

ARTICLE

Hoarding behaviour: building up the ‘R factor’[†]

Romina Lopez Gaston, Farida Kiran-Imran, Fairooz Hassiem & John Vaughan

This article was written while the authors were working in Malvern Community Mental Health Team, Worcestershire Mental Health Partnership Trust. **Romina Lopez Gaston** is a specialist registrar in adult psychiatry with a clinical interest in liaison psychiatry and substance misuse. **Farida Kiran-Imran** is a CT1 core medical trainee. **Fairooz Hassiem** works as an associate specialist in old age psychiatry and her clinical research interest is focused on the interface of psychiatric disorders that affect older and younger adults. **John Vaughan** is a consultant psychiatrist particularly interested in psychological interventions.

Correspondence Dr Romina Lopez Gaston, Newbridge House, 130 Hobmoor Road, Small Heath, Birmingham B10 9JH, UK. Email: logaston1@hotmail.com

[†]The photographs that appear in this article can be viewed in colour in its online version.

SUMMARY

Hoarding seems to be a non-specific symptom, as it has been associated with a wide range of psychiatric disorders. Validating hoarding as pathological is controversial and its nosological status remains unresolved. ‘Diogenes syndrome’ has been paradigmatic in this area, but its clinical use seems limited. Hoarding is not explicitly covered in either DSM–IV or ICD–10 and literature suggests that diagnosis of mental illness may consequently be missed in this population. In the context of these theoretical uncertainties, clinicians still need to accurately assess and treat patients who show hoarding behaviour. To this end, we summarise the available evidence, and present assessment and management algorithms together with a multicomponent psychological intervention that aims to teach patients to successfully apply the three Rs (reduce, recycle, reuse).

DECLARATION OF INTEREST

None.

Hoarding is defined as the acquisition of, and inability to discard, items even though they appear (to others) to have no value. It is usually associated with a combination of self-neglect, neglect of one’s surroundings and lack of concern about one’s living conditions. Hoarding seems to be a very non-specific symptom that is associated with a wide range of psychiatric disorders. The validation of hoarding as pathological is controversial, with reports of hoarders who have neither formal psychiatric nor physical conditions. Macmillan & Shaw (1966) studied a population of individuals living in squalor and they regarded the condition as a ‘senile breakdown’ of the standards of hygiene accepted by the local community. More than half of the sample was found to have a psychiatric disorder and an equal proportion presented hoarding personality traits. The term ‘Diogenes syndrome’ was subsequently introduced by Clarke et al (1975), and linked to a case series of 30 elderly people with extreme neglect of their homes and personal health, and with a behavioural abnormality: hoarding of rubbish. Diogenes syndrome was named after the Greek philosopher who lived in a barrel, eschewing material possessions. However,

the syndrome was not clearly defined; according to the original descriptions, it included both mentally ill people and people with extreme maladaptive personality traits. To add precision, Reyes-Ortiz (2001) suggested a distinction between primary and secondary Diogenes syndrome depending on whether a mental disorder is present. However, the condition also occurs in people younger than 65 (Fig. 1), widening even more the boundaries for its presentation and reducing diagnostic accuracy.

The nosological status of hoarding remains unresolved and the term is not explicitly covered in either DSM–IV (American Psychiatric Association 1994) or ICD–10 (World Health Organization 1992); DSM–IV currently lists hoarding as a symptom of obsessive–compulsive personality disorder (OCPD) (Wu 2005). However, available evidence argues strongly against this classification. Hoarding severity does not correlate with the severity of OCPD symptoms and only 15–45% of hoarders meet the criteria for OCPD (Steketee 2003; Saxena 2005).



FIG 1 The bedroom of a 57-year-old compulsive hoarder (see Case vignette). © Worcestershire County Council.

Epidemiology: can Diogenes explain it all?

The prevalence of mental health problems in populations of hoarders is poorly determined, as most studies have relied on referrals to specialist healthcare services, thus biasing the data towards certain groups, such as the elderly (Saxena 2007b). In one such study (Halliday 2000), standardised instruments were used to investigate relationships between squalor and mental or physical disorders in people referred to a local authority cleaning service. The study found that the group had high rates of mental disorder and that younger as well as older people were affected. Community studies and hospital-based samples show that between one-third and one-half of patients with hoarding and self-neglect are mentally ill (Cooney 2005), but only half of those with mental health problems had been in contact with mental health services in the previous year.

In the literature, hoarding has been linked with a vast range of psychiatric disorders (Stein 1999; Clarke 2002; Maier 2004; Saxena 2007b), including schizophrenia, intellectual disability, neurodegenerative disorders (in particular, frontal lobe dysfunction), autism-spectrum disorders, eating disorders and impulse-control disorders (pathological gambling and buying) as well as occurring in non-clinical populations. But it is most commonly found in obsessive-compulsive disorders (OCD), as 18–42% of people with OCD report hoarding and saving compulsions and 10–15% have compulsive hoarding as their most prominent symptom (Saxena 2004b; Samuels 2007a).

The diversity of associated mental and physical disorders supports the argument that hoarders who live in squalor require careful assessment and treatment, rather than being seen as having a rare syndrome due to reclusiveness or eccentricity (Halliday 2000). ‘Diogenes syndrome’ was a relevant starting point for raising awareness of the topic. However, ongoing research has broadened its boundaries, leaving Diogenes syndrome as an iconic term with limited clinical utility.

Assessment

Hoarding: symptom or syndrome?

In a comprehensive review, Maier (2004) brought clarity to the interpretation of hoarding in clinical practice. The key factor for practical diagnosis is the individual’s intentions and attachment to the hoarded objects. These features are strongly related to the person’s ability to discard or remove the objects and the degree of self-neglect and impact on living space that results from their behaviour. Maier proposed that patients with hoarding behaviour can be divided into two groups: those

for whom hoarding is a symptom – it is unintentional and hoarded objects can be discarded; and those for whom it is a syndrome – the hoarding is intentional, impairing and discarding of objects causes great anxiety.

