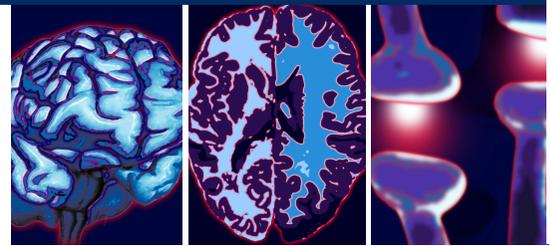
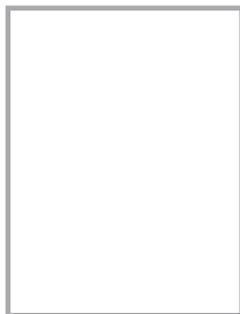


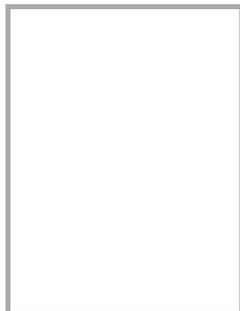
ASK THE EXPERTS



Hoarding disorder



Ashley E Nordsletten¹: Ashley Nordsletten is a post-doctoral researcher at the Karolinska Institutet (Stockholm, Sweden). She obtained her doctorate in psychology from the Institute of Psychiatry, King's College London (London, UK) where her studies focused on the nosology, epidemiology and assessment of hoarding disorder.



David Mataix-Cols^{*1}: David Mataix-Cols is now professor of child and adolescent psychiatric research at the Karolinska Institutet, and previously at the Institute of Psychiatry and Maudsley Hospital (London, UK). He runs a program of research aimed at understanding the causes of anxiety, obsessive-compulsive and related disorders across the lifespan and the development of better and more cost-effective treatments for these problems. He is author of over 150 peer-reviewed publications and recipient of multiple grants and awards from the UK, USA, EU, Sweden and Spain. As advisor to the DSM-5 Obsessive-Compulsive

Spectrum Sub-Work Group he was instrumental to the inclusion of hoarding disorder as a separate mental disorder in the nomenclature.

Q As the inclusion of a new mental disorder in the nomenclature is not a trivial matter, what evidence supports the introduction of hoarding as a stand-alone disorder?

In the psychiatric nomenclature, hoarding behavior has historically been associated with either obsessive compulsive personality disorder or obsessive compulsive disorder (OCD) – a simplified diagnostic view as hoarding symptoms are known to emerge in the context of multiple medical

(e.g., brain lesions), neuropsychiatric (e.g., autism spectrum disorders and schizophrenia) and neurodegenerative (e.g., dementia) conditions. In recent decades, research has converged to indicate that hoarding difficulties most often emerge independently from such conditions. For example, while 5–10% of OCD patients display hoarding symptoms, the majority (>80%) of individuals with hoarding difficulties do not endorse OCD criteria [1–3]. Research reviewed by the DSM-5 workgroup further

News & Views

News

Journal Watch

Ask the Experts

Interview

"Quote"

¹Department of Clinical Neuroscience, Karolinska Institutet, Stockholm, Sweden

^{*}Author for correspondence: david.mataix-cols@kcl.ac.uk

“Quote”

outlined significant differences between hoarding and OCD in regard to their symptom phenomenology, clinical course, cognitive–behavioral–emotional processes, neurocognitive correlates and genetics (for reviews see [4,5]). Importantly, research across large OCD samples indicated that the presence of hoarding symptoms consistently predicts suboptimal treatment outcomes (for a review, see [5]) – a finding which signaled the utility of splitting hoarding from OCD to establish tighter and more meaningful diagnostic boundaries, prompt the development of hoarding-specific treatments and, ultimately, improve patient outcomes across these conditions. Finally, extensive literature reviews concluded that the advantages of this new diagnostic entity (e.g., identification of the majority of cases who demonstrably suffer and need help, but who are currently missed or misclassified in existing diagnostic categories) outweighed the potential harms (e.g., danger of pathologizing normal behavior) [4,6] and ultimately prompted the inclusion of hoarding disorder (HD) in DSM-5. International Classification of Diseases-11, currently in preparation, will follow suit and include a similar diagnostic entity.

