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Do people with hoarding disorder under-report their symptoms?

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ABSTRACT

Previous research indicates that people with hoarding sometimes under- or over-report the severity of their symptoms. This article examines the results of two separate studies that evaluate severity ratings made by participants with hoarding disorder (HD) in comparison to ratings by family members or independent evaluators. In Study 1, HD participants' ratings of the severity of the clutter in their home and their hoarding behaviors were less severe than those made by their friends or family members. This result may be accounted for by family members' rejecting attitudes towards the participant. In Study 2, HD participants appeared to under-report specific hoarding symptoms while over-reporting their overall global impression of hoarding severity. A three-pronged assessment approach is recommended in which ratings of hoarding severity are made by the HD participant, their family member, and an independent observer or clinician. Such an approach would better inform future research, and also clinical treatment.

1. Introduction

According to proposed DSM-5 criteria, hoarding disorder (HD) includes the following major elements: (1) persistent difficulty discarding or parting with possessions due to a perceived need to save them and distress associated with discarding; (2) symptoms result in the accumulation of a large number of possessions which clutter living areas and compromise their use; and (3) symptoms cause clinically significant distress or impairment in important areas of functioning (American Psychiatric Association, 2010). HD is a debilitating and costly public health problem that can lead to medical complications, fire hazards, pest infestations, and eviction (Tolin, Frost, Steketee, Gray, & Fitch, 2008).

Previous research suggests that the pervasive negative impact of HD symptoms is often compounded by poor insight among sufferers, and that this poor insight poses a significant obstacle to treatment (Frost, Tolin, & Maltby, 2010; Tolin, Fitch, Frost, & Steketee, 2010). Poor insight may explain why individuals with HD often express little motivation to seek treatment (Damecour & Charron, 1998) and are more likely to drop out of treatment than are patients with non-hoarding obsessive-compulsive disorder (Mataix-Cols, Marks, Greist, Kobak, & Baer, 2002). Limited insight may also lead individuals with HD to minimize the severity of their symptoms or the resulting functional impairment, posing a problem for accurate assessment.

However, other research suggests that HD might not be characterized by a systematic under-reporting of symptom severity. Frost, Steketee, Tolin, and Renaud (2008) compared the self-rated Clutter Image Rating (CIR) scores of HD participants to CIR ratings made by independent evaluators who visited their homes. There was no significant difference between the two, and the two scores were highly correlated. However, when the authors compared the two groups' ratings on another measure of clutter, the Clutter Scale, HD participants actually over-reported their clutter severity in comparison to observer ratings. These findings are difficult to reconcile with reports of family members who generally describe their loved ones with HD as exhibiting poor insight into their problem (Tolin et al., 2010). One possible explanation is that family members, particularly those who are distressed about the hoarding, over-report the severity of the problem. Another possibility is that HD participants who elect to enroll in research studies tend to over-report the severity of their symptoms in order to qualify for the research.

The aim of the first study was to compare hoarding severity and functional impact reported by HD participants versus their loved ones (friends, family members). To accomplish this aim, we analyzed data collected from paired samples of individuals with HD and their loved ones who completed the same questionnaires regarding the HD participant's symptoms and level of

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impairment. Based on findings of limited insight among people who hoard, it was predicted that HD participants' would underreport their symptoms in comparison to their friends or family members (FFMs) due to limited insight. In the second study, we compared HD participants' ratings to those of trained independent evaluators (IEs). It was again predicted that, compared to the other evaluators, HD participants would systematically underreport the severity of their hoarding behaviors and associated functional impairment.

2. Study 1

2.1. Methods

2.1.1. Participants

Pairs of individuals with HD and friends or family members (FFM) were recruited via an advertisement in a free newsletter and via email sent to a database of over 8000 individuals who had contacted the researchers between January 2004 and January 2007 for information about HD. The advertisement/email indicated that the researchers were seeking pairs of individuals, one of whom had HD and the other of whom was a friend or family member who knows the HD individual well, to complete the study. Interested respondents were asked to send an email to the researchers. As shown in Fig. 1, 110 individuals replied and were sent a follow-up email. Those who responded to the second email were mailed two packets of questionnaires, one for the person with HD and one for the FFMFM.

Completed questionnaire packets were received from 22 pairs. Both the individuals with HD and their FFMs were predominantly female (77.3% HD, 66.7% FFM) and white (100% HD, 95.2% FFM). The individuals with HD were, on average, 7.4 years older than the other pair member (58.6 vs. 51.2). Ten (45.5%) FFMs were spouses or partners of an HD participant, seven (31.8%) were adult children of an HD participant, two (9.1%) were siblings, two (9.1%) were friends, and one (4.5%) was a parent. Eleven (50%) of the FFMs were living with the individuals with HD about whom they completed the measures; of these, eight (72.7%) were the HD individual's significant other, and the remaining three were the HD individual's parent (27.3%).

Participants were included only if they met standard Hoarding Rating Scale criteria: a score of "moderate" or above on subscale items assessing difficulty discarding, clutter, and impairment or distress (Tolin et al., 2008; Tolin, Frost, & Steketee, 2010). This inclusion criterion was utilized to ensure the validity of a clinical hoarding sample.

2.1.2. Materials

All packets contained an informed consent document, as well as a letter instructing participants not to discuss their responses with the other member of the pair until all measures were completed. All measures of symptom severity were completed in relation to the HD participant's home or behaviors unless otherwise noted. The HD and FFM packets contained the following measures:

A *Demographics Questionnaire* was used to collect information about the age, sex, race/ethnicity, relationship status, employment status, and educational status of all participants. FFMs were also asked to indicate the age and gender of the HD, their relationship to the HD, and whether they were currently living with the HD.

