



ORIGINAL ARTICLE

Prevalence of hoarding disorder among primary care patients

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Objectives: Despite the inclusion of hoarding disorder (HD) in the DSM-5, there is little epidemiological data on hoarding from low and middle-income countries. This study, the first from India, examines the prevalence and correlates of HD among primary care patients in the state of Kerala, India.

Methods: To assess correlates, the Hoarding Rating Scale-Interview (HRS-I) and other structured instruments were administered to 7,555 subjects selected by stratified random sampling from 71 primary health centers.

Results: The prevalence of HD was 1.02% (95%CI 0.8-1.3). Those with HD were more likely to be older and live alone. In the binary logistic regression analysis, after controlling for significant socio-demographic variables, subjects with HD had a higher odds of reporting chronic illness, depression, anxiety disorder, alcohol abuse, and tobacco dependence. Subjects with HD had significantly higher disability scores than unaffected individuals.

Conclusion: Although HD is not uncommon in India, this disorder is rarely reported in specialty settings in India, which suggests that awareness and detection should be improved, considering the co-occurring negative correlates and disability among affected individuals.

Keywords: hoarding disorder; prevalence; primary health care; India

Introduction

Hoarding disorder (HD) is increasingly recognized as a public health problem.¹ Interest in HD has furthered with its inclusion in the DSM-5.² In the DSM-5, HD is defined as a persistent inability to part with or discard possessions, irrespective of their actual value. Consequently, these possessions clutter living spaces, leading to significant distress and/or impairment.²

Hoarding behaviors impose a substantial personal and social burden. People with hoarding behaviors are more likely to be divorced or live alone. Psychiatric comorbidity is high: 30-57% of individuals with hoarding behaviors report co-occurring depression, generalized anxiety disorder, and social phobia.³ It has been reported that work impairment rates are equivalent to those of individuals with psychotic disorders.⁴ Moreover, hoarding behaviors pose a direct threat to the safety of patients and those who live with them. Excessive possessions and the consequent clutter are a significant fire hazard, with up to 6% of fire-related deaths being directly linked to hoarding behaviors.^{1,5} In addition, there is an increased risk of falls and contamination by rotting perishables.¹

Hoarding symptoms are widely prevalent, with three epidemiological studies reporting rates between 2 and 14%.⁶⁻⁸ These studies, however, did not assess interference and distress and, hence, it is unclear whether the subjects had clinically significant hoarding. Studies employing stringent criteria (including impairment) have reported prevalence rates between 1.3 and 5.8%.^{6,9-13} (Table 1).

Existing community studies are from high-income countries, mostly the United States, Europe, and Australia (Table 1), whereas community studies from low and middle-income countries are limited. Moreover, there is no community level data from India. However, although the main symptoms and severity of hoarding appear to be stable across different cultures, there seems to be a difference in sociodemographic and comorbidity profiles.²⁰ In addition to varying comorbidity rates of obsessive-compulsive disorder (OCD) and related disorders, one study reported significant differences in age, living arrangements, and marital status of the participants across different sites.²⁰ Community-level data is also essential to improve awareness and help plan public health services and policies to care for people with HD.

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Table 1 Major studies on the prevalence of hoarding from various countries

Description/ authors	Sample	Country	Sample size	Type	Instrument used	Prevalence (%)
Community studies using screening instruments						
Samuels ⁶	Community	United States	742	Screening	Hoarding question from the IPDE (DSM-I)	5.3%
Ruscio ⁷	Community	United States	2,073	Screening	Single hoarding question from the OCD section of CIDI 3.0	14.4*
Rodriguez ¹⁴	Community	United States	43,093	Screening	Single hoarding question from the NESARC	20.6
Subramaniam ¹⁵	Community	Singapore	6,616	Screening	Hoarding question from the OCD section of CIDI 3.0	2*
Community studies using specific self-rating instruments						
Iervolino ¹⁰	Adult twin registry	United Kingdom	5,022	Self-rating	HRS-I-SR	2.3
Mueller ¹²	Community	Germany	2,307	Self-rating	GCHI (modified version of the American SI-R)	4.6
Timpano ¹³	Community	Germany	2,512	Self-rating	GHR SUCLA UHSS	5.8
López-Solà ¹¹	Adult twin register	Australia	2,495	Self-rating	HRS-I-SR	2.6
Cath ⁹	Adult twin register	The Netherlands	15,194	Self-rating	HRS-I-SR abbreviated version	2.12
Community studies using specific structured interview						
Nordsletten ⁶	Community	United Kingdom	1,698	Structured interview and self-rating	SIHD HRS-I-SR CIR HEI	1.5
Prevalence of hoarding behaviors among OCD patients						
Samuels ¹⁶	Hospitals	United States	431	Structured interview	Modified Y-BOCS symptom checklist HRS-I-SR	33.17
Samuels ¹⁷	Hospitals	United States	126	Structured interview	Modified Y-BOCS symptom checklist SI-R	28.57
Chakraborty ¹⁸	Hospitals	India	200	Self-rating and Clinical interview	SI-R	10
Boerema ¹⁹	Hospitals	The Netherlands	419	Structured interview	Modified Y-BOCS	14.3*