Hoarding: the symptom

Hoarding can result from motor activity that has no clear intention or aim, taking the form of stereotypical rituals and grasping or tic-like behaviour (Clarke 1975; Stein 1999; Maier 2004). Hoarding may also be driven by delusional beliefs or cognitive impairment that results in an inability to discard things. Patients with these presentations may be quite indifferent to the removal of hoarded objects. Behaviours of these types have been described in disorders such as schizophrenia, intellectual disability, autism and neurodegenerative disorders (Hwang 1998). In these cases, the hoarding is simply a symptom of the primary disorder, and its management will emerge from treatment of the main diagnosis. Some authors suggest avoiding the term ‘hoarding’ in these clinical situations, using ‘collectionism’ or ‘prehension behaviour’ instead (Tracy 1996; Volle 2002).

Hoarding: the syndrome

Hoarding can also present with obsessive-compulsive traits but without ego-dystonicity or discomfort (Stein 1999). Neurocognitive deficits associated with problems of emotional attachment have been identified in this group (Frost 1995). Compulsive hoarding is most commonly driven by obsessional fears of losing items that it is believed will be needed later. Excessive acquisition of objects leads to clutter and causes significant impairment in social and occupational functioning (Saxena 2004a). Attempts to remove the hoarded objects are forcibly resisted and are a source of great anxiety. In these cases, hoarding becomes part of a syndrome described as ‘compulsive hoarding syndrome’.

Case vignette

The photographs in this article were taken in the house of Mr B, a 57-year-old single man, unemployed for more than 20 years and without previous contact with mental health services. He was referred by his GP to the local CMHT because local authorities and neighbours had raised concerns about his hoarding behaviour and hazards associated with it. Mr B showed pride in his possessions¹ and when visited he expressed no concern about his hoarding or living conditions. Six months after these photographs were taken, Mr B was admitted to a psychiatric unit, with a diagnosis of major depressive disorder with psychotic symptoms that developed soon after a forced clean out of his possessions by local authorities.

¹See the front cover of this issue of *Advances*. Ed.

Diagnosing compulsive hoarding syndrome

In the absence of accepted diagnostic criteria for compulsive hoarding syndrome, Steketee & Frost (2007) proposed the following, which are currently being tested.

- The client accumulates a large number of possessions that clutter active living areas of their home, workplace or other personal surroundings. If disorganised clutter is not present in these areas, it is only because of the efforts of others (e.g. family members, authorities) to keep these areas uncluttered.
- The client has current or past difficulty resisting the urge to collect, buy or acquire free things that contribute to the clutter.
- The client is extremely reluctant to part with items, even those with very limited monetary value or utility.
- The accumulation of clutter and difficulty parting with items: causes marked distress and/or interferes significantly with normal use of the home, workplace or other personal surroundings, occupational functioning, usual family and social activities; poses significant health or safety risks (e.g. blocked egress, fire hazard, cluttered stairs); and/or causes significant conflict with family members, neighbours or authorities.
- The problem has persisted for at least 6 months and is not the result of a recent move, repairs to the home, the accumulation of items resulting from the death of a family member or other temporary circumstances.
- The clutter and the difficulties parting with items are not better accounted for by another mental disorder, substance misuse or a general medical condition.

Specifiers are: compulsive hoarding with poor insight (the person does not recognise that the clutter, acquisition of and difficulty parting with items is excessive or unreasonable) and/or with unsanitary conditions (if the home is squalid or if personal hygiene is poor).

It is important to distinguish between people with compulsive hoarding syndrome and people who live in cluttered, neglected and messy conditions but do not show any specific collecting behaviour or avoidance of discarding objects. The latter group may include people with OCD (e.g. fears of contamination, checking rituals), dementia (e.g. cognitive impairment that interferes with decision-making and organising), major depressive disorder (e.g. diminished interest in normal activities, fatigue, indecisiveness resulting from lack of concentration), schizophrenia (e.g. retention of items resulting from delusions or

hallucinations), bipolar disorder (e.g. impulsive buying sprees, distractibility that interferes with organising), the physiological effects of substance misuse or a general medical condition (Maier 2004; Steketee 2007).

Degree of impairment

Excessive acquisition and difficulty discarding possessions are not sufficient to be considered compulsive hoarding. The extent of the clutter should prevent the use of living spaces for the purpose for which they were designed (Fig. 2), causing significant impairment in the individual's life (Saxena 2004a). In severe cases, hoarding produces risk of infestation, falls, fires and inability to cook and eat at home (Steketee 2007). This can become a serious problem involving clinicians, public health organisations and social workers. Hoarding frequently causes disruption of social and occupational functioning. Samuels et al (2002) describe a low rate of marriage among people who hoard that may be related to social anxiety and schizotypal features. The reclusiveness of hoarders and their embarrassment about their home and obsessive-compulsive symptoms might make them less likely to sustain relationships (Frost 1993).

Compulsive hoarding syndrome: the debate

There is currently debate regarding the classification of compulsive hoarding syndrome in relation to OCD (the symptom dimensions of which are

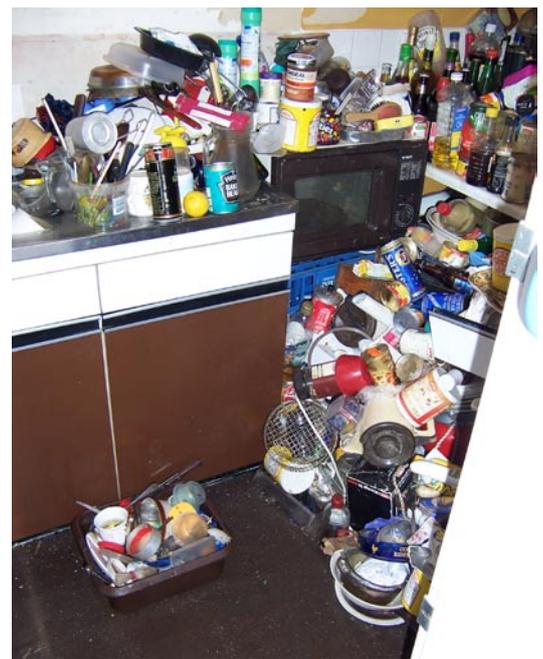


FIG 2 An almost unusable kitchen. © Worcestershire County Council.

