Annual Research Review: Hoarding disorder – potential benefits and pitfalls of a new mental disorder

David Mataix-Cols and Alberto Pertusa
Departments of Psychosis Studies and Psychology, King’s College London, Institute of Psychiatry, London, UK

Background: The inclusion of a new mental disorder in the nomenclature is not a trivial matter. Many have highlighted the risks of an ever-increasing number of mental disorders and of overpathologizing human behaviour. Given the proposed inclusion of a new hoarding disorder (HD) in DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, fifth edition), it is pertinent to discuss the potential benefits and pitfalls of such a development. Method: In this article, we examine whether HD fits with the current DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, fourth edition) and proposed DSM-5 definitions of ‘mental disorder’. We next discuss the potential benefits and risks of the creation of this diagnosis. Finally, we address some additional considerations that may arise when proposing a new disorder for the nomenclature and identify some of the gaps in the knowledge base. Conclusion: HD fits the current DSM-IV and proposed DSM-5 definitions for a mental disorder. On balance, the potential benefits of creating the new diagnosis (e.g. identification of the majority of cases who clearly suffer and need help but are currently missed out by the existing diagnostic categories) outweigh the potential harms (e.g. pathologizing normal behaviour). Whether the criteria will need modification for their use in children/adolescents is unclear and more research is needed to address this question. Keywords: Hoarding disorder, DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM-IV-TR)), DSM-5, obsessive-compulsive disorder.

Introduction
Collecting and saving are widespread human activities, with approximately 30% of the British population reportedly owning a collection (Pearce, 1998). Most normal children have collections of some sort (Evans et al., 1997; James, 1890; Zohar & Felz, 2001). A cross-sectional study amongst parents reported that their children began to collect or store objects on average from 25 to 27 months of age (Evans et al., 1997). This behaviour then showed a monotonic increase, at least until the age of 6 years, when nearly 70% of normal children displayed this trait (Evans et al., 1997).

From an evolutionary perspective, the tendency to collect or hoard possessions could be regarded as adaptive, by ensuring survival when resources become scarce (Grisham & Barlow, 2005; Leckman, Mataix-Cols, & Rosario-Campos, 2005). However, when hoarding behaviour is taken to extreme lengths the consequences can significantly interfere with many aspects of private, social and occupational life. For example, the degree of clutter can impede the completion of household chores and lead to relationship conflict, embarrassment, social withdrawal and the inability to work (Frost & Hartl, 1996). At its most severe state, hoarding can pose serious risks to health and safety, such as falling, fire and sanitation problems, which are especially common amongst older people (Frost, Steketee, & Williams, 2000; Kim, Steketee, & Frost, 2001).

Hoarding behaviour has been described in multiple organic and mental disorders, such as dementia, schizophrenia or autism (Pertusa, Frost, Fullana et al., 2010; Steketee & Frost, 2003). Although hoarding is commonly linked with obsessive-compulsive disorder (OCD), it is not directly mentioned in DSM IV-TR or ICD-10 as a symptom of OCD. In DSM IV-TR, hoarding is listed as one of the eight diagnostic criteria for obsessive-compulsive personality disorder (OCPD). In the description of the differential diagnosis between OCPD and OCD, DSM IV-TR states that a diagnosis of OCD should be considered especially 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). (p. 728)

Thus, DSM IV-TR assumes that in severe cases hoarding can be a symptom of OCD. Of note, this was not the case in any of the previous editions of the DSM (Mataix-Cols et al., 2010).

While there is little doubt that hoarding can be a symptom of OCD or secondary to typical obsessive fears, such as difficulties discarding items for fear of contaminating or harming others (Pertusa, Frost, & Mataix-Cols, 2010), there is an increasing body of evidence supporting the view that, in most cases, hoarding symptoms are not OCD-related. For example, although approximately 5–10% of patients...
with OCD display hoarding symptoms, the majority of individuals (>80%) with hoarding problems do not display other OCD symptoms (Frost, Steketee, & Tolin, in press; Pertusa et al., 2008; Samuels et al., 2008). In fact, the most common comorbidities amongst hoarding cases are depression and anxiety disorders other than OCD (Frost et al., in press). Furthermore, severe hoarding symptoms may be equally prevalent in individuals with anxiety disorders other than OCD, although these symptoms often go unnoticed as clinicians do not ask about them (Tolin, Meunier, Frost, & Steketee, 2011).

