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A comparison between community and treatment-seeking samples of hoarding disorder

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Abstract

Objective. Hoarding disorder studies are primarily based on persons who seek treatment and demonstrate good insight. The aim of the present study is to evaluate whether there are differences between community and treatment-seeking samples of individuals with hoarding disorder (HD).
Methods. Fourteen people with HD from the community and twenty treatment-seeking people with HD were assessed by a battery of instruments to evaluate HD features and other associated characteristics.
Results. Compared to the treatment-seeking sample, the HD community sample was older, had poorer insight, and had a lower prevalence of comorbid obsessive-compulsive disorder (OCD). There were no differences in gender, education, presence of psychiatric comorbidities, quality of life, and hoarding behavior characteristics between the samples. The final logistic regression model with the Dimensional Obsessive-Compulsive Scale (DOCS) as the single predictor of treatment-seeking status was statistically significant, indicating that it was able to distinguish between the two samples. The model explained between 20.7% and 27.9% of the variance of subjects, and correctly classified 67.6% of cases.
Conclusions. Our results indicate that there appear to be few differences between the treatment-seeking and community samples of individuals with HD. The presence of comorbid OCD in treatment-seeking groups seems to be more frequent than in HD community samples.

Introduction

Hoarding disorder (HD) is characterized by persistent difficulty discarding possessions, associated with clutter and substantial restriction of room use in the home, leading to significant distress and/or functional impairment. HD is associated with significant personal and social impact.[1] The symptoms cannot be attributed to other clinical conditions or psychiatric disorders. The estimated lifetime prevalence of HD is 1.7%, with equal prevalence in both sexes.[2] The HD prevalence increases by 20% every five years starting from the third decade of life.[3] The average age of symptom onset for hoarding is 17 years old, although approximately 25% of patients experience symptom onset after 40 years old.[4,5]

Currently, most studies on individuals formally diagnosed with HD are based on treatment-seeking samples, *i.e.*, individuals seeking psychiatric treatment and usually having good insight.[6] However, it is unclear how treatment-seeking samples may differ from nontreatment-seeking individuals with HD. One study reported that community samples of individuals with HD were more likely to be older, male, without a stable partner, and unemployed; to have lower levels of education, income, and insight, and to display increased self-stigma, resistance to seek treatment, and unclean houses with a higher risk of fire.[7] The aim of this study is to evaluate the differences between treatment-seeking and community samples of individuals with HD in terms of sociodemographic and psychiatric aspects, hoarding behavior characteristics, degree of insight, and quality of life.

We predicted that HD individuals from the community would be older, more frequently males, with lower educational levels, characterized by higher hoarding and clutter severity, and lower hygiene and quality of life.

Methods

Research participants

Participants were invited to the research, and the investigation was carried out in accordance with the latest version of the Declaration of Helsinki. The consent of the participants was

obtained after the nature of the procedures had been fully explained. The study design was reviewed by the Federal University of Minas Gerais (UFMG) ethical committee and approved under the number CAAE: 17768719.3.0000.5149. The following inclusion criteria were adopted: a diagnosis of HD according to the clinical criteria of DSM-5; and an age equal to or above 18 years. There were no exclusion criteria for study entry.

The treatment-seeking sample was recruited from the Anxiety and Obsessive-Compulsive Related Disorders outpatient clinic at the Institute of Psychiatry of the Federal University of Rio de Janeiro (IPUB-UFRJ), the only specialized public service for the diagnosis and treatment of these conditions in the great metropolitan Rio de Janeiro city area. In general, it receives suspected or confirmed cases of social anxiety disorder, panic disorder, obsessive-compulsive disorder (OCD), body dysmorphic disorder, HD, trichotillomania, and skin-picking disorder screened by the IPUB/UFRJ admission service, sent from other IPUB/UFRJ specialized services, referred by the local support groups, or informed about us by word of mouth.

The community sample was recruited through posters, and suspected cases of HD were evaluated by B.P.S.

Assessment instruments

Participants underwent a semi-structured interview containing sociodemographic features, hoarding behavior characteristics, degree of insight, quality of life, and comorbid psychiatric disorders. The following instruments were applied:

Structured clinical interview for DSM-5 disorders: clinical version (SCID-5-CV)

The Structured Clinical Interview for DSM-5 Disorders: Clinical Version (SCID-5-CV) was employed to identify major DSM-5 diagnoses.