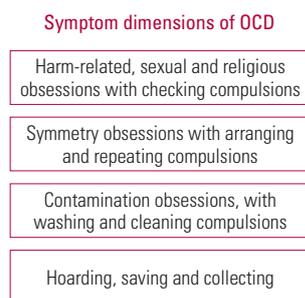


FIG 3 Symptom dimensions of OCD (based on Saxena 2007c).

shown in Fig. 3). Some authors maintain that it is a discrete entity with a characteristic profile of core symptoms, distinct susceptibility genes and unique neurobiological abnormalities that differ from those of (non-hoarding) patients with OCD (Saxena 2007a,b). Others maintain that there is substantial overlap of symptomatology with OCD and that compulsive hoarding is too phenomenologically and genetically heterogeneous to stand alone (Samuels 2007a; Van Grootheest 2007).

Far from being simply theoretical, this dilemma has an impact on clinical practice. A number of studies that specifically recruited compulsive hoarders found that many of them did not have other OCD symptoms, and therefore would not fulfil the criteria for this disorder. People with a diagnosis of OCD, on the other hand, did not report any more hoarding symptoms than healthy comparisons or people with other psychiatric disorders (Wu 2005). Thus, studies that recruited participants with OCD on the basis of structured diagnostic interviews that did not include hoarding symptoms in their diagnostic criteria for the disorder will have missed hoarders who had no other OCD symptoms. A community study of people living in squalor reported hoarding in over 50% of the households (Halliday 2000). Assessment using operationalised criteria to examine mental state (Schedules for Clinical Assessment in Neuropsychiatry, SCAN) found no one in the cohort who met criteria for ICD-10 OCD. However, the authors note that the predominance of anxious/avoidant and anankastic personality types suggests that obsessional traits may play a role in the aetiology of squalor. Tolin et al (2007) have estimated that 1–2% of the general population have hoarding problems that are bad enough to seriously affect their quality of life.

A discrete subtype of OCD?

Compulsive hoarders typically share a constellation of symptoms and features, including urges to save, fears of losing items that they considered valuable or meaningful, avoidance of discarding, indecisiveness, perfectionism, procrastination,

disorganisation of possessions/activities and circumstantial, overinclusive language (Saxena 2007c). People diagnosed with OCD with hoarding symptoms appear to be clinically different from those without hoarding symptoms. They have an earlier onset, greater prevalence of symmetry, ordering and counting compulsions, and indecisiveness (Samuels 2007b). They present for treatment later in life, with more severe family and social disability, lesser insight and lower global functioning. They also show a different pattern of comorbidity, with higher prevalence of social phobia, generalised anxiety disorder, and obsessive–compulsive and dependent personality disorders. Personality traits such as miserliness, preoccupation with details, difficulty making decisions, odd behaviour and appearance, and magical thinking are all independently associated with hoarding (Samuels 2007a; Saxena 2007a).

Genetic profile

Genetic and family studies suggest that the patterns of genetic inheritance and comorbidity found in compulsive hoarding differ from those found in other types of obsessions and compulsions (Samuels 2007c). The hoarding/saving symptom factor shows an autosomal recessive inheritance pattern and has been associated with genetic markers on chromosomes 4, 5 and 17 (Zhang 2002). One study found that 84% of hoarders reported a family history of hoarding behaviour in at least first-degree relatives but only 37% reported a family history of OCD (Winsberg 1999). The OCD Collaborative Genetics Study (Samuels 2007c) also found genetic markers associated with compulsive hoarding, suggesting that a region of chromosome 14 is linked to compulsive hoarding behaviour in OCD families, proposing that a genetic variant in this region increases the risk of hoarding behaviour in individuals who are susceptible to OCD.

To identify the specific genes involved in the aetiology of compulsive hoarding, genetic studies should be conducted in populations with well-defined categorical phenotypes (Saxena 2007a).

Functional neuroimaging

Most functional neuroimaging studies in patients with OCD have been done without taking into consideration phenotypical subgroups in this population. However, cerebral metabolic patterns of compulsive hoarders with OCD seem to differ from those of non-hoarders with the disorder (and also from non-OCD controls) (Saxena 2004b). In the OCD groups, the hoarders did not have the characteristic hypermetabolism in the orbitofrontal cortex, caudate nuclei and thalamus



FIG 4 When recycling is not an option. © Worcestershire County Council.

seen in the non-hoarders. Instead, they showed significantly lower activity in the dorsal anterior cingulate gyrus and occipital cortex. Hoarding severity was negatively correlated with glucose metabolism in the dorsal anterior cingulate gyrus. The study team suggested that diminished activity in the cingulate cortex may contribute to both the symptoms and the poor response to standard anti-obsessional treatments in compulsive hoarders.

Despite the limitations of existing studies, further research in this area is ongoing to elucidate the pathophysiology of hoarding with the view of developing more effective treatments.

When recycling is not an option: development of compulsive hoarding

Reports suggest that compulsive hoarding runs a chronic and unchanging course beginning in childhood or adolescence, although trauma can



FIG 5 Compulsive buying. © Worcestershire County Council.

precipitate the disorder at a later age (Frost 1993). Hoarders come to the attention of healthcare or community services at an average age of 50 with a well-established pattern of behaviour (Steketee 2007).

