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Phenomenology of childhood hoarding

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Review Article

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Abstract

Hoarding disorder (HD) has been recently added as a separate diagnostic category in the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders*. HD is a common and disabling disorder, with an estimated prevalence in the general population of 2–6%. Although evidence suggests that the onset of hoarding symptoms is usually during childhood and adolescence (youth), relatively little is known about HD in this population. The present article is a selective review of emerging literature on the clinical features of hoarding in youth.

Introduction

Hoarding disorder (HD) has been recently added as a separate diagnostic category in the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association [APA], 2013). The introduction of HD represented a break from traditional classification systems that considered hoarding symptoms as a subtype of obsessive–compulsive disorder (OCD). HD's main criteria are (1) persistent difficulty in discarding or parting with possessions; (2) perceived need to save items or distress associated with discarding items, regardless of their actual value; (3) the accumulation of possessions that congest and clutter active living and (4) associated clinically significant distress or impairment in important areas of functioning (APA, 2013). Excessive acquisition of items, which was considered a hoarding criterion in pre-DSM-5 conceptualisations of 'compulsive hoarding' (Frost & Hartl, 1996), was removed as a criterion, but can be added as a specifier.

HD is a common and disabling disorder with an estimated prevalence in the general population of 2–5% (Iervolino et al., 2009; Samuels et al., 2008; Timpano et al., 2011). Evidence suggests that HD, as defined by DSM-5, exists and presents similarly across different cultures (Nordsletten et al., 2018). This relatively high rate of prevalence and pancultural presence of hoarding are concerning as evidence points to the association of HD with marked functional and occupational impairments (Morris et al., 2016). For example, individuals who hoard reported more psychiatric-related work impairment days than females with major depressive disorder, social phobia or post traumatic disorder and were on par with those with bipolar disorder or non-affective psychosis (Tolin et al., 2008). Hoarding is associated with increased risks to health (Ayers et al., 2014; Tolin et al., 2008) and safety (Frost et al., 2000). Finally, there is evidence that HD is associated with substantial caregiver burden, comparable to or greater than that reported for relatives of individuals with dementia (Drury et al., 2014).

To date, the majority of hoarding studies have been conducted in adult populations. Thus, our understanding of hoarding symptoms in youth (childhood and adolescence) is still limited. The paucity of hoarding studies in youth may be attributed to the finding that hoarding symptoms are rarely the main reason for referral in this age group (Mataix-Cols & Pertusa, 2012). Parents also actively prevent acquisition and clutter and thus can mask paediatric hoarding symptoms (Grisham et al., 2006).

Learning more about HD in youth is important due to several reasons: (1) the age of onset of hoarding symptoms is often during childhood and adolescence (Zaboski et al., 2019); (2) the course of HD is chronic (Kichuk et al., 2013) and symptoms tend to worsen over time (Tolin et al., 2010) and (3) the presence of hoarding symptoms is a marker of poor prognosis (Samuels et al., 2014). With this in mind, the present article is a selective review on the presentation of hoarding symptoms in youth.

Case illustration

'Emily', an 11-year-old girl, presented with her parents for evaluation and treatment of anxiety and hyperactivity symptoms. According to the parents, Emily met all developmental milestones except for minor fine-motor difficulties. Parents reported that Emily was doing well socially. A psychiatric assessment suggested that Emily had met criteria for a primary diagnosis of OCD (with contamination, harm and sexual obsessions and rituals), attention-deficit hyperactivity disorder-combined type (ADHD-combined type) and HD. Parents reported that a trial of

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stimulant medication resulted in symptoms of activation. At the time of her initial presentation, Emily and her parents focused on her OCD and ADHD symptoms. Thus, a course of 14-session, family-based cognitive behavioural therapy (CBT) with exposure and response prevention was combined with a gradual introduction of 20 mg of Fluoxetine. The use of Fluoxetine was not associated with an increase in ADHD symptoms. Emily responded well, and her Children's Yale-Brown Obsessive–Compulsive Scale (CYBOCS) scores dropped from 26 to 10 in the remission range. In the following year, however, Emily continued to struggle with symptoms of ADHD and hoarding, so a decision was made to gradually switch her Fluoxetine to Guanfacine, a non-stimulant medication for the treatment of ADHD.