CIDI 3.0 = Composite International Diagnostic Interview; CIR = Clutter Image Rating; GCHI = German Compulsive Hoarding Inventory; GHR = German Hoarding Rating Scale; HEI = Home Environment Index; HRS-I-SR = Hoarding Rating Scale Interview Self-Report; IPDE (DSM-IV) = International Personality Disorder Examination; NESARC = National Epidemiologic Survey on Alcohol and Related Conditions; OCD = obsessive-compulsive disorder; SIHD = Structure Interview for Hoarding Disorder; SI-R = Saving Inventory-Revised; UHSS = UCLA Hoarding Severity Scale; Y-BOCS = Yale-Brown Obsessive-Compulsive Scale.

* Lifetime prevalence.

There are no Indian community studies on the issue. A previous study from an Indian clinic specializing in OCD reported clinically significant (10%) primary hoarding symptoms among OCD patients.¹⁸ In this context, we estimated the prevalence of HD among primary health care service clients in the state of Kerala, India. This study also attempted to explore the sociodemographic profile, medical and psychological correlates, and disability of individuals with HD. This was part of a larger study by the National Health Mission (Kerala), a governmental organization, on various mental health disorders among primary health care patients in Kerala.

Methods

The survey was conducted in 71 primary health centers (PHCs) in the state of Kerala, India. The state has 14 districts and a total of 852 PHCs. Each PHC caters to the health care needs of approximately 30,000 people.

To detect the prevalence of HD, a sample size of 7,000 was calculated based on an anticipated coverage of 90%, a confidence interval (CI) of 1%, and a design effect of 2.5. The assumption of a coverage level of 90% is based

on previous community/university studies conducted in the state of Kerala, which have reported a non-response/missing response of 5-10%.^{21,22} The National Mental Health Survey of 2016, the largest Indian epidemiological study to date,²³ was conducted in multiple states across the country and considered stratification and clustering, assuming a design effect of 3. Since the present survey was conducted in a single state, we assumed a design effect as 2.5. Health authorities granted permission to survey each PHC for 2 weeks. It was determined that during this time frame, approximately 100 patients could be evaluated. Hence, to achieve the desired sample size, the survey was conducted in 71 PHCs, which were chosen by random sampling from among the 852 state PHCs and were stratified by district and location (rural/urban).

After they had finished their consultation with their primary care physician in the selected PHCs, every sixth patient aged between 18-60 years was invited to take part in the survey. The questionnaire was administered by Block Public Relations Officers (Block PROs) of the National Health Mission (Kerala), who are graduate-level social workers with prior training in administering the

questionnaire. To ensure confidentiality, the survey was conducted in a specially allocated room.

The questionnaires were translated into Malayalam (the vernacular language) from English before back-translation to English by separate bilingual translators. Bilingual experts reviewed the translations and arrived at a final translation into Malayalam.

Instruments

Apart from the sociodemographic profile (age/sex/marital status/family structure/ education/employment/socioeconomic status) and self-reported chronic illnesses, we used the structured instruments described below.

Hoarding Rating Scale-Interview (HRS-I)

The HRS-I is a five-item semi-structured interview designed to measure HD. It includes clutter in the home, difficulty discarding possessions, excessive acquisition of possessions, distress, and functional impairment due to hoarding.²⁴ Each item is rated on a nine-point scale (0 to 8). A cutoff score of 11 distinguishes those with and without HD with excellent sensitivity and specificity.²⁵ Therefore, we used a cutoff of 11 to distinguish people with HD from those without HD.

Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9, a questionnaire designed specifically to assess depression, rates each of the 9 DSM-IV depression criteria based on the original Primary Care Evaluation of Mental Disorders mood module.²⁶ This instrument has been employed in a variety of situations and has been validated for screening depression in primary care settings in India.²⁷ The instrument can be used to screen for major depression. For this study, we employed a cut-off score of 10, which has been validated in Indian settings.²⁷

Generalized Anxiety Disorder 7 (GAD-7) and the PHQ for Panic Disorder (PHQ-PD)

Assessment was restricted to generalized anxiety disorder and panic disorder, the most common types reported in primary care. The GAD-7²⁸ and the PHQ-PD²⁹ were used to screen for GAD and panic disorder, respectively. The GAD-7 is a self-report questionnaire with seven items, each scored from 0 to 3. The cut-off score for a positive result is 10. The PHQ-PD consists of 15 questions based on the DSM-IV criteria for panic disorder. A positive result is when all four "major criteria" items are responded in the affirmative (sum score 4), along with a score of at least 4 for the "minor criteria" questions. Participants who reported probable panic disorder, GAD, or both were collapsed into the category of probable anxiety disorder.

The Alcohol Use Disorders Identification Test

This test was developed by the World Health Organization (WHO) as a screening tool for alcohol use, drinking behaviors and alcohol-related issues.³⁰ It consists of

10 items, and a score ≥ 8 (the cutoff used in this study) is considered indicative of alcohol abuse. This instrument also has been validated for use in primary health settings.

Fagerström Test for Nicotine Dependence

This test, a commonly used instrument to determine the intensity of physical addiction to nicotine, was used to assess nicotine dependence.³¹ It has been widely used and has excellent sensitivity, specificity, and validity.

WHO Disability Assessment Schedule

This 12-item self-administered questionnaire investigates the difficulties resulting from health conditions,³² such as diseases or illnesses, short- or long-term health issues, injuries, psychological or emotional problems, and problems related to alcohol or drugs. The total disability score was considered in the assessment.

Statistical analysis

The prevalence of HD was calculated. The sociodemographic profiles of participants with and without HD were compared with the chi-square test. Binary logistic regression analysis was used to assess the association of HD with chronic medical illness, depression, anxiety disorders, tobacco dependence, alcohol abuse, and disability, after controlling for sociodemographic variables. We also measured the correlation between the severity of hoarding, depression, anxiety, panic, alcohol/substance use, and disability using the Pearson correlation coefficient test. SPSS version 22.0 was used for the analyses. All tests were two-tailed, and the significance level was set at $p < 0.05$.

Ethics statement

Institutional ethics committee approval was obtained from the Government Medical College, Ernakulam, Kerala. Informed consent was obtained from the participants prior to administering the survey. This study was a part of a larger research project on psychological issues among primary care patients. Subjects with serious/life-threatening illness were excluded since the full assessment (of the larger study) took approximately 45 minutes, and the ethics committee suggested that they should be excluded to avoid discomfort. All subjects were informed that participation was voluntary, and they could choose not to answer any or all of the questions. They were also informed that refusal to participate would not affect their health or treatment benefits.

Results

A total of 7,555 patients were invited to participate in the survey, of whom 390 (5.2%) refused. Of the completed questionnaires, 377 (5.1%) were excluded due to a substantial number of missing responses, leaving 6,788 (89.7%) in the analysis. The respondents whose questionnaires were excluded were comparable in sociodemographic features

(age, sex, years of education etc.) to those whose questionnaires were not excluded. The sample was predominantly female (65.5%), with a mean age of 41.4 years (standard deviation [SD] 11.05). The majority of the participants (51.6%) were above the poverty line (a socioeconomic indicator of the Government of India) and had less than 10 years of formal education (72.9%). The prevalence of HD was 1.02% (n=69; 95% confidence interval (95%CI) 0.8-1.3). Individuals with HD were more likely to be older and not live with their families. Those with and without HD were comparable in all other sociodemographic variables (Table 2).

