (like repetition or symmetry compulsions). Other examples of hoarding resulting from prototypical obsessive-compulsive symptoms include the need to discard items in certain 'lucky' numbers, or the need to perform mental compulsions when discarding any item, so that hoarding appears as an avoidant behaviour⁹ (see Pertusa et al.⁴⁶ for a case series of OCD-related hoarding). In all these cases, hoarding should be conceptualised as a compulsion, and not as an independent entity of HD.

It has been suggested that hoarding and OCD might coexist in the same patient and yet be completely independent conditions (comorbid conditions). In such cases, careful differential diagnoses will be required to establish which behaviours stem from HD, and which are secondary to classical, prototypical obsessive-compulsive symptoms⁹.

Making a diagnosis of OCD and/or hoarding disorder may be confusing for many clinicians. Consideration of a few key clinical questions may be helpful for this differential process: 1) is the hoarding behaviour driven mainly by prototypical obsessions or is it the result of persistent avoidance of onerous compulsions (more likely in OCD-related hoarding)?; 2) is the hoarding behaviour generally unwanted and highly distressing for

TABLE IV.Phenomenological differences between accumulating behaviours due to macroscopic brain damage in brain injured or demented patients and hoarding in HD ³⁷.

	“Organic” object acquisition/accumulation	Hoarding Disorder
Onset	Generally sudden in cases of brain damage. Can be more insidious if secondary to a dementing process	Insidious. Usually starts in childhood/adolescence and has a long natural history
Ability to discard hoarded items	Variable (some are able to discard their possessions easily or do not care if others discard them, whereas others are very reluctant)	Inability to discard hoarded items is a core feature of HD
Nature of acquiring behaviour	Generally indiscriminate but can be more selective (acquisition of specific items – e.g. umbrellas – or according to their shape/colour) in some cases	Items are always acquire/hoarded according to their perceived intrinsic, practical, or emotional value, but can be more indiscriminate in some cases
Utility of hoarding behaviour	Often purposeless (individuals display little or no interest in the accumulated items) and items seldom used	More purposeful (items are hoarded for specific emotional or practical reasons), although items often not used
Hoarded items	Any item, including rotten food	Any items, though hoarding of rotten food is rare
Squalid living conditions and/or self-neglect	Frequent (especially in cases of dementia)	Thought to be relatively uncommon although more research is needed
Associated features	Severe personality changes as well as behaviours commonly attributable to brain dysfunction such as gambling, inappropriate sexual behaviour, excessive shopping leading to financial difficulties, theft, stereotypes, tics, and self-injurious behaviours	No severe personality changes or other behaviours clearly attributable to brain dysfunction. Excessive acquisition and shopping and stealing can be present
Cognitive processes and motivations for hoarding	Hoarding apparently devoid of identifiable cognitive and emotional processes, although more research is needed	a) information processing deficits: decision making, categorisation, organization, and memory difficulties; b) emotional attachment to possessions; c) behavioural avoidance; d) erroneous beliefs about possessions
Insight and help seeking behaviour	Poor or absent insight. Patients seldom seek help	Insight ranges from good to poor or absent. Initially, hoarding behaviour can be ego-syntonic; it becomes increasingly distressing as clutter increases. Help seeking probably related to degree of insight
Prevalence	Unknown (<1%)	Approximately 2-5%
Familial	Unknown but anecdotal reports of relatives independently living in squalor have been reported	Yes. Hoarding tends to run in families and appears to be moderately heritable

the patient (more likely in OCD-related hoarding)?; 3) does the individual show interest in the majority of the hoarded items (more likely in HD)? 4) is excessive acquisition present (more likely in HD)? ¹. The *Structured Interview for Hoarding Disorder* (SIHD) ^{39 47} provides a specific appendix aimed at assisting the clinician in assessing whether the hoarding behaviour is better conceptualised as a symptom of OCD.