The introduction of Guanfacine was associated with a marked decrease in ADHD symptoms, but no change in hoarding symptoms was observed. Emily, who was now 12 years old, together with her parents flagged hoarding as the primary issue. Emily described extreme difficulties parting with her possessions. Emily reported that she could not part with her old clothes, school notebooks, toys. Emily acknowledged that her tendency to hold on to possessions was excessive, but reported that thinking about letting go of her possessions made her feel sad. Initially, she struggled when asked to define her cognitions during discarding situations. On a subsequent appointment, however, she said, 'I feel sad for them when I have to give them away. I may also need them at some point'. Emily also identified an intense fear of having to give up all of her items.

Emily's parents reported that her room was cluttered with possessions. Everyone agreed that attempts to 'clear' Emily's room usually met with anger and tears. Parents also shared that they had to clear a section of their basement so that Emily could store more items there. They reported that they felt frustrated and, at times, angry with Emily.

Emily was reluctant when the option of individual CBT for hoarding was first raised but changed her decision on a subsequent visit. Upon completion of a course of 14 individual, family-based CBT sessions for hoarding, Emily and her parents reported a marked decrease in hoarding symptoms.

Presentation of youth hoarding symptoms

Traditional hoarding definitions have tended to include saving and collecting symptoms, which are common developmentally appropriate phenomena and appear to occur on a continuum of severity (Storch et al., 2011). The presence of hoarding symptoms in youth may be mediated by the early manifestation of anxiety. For example, studying a sample of youth aged 13–86 months, Evans and colleagues (1999) reported that bedtime fears were associated with an increased tendency to collect and store items.

Recent studies suggest that difficulty discarding may be the core hoarding dimension (Levy et al., 2019) and that not all individuals who hoard also engage in excessive acquisition. These findings are reflected in DSM-5's criteria for HD, which no longer require the presence of acquisition symptoms. There is preliminary evidence (Landau et al., 2011) that the onset of difficulty discarding symptoms precedes the onset of clutter symptoms in HD patients diagnosed with OCD. Youth and adults often hoard old clothes, bags, books, school-related paraphernalia, nonvaluable collectables (e.g., stones), food items and broken family possessions (Storch et al., 2011).

Clinical experience (Plimpton et al., 2009) suggests that difficulty discarding in youth is associated with exaggerated 'essentialism' – the view that each entity has a unique set of attributes that defines and constitutes it. Individuals who hoard associate the qualities of living beings with inanimate objects or items, leading to anthropomorphisation of those inanimate objects (Burgess et al., 2018). Indeed, the presence of hoarding symptoms is sometimes associated with feeling sorry for the discarded item. Frost and Steketee (2010) referred to how an individual with HD had felt upon throwing away a yoghurt container: 'the thought crossed my mind: maybe the container would rather be dry instead of sitting there for a long time, humid . . . I also had to resist apologising to the container . . . I felt responsible for giving it as comfortable a ride as possible'. Youth who hoard also assign increased emotional values to multiple items, a sense that giving up items equals giving up on parts of the self and the fear of letting go of items that may be needed in the future (Plimpton et al., 2009).

In many other cases, youth report that they are driven by the fear of experiencing distress upon discarding. It has been suggested that the impact of difficulty discarding may differ between adults and youth (Burton et al., 2015). In adults, there is often visible clutter to the point of compromising safe passage and living spaces. In contrast, parents often engage in active de-cluttering efforts. Indeed, a series of six studies of children with HD (Plimpton et al., 2009) reported lower than expected occurrence of clutter or acquisition.