In the early stages of the illness, the distinction between normal collecting and pathological hoarding can be problematic. Collecting is a normal and enriching leisure activity for both children and adults. The items collected are usually organised (Melamed 1998) and generally considered interesting and valuable (Steketee 2007). People with clinical compulsive hoarding tend to accumulate items deemed by others to be useless and of limited value (Fig. 4). In addition, the hoarded items are usually disorganised and hinder the person's ability to function. Hoarders tend to use their collection of clutter as a form of comfort and security, with deep emotional investment coined as 'hypersentimentality'; these individuals fear the grief-like emotions that would come with the disposal of clutter (Frost 1995).

The literature on compulsive hoarding has revealed two distinct forms of excessive and compulsive acquisition: compulsive buying (Fig. 5) and acquiring free and discarded items (Frost 1993). Occasionally, acquisition includes stealing and kleptomania. Another variant, animal hoarding, is defined as the accumulation of animals (20 or more) that are not intended for breeding or sale. In these cases, the owner fails to provide an adequate living environment (with overcrowded or unsanitary conditions) and veterinary care (Steketee 2007).

A model of compulsive hoarding

Figure 6 shows an explanatory model of hoarding behaviours suggested by Steketee & Frost (2007). They propose that problems with acquiring, saving and clutter are a direct consequence of personal vulnerabilities that contribute to cognitive appraisals about possessions, triggering emotional responses that lead to hoarding behaviours.

According to the model, hoarding behaviour is maintained through reinforcements related to core features: indecisiveness, concerns over mistakes, judgements about need and emotional attachment to possessions. Positive reinforcement is related to the pleasure gained from saving and acquiring; negative reinforcement involves avoidance of negative emotions such as grief, anxiety and guilt.

Treatment

Psychological interventions

Compulsive hoarders appear to have a different pattern of neurocognitive deficits than non-hoarding

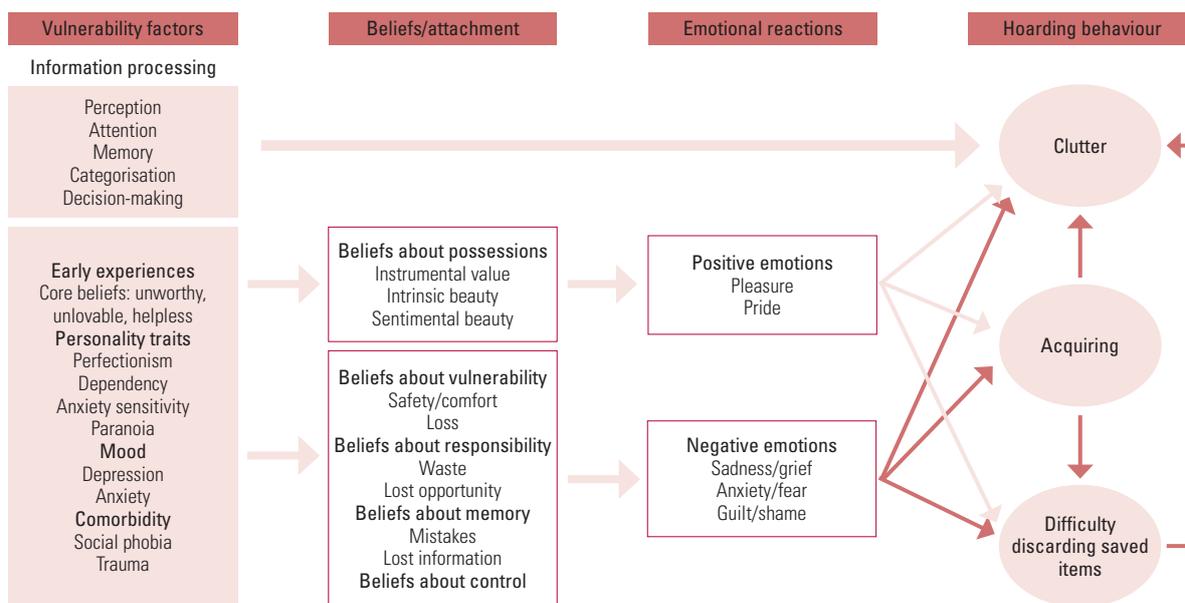


FIG 6 A model of compulsive hoarding (from Steketee 2007, reprinted by permission of Oxford University Press, Inc).

people with OCD, and their passive resistance to therapy makes it difficult to design interventions. Historically, cognitive-behavioural therapy (CBT) for compulsive hoarding has been associated with poor response and premature drop out. However, hoarders have been underrepresented in most CBT studies of OCD, limiting the generalisability of the results (Mataix-Cols 2002).

A multimodal psychological intervention

Steketee & Frost obtained more encouraging data when testing a multimodal intervention based on their model of compulsive hoarding behaviour (Fig. 6) and tailored to specific features of hoarding. The intervention programme, for which a therapist guide (Steketee 2007) and workbook (Tolin 2007) to aid treatment are now available, has been discussed in detail by Saxena & Maidment (2004a). The programme is designed for 26 weekly sessions (the number can range between 15 and 30, depending on severity, comorbidity and motivation) spaced over a period of 6–12 months, with every fourth session held in the patient’s home.

The intervention focuses on four main problem areas (Steketee 2003): information-processing deficits, problems forming emotional attachments, behavioural avoidance and erroneous beliefs about the nature of possessions.

Motivational interviewing aimed at addressing ambivalence and poor insight takes up part of several sessions, especially early in treatment.

The cognitive-behavioural component is directed at decreasing clutter, improving decision-making and organisational skills and strengthening resistance to urges to accumulate items (Fig. 7).

Cognitive restructuring is used to address the individual’s obsessive fears with regard to discarding objects. This involves working with the anxiety of letting go of something that feels important. Patients learn to conceptualise their hoarding in terms of problems with anxiety, avoidance and information-processing.