In the binary logistic regression analysis, after controlling for significant sociodemographic variables, participants with HD had a higher odds of reporting chronic medical illness, depression, anxiety disorder, alcohol

abuse, and tobacco dependence. Participants with HD also had significantly higher disability scores than participants without it (Table 3). There was a high positive correlation among severity measures of hoarding, depression, anxiety, panic, alcohol and tobacco use, and disability ($p < 0.001$).

Discussion

According to the HRS-I (score of 11 or more), the prevalence of HD among primary health care patients in Kerala, India, is 1.02%. The findings of previous studies on hoarding prevalence vary according to the nature and setting of the assessment. Studies that used structured instruments to assess impairment/disability due to hoarding symptoms have reported lower prevalence rates^{6,9-13}

Table 2 Sociodemographic profile of participants with (n=69) and without (n=6,719) hoarding disorder

	HD	Non-HD	χ^2/t	p-value
Age (mean \pm SD)	44.17 \pm 11.19	41.11 \pm 11.05	2.28	0.02
Gender				
Male	22 (31.88)	2,322 (34.56)	0.21	0.642
Female	47 (68.12)	4,397 (65.44)		
Family structure				
Alone	8 (11.59)	195 (2.90)	21.26	< 0.001
Family	53 (76.81)	6,082 (90.52)		
Institution/others	8 (11.59)	442 (6.58)		
Marital status				
Unmarried	12 (17.39)	727 (10.82)	3.89	0.14
Married	50 (72.46)	5,472 (81.44)		
Widow/divorced	7 (10.14)	520 (7.74)		
Socioeconomic status				
Above poverty line	32 (46.38)	3,469 (51.63)	0.75	0.39
Below poverty line	37 (53.62)	3,250 (48.37)		
Education, years				
\leq 10	53 (76.81)	4,902 (72.96)	0.51	0.47
$>$ 10	16 (23.19)	1,817 (27.04)		
Employment				
Unemployed	40 (57.97)	3,671 (54.64)	0.31	0.58
Employed	29 (42.03)	3,048 (45.36)		
Residence				
Urban	26 (37.68)	2,670 (39.74)	0.12	0.73
Rural	43 (62.32)	4,049 (60.26)		

Data presented as n (%), unless otherwise specified.

Bold type denotes HD vs. non-HD = $p < 0.05$.

HD = hoarding disorder; SD = standard deviation.

Table 3 Comorbidities and disability scores in individuals with HD (n=69) and without HD (n=6,719)

	HD	Non-HD	Unadjusted OR (95%CI)	Adjusted OR (95%CI)*
Chronic medical illness	49 (71.0)	2,989 (44.5)	2.92 (1.48-4.65)	2.62 (1.48-4.65)
Depression	23 (33.3)	324 (4.8)	9.69 (4.68-14.86)	8.23 (4.68-14.86)
Anxiety disorder	25 (36.2)	194 (2.9)	18.23 (8.18-25.66)	14.49 (8.18-25.66)
Alcohol abuse	8 (11.6)	108 (1.6)	7.81 (3.18-16.58)	7.26 (3.18-16.58)
Tobacco dependence	9 (13.1)	263 (3.9)	3.67 (1.79-8.23)	3.84 (1.79-8.23)
Disability scores (mean \pm SD)	16.5 \pm 12.67	4.12 \pm 7.31	1.09 (1.07-1.11)	1.09 (1.07-1.11)

Data presented as n (%), unless otherwise specified.

95%CI = 95% confidence interval; HD = hoarding disorder; OR = odds ratio; SD = standard deviation.

* Adjusted OR after controlling for sociodemographic details.

than those assessing only hoarding symptoms.^{7,8} The highest hoarding rates have been found among individuals with OCD in tertiary treatment settings, ranging from 10-33% (Table 1).¹⁶⁻¹⁹ The HD prevalence we found among primary care patients (1.02%) is lower than that reported in non-clinical samples (2-6%) from other countries. Studies on hoarding prevalence have varied regarding definitions, assessment methods, sampling strategies, and populations, which makes meaningful comparisons difficult.²⁰ It should be noted that, barring a few exceptions, most of the world literature on hoarding comes mainly from urban areas in Western countries.²⁰ If identical methods were used to identify and diagnose HD, it is unclear to what extent HD prevalence would vary between cultures. However, studies of various psychiatric disorders have shown that prevalence, symptom expression, and outcomes can vary depending on the patient's sociocultural setting.^{33,34} A previous study from our center examined the prevalence of clinically significant hoarding in people with OCD and found a relatively lower rate (10%)¹⁸ than that of similar studies (14-33%).^{16,17,19} Another recent study on HD with a small sample reported significant variance in sociodemographics and comorbidity across cultures.²⁰ It is possible that including more participants of lower socioeconomic status and from a rural background, i.e., people who typically have less living space, coupled with the fact that most of our participants lived with their families (the cultural norm) may have contributed to the lower rate of clinically significant hoarding behavior detectable by the screening instrument.

