

# Family Informants' Perceptions of Insight in Compulsive Hoarding

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Published online: 15 October 2008  
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**Abstract** Existing psychological and pharmacological interventions for obsessive-compulsive disorder have not been particularly successful for compulsive hoarding, perhaps due in part to poor insight on the part of sufferers. Individuals with compulsive hoarding problems commonly display lack of awareness of the severity of their behavior, sometimes denying that they have a problem and often resisting intervention attempts and failing to follow through with therapeutic assignments. Using an internet-based survey, family and friends of individuals with reported hoarding problems (*family/friend informants*,  $N = 584$ ) provided ratings of the hoarder's level of insight. They also made several ratings of the severity of the person's hoarding behavior, then rated the same items again with regard to how they thought the hoarder would respond to the items. Family/friend informants

described the hoarder on average as having fair to poor insight. More than half were described as having "poor insight" or "lacks insight/delusional," substantially worse insight than found in samples of OCD clinic patients using the same measure. Family/friend informants' ratings of hoarding severity were significantly greater than were their estimates of the hoarder's ratings. Hoarders described as showing less distress about the hoarding were described as showing poorer insight. These results suggest that compulsive hoarding is characterized by poor insight into the severity of the problem. Treatment development might need to emphasize strategies to bolster awareness, insight, and motivation.

**Keywords** Anosognosia · Overvalued ideation · Clutter · Saving · Delusions · Obsessive-compulsive disorder

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Compulsive hoarding is characterized by (a) the acquisition of, and failure to discard, a large number of possessions; (b) clutter that precludes activities for which living spaces were designed; and (c) significant distress or impairment in functioning caused by the hoarding (Frost and Hartl 1996). Although hoarding has frequently been considered a subtype of obsessive-compulsive disorder (OCD), studies have indicated that hoarding symptoms are distinct from more "traditional" OCD symptoms such as washing, checking, etc. (Calamari et al. 2004), and that

hoarding might not be associated with a particularly high rate of OCD compared to other anxiety and mood disorders (Frost et al. 2006; Meunier et al. 2006; Wu and Watson 2005). Hoarding is also associated with high rates of psychiatric comorbidity in general; in a study of 104 compulsive hoarding participants, 57% met diagnostic criteria for major depressive disorder, 29% for social phobia, and 28% for generalized anxiety disorder (Frost et al. 2006).

A growing body of evidence suggests that compulsive hoarding creates a substantial public health burden. Clutter has been reported to increase risk of fire, falling, poor sanitation and health risks (Steketee et al. 2001). Housing officials struggle with hoarding cases (Frost et al. 1999), and several cities in North America have developed inter-agency task forces to help them deal with individuals who hoard (Frost and Steketee 2003). A large sample of individuals with self-identified compulsive hoarding reported a mean 7.0 psychiatric work impairment days per month (Tolin 2008b), equivalent to that reported by National Comorbidity Survey (Kessler et al. 1994) participants with bipolar and psychotic disorders, and significantly greater than that reported by participants with most other anxiety, depressive, and substance use disorders. Eight percent reported that they had been evicted or threatened with eviction due to hoarding, and 0.1% reported having had a child or elder removed from the home (Tolin et al. 2008b). Burden on family members is also high (Frost and Gross 1993); a large survey of family members indicated that living with an individual who hoards during childhood was associated with elevated reports of childhood distress and family strain. Family members reported high levels of patient rejection attitudes, suggesting high levels of family frustration and hostility (Tolin et al. 2008a).

Well established medication and behavioral treatments for OCD have fared poorly in the treatment of compulsive hoarding (Abramowitz et al. 2003; Mataix-Cols et al. 2002; Mataix-Cols et al. 1999). One possible explanation for the attenuated response to treatment is the apparently poorer insight exhibited by patients with compulsive hoarding compared to those with OCD. Varying definitions of insight have been proposed in the literature. Within the fields of psychosis and neurological illness, “insight” is frequently used to describe awareness of illness; patients with conditions such as schizophrenia and

some forms of dementia frequently display *anosognosia* (Weinstein and Kahn 1950), insisting that they do not have a problem, or failing to recognize the social consequences of their behaviors (Amador et al. 1993; McGlynn and Schacter 1989). In OCD research, “insight” has more commonly been used to describe the extent to which the individual recognizes that his/her obsessive beliefs are irrational; lack of this form of insight has been labeled *overvalued ideation* (Kozak and Foa 1994) and is conceptually similar to delusionality; indeed, overvalued ideation may be associated with the development of psychotic disorders among OCD patients (Insel and Akiskal 1986). Both anosognosia and overvalued ideation have been associated with poorer treatment adherence and treatment outcome across diagnoses (Amador et al. 1993; Foa 1979; Neziroglu 1999b).