Treatment begins with a thorough assessment of the patient’s clutter, beliefs about possessions, information-processing, decision-making and organisational skills. Other factors addressed are avoidance behaviours, daily functioning, insight, motivation for treatment, social and occupational functioning, level of support in the community and medication adherence. Patients are asked to provide baseline photographs of their cluttered areas. Many compulsive hoarders have poor insight, which



FIG 7 Cognitive-behavioural therapy for compulsive hoarding: principles of treatment (based on a summary of an intervention described Saxena & Maidment 2004a).

affects their motivation for treatment. Comparing pictures of the home before and after treatment can help to raise their awareness of the degree of the problem.

The multimodal treatment is lengthy and labour intensive and success depends on the motivation and commitment of the patient (Frost 2003; Saxena 2004a). The ultimate aim of the intervention is to instil in patients the ability to employ the three Rs – reduce, recycle, reuse – to overcome their hoarding behaviour.

Assessment instruments

The Hoarding Scale and the Clutter Image Rating Scale are validated instruments for objective evaluation of the severity of the problem throughout treatment. Accuracy is necessary to overcome under- or overreporting and judge on clinical progress.

The Hoarding Scale (Frost 1993) is a 21-item questionnaire designed to measure various aspects of hoarding behaviour. The items reflect throwing away (emotional reactions and problems making decisions to throw things away), infrequent use of saved items and sentimental attachment to possessions. The individual is asked to respond to each statement using a Likert-type scale from 1 (strongly disagree) to 5 (strongly agree).

The Clutter Image Rating Scale (Frost 2008) is a pictorial scale that contains nine photographs of severity of clutter representing each of three main rooms of most people's homes: living room, kitchen and bedroom. It is useful in clinical and treatment contexts for measuring the clutter dimension of compulsive hoarding.

The risks of psychological intervention

Steketee & Frost recognise that their psychological intervention brings certain risks (for both patient and clinician), but believe that these are outweighed by potential benefits (Steketee 2007). Traumatic memories and unresolved grief reactions can resurface in the patient; the clinician may be confronted with issues of severe neglect (of both people and environment) that must be reported; and such squalor may be encountered on domiciliary visits that the clinician will have to wear protective clothing. Treatment has demonstrated good outcomes in significantly reducing clutter and excessive acquiring, increasing awareness of irrational reasons for saving and improving organisational skills (Steketee 2000). Hoarders continue therapeutic work using their acquired skills and the intervention tends to improve self-esteem, mood and functioning along with the reduction of clutter (Frost 2008).

Other interventions

Currently, there are no alternative evidence-based treatments. Standard exposure and response prevention for OCD symptoms works in some cases but is less successful for hoarding than for other OCD symptoms (Frost 2003; Steketee 2007). Forced 'clean-outs' evoke strong negative reactions and hoarding continues after them (Steketee 2007).

Pharmacological interventions

Antidepressants

Obsessive-compulsive disorder has traditionally been considered to be a single diagnostic entity. However, over the years analytical studies of its symptom dimensions (Fig. 3) have shown them to be relatively stable over time, showing different patterns of genetic inheritance and response to treatment (Saxena 2007c). Results from clinical series of patients with OCD suggest that those with hoarding symptoms or with higher scores on the hoarding factor dimension are less responsive to treatment with selective serotonin reuptake inhibitors (SSRIs) than are those without hoarding symptoms (Black 1998; Winsberg 1999). There is an underlying hypothesis that neurobiological differences in the non-hoarding patients could account for this. In one case series, only 1 of 18 compulsive hoarders treated with a variety of SSRIs showed adequate response and 9 showed no response at all (Winsberg 1999). Using a factor-analysed symptom dimension, Mataix-Cols (1999) showed that higher scores on hoarding predicted poorer response to SSRIs after controlling for baseline severity. However, results have been inconsistent in the literature: other studies on clinical predictors of treatment in OCD suggest no difference in the impact of hoarding on treatment outcomes (Alonso 2001; Erzegovesi 2001; Shetti 2005).

To date, only one study has been published that specifically targeted compulsive hoarding syndrome *a priori* using pharmacotherapy (Saxena 2007b,c). It found that paroxetine produced similar benefits for both hoarding and non-hoarding patients with OCD, although improvement was modest in both groups. An open trial of extended-release venlafaxine is currently being conducted in a population of compulsive hoarders (S. Saxena 2009, personal communication). Venlafaxine appears to be more effective and better tolerated than paroxetine. Ten out of eleven patients have completed a 12-week trial (mean final dose 180 mg/day, s.d. = 72 mg/day); the eleventh patient left the trial after moving area. Preliminary data from treatment completers show significant improvements in hoarding symptoms.

Cognitive enhancers and stimulants

Other targeted areas are brain dysfunctions specifically associated with compulsive hoarding; possible strategies include cognitive enhancers such as donepezil or galantamine, which increase cholinergic transmission in the cerebral cortex, or stimulant medication, which can increase the functioning of the medial prefrontal cortical areas involved in attention and executive functioning (Saxena 2007c, 2008 personal communication).

Combined therapy

Cognitive-behavioural therapy is still the most effective treatment for compulsive hoarding syndrome and pharmacotherapy in combination with CBT is an option for those with comorbid disorders (Steketee 2007). Research is ongoing into the use of SSRIs and, most recently, serotonin-noradrenaline reuptake inhibitors (SNRIs), with positive and to date modest results in this subpopulation.

Service provision

When diagnosed, most people with compulsive hoarding in the UK are included in the subgroup of patients with chronic and severe OCD refractory to the treatment modalities available in local community mental health teams. Services with specific expertise should therefore be accessible to local primary care trusts, as recommended by NICE guidelines (National Collaborating Centre for Mental Health 2005).