Structured interview for HD (SIHD)

The Brazilian version of the SIHD was used to evaluate each diagnostic criterion of hoarding disorder according to DSM-5, the presence of excessive acquisition, and the degree of insight related to HD.[8]

The DSM-5 hoarding disorder dimensional scale (HDDS)

The DSM-5 HDDS is an adapted instrument consisting of a five-item subscale of the Florida Obsessive-Compulsive Inventory.[9] The total score corresponds to the sum of scores for each item and ranges from zero to 20. Higher scores reflect greater severity of hoarding symptoms.[10] Scores of 12.6 or higher indicate compulsive hoarding.[11]

Clutter image rating scale (CIRS)

The CIRS was employed to assess household clutter.[12] It includes nine photographs, ranging in score from one (no clutter) to nine (severe clutter), for three rooms in the house.[12] The total score corresponds to the sum of scores for each room and ranges from three to 27. Scores of four or higher in a room indicate clinically significant clutter.[13]

Home environment index (HEI)

The HEI assesses household hygiene. It includes 15 items that are scored from zero (no dirt) to three (severe lack of household hygiene).[14] The total score corresponds to the sum of scores for each item and ranges from zero to 45.

Compulsive acquisition scale (CAS)

The CAS was employed to measure the extent to which individuals acquire/feel compelled to acquire possessions.[15] It is an 18-item inventory whose total scores range from 18 to 126. Scores of 48 or higher indicate compulsive acquisition.[13]

Saving cognitions inventory (SCI)

The SCI was used to assess maladaptive beliefs and attitudes individuals experience when attempting to discard items.[16] The total SCI score is obtained by summing the scores for each item and ranges from 24 to 168. Scores of 95.9 or higher indicate greater severity of maladaptive beliefs and attitudes associated with discarding items.[17]

Dimensional obsessions and compulsions scale (DOCS)

The DOCS is a 20-item self-report instrument that was employed to measure each of the four most identified dimensions of obsessive-compulsive symptoms: a) contamination; b) responsibility for harm or mischances; c) unacceptable thoughts; and d) symmetry.[18] The total DOCS score is obtained by summing the scores for each item and ranges from zero to 80. Scores of 18 or higher indicate obsessive-compulsive disorder.[18]

Brown assessment of beliefs scale (BABS)

The Brown Assessment of Beliefs Scale (BABS) is a 7-item semi-structured scale that assesses individuals' conviction and critical judgment of their beliefs.[19] Each item is scored from zero (nondelusional) to four (delusional). The total score corresponds to the sum of scores for each item and ranges from zero to 28. An individual is considered delusional regarding hoarding if the total score is 18 or higher, provided that the conviction item is scored as four.[19]

Work and Social Adjustment Scale (WSAS)

The WSAS was employed to evaluate the degree of functional impairment. The total score corresponds to the sum of scores for each item and ranges from zero to 40. Scores below 10 indicate subclinical impairment, scores between 11 and 19 indicate moderate impairment, and scores of 20 or higher indicate severe impairment.[20]

Statistical analysis

A descriptive analysis of qualitative variables was presented as frequency distribution. Normality was assessed using the Shapiro–Wilk test, and quantitative variables were presented as median and quartiles. The comparison of quantitative variables between treatment-seeking and community samples was conducted using the Mann–Whitney test. The association between two qualitative variables was assessed using the Chi-square test and Fisher's exact test. Spearman's correlation was used to assess the relationship between two quantitative variables.

Logistic regression analysis was performed whereby the predicted variable was community HD and the predictors were age, BABS, types of accumulated items, HDDS, CIRSself, and DOCS (variables $p < 0.10$ in univariate analyses). We used a backward elimination procedure and variables with the highest p-value were progressively deleted from the model. All statistical tests were two-tailed and were performed with a significance level of $\alpha = 0.05$. The statistical analyses were performed using SPSS software version 25.

