

Age of onset and progression of hoarding symptoms in older adults with hoarding disorder

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Objectives: We investigated (1) age of onset of hoarding disorder (HD) symptoms and diagnosis, (2) late-onset HD, (3) progression of HD symptoms, and (4) association between demographics and hoarding progression.

Method: Eighty-two older adults with HD provided retrospective ratings of their hoarding symptoms for each decade of life. Age of onset of symptoms (saving, difficulty discarding, and clutter) was operationalized as the first decade in which the participant reported at least minor symptom severity, and age of onset for possible HD diagnosis was operationalized as the first decade in which the participant reported all three symptoms. We used mixed effects modeling to examine the progression of HD symptoms.

Results: The median age of onset for symptoms was between 10 and 20 years, and the median age of onset for possible HD diagnosis was between 20 and 30 years. Twenty-three percent of participants reported onset of possible HD diagnosis after the age of 40. All HD symptoms increased in severity over time. Men reported higher initial clutter and a slower increase in hoarding severity for all symptoms. Increased education was associated with slower increase in saving. Having at least one parent with hoarding tendencies was associated with higher initial hoarding symptoms.

Conclusion: Generally, symptoms of HD begin relatively early and worsen across the lifespan. However, approximately one fourth of older adults with HD reported a possible onset after the age of 40.

Keywords: age of onset; hoarding disorder; older adults

Introduction

Hoarding disorder (HD), only recently codified in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013), has been linked with multiple risks to older adults, including medical problems, impairment in activities of daily living, and fire or falling hazards (Ayers, Iqbal, & Strickland, 2014; Ayers, Saxena, Golshan, & Wetherell, 2010; Ayers, Scheisher, Liu, & Wetherell, 2012; Ayers & Dozier, 2014). Although several papers have discussed the age of onset of compulsive hoarding (Grisham, Frost, Steketee, Kim, & Hood, 2006; Ayers et al., 2010) and hoarding symptoms in patients with obsessive compulsive disorder (Tolin, Meunier, Frost, & Steketee, 2010), none of the studies has examined the age of onset and progression of hoarding symptoms in older adults meeting DSM-5 criteria for HD. An older adult sample would provide particularly important retrospective information on symptom trajectory across the life course.

Grisham and colleagues (2006) interviewed ($N = 51$) individuals from across the lifespan (mean age: 51.14, range: 26–71) with compulsive hoarding problems about their recall of the onset and progression of their symptoms (e.g., clutter, saving, difficulty discarding). Reported onset of all hoarding symptoms was between the ages of 10 and 20, with symptoms of saving having a significantly later reported onset than symptoms of difficulty discarding or

clutter (Grisham et al., 2006). Grisham et al. (2006) concluded that the majority of individuals recalled that their symptoms related to compulsive hoarding began before the age of 20. However, this study did not require the simultaneous presence of all three symptoms required for diagnosis of HD in the DSM-5.

Ayers and colleagues (2010) studied the reported age of onset and progression of hoarding symptoms in 18 older adults (mean age: 67.5, range 60–87) with compulsive hoarding problems. All participants in the sample recalled that their hoarding symptoms began prior to the age of 30 and they perceived their symptoms to have increased steadily across the lifespan (Ayers et al., 2010). Unfortunately, there was no differentiation between the types of hoarding symptoms (e.g., saving, difficulty discarding, and clutter), and no demographic differences were examined in either the age of onset or progression of hoarding symptoms.

Finally, Tolin and colleagues (2010) utilized an online sample ($N = 751$) of primarily mid-life individuals (mean age = 49, $SD = 10.51$) with self-identified hoarding problems. Seventy percent of participants reported onset of hoarding behaviors before the age of 21 (Tolin et al., 2010). The majority of participants (73%) reported a chronic course of hoarding symptoms, though a minority (21.2%) reported that the hoarding symptoms increased across the lifespan (Tolin et al., 2010). This study was

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limited in that all questions were self-reported and no differentiation was made between the three core symptoms of hoarding.

The prior three studies suggested that hoarding symptoms generally begin early in the lifespan and increase across time. However, these studies were limited in that the onset of clinically severe hoarding was not examined in a way consistent with the DSM-5 diagnostic criteria for HD. Further, with the exception of Grisham et al. (2006), none of these studies examined the three core symptoms of HD (e.g., clutter, saving, and difficulty discarding) separately. These studies also did not examine whether an association existed between basic demographic variables and course of symptoms.