Research reviewed elsewhere has also revealed important differences between hoarding and OCD, including symptom phenomenology, degree of insight, clinical course, cognitive–behavioural–emotional processes, neurocognitive correlates, genetics and treatment response (Mataix-Cols et al., 2010; Pertusa, Frost, Fullana, et al., 2010; Rachman, Elliott, Shafran, & Radomsky, 2009; Saxena, 2008b). In light of this accumulating evidence, the DSM-5 Obsessive Compulsive Spectrum Sub-Work Group of the Anxiety, Obsessive-Compulsive Spectrum, Posttraumatic, and Dissociative Disorders Work Group is currently recommending the creation of a new diagnostic category in the nomenclature named hoarding disorder (HD; Mataix-Cols et al., 2010; http://www.dsm5.org). The provisional diagnostic criteria for HD are listed in Table 1. It is proposed that HD will be under a broader umbrella of Obsessive-Compulsive Spectrum Disorders (Phillips et al., 2010). The Sub-Work Group is also proposing the removal of the hoarding criterion of OCPD, a recommendation that is also endorsed by the DSM-5 Personality Disorders Workgroup (Mataix-Cols et al., 2010).

Table 1 Provisional diagnostic criteria for hoarding disorder in DSM-5

| A. Persistent difficulty discarding or parting with possessions, regardless of their actual value. |
| B. This difficulty is due to strong urges to save items and/or distress associated with discarding. |
| C. The symptoms result in the accumulation of a large number of possessions that fill up and clutter active living areas of the home or workplace to the extent that their intended use is no longer possible. If all living areas are uncluttered, it is only because of the interventions of third parties (e.g. family members, cleaners and authorities). |
| D. The symptoms cause 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 symptoms are not due to a general medical condition (e.g. brain injury and cerebrovascular disease). |
| F. The hoarding symptoms are not restricted to the symptoms of another mental disorder (e.g. hoarding due to obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in dementia, restricted interests in autism spectrum disorder, food storing in Prader–Willi syndrome). |

**Specifiers**

*Specify if with excessive acquisition:* If symptoms are accompanied by excessive collecting or buying or stealing of items that are not needed or for which there is no available space.

*Specify whether hoarding beliefs and behaviours are currently characterized by:*

- **Good or fair insight:** Recognizes that hoarding-related beliefs and behaviours (pertaining to difficulty discarding items, clutter or excessive acquisition) are problematic.
- **Poor insight:** Mostly convinced that hoarding-related beliefs and behaviours (pertaining to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary.
- **Absent insight** (delusional): Completely convinced that hoarding-related beliefs and behaviours (pertaining to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary.

The creation of a new mental disorder is not a trivial matter. Many have highlighted the risks of an ever-increasing number of mental disorders (e.g. Frances, 2009). For example, Dr Allen Frances, who chaired the DSM-IV taskforce, has convincingly warned us of the risks of overpathologizing normal behaviour and of the adverse consequences of drastic changes in the way mental disorders are defined (Frances, 2009, 2010). In the light of previous historical errors (e.g. First & Frances, 2008), it is of paramount importance that we try to anticipate and, if appropriate, prevent the possible adverse effects of creating any new disorders.

**Aims of this review**

In this article, we begin by examining whether HD fits with the current DSM-IV and proposed DSM-5 definitions of ‘mental disorder’ (Stein et al., 2010). We next discuss the potential benefits and risks of the creation of this diagnosis. Finally, we address some additional considerations that may arise when proposing a new disorder for the nomenclature and identify some of the gaps in the knowledge base.

**Is hoarding a mental disorder?**

Defining mental disorder has proven a challenge through the various editions of DSM. This is largely because the border between normal and abnormal is intrinsically fuzzy. Nevertheless, DSM-IV offers an operational definition of mental disorder, which emphasizes the presence of distress and disability. In the context of the development of DSM-5, Stein et al. (2010) have suggested slight changes to the DSM-IV definition of mental disorder, including the
requirements of diagnostic validity (e.g. prognostic significance, evidence of psychobiological disruption) and clinical utility (i.e. diagnoses should facilitate the process of patient evaluation and treatment rather than hinder it; Table 2). Next, we discuss the proposed DSM-5 definition of mental disorder vis-à-vis HD.