Although OCD patients display a range of insight into the irrational nature of their obsessions and compulsions, most exhibit at least some insight (Foa et al. 1995). By contrast, clinical observation suggests that individuals with compulsive hoarding problems often display a striking lack of awareness of the severity of their behavior, sometimes denying the problem and often resisting intervention attempts and defensively rationalizing their acquiring and saving (Greenberg 1987; Steketee and Frost 2003). Research reports indicate that many hoarders do not consider their behavior unreasonable (e.g., Frost and Gross 1993; Frost et al. 2000). Evidence of limited insight is also found in lower ratings of insight on a supplemental item of the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) (Goodman et al. 1989) compared to non-hoarding OCD patients (De Berardis et al. 2005; Frost et al. 1996; Matsunaga et al. 2002; Storch et al. 2007) and in the observation that recognition of a problem with hoarding typically does not occur until at least a decade after onset (Grisham et al. 2006). In a recent study of elderly hoarders receiving social services, providers reported that most hoarders showed little insight into their problem, and this was not explained by observable cognitive impairment (Steketee et al. 2001). In the OCD Collaborative Genetics Study, hoarding OCD patients exhibited poorer insight into the irrationality of their symptoms than did non-hoarding OCD patients (Samuels et al. 2007). All of these studies assessed individuals receiving mental health treatment or other social services, which potentially biases insight-related data. Presumably,

individuals with anosognosia-like insight problems would be unlikely to present for mental health treatment. Therefore, many previous studies may have underestimated the severity of insight limitations in hoarders. Furthermore, many studies examined hoarders within the context of an OCD study; therefore, patients entering these studies would have had to identify themselves as having OCD. To the extent that many hoarders do not identify with the diagnosis of OCD (and the majority of hoarders show no signs of non-hoarding OCD; Frost et al. 2006), these studies might not reflect the full range of individuals with hoarding problems.

The aim of the present study was to examine levels of insight (specifically, awareness of illness or the social consequences of hoarding behavior) in individuals who hoard. We considered examining insight into the irrationality of beliefs (overvalued ideation), as has been the norm in OCD research. Several scales have been developed to assess this form of insight, including the Brown Assessment of Beliefs Scale (Eisen et al. 1998), Overvalued Ideas Scale (Neziroglu et al. 1999a), and Fixity of Belief Scale (Foa et al. 1995). In our own work with hoarding patients, we have experienced difficulty with the use of such measures, as many patients have difficulty identifying obsessive beliefs or feared consequences. Attempting to survey such beliefs through a third party (family members) would likely be even more difficult. It was decided, therefore, to assess insight at the more basic level of anosognosia: the degree to which the individual recognizes the existence of a problem and its consequences.

Because of the difficulty inherent in asking sufferers about their level of insight, family members and friends of hoarders (*family/friend informants*) were surveyed. We sampled a large number of family members and friends of individuals reported to have compulsive hoarding problems, with the prediction that they (particularly those whose loved ones met strict criteria for hoarding) would report poor insight. We further predicted that poor insight would be associated with greater severity of clutter, difficulty discarding, acquisition, and impairment; and lower levels of reported distress about hoarding. To obtain a large sample, data were collected over the internet. The internet is increasingly being used for mental health research (Skitka and Sargis 2006), and several studies indicate that web-based data collection results

in greater sample diversity, generalizes across presentation formats, and yields findings consistent with data collected using more traditional means (Gosling et al. 2004). Equivalence of internet and paper-and-pencil measurement has been established in clinical disorders, including anxiety (Carlbring et al. 2007) and OCD (Coles et al. 2007).