Q What factors does a clinician need to consider in order to make a confident diagnosis of HD?

A diagnosis of HD requires endorsement of each of the disorder’s six core diagnostic criteria [7]: persistent difficulty discarding, distress associated with discarding, congestive clutter, clinically significant distress or impairment, symptoms not attributable to other relevant medical conditions and symptoms not attributable to other relevant psychiatric conditions. In cases where the patient has good insight, self-reports may suffice for establishing the presence or absence of each criterion (e.g., during a diagnostic interview; see [8]). However, as HD cases are often characterized by poor insight [9], use of more objective measures and/or the use of reliable informants is often a necessity. Where possible, home visits are ideal for establishing the degree of clutter and the extent of functional impairment. However, where such visits are precluded,

photographs may suffice for this information [10]. Reports gathered from informants may also help in establishing whether the current presentation is long-standing or transient (persistent difficulty discarding), whether third parties have intervened to clear some of the clutter away (congestive clutter) and whether there are any evident risks that require addressing.

A confident diagnosis of HD will also require that clinicians carefully exclude all other potential causes of the observed hoarding activity (symptoms not attributable to other relevant medical conditions and symptoms not attributable to other relevant psychiatric conditions). A thorough review of each patient’s medical and personal history is recommended, particularly to clarify the onset, course and motivations that characterize the hoarding behaviors. In the majority of HD cases, for example, onset is reported in early life with symptoms worsening over each subsequent decade (see below). Where hoarding symptoms have emerged suddenly or in late life, particular care would need to be taken to ensure that alternative medical (e.g., brain injury and neurodegenerative processes) or transient personal events (e.g., family death and relocation) do not account for the influx or disorganization of items. Consultation with pertinent third parties, such as family members or social services, is helpful to establish these facts and may be essential for low-insight cases [8].

Q What differentiates pathological hoarding from normative collecting?

At first glance hoarding bears a strong resemblance to collecting, with both activities centering on the accumulation of items that are highly, even inordinately, treasured by their owner. Further investigation, however, has indicated key differences between these activities. What primarily makes hoarding ‘problematic’, for example, is its characteristic disorganization – a feature that ultimately congests the sufferer’s living environment and results in significant functional impairments and emotional distress. By contrast, ‘normative’ collecting is widely viewed as a healthy leisure activity, ‘a form of play with classification’ that is typified by a high degree of organization

and enjoyment [11–13].

Use of the term ‘normative’ when referring to collecting, also reflects realities about the prevalence of this activity. While 70% of children and up to a third of adults have engaged in collecting behavior at a given time, the prevalence of problematic hoarding is estimated to be 2–5% of the population [12,14]. Differences in the content profiles of these hoards and collections have been readily observed. As a rule, the contents of a hoard lack a cohesive theme and are, typically, presented as an amalgam of widely varied objects. The items of a collection, conversely, are defined by their inter-relatedness – the constituent pieces being bound by a single, often highly specific, theme or feature. Even in situations where the number of collected items is extensive, this specificity of acquisition – paired with collectors’ emphasis on orderly arrangement and display – makes normative collecting readily distinguishable from hoarding in the majority of cases. The bottom line is that hoarding and collecting are qualitatively distinct entities, with collectors being unlikely to meet diagnostic criteria for HD. While it is possible for a person to have HD and engage in genuine collecting behaviors, research indicates that such instances are rare [13].

Q HD is often framed as an ‘old age’ problem. What is the prevalence of hoarding across different age groups?