Hoarding and the law: public health implications and personal rights

People with compulsive hoarding behaviour usually present in crisis, because public health hazards such as risk of infestation or fire have

been reported. The crisis is frequently fuelled by concerns raised by neighbours (Cooney 2005). There are complex ethical and medico-legal issues involved in managing such cases, and a balance needs to be struck between respecting the patient's individual rights, addressing their healthcare needs and safeguarding public health.

The role of the psychiatrist is to determine whether the patient has a mental illness, and for this it is necessary to develop a therapeutic relationship so that a comprehensive assessment of needs (Fig. 8) can be performed. A multidisciplinary approach is paramount, as many of these patients have complex needs and their care requires input from different healthcare disciplines.

A proper risk assessment involves a domiciliary visit to evaluate living conditions, assess hazards and ascertain the level of social support available (Cooney 2005).

On occasion, individuals refuse assessment, in which case a different approach is needed (Fig. 9). Recourse to mental health legislation may be necessary if a psychiatric disorder is present and accompanied by a serious risk of self-neglect and/or substantial risk to others. Individuals with dementia may require care and supervision rather than psychiatric treatment. There may be aspects of their overall care for which the Mental Capacity Act 2005 may be useful. If unsanitary conditions become a public threat, a community physician may invoke Section 47 of the National Assistance Act 1948 to have an individual removed from their home (Murray 2002).

Conclusions

Hoarding behaviour can be a disorder in its own right or part of another psychiatric disorder. This distinction becomes important in the assessment

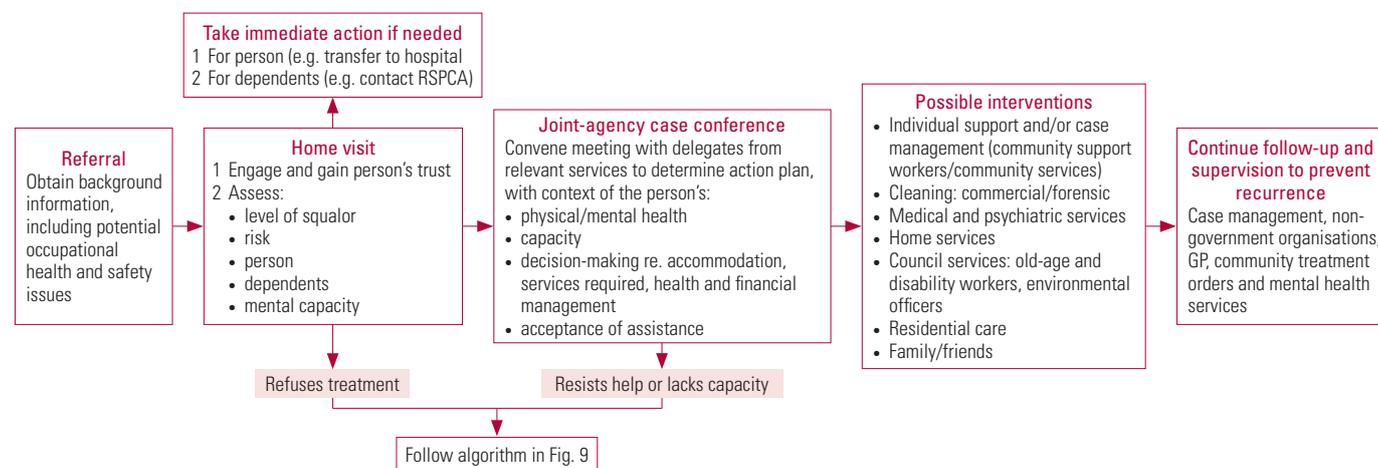


FIG 8 Assessment and management of people living in squalor (reprinted and modified with permission from Taylor et al, Northern Sydney Severe Domestic Squalor Working Party 2005).

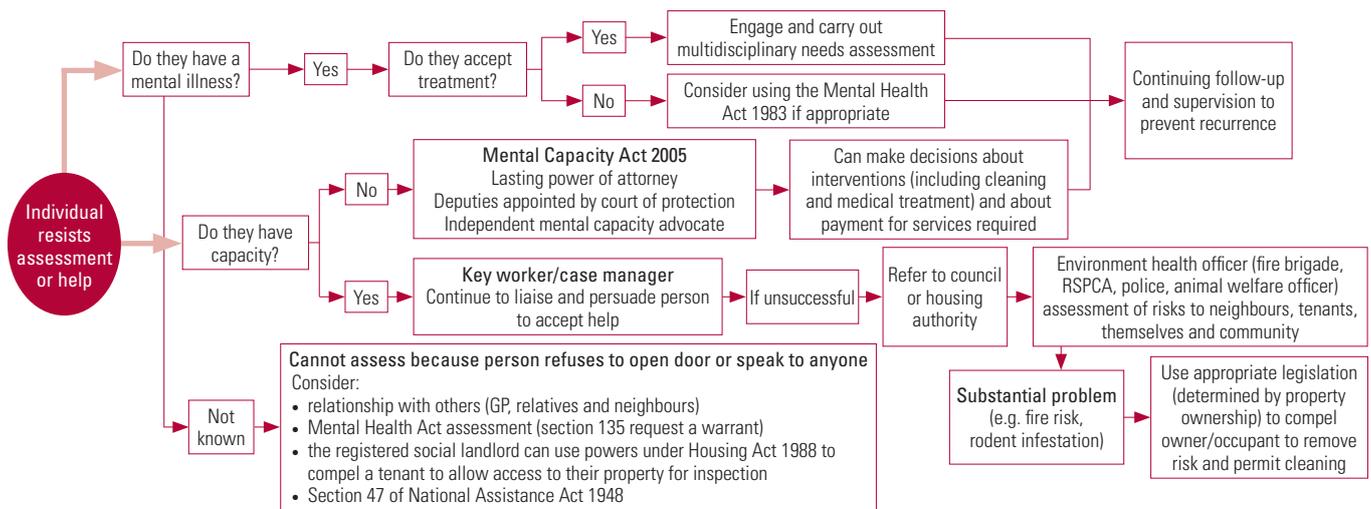


FIG 9 Assessment algorithm for individuals living in squalor and resisting treatment (reprinted and modified with permission from Taylor et al, Northern Sydney Severe Domestic Squalor Working Party 2005).

and management of the behaviour. Compulsive hoarding syndrome has not yet been established as a subtype of OCD. However, it describes an important discrete group for which treatment can be beneficial.