(A) The condition is a behavioural or psychological syndrome or pattern that occurs in an individual

The entity of hoarding has been described in the mental health literature for over a century and has its origins in the psychoanalytical descriptions of the ‘anal’ character (Mataix-Cols et al., 2010; Wu & Watson, 2005). The operational definition and provisional diagnostic criteria for ‘compulsive’ hoarding as a syndrome were put forward 15 years ago (Frost & Hartl, 1996):

1. The acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value.
2. Living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed.
3. Significant distress or impairment in functioning caused by the hoarding.

These early criteria have been widely adopted by the field and used, or adapted for use, in multiple psychopathological, epidemiological, neuroimaging and treatment studies over the last decade and a half (see Pertusa, Frost, Fullana, et al., 2010; Steketee & Frost, 2003; for comprehensive reviews). The proposed DSM-5 criteria for HD (Table 1) are based on the original criteria by Frost and Hartl (1996) and are the result of the cumulative knowledge gained over the last 15 years. These provisional criteria were posted online (http://www.dsm5.org) and commented upon by professionals, patient organizations and the general public, leading to several improvements in their wording.

Prevalence studies using the proposed diagnostic criteria for HD are not available. However, a series of recent epidemiological studies have been conducted using reliable and valid psychometric instruments, which closely mirror the proposed diagnostic criteria, such as the Savings Inventory–Revised (Frost, Steketee, & Grisham, 2004) and the Hoarding Rating Scale–Self Report (Tolin, Frost, & Steketee, 2010). The prevalence of clinically significant hoarding is estimated to be in the region of 2–5% of the general population (Fullana et al., 2010; Iervolino et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakraborty et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008) and 10–20% in anxiety disorder or OCD clinics (Chakrabo

(B) The consequences of which are clinically significant distress or disability

Although the ‘clinical significance’ criterion has been criticized for being redundant in some mental disorders (Spitzer & Wakefield, 1999), the proposed DSM-5 definition of mental disorder has retained this criterion as it is useful in differentiating normal from abnormal behaviour (Stein et al., 2010). This seems highly pertinent to HD because saving and collecting are widespread human behaviours and it can potentially be difficult to separate adaptive and dysfunctional forms of object accumulation.

The extant literature provides evidence that hoarding can directly cause significant distress and/or disability. When hoarding is severe enough to meet diagnostic criteria for HD, clutter prevents the normal use of space to accomplish basic activities, such as cooking, cleaning, moving through the...
Hoarding disorder

house and even sleeping. Interference with these functions can make hoarding a dangerous problem, putting people at risk for fire, falling (especially elderly people), poor sanitation and health risks (Damecour & Charron, 1998; Frost et al., 2000; Steketee & Frost, 2003; Thomas, 1997). In a survey of health department complaints about hoarding, officers judged hoarding to pose significant health risks and in 6% of such cases, hoarding was thought to contribute to the individual’s death in a house fire (Steketee & Frost, 2003). Pathological hoarding also represents a profound public health burden in terms of occupational impairment, poor physical health and social service utilization (Tolin, Frost, Steketee, Gray, & Fitch, 2008). For example, the work impairment index amongst hoarders significantly exceeds that of any other anxiety, mood or substance use disorders (Tolin, Frost, Steketee, et al., 2008). This study also found that 8–12% of hoarding participants had been evicted or threatened with eviction due to hoarding at some point in their lives (Tolin, Frost, Steketee, et al., 2008). Hoarding also has a substantial impact on the family members of the sufferers (Tolin, Frost, Steketee, & Fitch, 2008). In addition to these direct consequences of hoarding, some indirect consequences have also been described, such as social isolation or hostility from neighbours, which further add to the problem. Taken together, these direct and indirect consequences of hoarding are serious enough to warrant its consideration as a mental disorder.

(C) The proposed syndrome is not merely an expectable response to common stressors or losses, or a culturally sanctioned response to a particular event

Common lore suggests that HD could be linked to early material deprivation, but the research available to date has not supported this. Frost and Gross (1993) found that hoarders and nonhoarders did not differ in their responses to the question When you were young, was there a period of time when you had very little money? There was also no difference in ratings of how ‘impoverished’ or ‘well-off’ they described their childhood. In a more recent study, individuals meeting criteria for HD were no more likely than non-hoarding individuals to have experienced a lack of money, food, adequate clothing or shelter during their lifetime (Landau et al., 2010).