The majority of individuals presenting for treatment are in their 50’s. However, research has suggested that symptoms typically emerge well in advance of these first consultations and, in many cases, may be traced to the early years of life. While the majority of this research has involved retrospective reporting, the literature suggests that hoarding symptoms most often surface in the early years of adolescence (≤ 15 years of age) [15] and swell in severity thereafter as more items are amassed and the impacts of the resultant clutter become more pronounced [16]. Interference, as a product of this clutter, may initiate in the early years of adulthood, with clinically significant distress arising by the mid-30s and continuing to grow in tandem with the clutter over each subsequent decade [17]. The

observed delay in treatment seeking is, at least in part, accounted for by the incremental nature of this disorder – the central feature of which depends on the amassment of a large number of items over time. However, the ubiquity of poor insight among hoarding cases [9] may also explain that late initiation of treatment that characterizes this population – particularly as a subset of these cases are known to engage in treatment only at the behest of family members, local authorities or care services.

Q Are there currently identifiable genetic, environmental or other risk factors for developing HD? If so, what are they?

Preliminary research in twins has suggested that genetic factors account for approximately half of the variance in ‘compulsive hoarding’, with nonshared environmental factors also playing a significant role [18]. As yet, specific genes have not been consistently identified. While ‘material deprivation’ in childhood is often colloquially linked with hoarding, the relevant research has offered no support for this hypothesized association [19]. A growing number of studies have, however, recorded high rates of ‘traumatic events’ (e.g., physical abuse and burglary) in hoarding populations. Cross-sectional studies have suggested that these traumatic experiences may be predictive, not only of the presence of hoarding activity, but also the severity of the associated symptoms (e.g., clutter) [16,17,19]. The weight of these findings remains limited by a lack of prospective work, which has restricted researchers’ ability to confidently establish any temporal relationship between trauma and the onset or exacerbation of hoarding symptoms. As research on HD moves forward, investment in these studies will be essential for clarifying the disorder’s etiology and, ultimately, signaling viable routes for intervention.

Q What current treatment options exist for patients with HD? What are the positives and negatives of the various treatments?

Clinical research, in the context of HD, is still in its infancy. However, with findings suggesting that traditional evidence-based

“Quote”

OCD treatments (cognitive–behavior therapy and selective serotonin reuptake inhibitors) demonstrate suboptimal efficacy in hoarding patients, the need for new pharmacological and psychological intervention approaches is evident. Currently, the treatment with the most extensive evidence base for HD is a multimodal therapy derived from a cognitive–behavioral model of hoarding [20]. This approach blends motivational enhancement techniques and goal setting, with behavior modification (e.g., exposure to discarding) and skills training (e.g., object organization and decision-making when discarding/acquiring) [21]. In a recent wait-list controlled trial evaluating this method, 41% of patients were deemed to have made clinically significant improvements post-treatment [22]. However, issues with poor rates of enrollment and high rates of attrition, along with the high costs associated with this treatment, have limited the appeal of this approach.

Alternative treatment methods, such as bibliotherapy, peer group therapy and internet cognitive–behavior therapy, have been put forward as options for increasing the cost–effectiveness of hoarding treatment [23]. In addition, methods focused on the treatment of challenging cases (e.g., elderly

sufferers) have been proposed and initially tested [24]. While initial investigations suggest these methods are promising, more research is needed to test both traditional and novel pharmacological and psychological treatments, alone and in combination, in samples of patients who have been carefully diagnosed with primary HD. Monitoring of long-term outcomes, to examine whether short-term therapeutic gains are maintained, will also be essential for establishing optimal treatment regimes. Research concerned with how these regimes should be modified for complex populations – for example, among autism spectrum disorder cases with comorbid HD – is, furthermore, warranted.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