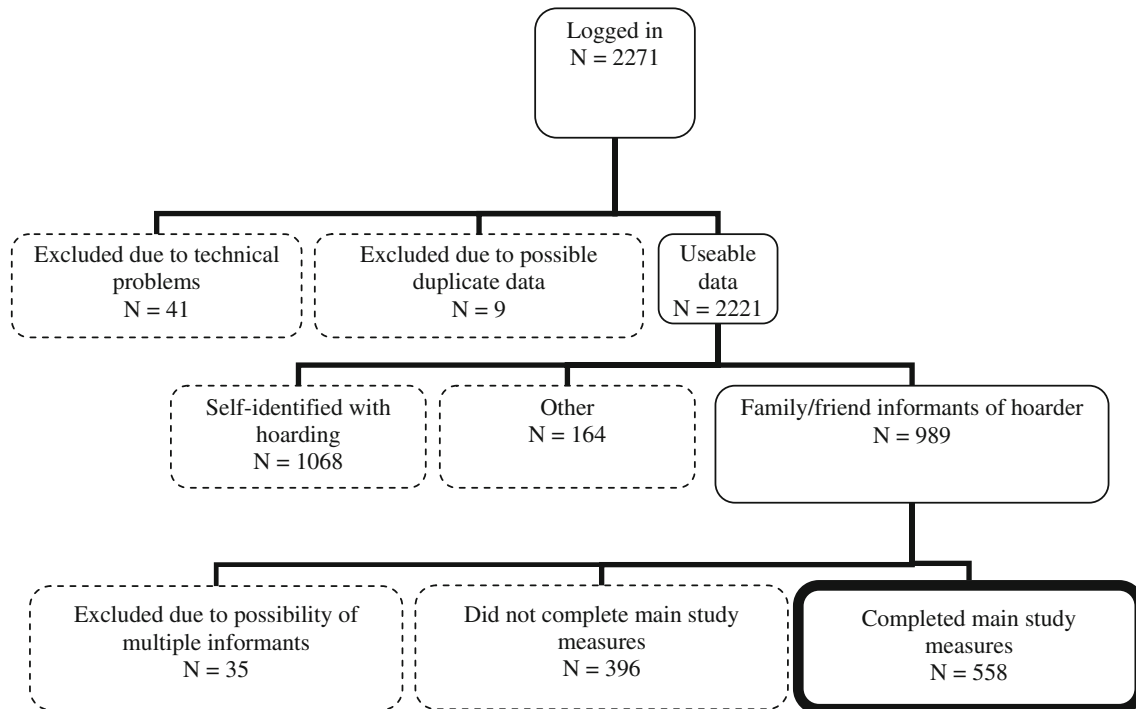
## Method

### Participants

The present sample was recruited from a database of individuals who have contacted the researchers over the past 3 years for information about compulsive hoarding after several national media appearances. Over 8,000 potential participants were sent an e-mail invitation to participate in the study, and were also allowed to forward the invitation to others with similar concerns. Data collection occurred from November 14, 2006 to January 15, 2007. Consistent with current recommendations (Kraut et al. 2004), prior to analysis the data were checked for apparent duplicates (i.e., a participant completing the survey more than once). To maintain independence of observations, we also identified cases in which multiple family members appeared to report on the same hoarder (as evidenced by similar first name and matching demographic information); in such cases, only one of these was selected at random for analysis. A flowchart of participation is shown in Fig. 1. Of 989 respondents who identified themselves as non-hoarding<sup>1</sup> *family/friend informants* and who answered questions about their family member who hoarded (*hoarders*), we analyzed data from 558 participants (because the present study was conducted as part of a larger study, respondents were able to opt out of specific questionnaires). To clarify, hoarders were not

<sup>1</sup> Although all participants described themselves as non-hoarding friends or family members of a hoarder, analysis of the 434 participants who completed the HRS-SR in reference to themselves indicated that 45 (10.4%) in fact met our research criteria for compulsive hoarding. These participants were included in the analyses. Comparisons between hoarding and non-hoarding respondents indicated that their ratings of family members did not differ from each other on the HRS-SR ( $t = 0.62$ ,  $P = .53$ ) or Y-BOCS insight item ( $t = 0.82$ ,  $P = .41$ ).

## Flow Chart of Participation



**Fig. 1** Flow chart of participation. *Note:* Exclusions are indicated by dashed lines. Final sample is indicated by bold line

assessed directly in the present study; any participants who identified themselves as having a hoarding problem participated in a separate study (described elsewhere).