HD: prevalence, aetiological factors and clinical characteristics

Prevalence estimates of hoarding behaviour are few in number and have often provided conflicting estimates. This is due, at least in part, to the only recent formalisation of diagnostic criteria for HD. Prior to their introduction, studies evaluating prevalence used their own defi-

TABLE V.Hoarding characteristics in patients with Hoarding Disorder versus OCD-related (or secondary) hoarding^{9-11 45}.

	Hoarding Disorder	Hoarding as a dimension of OCD
Relationship between hoarding and OC symptoms	Hoarding NOT related to obsessions/compulsions	Hoarding behaviour is driven mainly by prototypical obsessions or is the result of persistent avoidance of onerous compulsions ^a
Checking behaviour associated with hoarding	Rare and mild	Frequent and severe
Obsessions related to hoarding (i.e. catastrophic consequence or magical thinking)	No	Yes
Mental compulsions related to hoarding (e.g. need to memorise and recall discarded items)	No	Yes
Egosyntonic/egodystonic	Usually egosyntonic: hoarding thoughts are associated with pleasant feelings of safety	Usually egodystonic: intrusive or unwanted, repetitive thoughts
Presence of OC symptoms other than hoarding	No	Yes
Distress	Comes from clutter (product of behaviour)	Comes from intrusiveness
Main reason for hoarding	Intrinsic and/or sentimental value	Other obsessional themes
Type of hoarding		
Common items ^b	Yes	Yes
Bizarre items ^c	No	Yes
Excessive acquisition	Usually present	Usually not present
Age at onset of clutter problem (years)	Early 30s	Mid 20s
Insight	Poor or absent insight frequent	Generally good insight, although poor insight may be present
Course of hoarding behaviour	Hoarding tend to increase in severity as the person ages	Hoarding does not increase in severity as the person ages (usually)
Global severity/interference	Usually moderate	Usually severe

^a Fear of catastrophic consequence, need for symmetry/order, need to perform checking ritual because of the fear of losing an important item, etc.
^b Old clothes, magazines, CDs/videotapes, letters, pens, old notes, bills and newspapers, etc.
^c Faeces, urines, nails, hair, used diapers, and rotten food, etc.

nitions of clinically meaningful hoarding behaviour and identified members of populations who fulfil these definitions. Indeed, at present, only one study has evaluated prevalence using the DSM-5 criteria for HD, reporting a weighted prevalence of 1.5%⁴⁸. Other studies, using less restrictive characterisations of hoarding, have generally reported higher rates. For example, Samuels et al.⁴⁹ analysed data from the *Hopkins Epidemiology of Personality Disorder Study* (N=742) and estimated the lifetime prevalence of pathological hoarding, measured by means of the hoarding criterion for OCPD, at nearly 4% of the population. In a sample of 5022 twins, the point prevalence of severe hoarding – measured by the self-reported version of the *Hoarding Rating Scale* – was estimated to be low-

er, 2.3%⁵⁰. Using the same scale, Ivanov et al.⁵¹ found clinically-significant hoarding in 2% of adolescent twins. Timpano et al.⁵² found a higher prevalence rate (5.8%) in a representative sample of the German population using the *Hoarding Rating Scale*. Mueller et al.²⁰ found again a point prevalence of 4.6% in a representative sample of 2307 subjects using the *Savings Inventory-Revised*. Meanwhile, in Italy, a recent set of studies reported point prevalence estimates of self-reported hoarding behaviour (assessed by the *Saving Inventory-Revised*) of 3.7% and 6% in two non-clinical samples⁵³. Given this array of findings, and in the absence of additional work using the DSM-5 definition of hoarding, the true prevalence of HD remains unclear. Further studies will be necessary to es-

establish the proportion of the population impacted by this condition, and whether these proportions differ by key demographic factors (e.g., age, gender, ethnicity).