Difficulty discarding symptoms play an essential role in the cognitive-behavioural model of hoarding. Frost and Hartl (1996) identified excessive and maladaptive attachment to possessions and erroneous beliefs about the nature of possessions, as well as information processing difficulties (e.g. decision-making deficits), as critical factors for the development of hoarding symptoms. In the years since the model was introduced, it was updated by adding early developmental factors (Frost et al., 2007; Kyrios et al., 2018).

Family aspects of youth hoarding symptoms

Family accommodation is the process by which family members participate in hoarding symptoms or modify personal and family routines in response to the individuals' symptoms (Calvocoressi et al., 1999). Family accommodation has been well described in youth with OCD (Francazio et al., 2016; Riise et al., 2019; Wu et al., 2019).

A recent qualitative study of 10 parents of children with clinically significant hoarding and ADHD symptoms (Lynch et al., 2017) provided an in-depth look at common clinical themes of child hoarding. The authors reported that most parents acknowledged the presence of avoidance and accommodation behaviours. Parents reported that they often avoided exposing themselves and their child to the distress of discarding possessions and that they tended to accommodate acquisition symptoms. Furthermore, parents reported that hoarding symptoms had a significant negative impact on other individuals in the family (i.e. parents and siblings) and on the family unit as a whole. It is possible that these findings in children are associated with long-term effects, as found by a recent study of adults who hoard. Kyrios et al. (2018) reported that participants tended to have lower recollections of warmth in their families compared with non-hoarding groups. These findings highlight the importance of assessing family factors in the context of an assessment of youth hoarding symptoms.

Hoarding-related impairment in youth

There is robust evidence that adults with HD suffer marked social and functional impairment (Ong et al., 2015). Similarly, youth who

hoard have impaired social relationships (Plimpton et al., 2009) as well as associated weight gain and allergies (Storch et al., 2011). In children with OCD and ADHD, hoarding is associated with poor quality of life, the persistence of disorders into early adulthood (Bloch et al., 2009; Palermo et al., 2011) and oppositional symptoms (Hacker et al., 2016).

Measurement of hoarding symptoms in youth

To move beyond clinical case descriptions, the study of youth hoarding has to rely on valid and reliable assessment tools. An initial hoarding study in children and adolescents was based on the CYBOCS (Scahill et al., 1997), a clinician-administered, semi-structured clinical interview that includes a lengthy symptom checklist and a symptom severity scale. However, hoarding studies based on the CYBOCS were limited because the presence of hoarding symptoms was determined based on only two hoarding items on the symptoms' checklist. Furthermore, the CYBOCS symptom severity scale is a measure of overall OCD severity and, as such, cannot be used to assess hoarding severity. The Obsessive–Compulsive Inventory-Child Version (OCI-CV) (Foa et al., 2010) represents an improvement over the CYBOCS by providing a more comprehensive approach to the core symptom dimensions of HD. The OCI-CV includes a hoarding severity subscale that was found to have high internal consistency and test–retest reliability but contains only three items and, as such, is of limited scope.

The Children's Saving Inventory (CSI) (Storch et al., 2011) is the first and only measure specifically designed to assess the presence and severity of hoarding in youth. The CSI was adapted for use in youth from the Saving Inventory-Revised (SI-R) (Frost et al., 2004), a widely used measure of hoarding symptom severity. To date, the CSI has been used to study hoarding symptoms in youth populations with ADHD (Hacker et al., 2016), OCD (Soreni et al., 2018) and anxiety disorders (Hamblin et al., 2015). The CSI is a 23-item parent-rated questionnaire that assesses parent perceptions of their child's behaviour on a 0 (none) to 5 (almost all/completely) scale. The CSI's original four-factor solution included discarding, clutter, distress/impairment and acquisition. As such, the total CSI score does not conform with DSM-5's HD framework, which no longer requires the presence of acquisition symptoms.