A number of studies have found abnormally high levels of trauma or stressful life events amongst people who hoard (Cromer, Schmidt, & Murphy, 2007; Hartl, Duffany, Allen, Steketee, & Frost, 2005; Landau et al., 2010; Samuels et al., 2008). Such events are sometimes temporally linked to symptom onset or exacerbation (Grisham, Frost, Steketee, Kim, & Hood, 2006; Landau et al., 2010; Tolin, Meunier, Frost, & Steketee, 2010). However, once symptoms begin, the course of hoarding is often chronic, with a minority of patients experiencing a remitting and relapsing course (Tolin, Meunier, Frost, et al., 2010). Thus, in most cases, there is no evidence that HD is merely a transient and expectable response to common stressors or losses. For example, individuals who have large numbers of items due to transient life circumstances (e.g. inheritance of a relative’s possessions) would not meet criteria for HD because Criterion A emphasizes that the problem needs to be persistent.

(D) The proposed syndrome reflects an underlying psychobiological dysfunction

Research into the psychological and biological processes underlying hoarding has grown exponentially over the last decade and a half (Mataix-Cols et al., 2010), particularly after the publication of the initial operational definition of compulsive hoarding by Frost and Hartl (1996). This literature covers a wide range of topics, including psychopathology, epidemiology, cognitive-behavioural models, genetics, neuroimaging, neuropsychology, personality and treatment (see Pertusa, Frost, Pullana, et al., 2010; for a comprehensive review). For example, psychological research has found that hoarding may stem from four overlapping processes: (a) information-processing deficits relating to decision making, categorization and organization, as well as memory difficulties; (b) emotional attachment to possessions; (c) behavioural avoidance; and (d) erroneous beliefs about the nature of possessions (Frost & Hartl, 1996; Steketee & Frost, 2003). Family studies have demonstrated that hoarding runs in families and a recent twin study has found that this familiality is due to both genetic and nonshared environmental factors (Iervolino et al., 2009). Researchers have begun to search for candidate genes for hoarding traits (Perroud et al., 2011; Samuels et al., 2007). Resting state functional brain imaging studies have revealed that hoarders have abnormally low activity in the cingulate cortex, as compared with both normal healthy controls and patients with nonhoarding OCD (Saxena, 2008a; Saxena et al., 2004). Hoarders also have abnormal patterns of brain activation during provocation of hoarding symptoms and decision-making tasks, compared with controls (An et al., 2009; Tolin, Kiehl, Worhunsky, Book, & Maltby, 2008). Neuropsychological studies have shown that hoarders have deficits in executive functioning, attention, memory and categorization (Grisham, Brown, Savage, Steketee, & Barlow, 2007; Hartl et al., 2004; Lawrence et al., 2006; Wincew, Steketee, & Frost, 2007). The results of neuroimaging and neuropsychological studies converge to reveal that the pathophysiology of hoarding involves neural systems mediating decision making, attention, organization and emotional regulation (Mataix Cols, Pertusa, & Snowdon, 2011).
(E) The syndrome is not solely a result of social deviance or conflicts in society

In some cases, individuals with hoarding are not distressed by their behaviour, but their families may be distressed about clutter or expenses, and society may be concerned about health hazards or other negative consequences of hoarding. However, given the evidence of associated impairment and underlying disturbance, it seems clear that hoarding is not solely a result of social deviance or conflicts with society.

(F) The syndrome has diagnostic validity using one or more sets of diagnostic validators

Most research into hoarding has been conducted in the context of OCD but, increasingly, researchers have focused on hoarding as a standalone problem, a task that will be facilitated by the creation of the new diagnosis. As noted before, HD differs from OCD in several important ways but there are limited data on several of the standard diagnostic validators being used for DSM-5 (Phillips et al., 2010). While there is some evidence that HD differs from other disorders on symptom phenomenology, comorbidity, course of illness, cognitive-behavioural processes, neurocognitive profile, genetics and response to treatment, there are limited or no data on environmental factors and temperament correlates (Mataix-Cols et al., 2010; Phillips et al., 2010).

It is essential that the proposed criteria are able to discriminate HD from other ‘organic’ and mental disorders that are known to result in hoarding or in the passive accumulation of possessions. Criteria E and F (Table 1) are clear in that general medical conditions (e.g. brain injury) and mental disorders must be ruled out first before a diagnosis of HD can be made. This is particularly relevant in individuals with OCD who display hoarding symptoms as in these cases hoarding can sometimes be conceptualized as being secondary to OCD (in which case only OCD would be diagnosed) and other times as a comorbid disorder (i.e. both OCD and HD would be diagnosed; Mataix-Cols et al., 2010; Pertusa, Frost, & Mataix-Cols, 2010).