Our study is the first from India and possibly from any low- or middle-income country to report on HD and its correlates using specific assessment instruments in a primary care setting. The state of Kerala has a robust primary health care network, which has contributed to its position as the best-performing state in India in terms of health care indicators.³⁵ The PHCs, which are the lowest rung of the health care network in India, in addition to providing medical treatment, ensure delivery of a range of government health promotion and prevention programs. The services that PHCs provide are highly utilized and valued in the local community. Our sample had a higher preponderance of women and individuals from lower socioeconomic classes. This profile is consistent with primary health care patients around the world.³⁶ In addition, a higher proportion of people of lower socioeconomic background use government-owned PHCs, since they are eligible for free medical services. However, this may not have significantly influenced the overall prevalence of HD, since there were no prevalence differences according to gender ($p = -0.642$) or socioeconomic status ($p = -0.39$).

In our study, individuals with HD were older, which is consistent with the findings of previous epidemiological studies.^{6,8,10,12-14} Although statistically significant, this finding may have limited clinical significance, since the mean age difference between those with and without HD was only 3 years. In our study, there was no gender difference in the prevalence of HD. Previous studies have reported inconsistent findings, most reporting no gender difference,^{6,9,12,13} one showing an increased prevalence in men,¹⁰ and another in women.¹¹

In our study, a significant number of people with HD lived alone or in institutions. In India, it is a cultural norm that adults live with their partners or with their extended families if they do not have a partner. Our finding that more people with HD were living alone may have been a result of a high degree of rejection due to their hoarding behavior. Family rejection towards individuals with HD was reported in an previous Internet survey.⁵ Alternatively, it could be possible that these patients had fewer family members to look after them, which lead to isolation and, thus, increased hoarding.

In our sample, individuals with HD were 2.5-fold more likely to self-report a chronic illness, which is consistent with the findings of a well-conducted community study from London.⁶ Higher rates of anxiety and depression in HD have also been reported.^{6,37} In this study, participants with HD had a higher likelihood of reporting alcohol abuse and nicotine dependence. While individual symptoms of HD have been correlated with alcohol use and dependence,^{8,14} this finding has not been universally replicated.⁶ In our study, participants with HD were more likely to have a disability. This finding has been consistently reported in both community samples and in people with OCD, which highlights the severe dysfunction involved in HD.^{8,14,15,18}

The study has certain limitations. Although the HRS-I cutoff score of 11 separates those with HD from healthy controls, it is not necessarily equivalent to a DSM-5 diagnosis of HD. This should be kept in mind while interpreting our findings. Other measures of co-occurring mental health issues do not indicate diagnoses, although their cutoff scores may identify people with clinically significant problems. Individuals with less insight may not have acknowledged presence of hoarding symptoms, resulting in possible underestimation of the true prevalence. Given the cross-sectional design of the study, causality cannot be inferred between HD and the clinical correlates.

To conclude, this study suggests that the HD is not uncommon in India. Nevertheless, treatment seeking for hoarding is rare even in specialized clinics. For example, in a previous study at our center, none of the OCD subjects with clinically significant hoarding behavior sought treatment for hoarding; their primary reason for consultation was OCD.¹⁸ The scenario is no different in other clinical settings across the country. There seems to be a lack of awareness of hoarding as an illness among patients, families, and medical professionals. This should be addressed, since our study indicates that subjects with HD have numerous negative correlates, including medical and psychiatric comorbidity and greater disability. Underdiagnosis of hoarding may have crucial public health implications. Developing countries like India have scarce mental health resources and tend to accord lesser priority to disorders such as hoarding. Sensitization of health administrators, health care workers, and the community about HD is essential to ensure early recognition and treatment in order to improve outcomes and reduce chronicity.

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Disclosure

The authors report no conflicts of interest.

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