Initial psychometric evaluation of the CSI in youth with OCD suggested good to strong internal consistency, excellent test–retest reliability and good overall convergent and discriminant validity (Storch et al., 2011). To date, the CSI has been used to study hoarding symptoms in youth populations with ADHD (Hacker et al., 2016; Lynch et al., 2017), OCD (Soreni et al., 2018) and anxiety disorders (Hamblin et al., 2015). However, a recent psychometric evaluation of the CSI in Canadian children and adolescents with OCD (Soreni et al., 2018) failed to support the previously reported four-factor solution. Instead, the authors proposed a robust three-factor solution (difficulty discarding, clutter and distress/impairment) with good reliability and validity for a shorter 15-item version of the CSI (CSI-15) that has the additional advantage of conforming to DSM-5's HD criteria.

The Hoarding Rating Scale-Interview is a promising brief 5-item semi-structured interview that assesses hoarding symptoms. Initial validation studies in adult populations (Tolin et al., 2010, 2018) reported high internal consistency and reliability and suggested that the instrument was able to differentiate hoarding and non-hoarding participants. Although Park et al. (2016) reported excellent internal consistency of the Hoarding Rating Scale-Interview in a sample of 431 youth, no validation studies have been conducted in youth populations to date.

Prevalence

There is only scarce evidence on the prevalence of clinically significant hoarding in community samples of youth. Alvarenga et al. (2015) studied 9,937 Brazilian children between the ages of 6 and 12 years old and 3,305 of their older (13–18 years) siblings. Based on caregivers' responses to a single hoarding question ('has anyone in your family needed to collect or store MANY things or useless objects?'), authors reported prevalence rates of 9.27% and 9.68% for 6–12 years old and 13–18 years old age ranges, respectively. Ivanov et al. (2013) reported the prevalence of clinically significant hoarding symptoms in 15-year-old twins with a population-based Swedish sample of 3,974 participants. The authors reported that the prevalence of clinically significant hoarding symptoms was 2% (95% CI 1.6–2.5%) but then rose to 3.7% when they excluded the clutter criterion. Finally, higher prevalence rates were reported in a more recent Canadian sample of 17,263 youth (aged 6–17 years) (Park et al., 2016). Using the Toronto Obsessive–Compulsive Scale (Park et al., 2016), the authors reported that 8.9% of participants had high hoarding symptoms.

Interestingly, a US adult population study (Rodriguez et al., 2013) reported that the prevalence of difficulty discarding worn out/worthless items in the general adult population was 20.6%. That difficulty discarding was much more prevalent than reported rates for hoarding, which suggests that additional factors are required for the development of a full-blown HD. Moreover, the presence of difficulty discarding was strongly correlated with psychiatric disorders, level of impairment and use of mental health services.

Sex differences

Community and clinical samples provide mixed evidence of sex differences in the prevalence of youth hoarding (Morris et al., 2016). In community samples, the Swedish study by Ivanov et al. (2013) reported high girls/boys ratios; the Brazilian sample by Alvarenga et al. (2015) reported lower girls/boys ratios and a recent Canadian study (Park et al., 2016) reported lack of sex differences. As for clinical populations, two studies of hoarding symptoms in two paediatric OCD samples (Mataix-Cols et al., 2008; Samuels et al., 2014) reported that girls were more likely than boys to exhibit hoarding symptoms. These findings are in general agreement with two CSI-based studies in paediatric OCD samples (Soreni et al., 2018; Storch et al., 2011). Storch reported that girls had significantly higher discarding and clutter scores, although the total score did not differ. Similarly, Soreni et al. (2018) reported that girls had higher CSI-15 total and CSI-15 discarding subscale scores than did boys. In contrast, no sex differences were found when the presence of clinically significant hoarding measured in a sample of youth with ADHD (Hacker et al., 2016).