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Table 1. Sociodemographic Data, Psychiatric Comorbidities, and Quality of Life of Treatment-Seeking and Community HD Samples

	Treatment-seeking sample (n = 20)	Community sample (n = 14)	p-value
Age (years) median (Q1–Q3)	53 (41–63)	67.5 (49–77.3)	0.04[a]
Male prevalence	50%	64.3%	0.41[b]
Level of education			
Primary school	20%	42.9%	0.35[b]
High school	30%	21.4%	
College	50%	35.7%	
WSAS prevalence			
Subclinical	25%	50%	0.35[b]
Moderate functional	35%	30%	
Severe functional	40%	20%	

Abbreviation: WSAS, work and social adjustment scale.
[a]Mann Whiney test.
[b]Chi-square test.

Table 2. Hoarding Behavior Features, Degree of Insight, and Presence of Comorbid OCD in Treatment-Seeking and Community HD Samples

	Treatment-seeking sample (n = 20)	Community sample (n = 13)	p-value
Prevalence excessive acquisition	85%	78.6%	0.67[a]
Degree of insight			0.003[a]
Absent insight[b]	10%	0%	
Poor insight[b]	10%	64.3%	
Good insight[b]	80%	35.7%	
Prevalence BABS delusional	0%	28.6%	0.02[a]
Types of accumulated items median (Q1 - Q3)	13 (9–18.8)	10.5 (5–13.3)	0.08[c]
Onset interference age median (Q1-Q3)	35 (30–51.5)	48 (28.8–58.3)	0.29[c]
Prevalence HDDS compulsive hoarder	55%	23.1%	0.09[a]
Prevalence CAS compulsive acquisition	65%	54.5%	0.57[a]
Prevalence of SCI severe beliefs	45%	18.2%	0.24[a]
Prevalence CIRSself clutter	50%	14.3%	0.07[a]
Prevalence CIRSc clutter	33.3%	20%	0.99[a]
Prevalence HEI Squalor	40%	27.3%	0.70[a]
Prevalence DOCS Comorbid OCD	50%	7.1%	0.01[a]

Abbreviations: BABS, brown assessment of beliefs scale; CAS, compulsive acquisition scale; CIRS, clutter image rating scale; CIRSself, clutter image rating scale rated by participant; CIRSc, clutter image rating scale rated by family member; DOCS, dimensional obsessions and compulsions scale; HDDS, hoarding disorder dimensional scale; HEI, home environment index; SCI, saving cognitions inventory; HD, hoarding disorder; OCD, obsessive-compulsive disorder.
[a]Chi-square test.
[b]Difference between the two categories.
[c]Mann Whiney test.

Results

Table 1 shows the sociodemographic features and quality of life of participants in the treatment-seeking and community samples of individuals with HD. There were no differences in terms of sex, education level, and quality of life. The community sample was older than the treatment-seeking sample (p = 0.04).

Table 2 demonstrates the comparison of the groups considering characteristics of hoarding behavior, degree of insight, and presence of comorbid OCD. Compared to the treatment-seeking sample, the community sample showed poorer insight (p = 0.003), a higher prevalence of delusional individuals (p = 0.02), and a lower prevalence of comorbid OCD (p = 0.01). There are no differences between the groups regarding the HDDS, CIRS, HEI, CAS, and SCI.

In the community sample, age had a strong positive correlation with interference age (rho = 0.763; p < 0.01); interference age had a strong negative correlation with SCI (rho = −0.736; p < 0.01); and WSAS had a strong positive correlation with HDDS (rho = 0.853; p < 0.01).

The final logistic regression model with DOCS was statistically significant (Wald = 5.16, df = 1, p = 0.023), indicating that it was able to distinguish between the HD community and treatment-seeking samples. The model as a whole explained between 20.7% (Cox & Snell R Square) and 27.9% (Nagelkerke R Square) of the variance of subjects, and correctly classified 67.6% of cases.

Discussion

In this study, we aimed to identify the fundamental reasons explaining why some individuals with HD seek treatment while others do not. We hoped to clarify whether studies including HD treatment-seeking *versus* nontreatment-seeking samples are comparable and result in findings that are generalizable to HD across settings. Our hypotheses were partially supported. We found the community sample of individuals with HD was older, had poorer insight, and displayed a decreased prevalence of comorbid OCD. The only predictor that differentiates individuals from the HD treatment-seeking group to the community group seems to be the presence of comorbid OCD.