Epidemiological studies are still needed and there is ongoing work in determining how many compulsive hoarders meet the DSM-IV or ICD-10 criteria for OCD. The emergent evidence is that a population with compulsive hoarding syndrome exists and work needs to be done to establish specific defining criteria for the syndrome.

The therapeutic alliance is paramount, owing to the nature of the problem, and a comprehensive assessment of needs should involve professionals from different backgrounds. Hoarding is a challenging behaviour that can have detrimental public health consequences; therefore the clinician needs to be aware of available legislation and public resources to deal with individuals living in squalid conditions.

Treatment options such as SSRIs have shown positive but modest results and trials using SNRIs are underway. Treatment with cognitive enhancers and stimulants has been suggested, on the basis of neurophysiological deficits, but no trials have been conducted to date. Cognitive-behavioural therapy targeting specific cognitions is still the most effective treatment for compulsive hoarding syndrome. Increased awareness and diagnosis of this subpopulation will enhance pathways to care and accessibility to specialised services, as recommended by national guidelines.

Acknowledgments

We thank Mr B for inspiring this review and consenting to the publication of the photographs; Dr Sanjaya Saxena for

contributing unpublished data; Sian Smith & Phil Barnfield (housing association) for providing the photographs; and Chris Taylor for authorising the adaptation and reprint of assessment algorithms. We also thank Professor Femi Oyeboode, Nick Jackson (social worker), Nicholas Smith (Rowlands Library, Worcester), Dr R. Holmes and the anonymous reviewers for their encouragement, help and guidance.

References

Alonso P, Menchon JM, Pifarre J, et al (2001) Long term follow up and predictors of clinical outcome in obsessive compulsive patients treated with serotonin reuptake inhibitors and behavioural therapy. *Journal of Clinical Psychiatry*; 62: 535–40.

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders (4th edn) (DSM-IV)*. APA.

Black DW, Monahan P, Gable J, et al (1998) Hoarding and treatment response in non-depressed subjects with obsessive compulsive disorder. *Journal of Clinical Psychiatry*; 59: 420–5.

Clarke ANG, Manikar GO, Gray I (1975) Diogenes syndrome: a clinical study of gross self neglect in old age. *Lancet*; 1: 366–8.

Clarke DJ, Boer H, Whittington A, et al (2002) Prader-Willi syndrome and compulsive ritualistic behaviour: the first population-based survey. *British Journal of Psychiatry*; 180: 358–62.

Cooney C (2005) Diogenes syndrome. *Irish Psychiatrist*; 6: 13–6.

Erzegovesi S, Cavallini MC, Cavedini P (2001) Clinical predictors of drug response in obsessive-compulsive disorder. *Journal of Clinical Psychopharmacology*; 21: 488–92.

Frost R, Gross R (1993) The hoarding of possessions. *Behaviour Research and Therapy*; 31: 367–81.

Frost RO, Hartl TL, Christian R, et al (1995) The value of possessions in compulsive hoarding: patterns of use and attachment. *Behavior Research and Therapy*; 33: 897–902.

Frost RO, Sketetee G, Greene KA (2003) Cognitive behavioural treatment of compulsive hoarding. *Brief Treatment and Crisis Intervention*; 3: 323.

Frost R, Steketee G, Tolin D, et al (2008) Development and validation of the clutter image rating. *Journal of Psychopathology and Behavioural Assessment*; 30: 193–203.

Halliday G, Banerjee S, Philpot M, et al (2000) Community study of people who live in squalor. *Lancet*; 355: 882–6.

Hwang J, Tsai S, Yang C, et al (1998) Hoarding behaviour in dementia. *American Journal of Geriatric Psychiatry*; 6: 285–9.

