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Hoarding Disorder: More than just a problem of too much stuff

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Compulsive or problematic hoarding behaviors occur in a variety of neuropsychiatric disorders, including obsessive compulsive disorder (OCD), schizophrenia, and dementia. Such behaviors have until recently been considered as a subtype of obsessive compulsive disorder (OCD), despite the fact that clinicians and researchers have long known that these symptoms often occur independently of OCD or other neuropsychiatric disorders. However, with the publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Hoarding Disorder (HD) has at long last achieved recognition as a clinical syndrome in its own right(1). Research suggests that this recognition is appropriate, despite the current trend away from disorder-specific approaches and towards cross-diagnostic approaches.

HD is defined as a pattern of persistent difficulties with discarding personal possessions, even those with no clear value, because of strong desires to save along with distress or indecision about what to discard. Difficulty discarding is often, but not always, accompanied by excessive acquiring of unneeded objects, and, in the absence of intervention, leads over time to the accumulation of so many items that the space or room cannot be used for its usual purposes, and thus to substantial functional impairment(1). This definition allows for a distinction to be made between HD, where the core problem is desire to save leading to difficulty discarding, and hoarding behaviors typically seen in other neuropsychiatric disorders, where the main feature is often excessive collecting or acquiring of rubbish (e.g., cigarette butts, bottles from garbage cans, etc) or passive difficulties with discarding(2, 3). HD does co-occur with OCD, however, and there is evidence of etiological overlap between the two disorders. Nevertheless, HD occurs independently of OCD in 60-80% of cases, these disorders have different epidemiological and neurocognitive profiles, and most importantly, different treatment outcomes(4).

Epidemiology of HD compared to OCD

Prevalence rates of OCD are fairly stable across the lifespan, affecting approximately 2% of children, adolescents, and adults(5, 6). The age of onset varies, but for many, symptoms begin in childhood or early adolescence. Symptoms of OCD wax and wane with time, but tend to become problematic and/or distressing relatively soon after onset, and without treatment, continue at fairly consistent levels into old age.

Unlike OCD, HD appears to be a progressive disorder. The overall prevalence of HD is between 2 and 4%, increasing to over 6% in individuals age 55 and older(7). Rather than waxing and waning, hoarding symptoms tend to be chronic and slowly increase over time(4). While the age of onset for hoarding symptoms is similar to that of OCD (ages

12-15), these symptoms do not initially cause impairment or distress, but typically become problematic later in life, usually around the 4th or 5th decades. This progression of severity may be in part due to parental or other influences (e.g., spouse, roommate) that require or assist individuals to discard items, preventing the accumulation of clutter.

Insight into illness/help-seeking

Most individuals with OCD have good insight into their illness, recognizing that their obsessions and compulsions are not logical, although they may or may not recognize that their symptoms are due to OCD(4). Symptoms are ego-dystonic except in children, where, depending on developmental stage, symptoms may be ego-syntonic. In contrast, hoarding, while distressing, is often not completely ego-dystonic, and insight into illness is quite variable(4). Individuals with HD may be distressed by their hoarding, but may not able to recognize the cause as being due to an inherent difficulty in discarding or to excessive acquiring of un-needed objects, despite clear evidence of this, citing instead external causes such as limited space, difficulties with organization, or the possibility that the items may be at some point needed and will not be obtainable at that future point. Poor or variable insight and lack of ego-dystonicity of symptoms can lead to reluctance to seek help, and possibly also to poor response to treatment.

Neurocognition in HD

Although the core feature of HD is difficulty discarding unnecessary and/or useless items, there is a growing body of evidence to suggest that this difficulty is due to an even more fundamental deficit of executive function. Although somewhat inconsistent due to methodological differences and small sample sizes, neuropsychological and electrophysiological studies of HD have identified deficits in categorization, working memory, decision making, attention, and error processing, and there is emerging data to suggest that deficits in memory and learning, particularly in the visual domain, are also seen in individuals with HD(8). Perhaps more directly relevant for clinicians, a history of childhood attention deficit hyperactivity disorder (ADHD), in particular, the inattentive subtype, has been associated with HD in a number of studies(9), providing indirect evidence that executive dysfunction may predate the onset of hoarding symptoms, and also suggesting that pharmacotherapy for ADHD (e.g., stimulants, buproprion, atomoxetine) may be of benefit in HD.

Pharmacologic treatment of HD

The treatment of HD has for the most part been based on and modified from current treatment strategies for OCD, and most of the focus has been on behavioral approaches. The most commonly used pharmacotherapeutic options currently include the selective serotonin reuptake inhibitors (SSRIs) and the serotonin-norepinephrine reuptake inhibitors (SNRIs), although other agents such as stimulants have been tried in a very small number of individuals(10). Unfortunately, however, very little is known about the efficacy of pharmacotherapy in HD; most of the studies that do exist examine the relationship between treatment response and symptom subtypes, including hoarding, in individuals with a primary diagnosis of OCD. These studies have been mixed, with some suggesting that individuals