We have recently conducted a survey amongst 211 OCD/hoarding experts and 48 random members of the American Psychiatric Association (APA) to examine the reliability and acceptability of the proposed new diagnosis (Mataix-Cols, Fernández de la Cruz, Nakao, & Pertusa, in press). Participants were shown eight brief clinical vignettes (four cases meeting criteria for HD, three with hoarding behaviour secondary to other mental disorders such as OCD and one with subclinical hoarding behaviour) and asked to decide the most appropriate diagnosis in each case. The sensitivity and specificity of the HD diagnosis and the individual criteria were high (80–90%) across various types of professionals irrespective of their experience with hoarding cases. Participants found it straightforward to distinguish HD from OCD when these appear in isolation. Not surprisingly, the comorbid OCD + HD case was the hardest to diagnose correctly (classified correctly by approximately 70% of participants). It appears that participants were slightly more reluctant to diagnose HD when OCD was present, even if the hoarding behaviour was clearly independent of the main OCD presentation. Our recommendation is that the text accompanying the HD criteria should be very explicit about the distinction between hoarding as a symptom of OCD and hoarding as a separate diagnosis.

The development of relevant materials such as case vignettes, videos and semi-structured interviews such as the recently developed Structured Interview for Hoarding Disorder (SIHD; Pertusa & Mataix-Cols, unpublished) should facilitate this endeavour. The ongoing field trials should provide additional information on the diagnostic validity of HD.

(G) The syndrome has clinical utility

The inclusion of hoarding as a separate diagnosis has the potential to increase the usefulness of the nosological system and improve clinical utility in a number of ways. As mentioned earlier, hoarding is a relatively prevalent problem, representing a substantial burden for the sufferers, their families and society at large. Yet, it remains largely unrecognized and undertreated. The public recognition of hoarding is changing, as illustrated by the existence of several TV shows in US television. Including hoarding as a separate disorder would further increase public awareness, improve identification of cases, accuracy of diagnosis and tailoring of treatment. In fact, by recognizing the unique status of hoarding researchers are already developing specific psychological interventions for this problem (Muroff et al., 2009; Steketee & Frost, 2007; Steketee, Frost, Tolin, Rasmussen, & Brown, 2010; Tolin, Frost, & Steketee, 2007), as these patients do not respond optimally to standardized protocols developed for other disorders, such as OCD (see Pertusa, Frost, Fullana, et al., 2010, for a review).

The provisional DSM-5 criteria for HD include two specifiers, excessive acquisition and degree of insight (Table 1). Although the presence of excessive acquisition is not required for diagnosis, a significant majority of HD patients suffer from it, and ignoring it in treatment will likely result in treatment failure (Frost, Tolin, Steketee, Fitch, & Selbo-Bruns, 2009). On the other hand, including an insight specifier is relevant to hoarding given that many sufferers underestimate the extent of their difficulties (Tolin, Fitch, Frost, & Steketee, 2010). Adding motivational interviewing techniques is recommended for those patients who appear ambivalent about the need to receive cognitive-behavioural treatment for HD (Stekete et al., 2010). Thus, the inclusion of these
specifiers also increases the clinical utility of the proposed diagnosis.

It seems highly likely that many sufferers do not present for treatment at all, in part because there is a lack of public awareness that the symptoms represent a valid clinical entity. In our clinical experience, many individuals with hoarding problems often receive no diagnosis or an inaccurate diagnosis in clinical settings. Hoarding symptoms are often not routinely asked about (Tolin et al., 2011). Many hoarders may seek help when they have substantial comorbidities, particularly OCD, simply because hoarding has traditionally been associated with OCD. When this happens, treatment is according to available treatment guidelines for OCD, but hoarding symptoms are rarely treated on their own. Treatment failures are frequent (Pertusa, Frost, Fullana, et al., 2010). Although HD is sometimes complicated by comorbidity, it often occurs in isolation and is sufficiently disabling on its own to require specific treatment. The creation of a new diagnosis in DSM-5 would address much of this unmet need. It would also likely stimulate research into the aetiology and treatment of hoarding using an agreed-upon set of diagnostic criteria. Furthermore, routine exclusion of individuals with comorbid HD would also increase the reliability and replicability of OCD studies. In fact, many OCD studies now routinely exclude hoarders from their samples as severe hoarding behaviour very rarely constitutes a genuine OCD symptom (Pertusa, Frost, & Mataix-Cols, 2010).