With regards to aetiology, the causes of HD are still largely unknown. Twin studies suggest that a predisposition to HD is genetically transmitted, with approximately 50% of the variance in hoarding behaviours attributable to genetic factors and the remaining variation being attributable to non-shared environment⁵⁰. Candidate genes have yet to be consistently identified for this disorder⁵⁴. While associations have been found between traumatic life events and hoarding symptoms and severity – retrospective studies have found, for instance, that subjects with HD have a greater number of life events – prospective studies are lacking and results remain unreliable^{27 30 55}. According to the cognitive-behavioural model of HD, three primary factors contribute to the emergence of hoarding behaviour: 1) beliefs about and emotional attachment to possessions, 2) avoidance behaviours that develop as a result of the emotional distress associated with discarding possessions, and 3) information-processing deficits in the areas of attention, categorisation, memory and decision making^{5 56 57}. It is possible that several genetic and psychological vulnerability factors may interact with stressors in order to determine who will develop (and when) hoarding symptoms. However, further research will be needed to untangle such predisposing, contributing and maintaining factors.

Clinical characteristics of HD, such as age at onset or course of the hoarding symptoms, have primarily been derived from studies that investigated hoarding with criteria that are not those of DSM-5. Notwithstanding such limitations, the available literature suggests that hoarding behaviours often begin early in life and tend to increase in severity as the person ages³¹. The threshold for the diagnosis (interference with the person's everyday functioning) is generally reached by the mid-20s, with symptoms continuing to worsen thereafter in the majority of individuals^{27 30 51}. Comorbidity is common, with HD clinical samples often presenting with major depressive disorder, anxiety disorders, or attention deficit-hyperactivity disorder^{21 39}.

The burden of HD often extends beyond the affected individual, and is shared by those around them including family, friends and community members^{21 34}. In a recent study, for example, the level of carer burden experienced by HD relatives was found to be comparable to or greater than that reported by relatives of individuals with dementia. Perceived level of squalor, co-habitation with the HD individual and increasing age of the HD individual were all significant predictors of carer burden and functional impairment in relatives³⁴.

Evaluation of hoarding disorder

Hoarding symptoms often need to be specifically asked about, as many patients do not spontaneously volunteer this information. Even patients with good insight often underestimate the extent of their hoarding and the consequences of the disorder. The use of some simple screening questions, such as 'are the rooms of your home so full of items that it is hard for you to use these rooms normally?', may initiate a fruitful dialogue and can rapidly lead to the diagnosis.

A formal HD diagnosis requires an interview with a trained assessor, ideally in the person's home environment. The *Structured Interview for Hoarding Disorder* (SIHD)^{39 47} is a freely available, validated, semi-structured instrument that has been designed to assist clinicians with the nuanced evaluation of this disorder. The content of this interview maps directly onto the DSM-5 criteria for HD, with questions relating to each diagnostic criterion and specifiers. Its suitability for establishing the HD diagnosis has been demonstrated in several studies, including the *London Field Trial for Hoarding Disorder*, which showed that diagnoses determined using the instrument showed an excellent balance of sensitivity (0.98) and specificity (1.0)³⁹.

Because the diagnosis of HD requires the presence of obstructive clutter (Criterion C), diagnostic assessments (such as the SIHD) are ideally done in the sufferer's home environment. This approach enables the clinician to tangibly evaluate the scale of the clutter, assess the extent of the resulting obstruction/impairment, and determine the presence of health and safety risks (e.g., fire hazards, infestations and/or unsanitary living conditions)^{35 37}. To assist with this process, the SIHD also contains a risk assessment module.

When in-home assessments are not possible, clinicians can use photographs to assess the extent of clutter⁵⁸. These photographs can be used in combination with the *Clutter Image Rating* (CIR)⁵⁹, which consists of a series of photographs depicting increasingly obstructive levels of clutter across the bedroom, kitchen, and living room. When a patient with HD shows limited or absent insight into their hoarding activity, a situation that may arise in a substantial proportion of hoarding cases, a multiple-informant approach (e.g., seeking both patient reports and information available from third parties) may be helpful⁶⁰. Given that much of this population does not recognise their problem, clinicians may find that few of their hoarding patients are voluntarily presenting for assessment or treatment. Accordingly, during the assessment process, clinicians should be aware that conflicts may arise between the patient's account of their behaviour and the portrait provided by third parties (e.g., patient records, so-

cial service reports, consultation with family members). Discrepancies should be tactfully addressed and clarification requested from all relevant sources. Should discrepancies persist, clinicians will need to exercise their clinical judgment in making a diagnostic determination.