with prominent hoarding symptoms tend to have a worse treatment response to SSRIs than do those without prominent hoarding symptoms, and others indicating that the treatment response is similar with and without hoarding (reviewed in Samuels 2007)(11). To date, there have been no blinded, placebo-controlled studies of treatment response in HD, and only two open-label studies(12-14). The first was an open-label trial of paroxetine in 32 individuals with HD and 47 with non-hoarding OCD, and the second was a trial of extended release venlafaxine(14). In contrast to the studies of hoarding as an OCD subtype, which suggested that individuals with hoarding symptoms had poorer responses to SSRIs, the paroxetine study showed a similar response rate for individuals with HD and those with non-hoarding OCD (approximately 50% had at least a partial response, defined as a ≥25% improvement in symptoms) on 40-60 mg of paroxetine per day. However, a substantial number of individuals from both groups were unable to tolerate the target dose of 40 mg a day, and only 16 were able to tolerate the full dose of 60 mg per day, somewhat limiting the interpretability of the results. This group also reported on an open label trial of extended release venlafaxine. In this trial, which examined 24 individuals with HD (no control group was included), sixteen of the 23 who completed treatment were classified as treatment responders, with a ≥30% improvement in hoarding symptoms. The mean final dose for these individuals was about 200 mg per day—only sixteen were able to tolerate a dose of 225 mg per day. Although somewhat contradictory to the early studies showing poorer treatment response among individuals with OCD + hoarding symptoms, and limited by small sample sizes and open-label designs, these studies provide some hope that pharmacotherapy with SSRIs and/or SNRIs have a role in the treatment of HD. Importantly, however, recent studies examining willingness to undergo treatment suggest that individuals with HD or OCD-related hoarding are less willing than individuals with non-hoarding OCD to take medication for their symptoms, although they may be willing to participate in behavioral therapy(15). This reluctance may in part be related to the problems with insight discussed above, or it may be due to the fact that HD has only recently been recognized as a psychiatric disorder with clear biological underpinnings, and thus a medical model approach may not feel appropriate for affected individuals.

Psychotherapy for HD

In contrast to pharmacotherapy, there is a reasonably sized literature on psychotherapy for HD. As with medication treatment, behavioral treatment for HD is based on the standard of care for OCD, and has been modified over time to more specifically address the unique challenges faced by individuals with HD. The core component of psychotherapy for HD is cognitive behavioral therapy (CBT); components on motivational interviewing and harm reduction are also common(16, 17). The cognitive component typically focuses on addressing cognitive distortions related to fear of discarding and urges to acquire, while the behavioral component focuses on sorting through and discarding materials in a systematic and structured way, either in the therapy session or at home. CBT can be administered either in a group setting or in individual treatment. Home visits by the clinician are incorporated into most behavioral treatments for HD, primarily to provide an accurate assessment of functional impairment in the context of limited insight, but also to assess progress and if needed, to assist with further tailoring of the behavioral intervention. Motivational

interviewing has become a key component of behavioral interventions for HD(18), aimed at decreasing ambivalence for treatment by helping patients identify areas of impairment that they recognize to be caused by hoarding symptoms, and that they wish to improve (e.g., social relationships impaired by not being able to let family members or friends into the home, safety issues related to piles on the floor or on surfaces, etc). Harm reduction is similar in concept to motivational interviewing, and the aim of this component is not to cure the hoarding problem, but to reduce the impairment (harm) caused by the symptoms and thus improve quality of life for the affected individual(19).

More recently, a form of behavioral therapy led by peers rather than by mental health providers, called peer-faciliated support group therapy, has been developed(20). This approach uses the same CBT concepts used in standard group treatment, and is based on working through the exercises laid out in a self-help manual called Buried in Treasures. Peer-facilitated support groups are meant to provide a more supportive and potentially less stigmatizing environment than CBT groups led by mental health providers, as the group leaders typically have lived experience of problematic hoarding, and, in addition to meeting on a weekly basis in a group format, call participants prior to each group to check in and encourage them to attend the following group session.

Although there are as yet no studies that directly compare peer-facilitated support group treatment to group CBT led by a mental health provider, the mean response rates for published studies, including individual CBT, group CBT, and peer-facilitated support group treatment, are between 12 and 14 points improvement (range 7.5 to 18.5) on the Savings Inventory-Revised (SI-R)(21), a self-report assessment of hoarding symptoms. As most treatment studies reported mean pre-treatment scores of ≥60 (a score of ≥42 is typically used as the cutoff for clinically significant hoarding), a 14-point improvement represents at best a 23% improvement over baseline(22). Thus, while comparable to the commonly used definition of treatment response in OCD (≥25-35% improvement in Yale Brown Obsessive Compulsive Scale or YBOCS severity score), it is clear that, although perhaps more tolerable to participants, currently-available behavioral treatments rarely, if ever, result in remission of symptoms, and improvements are modest for most individuals.

Clearly, more work is needed to identify effective treatments for HD, both pharmacologic and psychotherapeutic. Given the relatively poor response rates for currently available treatments (≤30% improvement of symptoms) and evidence of potential underlying neurocognitive deficits, new avenues for treatments might include cognitive remediation in addition to medication and therapy and/or medications that target executive dysfunction (anticholinesterase inhibitors, stimulants, etc).

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