The inclusion of HD and removal of the OCPD hoarding criterion in DSM-5 also would help reduce the current ambiguities in DSM-IV-TR, where hoarding is simultaneously considered an associated symptom of OCD and a diagnostic criterion for OCPD (Mataix-Cols et al., 2010). This would facilitate professional communication, as the proposed criteria have face validity and are easily understood by clinicians. The criteria are also ‘patient friendly’, as in our experience many hoarders are unhappy with a diagnosis of OCD and feel they do not fit in OCD patient organizations. In the aforementioned DSM-5 survey, we found that about 90% of participants in both the expert and APA samples thought the criteria would be very/somewhat acceptable for professionals and sufferers alike (Mataix-Cols et al., in press).

Potential pitfalls associated with the creation of a new HD diagnosis

It is also important to consider the potential disadvantages or even risks of the creation of this disorder. We are not aware of how such a diagnosis could be misused in a way that might produce harm, nor is this issue mentioned in the published literature. However, as in many areas of psychopathology, it can be difficult to establish the dividing line between normal and pathological behaviour. Therefore, there is a potential risk of pathologizing essentially normal behaviour (e.g. Frances, 2009). Should collectors, even ‘eccentric’ ones, be diagnosed with a mental disorder? Clearly, the answer is no. It is crucial that the proposed diagnostic criteria discriminate between adaptive and maladaptive degrees of hoarding behaviour. For this reason, the criteria have been worded conservatively to only include individuals who have persistent difficulties discarding (Criterion A) and have accumulated such a large number of possessions that they are no longer able to use their living spaces (Criterion C), for example, not being able to cook in the kitchen, sit on their living room or sleep in their bed. In addition, the person must have substantial distress or interference as a result of their difficulties discarding or resulting clutter (Criterion D). For example, a person who, by most standards, has a large number of possessions but the items are generally not impeding normal use of most living spaces and who is not distressed or impaired in other ways, would clearly not meet criteria for HD. By making the criteria conservative, the hope is to avoid any false positives and only diagnose individuals who genuinely suffer and require help. Conversely, it may be that Criterion C (clutter) is worded too conservatively. This could potentially result in ‘false negatives’, as individuals who have accumulated enough clutter to experience distress or interference but can still use most of the active living areas of their homes will not qualify for the diagnosis. Hopefully, the ongoing field trials will shed some light on this important issue.

Regarding the distress/impairment criterion (Criterion D), one potential pitfall is that many hoarders have limited or no insight into their problem and may deny that they have a problem, let alone a mental disorder (Tolin, Fitch, Frost, et al., 2010). In our experience, third parties such as spouses or local authorities can sometimes insist that these individuals seek help. This may raise ethical issues about coercing people to receive treatment against their will.

Other important considerations are the social and economic consequences of a new disorder with an estimated prevalence between 2% and 5% of the population. Should all these individuals be in treatment? As treatments for HD may require intensive treatment approaches, often involving multiple agencies, what are the financial implications for our health systems? On the other hand, we do not consider the potential treatment cost to be a reason to exclude this disorder from DSM.

We believe that, on balance, the potential benefits of creating a new diagnosis (e.g. identification of cases that clearly suffer and need help but are currently missed out by the existing diagnostic categories, provide better patient care, stimulate new research) outweigh the potential harms (e.g. hurt particular individuals, be subject to misuse and pathologize normal behaviours).
Additional considerations and gaps in the knowledge base

Several additional considerations may arise when proposing a new disorder for the nomenclature. These include the following.

Subtype or ‘spectrum disorder’?