Treatment

Traditionally, hoarding has been treated using approaches designed for OCD, with a focus on serotonergic compounds or cognitive-behavioural therapies (mainly exposure and response prevention). This clinical approach, which is the evidence-based treatment for OCD, has failed to produce satisfactory results in HD. A recent meta-analysis confirmed that patients with OCD and hoarding symptoms are less likely to respond to traditional OCD treatments, this finding being consistent across treatment modalities⁶¹.

In the case of secondary hoarding (i.e., hoarding symptoms in the context of OCD), treatment protocols indicated for OCD should be applied. It may be reasonable to assume that, in these cases, response will be similar to that achieved among OCD cases without hoarding symptoms/behaviours, though this has not been formally tested. Previous studies conducted in the context of OCD likely contained a mix of HD cases and of OCD-related hoarding cases, hence precluding firm conclusions in this regard.

Conversely, when hoarding is conceptualised as an independent or comorbid disorder (e.g., diagnosis of HD and OCD) specific treatment strategies for HD should be applied. Tailored cognitive behavioural therapy for HD, including education and case formulation, motivational interviewing, skills training for organising and problem solving, direct exposure to non-acquiring and discarding, and cognitive therapy, has been found to be effective for hoarders⁴⁰. Several other specific psychological interventions for HD have been developed, and these treatments may be used when HD is diagnosed. A recent meta-analysis confirmed that CBT is a promising treatment for HD, although there is significant room for improvement⁶². Empowering family members of subjects with HD with specific training programs seems to be an effective add-on treatment as well⁶³.

Only two studies have specifically investigated the effectiveness of pharmacological treatments in HD. Both studies, one for paroxetine⁶⁴ and the other for venlafaxine extended-release⁶⁵ were positive; however, both are small, uncontrolled studies and are hampered by methodological limitations (particularly regarding recruitment and assessment methods).

Although the number of studies investigating treatment

in the field is growing and results are generally positive and promising, it also has to be acknowledged that effective treatments for HD are still far from satisfactory. Double-blind, psychological and pharmacological placebo-controlled trials are strongly warranted and needed in patients with HD.

Conclusions

The inclusion of the new diagnosis of HD in DSM-5 within the OCRDs chapter will help researchers in studying clinical characteristics of the disorder and implementing effective treatments for those patients. There is, in fact, a strong need at present for finding treatment strategies which are both acceptable by patients and effective in treating the disorder.