References

- 1 Frost RO, Steketee G, Tolin D. Comorbidity in hoarding disorder. *Depress. Anxiety* 28(10), 876–884 (2011).
- 2 Mataix-Cols D, Billotti D, Fernandez de la Cruz F, Nordsletten AE. The London field trial for hoarding disorder. *Psychol. Med.* 43(4), 837–847 (2013).
- 3 Pertusa A, Fullana MA, Singh S, Alonso P, Menchón JM, Mataix-Cols D. Compulsive hoarding: OCD symptom, distinct clinical syndrome, or both? *Am. J. Psychiatry* 165(10), 1289–1298 (2008).
- 4 Mataix-Cols D, Frost RO, Pertusa A *et al.* Hoarding disorder: a new diagnosis for DSM-V? *Depress. Anxiety* (27)6, 556–572 (2010).
- 5 Pertusa A, Frost RO, Fullana MA *et al.* Refining the diagnostic boundaries of compulsive hoarding: a critical review. *Clin. Psychol. Rev.* 30(4), 371–386 (2010).
- 6 Mataix-Cols D, Pertusa A. Annual research review: hoarding disorder: potential benefits and pitfalls of a new mental disorder. *J. Child Psychol. Psychiatry* 53(5), 608–618 (2012).
- 7 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Health Disorders: DSM-5(5th edition)*. American Psychiatric Publishing, DC, USA (2013).
- 8 Nordsletten AE, Fernández de la Cruz L, Pertusa A, Reichenberg A, Hatch SL, Mataix-Cols D. The Structured Interview for Hoarding Disorder (SIHD): development, usage and further validation. *J. Obsessive Compuls. Relat. Disord.* 2(3), 346–350 (2013).
- 9 Tolin DF, Fitch KE, Frost RO, Steketee G. Family informants' perceptions of insight in compulsive hoarding. *Cogn. Ther. Res.* 34, 69–81 (2010).
- 10 Fernández de la Cruz L, Nordsletten AE, Billotti D, Mataix-Cols D. Photograph-aided assessment of clutter in hoarding disorder: is a picture worth a thousand words? *Depress. Anxiety* 30(1), 61–66 (2013).
- 11 Long MM, Schiffman LG. Swatch fever: an allegory for understanding the paradox of collecting. *Psychol. Mark.* 15(5), 495–509 (1998).
- 12 Nordsletten AE, Mataix-Cols D. Hoarding versus collecting: where does pathology diverge from play? *Clin. Psychol. Rev.* 32(3), 165–176 (2012).
- 13 Nordsletten AE, Fernández de la Cruz L, Billotti D, Mataix-Cols D. Finders keepers: the features differentiating hoarding disorder from normative collecting. *Compr. Psychiatry* 54(3), 229–237 (2013).
- 14 Pearce A. *Collecting in Contemporary Practice*. SAGE Publications, London, UK (1998).
- 15 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* 8(7), e69140 (2013).
- 16 Tolin DF, Meunier SA, Frost RO, Steketee G. Course of compulsive hoarding and its relationship to life events. *Depress. Anxiety* 27(9), 829–838 (2010).
- 17 Grisham JR, Frost RO, Steketee G, Kim HJ, Hood S. Age of onset of compulsive hoarding.

- J. Anxiety Disord.* 20(5), 675–686 (2006).
- 18 Iervolino AC, Perroud N, Fullana MA *et al.* Prevalence and heritability of compulsive hoarding: a twin study. *Am. J. Psychiatry* 166(10), 1156–1161 (2009).
- 19 Landau D, Iervolino AC, Pertusa A, Santo S, Singh S, Mataix-Cols D. Stressful life events and material deprivation in hoarding disorder. *J. Anxiety Disord.* 25(2), 192–202 (2011).
- 20 Frost RO, Hartl TL. A cognitive-behavioral model of compulsive hoarding. *Behav. Res. Ther.* 34(4), 341–350 (1996).
- 21 Frost RO, Steketee G. *Compulsive Hoarding and Acquiring: Therapist Guide*. Cambridge University Press, Cambridge, UK (2006).
- 22 Steketee G, Frost RO, Tolin DF, Rasmussen J, Brown TA. Waitlist-controlled trial of cognitive behavioral therapy for hoarding disorder. *Depress. Anxiety* 27(5), 476–484 (2010).
- 23 Gilliam CM, Norberg MM, Villavicencio A, Morrison S, Hannan SE, Tolin DF. Group cognitive-behavioral therapy for hoarding disorder: an open trial. *Behav. Res. Ther.* 49(11), 802–807 (2011).
- 24 Ayers CR, Wetherell JL, Golshan S, Saxena S. Cognitive-behavioral therapy for geriatric compulsive hoarding. *Behav. Res. Ther.* 49(10), 689–694 (2011).