We have previously referred to the differences between hoarding and OCD, which have led to the proposal of a separate disorder in DSM-5. However, given the historical link between the ‘anal character’ and hoarding, and the DSM-IV notion that extreme hoarding might warrant consideration of OCD as a diagnosis, why not consider hoarding a subtype of OCD rather than a separate disorder? Could hoarding be a form of OCD that presents in the absence of other OCD symptoms, that is, a monosymptomatic form of OCD? The fact that hoarding often appears in the absence of other significant OCD symptoms does not fully rule out the possibility that it may be a variant or subtype of OCD (Mataix-Cols et al., 2010). Similar arguments have been put forward for other OCD-related disorders, such as body dysmorphic disorder (BDD; Hollander, Neville, Frenkel, Josephson, & Liebowitz, 1992) or hypochondriasis (Abramowitz, Schwartz, & Whiteside, 2002; Fallon, Qureshi, Laje, & Klein, 2000). Like HD, these disorders are somewhat similar to OCD but also appear sufficiently distinct. In a sense, whether HD is considered a subtype of OCD or a separate OCD ‘spectrum’ disorder is like splitting hairs as both subtypes and spectrum disorders are based on the idea that hoarding is related to but also different from OCD (Taylor, Jang, & Asmundson, 2010). However, we have argued that patients with HD do not experience obsessions and compulsions, as currently defined in DSM-IV or ICD-10 and required for a diagnosis of OCD (for a detailed discussion, see Mataix-Cols et al., 2010). The concept of subtype entails the presence of different symptom manifestations of the same disorder, but the same core symptoms and phenomenology; that is, obsessions and compulsions must be present (McKay & Neziroglu, 2009). Therefore, strictly speaking, hoarding cannot be considered a subtype of OCD as it lacks the key features that define the supraordinate OCD class. Naturally, this does not apply to those cases where hoarding is clearly secondary to other OCD symptoms, in which case the appropriate diagnosis would be OCD rather than HD.

Do the proposed diagnostic criteria have clinical face validity, reliability, and adequate sensitivity and specificity?

As described before, a recent survey amongst OCD experts, hoarding experts and nonexpert psychiatrists randomly selected from the APA directory indicated high sensitivity, specificity and acceptability of the proposed diagnostic criteria for HD (Mataix-Cols et al., in press). Field trials are currently ongoing to test the HD criteria with real patients in real clinical settings.

Can the criteria be easily implemented in a typical clinical interview and reliably operationalized/assessed for research purposes?

In our experience to date, the criteria are easy to use in research settings. We have developed and are now testing a semi-structured interview that closely maps the proposed DSM-5 criteria (SIHD; Pertusa and Mataix-Cols, unpublished, available upon request).

Are the criteria suitable for children and adolescents?

As mentioned earlier, most normal children have collections of some sort (Evans et al., 1997; James, 1890; Zohar & Felz, 2001) but pathological hoarding in children appears to be easily distinguished from normal saving/collecting behaviour (Pimplinton, Frost, Abbey, & Dorer, 2009). The prevalence of hoarding problems in children and adolescents is currently unknown. Clinically significant hoarding problems seem to be more prevalent in older than younger adults and children (Samuels et al., 2008). The approximate mean age of participants taking part in research studies is around 50 years (e.g. Pertusa et al., 2008). However, there is evidence that hoarding problems may start several decades before these individuals present to clinics or research studies. Although the natural history of hoarding remains to be investigated systematically in prospective studies, several retrospective studies suggest that hoarding symptoms first emerge in childhood or early adolescence, at an average age of 12–13 years (e.g. Ayers, Saxena, Golshan, & Wetherell, 2010; Fontenelle, Mendelowicz, Soares, & Versiani, 2004; Frost & Gross, 1993; Grisham et al., 2006; Seedat & Stein, 2002) and start interfering with individuals’ everyday functioning by the mid-thirties (Greenberg, 1987; Grisham et al., 2006; Pertusa et al., 2008). Grisham et al. (2006) reported that amongst the different symptoms of hoarding, acquisition had a somewhat later onset than either difficulty discarding or clutter, possibly due to greater financial and physical independence and the means to store a greater volume of possessions. In this study, recognition of the problem typically began more than a decade after initial onset. A recent study of elderly compulsive hoarders found that the initial reported average age of onset was 29.5 years, although when participants were then invited to systematically review events over the lifespan, hoarding problems were recalled to have been present much earlier, in childhood and adolescence (Ayers, Saxena, Golshan, & Wetherell, 2010).
2009). Thus, while most work has been performed in adult populations, there is evidence that the seeds of hoarding are present early in life and span well into the late stages of life. The proposed criteria, therefore, should be largely suitable across the lifespan, although they may need to be adapted for children as they typically do not control their living environment and discarding behaviours (Plimpton et al., 2009; Storch et al., 2007, 2010). For example, should the clutter criterion (Criterion C) strictly apply to children or should it be narrowed down to the space directly controlled by the young person (i.e. their own bedroom)? Regarding Criteria A and B, if the young person does not report difficulty discarding or urges to save/distress, perhaps information from a reliable informant (e.g. the parents) would suffice to endorse these criteria. Finally, regarding Criterion D, if the young person does not self-report distress or impairment, the possible intervention of third parties (e.g. parents keeping the spaces useable, thus reducing interference) should possibly be taken into account. Further research on the prevalence and other aspects of HD in children and adolescents is sorely needed.