References

- Mataix-Cols D, Frost RO, Pertusa A, et al. *Hoarding Disorder: a new diagnosis for DSM-V?* *Depress Anxiety* 2010;27:556-72.
- Bolman WM, Katz AS. *Hamburger hoarding: a case of symbolic cannibalism resembling Whitico psychosis.* *J Nerv Ment Dis* 1966;142:424-8.
- Snowdon J. *Accumulating too much stuff: what is hoarding and what is not.* *Australas Psychiatry* 2015;23:354-7.
- Frost RO, Gross RC. *The hoarding of possessions.* *Behav Res Ther* 1993;31:367-81.
- Frost RO, Hartl TL. *A cognitive-behavioral model of compulsive hoarding.* *Behav Res Ther* 1996;34:341-50.
- Bloch MH, Landeros-Weisenberger A, Rosario MC, et al. *Meta-analysis of the symptom structure of obsessive-compulsive disorder.* *Am J Psychiatry* 2008;165:1532-42.
- Mataix-Cols D, Rosario-Campos MC, Leckman JF. *A multi-dimensional model of obsessive-compulsive disorder.* *Am J Psychiatry* 2005;162:228-38.
- Mataix-Cols D, Pertusa A. *Hoarding disorder: potential benefits and pitfalls of a new mental disorder.* *J Child Psychol Psychiatry* 2012;53:608-18.
- Pertusa A, Fullana MA, Singh S, et al. *Compulsive hoarding: OCD symptom, distinct clinical syndrome, or both?* *Am J Psychiatry* 2008;165:1289-98.
- Rachman S, Elliot CM, Shafran R, et al. *Separating hoarding from OCD.* *Behav Res Ther* 2009;47:520-2.
- Pertusa A, Frost RO, Fullana MA, et al. *Refining the diagnostic boundaries of compulsive hoarding: a critical review.* *Clin Psychol Rev* 2010;30:371-86.
- Saxena S. *Is compulsive hoarding a genetically and neurobiologically discrete syndrome? Implications for diagnostic classification.* *Am J Psychiatry* 2007;164:380-4.
- Hwang JP, Tsai SJ, Jang CH, et al. *Hoarding behavior in dementia. A preliminary report.* *Am J Geriatr Psychiatry* 1998;6:285-9.

