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Accuracy of self and informant reports of symptom severity and insight in Hoarding Disorder



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ABSTRACT

Background: Previous literature on Hoarding Disorder (HD) has largely recruited individuals with self-identified hoarding difficulties or informant-ratings of individuals who are not seeking help. Little is known about the reliability of self- and informant-ratings of hoarding severity and insight, and whether individuals who self-identify with HD differ from those who do not.

Method: Twenty-four pairs of individuals meeting criteria for HD and their relatives took part in the study, plus 40 relatives of individuals meeting likely criteria for HD who did not agree to participate. All participants completed a clinician-administered diagnostic interview for HD and online questionnaires assessing hoarding severity, squalor and insight.

Results: Good correspondence was found between self- and informant-ratings of hoarding severity, although informants gave significantly higher squalor ratings. Relative to clinician-ratings, informants under-estimated the insight of HD individuals. Higher hoarding severity and lower insight informant-ratings were made for individuals with HD who did not agree to participate, compared to those who did. **Conclusions:** A multi-informant approach guided by expert clinicians is desirable for the assessment of HD, particularly in low-insight individuals. When individuals do not seek help for HD, family members may benefit from education and support to help them understand how best to assist their relatives.

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1. Introduction

Hoarding Disorder (HD) is a psychiatric condition characterized by persistent difficulties discarding or parting with possessions, leading to the accumulation of items that congest and clutter active living areas, substantially restricting their use and generating clinically significant distress or functional impairment. A requirement for the diagnosis is that these symptoms are not attributable to other medical or psychiatric conditions (American Psychiatric Association, 2013). Individuals fulfilling diagnostic criteria for HD are further categorized according to the presence of two specifiers. One is whether the individual engages in “excessive acquisition” of items that are not needed; the other refers to the extent to which the individual recognizes that hoarding-related beliefs and behaviors are problematic (‘insight’ specifier).

Though the negative impacts of this condition are clear to the observer, those with hoarding problems are often characterized as lacking insight into the presence and problematic nature of their hoarding difficulties (Tolin, Fitch, Frost, & Steketee, 2010). Attempts to document the insight profile of this population, however, have faced challenges in verifying this observation. In the London Field Trial for Hoarding Disorder (Mataix-Cols, Billotti, Fernández de la Cruz, & Nordsletten, 2013), for example, two elements of clinician-rated insight were explicitly assessed among HD participants: (1) the extent to which the affected individual acknowledges the problematic nature of their hoarding activity (the concept of “insight” that appears as a specifier for HD in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition [DSM-5]), and (2) the presence of overvalued ideation (that is, the fixity of delusional beliefs relating to the hoarding activity). However, the self-selected nature of the trial's HD sample proved problematic for investigating these constructs, with only a minority of the cases (10.3–13.7%, according to clinical ratings) showing poor or absent insight into their hoarding activity. These rates contrast sharply with those reported by the family members of individuals with hoarding difficulties, which suggest that at least

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half of hoarding cases lack insight into their behavior (e.g., Frost, Tolin, & Maltby, 2010).

The difference in these estimates raises some questions about current methodological practices in hoarding research. Faced with a population that appears reluctant to acknowledge their difficulties – perhaps for reasons relating to insight, but alternatively for issues such as embarrassment or legal worries (such as threats of eviction or forced clearings) – research concerned with hoarding has often turned to family members and carers for insights into individuals with this condition. In such cases, these third-parties provide informant-reports of an individual's hoarding severity which are, in turn, used to explore other features of interest (e.g., the relationship between hoarding severity and level of family frustration)(Tolin et al., 2010). The extent to which these informant-reports reflect reality, however, has received only minimal consideration – an oversight which leaves open the question of whether there are biases in this approach which are meaningfully compromising the accuracy of assessments, and thus the information derived from a given study.

Studies that have assessed the relationship between informant and patient report, in the context of hoarding, have done so largely for elements of the core diagnostic criteria. Frost, Steketee, Tolin, and Renaud (2008) and Mataix-Cols et al. (2013), for example, both reported good correspondence among patients and clinicians completing the Clutter Image Rating, a pictorial scale that evaluates the degree of clutter produced by hoarding activity (CIR; Frost et al., 2008). A recent set of studies by DiMauro, Tolin, Frost, and Steketee (2013), however, extended this examination to the full HD criteria and evaluated the relationship of sufferer's self-reports to informant reports provided, first, by family informants and, separately, among a group of sufferers and their clinicians. While only subtle differences emerged opposite the clinician reports, comparison of family ratings with patient's self-ratings suggested that hoarding individuals reported significantly less clutter, squalor, and acquisition difficulties than perceived by their relatives. In addition, these patients believed they were significantly more insightful than their family members indicated – a finding that did not dissipate when controlling for family member's attitudes (e.g., presence of rejection).