Despite finding that individuals with HD from the community were older than the treatment-seeking sample, we were unable to confirm our initial predictions in terms of sex and education. Woody et al.[7] evaluated 337 individuals from treatment-seeking and 487 from community samples in North America, all with HD, and showed a predominance of older age, male sex, and low educational level in the community sample. Likewise, two other studies also did not find differences in sex and education level in community samples.[1,21]

We also found that individuals with HD from the community exhibited lower insight than the treatment-seeking sample. Actually, poor insight may be one of the reasons why individuals with HD often do not seek treatment or are more prone to discontinue treatment.[22,23] Insight is a complex construct and may be related to a lack of knowledge about the existence of a disorder, the presence of rigid and inflexible beliefs, or the tendency to interpret input from others as attempts to control and restrict one's freedom, leading to social isolation.[22] The insight may result from deficits in brain systems supporting conscious awareness, *i.e.*, primary insight; from deficits in memory systems, *i.e.*, mnemonic insight; or from deficits in executive functions, *i.e.*, executive insight.[24] Insight predicted altered performance on inhibitory performance tasks in individuals with HD[25] Poor insight can also lead individuals with HD to

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minimize symptoms or functional impairment, which predicts rejecting attitudes toward them by family members and healthcare professionals.[26,27]

We also demonstrated that community individuals with HD described their clutter as less severe than their family members,[27-29] whereas treatment-seeking individuals with HD described their clutter as more severe than their family members. One possible explanation is that individuals with HD whose ultimate objective is treatment for mental health issues or research participation may overemphasize the severity of symptoms.[27] Of note, one study showed higher agreement between assessments by individuals with HD and independent examiners than between individuals with HD and their family members.[27]

There was no difference in quality of life and characteristics of hoarding behavior between the samples. Possible explanations are the small sample size and the exclusive use of self-report scales in evaluating these aspects of HD, as the poor or absent insight, especially in the community sample, compromises the reliability of responses regarding quality of life aspects.[30]

Our final regression model demonstrated that not having OCD was the only predictor of belongingness to the community sample of HD. The higher proportion of participants with comorbid OCD in the treatment-seeking sample might be explained by the distress caused by the presence of comorbid OCD leading to an increased perceived need for psychiatric treatment. OCD is a psychiatric disorder associated with decreased quality of life, caregiver burden, social and personal economic costs, and suffering for individuals and their families.[31] It may be, for instance, that the increased insight typically seen in OCD samples may generalize to other associated disorders, including HD, thereby increasing treatment-seeking. However, one study compared 1001 OCD patients with and without hoarding symptoms and reported that, after logistic regression, the following variables remained independently associated with hoarding symptoms: being older, living alone, earlier age of symptoms onset, insidious onset of obsessions, higher anxiety scores, poorer insight and higher frequency of the symmetry-ordering symptom dimension.[32]

Despite the high prevalence of other psychiatric comorbidities in individuals with HD,[33,34] community and treatment-seeking individuals with HD did not differ in terms of psychiatric comorbidities. It is now known that HD is associated with increased stigma,[34,35] but it is unclear whether stigma may vary according to the treatment-seeking status in HD samples. For instance, increased stigma may falsely decrease the endorsement of comorbid conditions in nonclinical samples or falsely increase the prevalence of psychiatric disorders in treatment-seeking samples, therefore eliminating any expected difference between groups.

Our study has some significant limitations. The most obvious one is related to the sample size, which is substantially small. The second limitation is related to sample selection, which included participants from sites almost 500 km apart. Ideally speaking, to test our initial hypotheses, a study like ours should have selected participants from the same catchment area, with availability to similar services. It is difficult to tell, for instance, if community individuals from Minas Gerais would be treatment seekers if they were in Rio, provided they had access to similar services. The third limitation is regarding the use of self-report scales in individuals with poor or absent insight to assess the quality of life and hoarding behavior features. Insight interferes with the quality of self-report data. The cross-sectional design only describes associations between the dependent and independent variables; no causal relations can be inferred. An additional limitation is a possible type II error.

Conclusion

In summary, our results indicate that there appear to be differences between the treatment-seeking and community samples of individuals with HD. The presence of comorbid OCD in treatment-seeking groups seems to be more frequent than in community samples of individuals with HD.

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Author contribution. Bárbara Perdigão Stumpf: investigation, writing - original drafting. Fábio Lopes Rocha: writing - review & editing. Leonardo F. Fontenelle: conceptualization, writing - review & editing. Izabela Guimarães Barbosa: conceptualization, methodology, investigation, writing - original draft, supervision, project administration.

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