- 14 Marx MS, Cohen-Mansfield J. *Hoarding behavior in the elderly: a comparison between community-dwelling persons and nursing home residents*. *Int Psychogeriatr* 2003;15:289-306.
- 15 Dykens EM, Leckman JF, Cassidy SB. *Obsessions and compulsions in Prader-Willi syndrome*. *J Child Psychol Psychiatry* 1996;37:995-1002.
- 16 Gothelf D, Presburger G, Zohar AH, et al. *Obsessive-compulsive disorder in patients with velocardiofacial (22q11 deletion) syndrome*. *Am J Med Genet B Neuropsychiatr Genet* 2004;126B:99-105.
- 17 Stein DJ, Laszlo B, Marais E, et al. *Hoarding symptoms in patients on a geriatric psychiatry inpatient unit*. *S Afr Med J* 1997;87:1138-40.
- 18 Wustmann T, Brieger P. *[A study of persons living in neglect, filth and squalor or who have a tendency to hoard]*. *Gesundheitswesen* 2005;67:361-8.
- 19 Tolin DF, Meunier SA, Frost RO, et al. *Hoarding among patients seeking treatment for anxiety disorders*. *J Anxiety Disord* 2011;25:43-8.
- 20 Mueller A, Mitchell JE, Crosby RD, et al. *The prevalence of compulsive hoarding and its association with compulsive buying in a German population-based sample*. *Behav Res Ther* 2009;47:705-9.
- 21 Frost RO, Steketee G, Tolin DF. *Comorbidity in hoarding disorder*. *Depress Anxiety* 2011;28:876-84.
- 22 Olatunji BO, Williams BJ, Haslam N, et al. *The latent structure of obsessive-compulsive symptoms: a taxometric study*. *Depress Anxiety* 2008;25:956-68.
- 23 An SK, Mataix-Cols D, Lawrence NS, et al. *To discard or not discard: the neural basis of hoarding symptoms in obsessive-compulsive disorder*. *Mol Psychiatry* 2009;14:318-31.
- 24 Saxena S, Brody AL, Maidment KM, et al. *Cerebral glucose metabolism in obsessive-compulsive hoarding*. *Am J Psychiatry* 2004;161:1038-48.
- 25 Tolin DF, Kiehl KA, Worchunsky P, et al. *An exploratory study of the neural mechanism of decision making in compulsive hoarding*. *Psychol Med* 2009;39:325-36.
- 26 Ayers CR, Saxena S, Golshan S, et al. *Age at onset and clinical features of late life compulsive hoarding*. *Int J Geriatr Psychiatry* 2010;25:142-9.
- 27 Grisham JR, Frost RO, Steketee G, et al. *Age of onset of compulsive hoarding*. *J Anxiety Disord* 2006;20:675-86.
- 28 Mataix-Cols D, Rauch SL, Manzo PA, et al. *Use of factor-analyzed symptom dimensions to predict outcome with serotonin reuptake inhibitors and placebo in the treatment of obsessive-compulsive disorder*. *Am J Psychiatry* 1999;156:1409-26.
- 29 Stein DJ, Carey PD, Lochner C, et al. *Escitalopram in obsessive-compulsive disorder: Response of symptom dimensions to pharmacotherapy*. *CNS Spectrum* 2008;13:492-8.
- 30 Tolin DF, Meunier SA, Frost RO, et al. *Course of compulsive hoarding and its relationship to life events*. *Depress Anxiety* 2010b;27:829-38.
- 31 Mataix-Cols D. *Hoarding Disorder*. *N Engl J Med* 2014;370:2023-30.
- 32 Frost RO, Steketee G, Williams L. *Hoarding: a community health problem*. *Health Soc Care Community* 2000;8:229-34.
- 33 Saxena S, Ayers CR, Maidment KM, et al. *Quality of life and functional impairment in compulsive hoarding*. *J Psychiatr Res* 2011;45:475-80.
- 34 Drury H, Ajmi S, Fernández de la Cruz L, et al. *Caregiver burden, family accommodation, health, and well-being in relatives of individuals with hoarding disorder*. *J Affect Disord* 2014;159:7-14.
- 35 Tolin DF, Frost RO, Steketee G, et al. *The economic and social burden of compulsive hoarding*. *Psychiatr Res* 2008;160:200-11.
- 36 Nordsletten AE, Fernández de la Cruz L, Billotti D, et al. *Finders keepers: the features differentiating hoarding disorder from normative collecting*. *Compr Psychiatry* 2013a;54:229-37.
- 37 Snowdon J, Pertusa A, Mataix-Cols D. *On hoarding and squalor: a few considerations for DSM-5*. *Depress Anxiety* 2012;29:417-24.
- 38 Frost RO, Tolin DF, Steketee G, et al. *Excessive acquisition in hoarding*. *J Anxiety Disord* 2009;23:632-9.
- 39 Mataix-Cols D, Billotti D, Fernandez de la Cruz L, et al. *The London field trial for hoarding disorder*. *Psychol Med* 2013;43:837-47.
- 40 Steketee G, Frost RO, Tolin DF, et al. *Waitlist-controlled trial of cognitive behavior therapy for hoarding disorder*. *Depress Anxiety* 2010;27:476-84.
- 41 Lochner C, Kinnear CJ, Hemmings SM, et al. *Hoarding in obsessive-compulsive disorder: clinical and genetic correlates*. *J Clin Psychiatry* 2005;66:1155-60.
- 42 Samuels JF, Bienvenu OJ, Pinto A, et al. *Hoarding in obsessive-compulsive disorder: results from the OCD Collaborative Genetics Study*. *Behav Res Ther* 2007c;45:673-86.
- 43 Wheaton M, Timpano KR, Lasalle-Ricci VH, et al. *Characterizing the hoarding phenotype in individuals with OCD: associations with comorbidity, severity and gender*. *J Anxiety Disord* 2008;22:243-52.
- 44 Matsunaga H, Hayashida K, Kiriike N, et al. *Clinical features and treatment characteristics of compulsive hoarding in Japanese patients with obsessive-compulsive disorder*. *CNS Spectr* 2010;15:258-65.
- 45 Albert U, Barbaro F, Aguglia A, et al. *Hoarding and obsessive-compulsive disorder (OCD): two separate, comorbid disorders or hoarding secondary to OCD? Quaderni Italiani di Psichiatria* 2012;31:164-73.
- 46 Pertusa A, Frost RO, Mataix-Cols D. *When hoarding is a symptom of OCD: a case series and implications for DSM-V*. *Behav Res Ther* 2010b;48:1012-20.
- 47 Nordsletten A, Fernandez de la Cruz L, Pertusa A, et al. *The Structured Interview for Hoarding Disorder (SIHD): development, usage and further validation*. *J Obsess Compuls Related Dis* 2013;2:346-50.
- 48 Nordsletten AE, Reichenberg A, Hatch SL, et al. *Epidemiology of hoarding disorder*. *Br J Psychiatry* 2013;203:445-52.