Firm conclusions are difficult to draw from these studies. For instance, while the DiMauro et al. (2013) work suggests that family informant ratings might accord, to a lesser degree than clinician ratings, with patient self-report, differences in the sample recruitment and mode of hoarding assessment make a direct comparison impossible. Hoarding participants in the family study, for instance, were volunteers who were only assessed for hoarding using a self-report, mailed questionnaire; hoarding participants in the clinician study, meanwhile, were recruited in part from clinical settings and were assessed by independent evaluators. Such variations in assessment are common in the hoarding literature, with very few samples using the tightly defined, full diagnostic criteria for HD. As hoarding behavior can arise as a consequence of myriad organic and psychiatric conditions, an accurate diagnosis of HD truly requires a thorough assessment to ensure that the information derived from a study is specific to the disorder of interest. This point is particularly critical when examining insight, which may be considerably impacted by the nature of the condition underlying the observed hoarding behavior.

The present study sought to improve on the methodological limitations of previous studies by focusing on participants meeting diagnostic criteria for HD and aimed to assess (1) the extent to which informant ratings of the severity of hoarding features are consistent with self-report ratings, (2) the extent to which clinicians' ratings of insight are consistent with informant ratings of insight, and (3) the differences between self-identified individuals with HD who are willing to take part in research studies and those who are not, based on informant ratings of hoarding severity and insight.

2. Methods

2.1. Participants and procedures

Individuals with hoarding difficulties (hereafter "HD group") were recruited primarily from London-based support groups. Additional members of these groups were recruited through existing contacts, many of whom had previously engaged with our research at the Institute of Psychiatry. All those expressing an interest were asked to also provide the name of a family member to act as an informant. The final "HD group" sample included 22 individuals meeting DSM-5 criteria for HD, each of who completed the study with at least one informant (2 HD individuals provided 2 family informants, giving a total of 24 "HD relatives"). An additional set of 40, unpaired HD relatives – that is, individuals who reported a relationship with someone meeting HD criteria, but who could not secure the participation of this individual – also took part independently. For clarity, relatives of individuals with HD will be hereafter be referred to as the "HD relative group". Where relevant, the "HD relative group" may be further sub-divided into relatives who have participated without an index HD individual (hereafter "unpaired HD relatives") and those who have participated with their HD relative (hereafter "paired HD relatives"). Further details on this sample can be found in the initial study publication (Drury, Ajmi, Fernández de la Cruz, Nordsletten, & Mataix-Cols, 2014).

After a brief screening to gauge suitability for the study, participants were evaluated for HD using a telephone-delivered version of the Structured Interview for Hoarding Disorder (SIHD; Nordsletten, Fernández de la Cruz, Pertusa, et al., 2013). Near-perfect sensitivity and specificity (ranging from 0.98 to 1) has been reported for the use of the SIHD (in combination with objective measures of clutter) to screen for the diagnostic criteria of hoarding disorder (Mataix-Cols et al., 2013). The HD group reported on their own hoarding behavior, whilst the HD relative group reported on their family member's hoarding behavior. Information gathered during administration of the SIHD was used to make clinician ratings of insight, which were categorized into one of three insight categories: good/fair, poor, and absent. Following the telephone interview, participants were also asked to complete a series of online questionnaires (see Measures section), accessible via a dedicated, study-specific website. Following completion of the diagnostic interview and questionnaires, the presence of HD was determined using a best estimate diagnostic procedure (Leckman, Scholomskas, Thompson, Belanger, & Weissman, 1982). Details concerning this methodology, and its particular application in this study, can be found elsewhere (Drury et al., 2014).

In thanks for their time, participants in the current study were provided with a small gift voucher (£5). The study was reviewed and approved by the King's College Research Ethics Committee, with informed consent being sought accordingly and secured from each participant.

2.2. Measures

Individuals meeting criteria for HD completed the following measures: a scale assessing the severity of the hoarding symptoms, the Hoarding Rating Scale – Self Report (HRS-SR; Tolin, Frost, Steketee, & Fitch, 2008); a visual measure of clutter severity, the Clutter Image Rating (CIR; Frost et al., 2008); and a self-report measure of perceived level of squalor, the Home Environment Index revised (HEI; Rasmussen, Steketee, Frost, Tolin, & Brown, 2014). High internal consistency has been reported for the HRS ($\alpha=0.83$; Tolin et al., 2008) and the HEI ($\alpha=0.89$; Rasmussen et al., 2014). The CIR has strong reliability across time, context and raters and has good convergent and divergent validity (Frost et al., 2008). In the current study, internal consistencies for the HRS and HEI were in the good to excellent range, except for informant-report HRS scores for the whole HD relatives group (see Tables 1 and 2). For each of these measures, higher scores indicate greater hoarding severity/impairment.

HD relatives completed informant-report versions of the HRS-SR, the CIR, and the HEI. HD relatives also rated the extent to which their relatives with HD had insight into any difficulties caused by their hoarding using an adapted item from the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS; Goodman et al., 1989) as described by Tolin et al. (2010). A five-point scale was used for this item, with responses ranging from "excellent insight" to "lacks insight/delusional". Participants were also provided with a brief example of how each level of insight might manifest in everyday life. Insight ratings were also obtained by clinician interviews with HD individuals and their relatives, as described above.

2.3. Statistical analyses

Data were analyzed using SPSS version 20. Categorical data were compared using chi-square tests. Continuous, independent data were compared using Student's *t* tests. Analysis of Variance (ANOVA), with gender and age as a covariate, was used when appropriate. All tests were two-tailed at $p=0.05$.

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