Age of onset and course of hoarding symptoms in youth

The diagnosis of HD is typically made during or after the third decade of life (Dozier et al., 2016), though the onset of hoarding symptoms occurs much earlier, often during childhood and adolescence. For example, the retrospectively reported mean age of hoarding in a sample of 36 adults was 12 years (Samuels et al., 2002). Similarly, a retrospective study of 751 adults with

OCD (Tolin et al., 2010) showed that the median age of onset of pathological hoarding symptoms was between 11 and 15 years. A recent meta-analysis (Zaboski et al., 2019) reported that the mean age of onset of hoarding symptoms was 16.7 years. Authors also reported a possible bimodal pattern of onset with means of 11.8 and 18.7 years. Furthermore, authors also reported that an average age of onset was lower by 4 years among individuals with co-occurring hoarding and OCD compared to those without OCD. The majority of age of onset studies, however, relied on retrospective data, underscoring the need for future longitudinal studies.

Of note, however, is that findings of childhood and adolescence symptom onset of adult HD cases do not necessarily imply that youth diagnosed with HD will go on to meet criteria in later decades of life. Although preliminary evidence suggests that hoarding symptoms in youth are temporally stable (Besiroglu et al., 2007) and can extend into adulthood (Palermo et al., 2011), data are lacking regarding the developmental course of the disorder.

Association of youth HD with OCD

The nosology of HD was an often debated topic in early hoarding literature (Pertusa et al., 2008; Van Grootheest & Cath, 2007). DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision) (APA, 2004) referred to hoarding symptoms as a diagnostic criterion in the context of obsessive–compulsive personality disorder. However, the text suggested that clinically significant hoarding symptoms should be considered an OCD subtype. The inclusion of hoarding in OCD was based on observations of phenomenological similarities between these two conditions (Frost et al., 2012). For example, individuals with hoarding symptoms often report more OCD symptoms than those without hoarding (Frost & Hartl, 1996). Also, difficulty discarding possessions can sometimes be interpreted and understood as a fear of losing important things, and, as such, an obsession. Because of the perception that hoarding was an OCD subtype, much of the initial, first-wave HD research has been conducted in OCD samples.

A separate diagnostic category for HD was included in DSM-5 after studies in adults have established phenomenological differences between hoarding and OCD symptoms (Frost et al., 2012). First and foremost, the prevalence of HD appears to be much higher than that reported for OCD (Samuels et al., 2008). In addition, many individuals with hoarding symptoms do not meet the diagnostic criteria for OCD. Frost et al. (2011) reported that only 18% of 217 adults with HD met OCD criteria. Also, rates for major depressive disorder and impulse control disorder were more frequent in HD than OCD participants.

Association of youth HD with ADHD

In the years that followed the publication of DSM-5, evidence emerged supporting a strong association of HD with ADHD. Although initial evidence linking HD with ADHD came from adult studies (Sheppard et al., 2010; Tolin & Villavicencio, 2011), later studies have been based mainly on paediatric samples. Sheppard et al. (2010) reported that, in a sample of youth and adults with childhood-onset OCD, hoarding was present in 41.9% of participants with ADHD compared to 29.2% in participants without ADHD. Further, a study of adults reported that inattention, not hyperactivity or OCD symptoms, predicted severity of difficulty discarding, clutter and acquiring, with Raines et al. (2014) reporting that, in a sample of 34 individuals with HD, hoarding severity was associated with difficulties in sustained attention.

Further evidence of the association between hoarding and ADHD came from a study of 99 youth diagnosed with ADHD (Hacker et al., 2016) who were assessed for hoarding symptoms using the CSI. The authors reported that inattentive and hyperactive and impulsive symptoms were the only indicator that differentiated youth with and without high hoarding symptoms. In line with earlier studies in adults with OCD, non-hoarding obsessive–compulsive symptoms did not predict hoarding symptoms. Studying 431 youth with OCD, Park et al. (2016) reported that the hoarding group had a significantly higher number of inattention and hyperactivity symptoms compared to the non-hoarding group.