### Materials

Diagnosis and severity of compulsive hoarding for hoarders was determined using a self-report version of the *Hoarding Rating Scale-Interview* (HRS-I) (Tolin et al. 2007a), termed the *Hoarding Rating Scale-Self-Report* (HRS-SR). Like the interview, the HRS-SR consists of 5 Likert-type ratings from 0 (none) to 8 (extreme) of clutter, difficulty discarding, excessive acquisition, distress, and impairment. The interview format has shown high internal consistency and inter-rater reliability, correlated strongly with other measures of hoarding, and reliably discriminated hoarding from non-hoarding participants (Tolin et al. 2007a). The self-report version shows strong correlations with the HRS-I (range  $r = .74-.92$ ), and 73% agreement of diagnostic status between self- and interviewer-report (Tolin et al. 2008b). Internal

consistency in the present sample was acceptable ( $\alpha = .67$ ).

It is not clear whether compulsive hoarding represents a dimensional phenomenon continuous with normal variations in saving behavior, or a categorical taxon. Preliminary evidence from a nonclinical sample suggests that unlike most OCD symptoms, hoarding shows some evidence of taxonicity (Olatunji et al., in press). The present analyses, therefore, address hoarding both dimensionally (i.e., as a continuous score) and categorically (i.e., using diagnostic thresholds). Severity of hoarding on the HRS-SR was determined by calculating the mean of all 5 items, with 0 = no hoarding symptoms, 2 = mild hoarding, 4 = moderate, 6 = severe, and 8 = extreme hoarding. Diagnostically, participants were considered to meet diagnostic hoarding criteria if they described moderate (4) or greater clutter and difficulty discarding, as well as either moderate (4) or greater distress or impairment caused by hoarding. The cutoff of 4 is arbitrary, but consistent with diagnostic strategies used for other disorders on similar rating scales (Brown et al. 1994). Family/

friend informants completed the HRS-SR for the hoarder. Internal consistency was adequate in the present sample ( $\alpha = .67$ ).

Severity of clutter was assessed using the recently-developed *Clutter Image Rating* (CIR) (Frost et al. 2008), a series of 9 photographs each of a kitchen, living room, and bedroom with varying levels of clutter. Family/friend informants selected the photograph that most closely resembles each of the three rooms in the hoarding family member's home. Scores for each room were scaled from 1 to 9, and a mean composite score was calculated across the three rooms (range 1–9). In the original study, internal consistency ( $\alpha = .84$ ), test–retest reliability ( $r = .82$ ), and inter-rater reliability ( $r = .94$ ) for the CIR were high, as were correlations with validated hoarding measures (Frost et al. 2008). Internal consistency was excellent in the present study ( $\alpha = .92$ ).

Insight was assessed using an adaptation of item 11 from the *Yale-Brown Obsessive-Compulsive Scale* (Y-BOCS) (Goodman et al. 1989). In response to the question, “We would like to know just how clearly

[name; the computer inserted the hoarder's first name] recognizes the problem he/she has with hoarding. Please select the description below that most closely matches [name]'s level of insight into his/her problem.” The adapted response categories are depicted in Table 1. Originally designed for clinician interviewers, the Y-BOCS has shown good psychometric properties as a self-report instrument (Steketee et al. 1996). The psychometric properties of Y-BOCS item 11 as a self-report are not known; however, the interview item shows adequate inter-rater reliability (Matsunaga et al. 2002), correlates significantly with strength of belief in obsessions (O'Connor et al. 2005), and readily differentiates OCD patients with and without the “poor insight” specifier (De Berardis et al. 2005). OCD patients with comorbid psychosis score higher on this measure than do those with OCD alone (Matsunaga et al. 2002), suggesting sensitivity to delusional beliefs. Twenty-five to 36% of OCD patients receive a “poor insight” or “lacks insight/delusional” score, with few patients described as having “excellent insight” (Matsunaga