- ⁴⁹ Samuels JF, Bienvenu OJ, Grados MA, et al. *Prevalence and correlates of hoarding behavior in a community-based sample*. Behav Res Ther 2008;46:836-44.
- ⁵⁰ Iervolino AC, Perroud N, Fullana MA, et al. *Prevalence and heritability of compulsive hoarding: a twin study*. J Am Acad Child Adolesc Psychiatry 2009;166:1156-61.
- ⁵¹ Ivanov VZ, Mataix-Cols D, Serlachius E, et al. *Prevalence, comorbidity and heritability of hoarding symptoms in adolescence: a population based twin study in 15-year olds*. PLoS One 2013;8:e69140.
- ⁵² Timpano KR, Exner C, Glaesmer H, et al. *The epidemiology of the proposed DSM-5 hoarding disorder: exploration of the acquisition specifier, associated features, and distress*. J Clin Psychiatry 2011;72:780-6.
- ⁵³ Bulli F, Melli G, Carraresi C, et al. *Hoarding behaviour in an Italian non-clinical sample*. Behav Cogn Psychother 2014;42:297-311.
- ⁵⁴ Perroud N, Guipponi M, Pertusa A, et al. *Genome-wide association study of hoarding traits*. Am J Med Genet B Neuropsychiatr Genet 2011;156:240-2.
- ⁵⁵ Landau D, Iervolino AC, Pertusa A, et al. *Stressful life events and maternal deprivation in hoarding disorder*. J Anxiety Disord 2011;25:192-202.
- ⁵⁶ Grisham JR, Baldwin PA. *Neuropsychological and neurophysiological insights into hoarding disorder*. Neuropsychiatr Dis Treat 2015;11:951-62.
- ⁵⁷ DiMauro J, Tolin DF, Frost RO, et al. *Do people with hoarding disorder under-report their symptoms?* J Obsessive Compuls Relat Disord 2013;2:130-6.
- ⁵⁸ Fernández de la Cruz L, Nordsletten AE, Billotti D, et al. *Photograph-aided assessment of clutter in hoarding disorder: is a picture Worth a thousand words?* Depress Anxiety 2013;30:61-6.
- ⁵⁹ Frost RO, Steketee G, Tolin D, et al. *Development and validation of the clutter image rating*. J Psychopathol Behav Assess 2008;30:193-203.
- ⁶⁰ Tolin D, Fitch K, Frost R, et al. *Family informants' perceptions of insight in compulsive hoarding*. Cognit Ther Res 2010;34:69-81.
- ⁶¹ Bloch MH, Bartley CA, Zipperer L, et al. *Meta-analysis: hoarding symptoms associated with poor treatment outcome in obsessive-compulsive disorder*. Mol Psychiatry 2014;19:1025-30.
- ⁶² Tolin DF, Frost RO, Steketee G, et al. *Cognitive behavioral therapy for hoarding disorder: a meta-analysis*. Depress Anxiety 2015;32:158-66.
- ⁶³ Chasson GS, Carpenter A, Ewing J, et al. *Empowering families to help a loved one with hoarding disorder: pilot study of Family-As-Motivators training*. Behav Res Ther 2014;63:9-16.
- ⁶⁴ Saxena S, Brody AL, Maidment KM, et al. *Paroxetine treatment of compulsive hoarding*. J Psychiatr Res 2007b;41:481-7.
- ⁶⁵ Saxena S, Sumner J. *Venlafaxine extended-release treatment of hoarding disorder*. Int Clin Psychopharmacol 2014;29:266-73.