In contrast to the evidence for early onset of HD symptoms, several case studies have presented reports of late onset hoarding (e.g., Anderson, Damasio, & Damasio, 2005). Understanding symptom onset and course would inform research examining the possible etiology of HD as well as evidence-based interventions for HD across the lifespan. In the current study, we examined the progression of HD across the lifespan, as well as demographic differences in the development of initial symptoms and course, which may provide insight on the relationship between aging and hoarding symptoms.

The primary purpose of the present study was to investigate the approximate age of onset of the three core symptoms of HD (e.g., clutter, difficulty discarding, and saving), as well as the approximate earliest age at which an individual might have met criteria for HD (operationalized as the earliest age at which an individual reported having all three core symptoms). The second aim of the present study was to investigate prevalence of late onset HD. Next, we examined the progression of HD symptoms over time. Finally, we sought to explore the association between hoarding progression and demographic variables, including gender, years of education, ethnicity, and presence of self-reported first-degree relatives with HD.

Methods

Participants

A geriatric sample was used in order to acquire most data points possible in individuals' recall of symptom progression over the lifespan. The current study utilized the baseline assessment scores for 82 community-dwelling older adults meeting DSM-5 criteria for HD recruited between July 2008 and April 2014 for either two individual intervention studies for late-life HD ($n = 74$) or for a group intervention study for HD that recruited individuals across the lifespan ($n = 8$). All participants were required to be at least 60 years of age at the time of assessment.

Study protocols were approved by the Institutional Review Board of the University of California, San Diego, and by the VA San Diego Healthcare System. Assessments were conducted at the VA San Diego Healthcare System. No monetary compensation was provided for participation, and all participants provided written informed consent. Participants were required to meet DSM-5 HD symptom criteria, determined by a consensus diagnosis

supervised by a licensed clinical psychologist using clinician-administered and self-report measures. Participants identified as having comorbid obsessive-compulsive disorder (OCD) (28%) were required to have HD as the primary diagnosis and for their hoarding symptoms to not be related to their OCD.

Measures

Participants were administered a demographic questionnaire and asked to rate the severity of their hoarding symptoms (saving, difficulty discarding, and clutter) in each decade of their lives, from 0 (none) to 3 (extreme) using the questionnaire employed in Grisham et al. (2006). Participants were also administered two self-report measures of HD severity, the Saving Inventory-Revised (SI-R; Frost, Steketee, & Grisham, 2004) and the Clutter Image Rating (CIR; Frost, Steketee, Tolin, & Renaud, 2008).

The SI-R is a self-report 23-item Likert-type scale of hoarding symptoms and includes three subscales: Acquisition, Difficulty Discarding, and Clutter. The Acquisition subscale includes items related to both saving and excessive acquisition. The CIR is a 3-item pictorial assessment of clutter in which the participant selects a picture that best matches the level of clutter in three rooms of their home (kitchen, living room, and bedroom). The CIR has been validated in older adults (Dozier & Ayers, 2015). Internal reliability was adequate for both hoarding severity measures (SI-R total: $\alpha = .90$; CIR: $\alpha = .86$).

Data analysis

All analyses were performed using Stata version 13.0 (StataCorp, 2013). Age of onset of symptoms was operationalized as the first decade in which the participant reported at least mild severity of the symptom. The age of onset for possible HD diagnosis was operationalized as the first decade in which the participant reported co-occurring symptoms of at least mild saving, difficulty discarding, and clutter. Descriptive statistics of hoarding severity and age of onset were assessed. Correlations between hoarding severity measures and ages of onset were assessed. Univariate differences in demographic factors, including gender, years of education, ethnicity (Caucasian or ethnic minority), and having a parent with hoarding tendencies as well as the number of first-degree relatives with reported hoarding tendencies were assessed for all variables. Associations between categorical demographic variables and age of onset were analyzed using the unpaired Welch's t test to account for unequal variance.

Because individuals reported hoarding across multiple time points, we used mixed effects modeling with a random intercept to control for nonindependence of the data. We also examined the effect of demographic factors (e.g., gender, years of education, ethnicity, and having at least one parent with hoarding symptoms) as covariates in the longitudinal models. Each model contained main and interaction effects of time and the demographic factors on hoarding symptoms. Because only 14 participants were over 70 and only 5 participants were over 80, the trends

observed for those decades were excluded from the analyses.