Are the criteria likely to work in other languages and cultures?

While most of the work has been performed in English-speaking countries, the clinical impression from colleagues around the world suggests that hoarding is a universal phenomenon. A recent meta-analysis of 21 studies involving over 5,000 individuals with OCD worldwide confirmed that hoarding appears to be independent from other OCD symptoms in both English and non-English speaking countries (Bloch, Landeros-Weisenberger, Rosario, Pittenger, & Leckman, 2008). This included studies from geographically and culturally diverse countries, such as Japan, India, South Africa and Brazil. Just as in Western countries, OCD patients with hoarding symptoms from other countries have been described as having more severe OCD symptoms, longer illness duration, lower global functioning, poorer insight, more comorbidity and poorer treatment outcome than OCD patients without such symptoms (Fontenelle et al., 2004; Lochner et al., 2005; Matsunaga, Hayashida, Kiriike, Nagata, & Stein, 2010; Matsunaga et al., 2008; Seeadt & Stein, 2002). A recent Japanese study carefully examined the characteristics and severity of hoarding in a large sample of OCD patients (Matsunaga et al., 2010) and found that these patients are very similar to their Western counterparts in terms of clinical characteristics, items being hoarded and extent of clutter.

There is a paucity of data from developing countries. A recent study conducted in India (Chakraborty et al., submitted) has systematically studied the presence of hoarding symptoms in a large sample of OCD patients (n = 200) using empirically derived cut-offs of the Saving Inventory Revised (Frost et al., 2004), followed by a clinical interview. They found that 20 patients (10%) had clinically significant hoarding and that hoarding did not appear to be related or secondary to other OCD symptoms on any of these cases. An interesting finding was that all hoarders hailed exclusively from an urban background, compared with 80% of non-hoarders, a difference that reached statistical significance. As in previous studies, the presence of comorbid hoarding was associated with more severe OCD, high comorbidity, low insight, suicidal attempts and lower level of functioning. If replicated, the finding of the urban nature of hoarding is thought provoking as it raises the question of whether the criteria will be relevant to rural communities, where space is less of an issue.

To conclude, there are no data suggesting that the criteria need modification for different cultures, although more epidemiological and transcultural research is needed.

Conclusions

It is important to remind ourselves that classifications are fictions imposed on a complex world to understand it and manage it (Marks & Mataix-Cols, 2004). Psychiatric diagnoses should be seen as dynamic entities that evolve and improve over time, as the evidence base increases. The crucial question is: What purpose should DSM-5 serve? Psychiatric disorders could be classified in endless ways, the value of which depends entirely on the purpose of the classification. The fact remains that the existing DSM-IV and ICD-10 diagnostic categories leave out a large majority of hoarding sufferers and that available treatments for other mental disorders (e.g. OCD) are grossly ineffective. Thus, we believe that the advantages of creating a new HD outweigh the disadvantages. Whether the criteria will need modification for their use in children/adolescents or in other cultures is unclear and more research is needed to address these questions.

Acknowledgements

This review article was invited by the journal, for which the principal author has been offered a small honorarium payment towards personal expenses.

The authors have declared that they have no competing or potential conflicts of interest.

Correspondence to

David Mataix-Cols, King’s College London, PO 69, Institute of Psychiatry, De Crespigny Park, London SE5 8AF, UK; Tel: +4420 7848 0543; Fax: + 44 207 848 0379; Email: david.mataix-cols@kcl.ac.uk
Key points

- Up to 70% of normally developing children and 30% of adults are thought to own collections at some point. Thus, collecting and saving are widespread human activities, but taken to the extreme they can cause distress and disability.
- Although hoarding can sometimes be a symptom of several medical and psychiatric conditions, in most cases, hoarding is independent of those conditions. This has led to the proposal to include a new HD in DSM-5.
- The current definition and provisional criteria for HD fit the DSM-5 definition for a mental disorder.
- On balance, the potential benefits of creating the new diagnosis (e.g., identification of the majority of cases who clearly suffer and need help but are currently missed out by the existing diagnostic categories) outweigh the potential harms (e.g., pathologizing normal behaviour).
- More research is needed to determine if the proposed criteria require modification for their use in children and adolescents.

References


Accepted for publication: 29 July 2011
Published online: 5 September 2011