MCQ answers				
1	2	3	4	5
a	f	a	f	a
b	t	b	t	b
c	f	c	f	c
d	f	d	f	d
e	f	e	f	e

- Macmillan D, Shaw P (1966) Breakdown in standards of personal and environmental cleanliness. *BMJ*; **2**: 1032–7.
- Maier T (2004) On phenomenology and classification of hoarding: a review. *Acta Psychiatrica Scandinavica*; **110**: 323–37.
- Mataix-Cols D, Rauch SL, Manzo PA, et al (1999) Use of factor analysed symptoms dimensions to predict outcome with serotonin reuptake inhibitors and placebo in the treatment of obsessive compulsive disorder. *American Journal of Psychiatry*; **156**: 1409–16.
- Mataix-Cols D, Marks IM, Greist JH, et al (2002) Obsessive compulsive symptom dimensions as predictors of compliance with and response to behaviour therapy: results from a controlled trial. *Psychotherapy and Psychosomatics*; **71**: 255–62.
- Melamed Y, Szor H, Barak Y, et al (1998) Hoarding – what does it mean? *Comprehensive Psychiatry*; **39**: 400–2.
- Murray B, Jacoby R (2002) The interface between old age psychiatry and the law. *Advances in Psychiatric Treatment*; **8**: 271–80.
- National Collaborating Centre for Mental Health (2005) *Obsessive–Compulsive Disorder: Core Interventions in the Treatment of Obsessive–Compulsive Disorder and Body Dysmorphic Disorder*. National Institute for Health and Clinical Excellence (<http://www.nice.org.uk/CG031>).
- Northern Sydney Severe Domestic Squalor Working Party (2005) *Dealing with Domestic Squalor. Northern Sydney Information Pack*. North Sydney Council (http://www.northsydney.nsw.gov.au/resources/documents/DomesticSqualor_InformationPack.pdf).
- Reyes-Ortiz CA (2001) Diogenes syndrome: the self-neglect elderly. *Comprehensive Therapy*; **27**: 117–21.
- Samuels J, Bienvenu III, Riddle MA, et al (2002) Hoarding in obsessive compulsive disorder. Results from a case control study. *Behaviour Research and Therapy*; **40**: 517–28.
- Samuels J (2007a) Compulsive hoarding and OCD: two distinct disorders? Reply. *American Journal of Psychiatry*; **164**: 1436.
- Samuels J, Bienvenu III OJ, Pinto A, et al (2007b) Hoarding in obsessive compulsive disorder. Results from the OCD Collaborative Genetics Study. *Behaviour Research and Therapy*; **45**: 673–86.
- Samuels J, Bienvenu III OJ, Pinto A, et al (2007c) Significant linkage to compulsive hoarding on chromosome 14 in families with obsessive compulsive disorder. Results from the OCD Collaborative Genetics Study. *American Journal of Psychiatry*; **164**: 493–9.
- Saxena S, Maidment KM (2004a) Treatment of compulsive hoarding. *Journal of Clinical Psychology*; **60**: 1143–54.
- Saxena S, Brody A, Maidment K, et al (2004b) Cerebral glucose metabolism in obsessive compulsive hoarding. *American Journal of Psychiatry*; **161**: 1038–48.
- Saxena S (2005) Comment on hoarding: reply. *American Journal of Psychiatry*; **162**: 1031.
- Saxena S (2007a) Compulsive hoarding and OCD: two distinct disorders? Reply. *American Journal of Psychiatry*; **164**: 1435.
- Saxena S (2007b) Is compulsive hoarding a genetically and neurobiologically discrete syndrome? Implications for diagnostic classification. *American Journal of Psychiatry*; **164**: 380–4.
- Saxena S, Brody AL, Maidment KM, et al (2007c) Paroxetine treatment of compulsive hoarding. *Journal of Psychiatric Research*; **41**: 481–7.
- Shetti CN, Reddy YCJ, Kandavel T, et al (2005) Clinical predictors of drug nonresponse in obsessive compulsive disorder. *Journal of Clinical Psychiatry*; **66**: 1517–23.
- Stein DJ, Seedat S, Potocnik F (1999) Hoarding: a review. *Israel Journal of Psychiatry and Related Sciences*; **36**: 35–46.
- Steketee G, Frost RO (2000) Group and individual treatment of compulsive hoarding: a pilot study. *Behavioural and Cognitive Psychotherapy*; **28**: 259–68.
- Steketee G, Frost R (2003) Compulsive hoarding: current status of research. *Clinical Psychology Review*; **23**: 905–7.
- Steketee G, Frost R (2007) *Compulsive Hoarding and Acquiring*. Therapist Guide. Oxford University Press.
- Tolin DF, Frost RO, Steketee G (2007) *Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding*. Oxford University Press.
- Tracy JL, de Leon J, Qureshi G, et al (1996) Repetitive behaviours in schizophrenia: a single disturbance or discrete symptoms? *Schizophrenia Research*; **20**: 221–9.
- Van Grootheest D, Cath D (2007) Compulsive hoarding and OCD: two distinct disorders? *American Journal of Psychiatry*; **164**: 1435.
- Volle E, Beato R, Levy R, et al (2002) Forced collectionism after orbitofrontal damage. *Neurology*; **58**: 488–90.
- Wu K, Watson W (2005) Hoarding and its relation to obsessive–compulsive disorder. *Behaviour Research and Therapy*; **43**: 897–921.
- Winsberg ME, Cassic KS, Koran LM (1999) Hoarding in obsessive compulsive disorder: a report of 20 cases. *Journal of Clinical Psychiatry*; **60**: 591–7.
- World Health Organization (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. WHO.
- Zhang H, Leckman JF, Pauls DL, et al (2002) Genomewide scan of hoarding in sib pairs in which both sibs have Gilles de la Tourette syndrome. *American Journal of Human Genetics*; **70**: 896–904.

MCQs

1 Hoarding:

- a is exclusively associated with OCD
- b can be part of a variety of mental disorders
- c is exclusively associated with Diogenes syndrome
- d is exclusively associated with dementia
- e is exclusively associated with Prader–Willy syndrome.

2 Diogenes syndrome:

- a is well-established in ICD–10 and DSM–IV
- b describes both older and younger adults living in squalid conditions
- c was coined by Clarke in 1975
- d originally described a large proportion of mentally ill people living in squalor
- e is a clinically useful term for diagnosis and management.

3 As a symptom, hoarding:

- a should be identified as a target symptom for treatment regardless of the main diagnosis
- b usually presents with ritualistic, stereotypical and grasping behaviour
- c is usually a sign of an accompanying OCD
- d is always associated with high levels of stress on the removal of hoarded objects
- e is associated with a distinct genetic profile.

4 Compulsive hoarding syndrome:

- a is an established discrete subtype of OCD
- b involves acquisition of objects that appear (to others) to have no value
- c does not necessarily involve functional impairment
- d is associated with ego-dystonicity
- e is usually diagnosed at an early stage.

5 As regards the treatment of compulsive hoarding syndrome:

- a SSRIs are more effective in this population than in other subtypes of OCD
- b exposure and response prevention and forced cleaning are effective treatment options
- c CBT is labour intensive but studies have demonstrated good outcome in reducing acquisition of items and improving organisation skills
- d cholinesterase inhibitors and stimulants are recognised treatment for compulsive hoarding syndrome
- e patients present with full insight into their condition and welcome treatment options.