Results

The current sample reported high current mean scores on measures of hoarding symptom severity (SI-R: 57.49, $SD = 12.5$; CIR: 4.04, $SD = 1.89$). The mean age of the overall sample was 66.3 ($SD = 5.8$, range: 60–86) and the sample was mostly female (64%) and Caucasian (87%). Participants had an average of 16 years of education ($SD = 2.19$, range: 10–20). The majority of participants reported as being divorced (33%), single and never married (32%), or currently married (20%). A small percentage of participants reported as being separated (4%), living with a partner (7%), or widowed (4%).

The participants reported as having an average of 1.7 ($SD = 1.62$) biological relatives (e.g., parents, siblings, grandparents, children) who ‘save many things or have a lot of clutter in their living space.’ Over half of all participants (58%) reported having had at least one parent with hoarding tendencies; 45% reported having had a mother with hoarding tendencies; 27% reported having had a father with hoarding tendencies; and 14% of participants reported having had two parents with hoarding tendencies.

Age of onset

The median age of onset for all individual symptoms (urges to save, difficulty discarding, and clutter) was between 10 and 20 years, and the median age of onset for possible HD diagnosis was between 20 and 30 years, with 77% of participants reporting onset of possible HD diagnosis before the age of 40. No individuals reported possible onset of HD after their 60s.

Late-onset hoarding

There were 19 reports of possible late onset hoarding (simultaneous presence of all three symptoms after the age of 40). Further investigation of those cases revealed that prior to the age of 40, 68% of the individuals experienced urges to save items, 21% experienced excessive clutter, and 37% reported difficulty discarding. Of the 19 individuals with possible late onset HD, 53% experienced at least two HD symptoms prior to the age of 40, and 74% reported experiencing at least one symptom prior to the age of 40. Only five individuals reported experiencing no HD symptoms prior to the age of 40. Of these individuals, three reported possible HD onset between the ages of 50 and 60 and two reported possible HD onset between the ages of 60 and 70. When queried about the events in their lives during the decades preceding the onset of HD symptoms, the individuals who reported experiencing no HD symptoms until after the age of 40 all reported major life changes (e.g., retirement, losing a job, changing job, kids leaving for college), with the exception of one individual, who simply noted that his car was stolen during that time. Generally, there were no significant health events that

might explain the late onset with the exception of one participant who reported a prior history of head injury.

Progression of HD symptoms

Mixed effects analyses were conducted in which time was used to predict reported hoarding symptoms (e.g., saving, discarding, and clutter) separately (see Table 1 for parameter estimates). All hoarding symptoms were reported to have increased over the lifespan (saving: $\beta = .379$, $SE = .017$, $p < .001$; clutter: $\beta = .428$, $SE = .017$, $p < .001$; difficulty discarding: $\beta = .423$, $SE = .017$, $p < .001$) (see Figure 1).

Exploratory post-hoc analyses were conducted to determine whether symptoms stabilize at the end of the life course. *T*-tests comparing the symptom severity in the fifth and sixth decades revealed that clutter continued to increase with each decade of life ($t_{65} = 2.87$, $p = .0028$), while symptoms of saving and difficulty discarding stabilization in the fifth decade of life (saving: $t_{65} = -.047$, $p = .322$; difficulty discarding: $t_{65} = 1.13$, $p = .131$). No participants reported remission or decreasing of symptoms between these two decades.

Demographic differences in progression of HD symptoms

Mixed effects analyses were conducted in which demographic variables, time, and the interaction of each demographic variable with time were used to predict reported hoarding symptoms separately (see Table 1 for parameter estimates).

Gender had a significant main effect for clutter such that men reported higher clutter symptoms in early life than did women ($\beta = .344$, $SE = .170$, $p = .043$). There was no main effect for gender for difficulty discarding or saving. There was a significant gender by time interaction effect for all hoarding symptoms such that men’s reported symptoms increased more slowly than did women’s across time for all symptoms (difficulty discarding: $\beta = -.108$, $SE = .035$, $p = .002$; clutter: $\beta = -.114$, $SE = .035$, $p = .001$; saving: $\beta = -.091$, $SE = .036$, $p = .011$).