Overall, clinical and genetic evidence supports a complex association between hoarding, OCD and ADHD symptoms. Burton et al. (2016) reported that 10% of a community sample of 16,718 youth (aged 6–17 years) had high hoarding scores on the Toronto Obsessive–Compulsive Scale. Moreover, a more recent analysis of the same dataset suggested that hoarding was not highly correlated with other OC dimensions in the same sample (Burton et al., 2018). However, 40% of these participants did not have increased obsessive–compulsive scores. The authors reported that ADHD symptoms were more common in participants with high hoarding and low OCD. In contrast, participants with high OCD and low hoarding had more anxiety symptoms. Similarly, genetic studies suggest a complex association between hoarding symptoms and other dimensions of psychopathology. For example, Burton et al. (2018) reported that although hoarding was not highly correlated with other obsessive–compulsive dimensions, it did share with them genetic effects. Overall, the study of the association of hoarding symptoms with OCD and ADHD has led to a growing support of DSM-5's conceptualisation of HD as a distinct disorder. However, empirical validation of HD in paediatric populations is still lacking (Morris et al., 2016).

Association of youth HD with other disorders

Existing findings suggest an association between hoarding symptoms and early-onset neurodevelopmental disorders such as autism spectrum disorder (ASD) and Prader-Willi syndrome (PWS). ASD is a chronic condition of early childhood onset defined by impaired social interaction and social communication as well as repetitive behaviour and restricted interests. In a psychometric study of the CYBOCS version for ASD in 272 medication-free children, Scahill et al. (2014) reported a frequency of 24.3% for difficulty discarding or saving of possessions. Interestingly, symptoms of difficulty discarding were more prevalent than counting, checking, ordering, rereading or the need to repeat routine activities. Storch et al. (2016) studied a sample of 40 children with ASD and a comorbid anxiety disorder and reported that 25% of their sample presented with clinically significant hoarding symptoms. A more recent study of a larger sample of 204 children with ASD and comorbid anxiety or OCD (La Buissonniere-Ariza et al., 2018) reported that 33.9% of participants presented with at least moderate levels of hoarding and 6.9% were found to have severe to extreme levels. Furthermore, more than 40% and 30% presented with moderate to extreme difficulties discarding possessions and clutter, respectively.

PWS is a genetic condition characterised by hypotonia, mild intellectual disability, insatiable appetite and chronic overeating. Children with PWS have shown high rates of hoarding symptoms

(Dykens et al., 1996). In a sample of 91 youth and adults with PWS, 58% had hoarding symptoms that appeared to be unrelated to food seeking (Dykens et al., 1996). A more recent study of 61 children with PWS (Lo et al., 2015) found that 37% of participants had symptoms of hiding, collecting or hoarding objects. Interestingly, the prevalence of hoarding behaviour was higher than any other compulsion.

Much like PWS, youth with Anorexia Nervosa often engage in food acquisition and saving. Halmi et al. (2003) administered the Yale-Brown Obsessive Compulsive Scale to 324 patients with Anorexia Nervosa and reported that frequency of hoarding symptoms was similar to that of a control group with OCD.

Summary

The identification of the unique features of, and factors associated with, hoarding symptoms has led to the addition of HD in DSM-5. Studies conducted over the past two decades have shown that hoarding symptoms in youth are common, that youth hoarding is often associated with multiple comorbid conditions and that hoarding cognitions in youth are similar in nature to those found in adults. Although our understanding of hoarding symptoms is continuously growing, relatively scarce data are available on children and adolescents who hoard. Given that recent studies have identified childhood and adolescence as a critical period for the onset and development of hoarding symptoms, this knowledge gap is concerning. Perhaps most important at this stage of the research are the introduction of both developmentally sensitive youth hoarding instruments and the design and implementation of longitudinal studies of hoarding. The latter approach may prove to be invaluable in determining the association between youth and adult HD.

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