The *Clutter Image Rating* (CIR; Frost et al., 2008) includes a series of nine photographs each of a kitchen, living room, and bedroom with varying degrees of clutter. Participants are requested to select the photograph that most closely resembles each of the three rooms in the HDs home. Internal consistency, test–retest reliability, and inter-rater reliability for the CIR are high, as are correlations with validated hoarding measures (Frost et al., 2008).

The *Saving Inventory-Revised* (SI-R; Frost, Steketee, & Grisham, 2004) is a 23-item questionnaire of compulsive hoarding severity. The SI-R is composed of three subscales, mirroring the core symptoms of compulsive hoarding: Clutter (nine items), Difficulty Discarding (seven items), and Acquisition (seven items). Internal consistency was excellent for the total score (α=0.92) and for the three subscales (α=0.87–0.91) (Frost et al., 2004). Principal component analysis demonstrated that the aforementioned factors account for 70.82% of the total variance, and the results of a multivariate regression analysis indicated favorable convergent validity (Mohammadzadeh, 2009).

The *Activities of Daily Living in Hoarding Scale* (ADL-H; Frost, Hristova, Steketee, & Tolin, in press) contains 15 questions about daily activities that may be affected by hoarding (i.e., eating, sleeping, use of furniture). The ADL-H was modeled after similar measures used in health service settings to assess impairment of behavioral activities due to illness. Preliminary findings indicated good internal consistency and discriminant validity in relation to measures of hoarding severity and other psychopathology. As in the original publication, the ADL-H scores in the present research are means rather than total scores.

The *Sheehan Disability Scale* (SDS; Leon, Shear, Portera, & Klerman, 1992) is a brief self-report measure of work, social, and family disability on 10-point scales. The SDS has demonstrated acceptable reliability and satisfactory construct and criterion-related validity in a study of panic patients (Leon et al., 1992) and has proven sensitive to treatment effects in obsessive-compulsive disorder (OCD) patients (Diefenbach, Abramowitz, Norberg, & Tolin, 2007).

The *Clinical Global Impression Severity Scale* (CGI; Guy, 1976) is a widely used single-item instrument assessing global severity on a 7-point scale from 1 ("*Not at all ill*") to 7 ("*Extremely ill*"). The CGI has demonstrated good inter-rater reliability and is frequently used in clinical and research settings to establish baseline severity of illness, as well as assess changes during and after treatment. We used a participant-rated version of the CGI (Hannan & Tolin, 2007) to assess both participants' overall impressions of illness severity.

The *Home Environment Index* (HEI; Rasmussen, Steketee, Tolin, Frost, & Brown, submitted for publication) is a 20-item self-report measure containing items that assess squalor in hoarding, particularly in terms of domestic conditions and personal care. Internal reliability for the scales was good (α=0.89). Convergent validity was evident in stronger correlations of the HEI with measures of hoarding than measures of OCD, depression, anxiety, and stress.

The *Hoarding Rating Scale-Self-Report* (HRS-SR; Tolin et al., 2008) is a self-report adaptation of the interview version of the HRS (HRS-I; Tolin et al., 2010). This measure was used to determine the severity of illness of the HDs. Like the interview, the HRS-SR consists of five Likert-type ratings from 0 ("*None*") to 8 ("*Extreme*") of clutter, difficulty discarding, excessive acquisition, distress, and impairment. The HRS-I showed excellent internal consistency and test–retest reliability (Tolin et al., 2010); the HRS-SR correlated strongly with the HRS-I (Tolin et al., 2008) and demonstrated 73% agreement of diagnostic status between clinician- and self-report (Tolin et al., 2008).

The *Depression Anxiety Stress Scale* (DASS; Lovibond & Lovibond, 1995) is a 42-item self-report measures that assesses symptoms of depression, anxiety, and stress experience over the past week. Items are rated on a 4-point scale from 0 ("*Did not apply to me at all*") to 3 ("*Applied to me very much, or most of the time*"). Previous studies have shown that the three scales demonstrated good internal consistency, and factor analyses supported the convergent and discriminant validity of the scales. In addition, the DASS demonstrated adequate test–retest

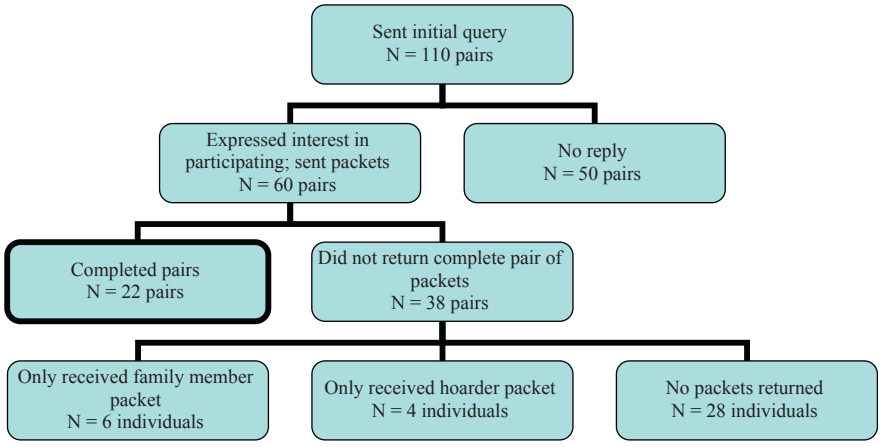

Fig. 1. Flow chart of enrollment.