There was no main effect for years of education for any of the hoarding symptoms. There was a significant education by time interaction effect for saving such that individuals with higher levels of education reported a slower rate of increase for saving symptoms than did individuals with lower levels of education ($\beta = -.031$, $SE = .008$, $p < .001$). There was no main effect for ethnicity and no ethnicity by time interaction for any of the hoarding symptoms.

Having one parent with hoarding tendencies had a significant main effect for all hoarding symptoms such that individuals who reported having at least one parent with hoarding tendencies recalled higher hoarding symptoms in early life than did individuals who reported having no parents with hoarding tendencies (difficulty discarding: $\beta = .439$, $SE = .188$, $p = .020$; clutter: $\beta = .456$, $SE = .185$, $p = .014$; saving: $\beta = .478$, $SE = .178$, $p = .007$). There was no interaction of having a hoarding parent with time for any of the hoarding symptoms.

Table 1. Parameter estimates from mixed effects models predicting hoarding symptoms with demographic covariates.

	Parameter	Difficulty discarding	<i>p</i> =	Clutter	<i>p</i> =	Saving	<i>p</i> =
No covariate	Fixed effects— β (SE)						
	Intercept	.317 (.085)	<.001	.230 (.082)	.005	.417 (.080)	<.001
	Time	.423 (.017)	<.001	.428 (.017)	<.001	.379 (.017)	<.001
	Random effects—variance [95% CI]						
	Random intercept	.265 [.174–.405]		.233 [.150–.360]		.203 [.128–.322]	
Residual variance	.566 [.496–.647]		.569 [.498–.649]		.585 [.513–.669]		
Gender	Fixed effects— β (SE)						
	Intercept	.216 (.105)	.040	.105 (.102)	.302	.304 (.100)	.002
	Gender	.283 (.176)	.108	.344 (.170)	.043	.312 (.166)	.060
	Time	.461 (.021)	<.001	.469 (.021)	<.001	.412 (.021)	<.001
	Gender \times time	-.108 (.035)	.002	-.114 (.035)	.001	-.091 (.036)	.011
Random effects—variance [95% CI]							
Random intercept	.270 [.178–.410]		.236 [.152–.363]		.206 [.130–.325]		
Residual variance	.554 [.485–.633]		.555 [.486–.634]		.576 [.505–.658]		
Education	Fixed effects— β (SE)						
	Intercept	.186 (.701)	.791	1.15 (.672)	.088	-.799 (.658)	.224
	Education	.004 (.044)	.921	-.061 (.042)	.147	.073 (.041)	.075
	Time	.577 (.133)	<.001	.339 (.130)	.009	.873 (.130)	<.001
	Education \times time	-.009 (.008)	.286	.007 (.008)	.395	-.031 (.008)	<.001
Random effects—variance [95% CI]							
Random intercept	.307 [.194–.485]		.271 [.169–.433]		.246 [.152–.398]		
Residual variance	.543 [.467–.632]		.522 [.449–.608]		.528 [.453–.613]		
Ethnicity	Fixed effects— β (SE)						
	Intercept	.261 (.232)	.261	-.114 (.224)	.610	.237 (.220)	.282
	Ethnicity	.065 (.249)	.795	.395 (.241)	.101	.207 (.236)	.381
	Time	.432 (.049)	<.001	.506 (.049)	<.001	.427 (.049)	<.001
	Ethnicity \times time	-.011 (.052)	.834	-.089 (.052)	.087	-.055 (.053)	.300
Random effects—variance [95% CI]							
Random intercept	.265 [.174–.405]		.231 [.149–.358]		.203 [.128–.322]		
Residual variance	.566 [.496–.647]		.565 [.495–.645]		.584 [.511–.667]		
Hoarding parent	Fixed effects— β (SE)						
	Intercept	.066 (.147)	.653	-.047 (.145)	.747	.156 (.139)	.261
	Hoarding parent	.439 (.188)	.020	.456 (.185)	.014	.478 (.178)	.007
	Time	.458 (.030)	<.001	.470 (.030)	<.001	.397 (.030)	<.001
	Hoarding parent \times time	-.051 (.038)	.183	-.068 (.038)	.075	-.042 (.039)	.278
Random effects—variance [95% CI]							
Random intercept	.266 [.168–.421]		.249 [.156–.397]		.201 [.122–.332]		
Residual variance	.580 [.502–.669]		.582 [.504–.672]		.597 [.517–.689]		

Note: Ethnicity: Caucasian vs. ethnic minority.

Hoarding parent: participant reported having at least one parent with hoarding tendencies.

Discussion

This investigation represents the first examination of the course of hoarding symptoms throughout the lifespan in older adults meeting DSM-5 criteria for HD. Without the availability of longitudinal data, utilizing retrospective recall among an older adult sample is the next best option to begin to understand HD progression. The majority of participants recalled that their hoarding symptoms began before the end of their 20s, which is consistent with previous studies of the reported age of onset of hoarding symptoms (Ayers et al., 2010; Grisham et al., 2006; Tolin

et al., 2010) as well as research on the age of onset of OCD symptoms (Weissman et al., 1994). Most participants reported that they experienced all three core hoarding symptoms (e.g., urges to save, difficulty discarding, and clutter) simultaneously by the end of their 30s.

The current study found that individuals with HD recall that their hoarding severity increased across the lifespan, which is congruent with a previous investigation of the progression of hoarding symptoms (Ayers et al., 2010). Participants reported that their clutter continued to increase in severity; however, they reported experiencing

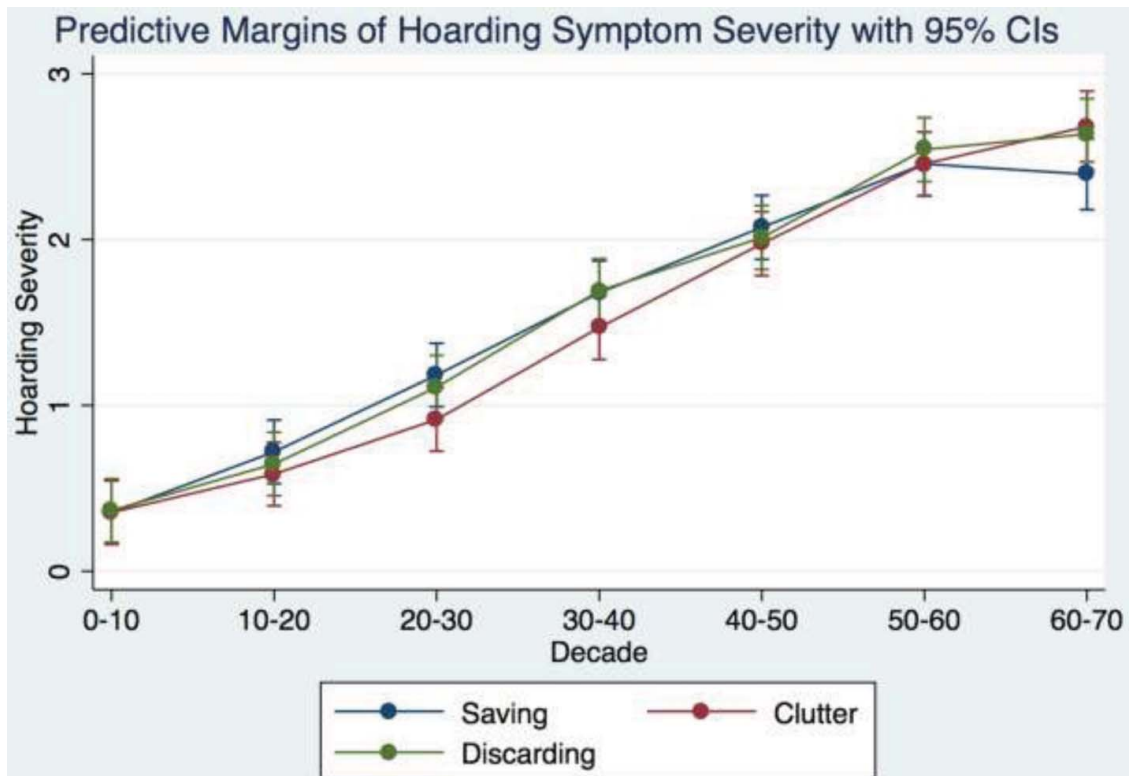


Figure 1. Severity of hoarding symptoms across the lifespan for $N = 82$ older adults with HD.

that their symptoms of saving and difficulty discarding stabilized in later adulthood. It is unclear if this is part of the natural disease progression or the result of psychosocial factors that may inhibit acquiring and artificially increase discarding (e.g., moving into an assisted living center). A third possible explanation of the observed stabilization of symptoms of saving and difficulty discarding might be the result of ceiling effects caused by the limited range (0–3) of reported symptoms over time. Over 60% of participants reported having the maximum level of symptom severity as allowed by the scale during their 50s (saving: 62%; clutter: 62%; discarding: 67%). This suggests that use of a severity scale with a larger response range might demonstrate that all symptoms continue to increase across the lifespan. Further research is needed to determine the exact nature of symptom progression in later decades.

These results may be in contrast to a finding in a self-diagnosed internet sample that individuals with compulsive hoarding problems report that their general hoarding symptoms stabilized in mid-life (Tolin et al., 2010). However, there were numerous confounds to the study by Tolin et al. (2010), including a dearth of older adults in the study sample, a lack of verification of hoarding status, and no differentiation in the type of hoarding symptom (e.g., saving, difficulty discarding, or clutter). Most important, the course of symptoms was not waxing and waning as seen in the trajectory of other mental health disorders across the lifespan, such as in OCD (Fineberg et al., 2013; Ravizza, Maina, & Bogetto, 1997; Skoog & Skoog, 1999) and in mood disorders (Coryell, Endicott, & Keller, 1990; Coryell et al., 1994; Richards, 2011). However, this may

also be the result of our use of retrospective instead of longitudinal analyses.

This study suggests that gender differences in the progression of hoarding may exist such that women recall having experienced a steeper increase in hoarding severity over the lifespan. Clutter was the only symptom to demonstrate gender differences in the reported age of onset. Women may have few clutter symptoms early in life, but this does not seem to impact clutter levels in older adulthood. These results are interesting in light of gender disparity in treatment-seeking samples of adults with compulsive hoarding, with more women than men volunteering to participate in hoarding studies (Ayers & Dozier, 2014; Gilliam et al., 2011; Muroff et al., 2009; Steketee et al., 2010), suggesting that gender may factor into symptom presentation.

In addition to gender, several other demographic factors were also associated with the reported trajectory of hoarding symptoms. Having reported at least one parent with hoarding tendencies was associated with a higher severity of recalled hoarding symptoms in early life, which is consistent with the previous research about the associations of having family members with hoarding tendencies and current HD severity (Ayers & Dozier, 2014).

A major limitation of this study was the lack of older adults in their later decades (i.e., past age 70). Further, the progression of HD symptoms was based on patient recall of their symptom severity over the lifespan, which may be vulnerable to recall biases, especially in a geriatric sample. Symptom reports were not substantiated by collateral information (e.g., family member, spouse).

Because patients self-referred for treatment, we cannot generalize these findings to non-treatment seeking or low insight HD patients, who may experience a different pattern of HD symptom progression. Future studies may also wish to account for possible differences in the size of participants' home, which may affect the level of clutter in the home.

An additional limitation of the current study was the assumption that the participants were able to accurately recall the severity of their symptoms across their lifespans. Participants were asked to report up to three life events that occurred during each decade in order to help them in the recall of their symptom severity, but a longitudinal study would be able to eliminate this error variance, especially for the differentiation of urges to save and difficulty discarding, which may be more challenging for participants to distinguish than clutter levels across the lifespan. Furthermore, the label of possible DSM-5 HD diagnosis across the lifespan was used liberally. In addition to urges to save, difficulty discarding, and excessive clutter, the DSM-5 criteria also require that the symptoms are not caused by a primary psychiatric or physical condition and that the symptoms create impairment in functioning. Because we did not query for psychiatric and physical comorbidities and functioning across the lifespan, we cannot conclude that participants who reported all three symptoms, at any severity, would have met DSM-5 criteria for HD. We also did not inquire about excessive levels of acquisition, a specifier in the DSM-5 criteria for HD. Future studies may want to examine changes in the presentation of HD, including HD with excessive acquisition and HD with animal hoarding.

Prospective longitudinal studies will be needed to definitively characterize the onset and progression of HD symptoms. However, the current study extends findings from earlier studies indicating that hoarding generally begins in young life and symptoms worsen over time. This finding indicates the need to develop early interventions that prevent the progression of HD symptoms, as well as validated measures to detect preclinical symptoms of hoarding in young adults. Furthermore, the current study indicates that there may be a small sub-population of individuals with hoarding disorder for whom hoarding symptoms may begin later in life. Future research is needed to determine the etiology of disease within these individuals, but it appears that the onset of hoarding is more strongly related to significant life events rather than significant medical events.

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Disclosure statement

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