**Table 1** Adaptation of the Yale-Brown Obsessive-Compulsive Scale Insight item

Score	Label	Modified description	Original description
0	Excellent, fully rational	[Name]'s hoarding behaviors may be bad, but [name] fully recognizes that they are a problem	None
1	Good insight	[Name] readily acknowledges that his/her acquisition, clutter and/or difficulty discarding is a problem. However, when at home or out shopping/acquiring, [name] has difficulty seeing the problem with acquiring or not discarding items	Readily acknowledges absurdity of excessiveness of thoughts or behaviors but does not seem completely convinced that there is not something besides anxiety to be concerned about (i.e., has lingering doubts)
2	Fair	[Name] may admit clutter is a problem, but only reluctantly admits that his/her behavior (such as acquiring too many things, or failing to discard things) has caused the problem. When at home or out shopping/acquiring, [name] has difficulty seeing that he/she has a problem with acquiring or not discarding things	Reluctantly admits thoughts or behavior seem unreasonable or excessive, but wavers. May have some unrealistic fears, but no fixed convictions
3	Poor	[Name] maintains that acquisition, difficulty discarding, and clutter are under control or not a problem. When someone discusses the problem with him/her, [name] acknowledges that he/she might have a problem, but still underestimates the severity of the problem	Maintains that thoughts or behaviors are not unreasonable or excessive, but acknowledges validity of contrary evidence (i.e., overvalued ideas present)
4	Lacks insight, delusional	[Name] is convinced that he/she has no problems with acquisition, clutter or difficulty discarding at all. He/she will argue that there is no problem, despite contrary evidence or arguments	Definitely convinced that concerns and behavior are reasonable, unresponsive to contrary evidence

**Table 2** Questions about the informant's perceptions of hoarding severity and their predictions of the hoarder's perceptions

1. How much of the living area in [name's] home was cluttered with possessions?	0	1	2	3	4
	Not at all		Somewhat		Very much
2. How much of the living area in [name's] home would [name] say was cluttered with possessions?	0	1	2	3	4
	Not at all		Somewhat		Very much
3. To what extent did [name] think the clutter was a problem?	0	1	2	3	4
	Not at all		Somewhat		Very much
4. To what extent did you think the clutter was a problem?	0	1	2	3	4
	Not at all		Somewhat		Very much
5. To what extent did [name] have difficulty throwing things away?	0	1	2	3	4
	Not at all		Somewhat		Very much
6. To what extent would [name] say he or she had difficulty throwing things away?	0	1	2	3	4
	Not at all		Somewhat		Very much
7. To what extent did [name] think his/her difficulty discarding was a problem?	0	1	2	3	4
	Not at all		Somewhat		Very much
8. To what extent did you think his/her difficulty discarding was a problem?	0	1	2	3	4
	Not at all		Somewhat		Very much
9. To what extent did you think his/her acquisition was a problem?	0	1	2	3	4
	Not at all		Somewhat		Very much
10. To what extent did [name] think his/her acquisition was a problem?	0	1	2	3	4
	Not at all		Somewhat		Very much

et al. 2002; Okasha et al. 1994). Notably, patients with hoarding behaviors have been shown to exhibit poorer insight on this measure than do patients with other forms of OCD (De Berardis et al. 2005; Frost et al. 1996; Matsunaga et al. 2002).

As an alternative measure of insight, consistent with previous research (Rimel et al. 1981; Schacter et al. 1990), we calculated *Discrepancy Ratings* between the family/friend informant's beliefs about the severity of the hoarding problem during the worst 1-year period of the disorder, and their predictions about how the hoarder would endorse the same items during the same period. The questions are shown in Table 2. Discrepancy ratings were calculated as (family/friend informant's rating—hoarder's predicted rating). Therefore, a discrepancy score of 0 indicates no difference of opinion between the family/friend informant and the hoarder, a positive discrepancy score (maximum 4) indicates that the family/friend informant viewed the symptom as more severe, and a negative discrepancy score (maximum 4) indicates that the hoarder viewed the symptom as more severe.

## Procedure

The present study was approved by the Institutional Review Boards at Hartford Hospital, Smith College, and Boston University. Human subjects protection was consistent with current recommendations for web-based studies (Kraut et al. 2004). Prior to data collection, participants read an informed consent page (indicating that the purpose of the study was to gather family informants' reports of hoarding behavior) and indicated consent by clicking an icon on the page. No protected health information was collected and it was not possible to link study data to an individual or computer. As incentive, participants were given an email address to enroll in a raffle to receive one of 10 copies of a self-help book on compulsive hoarding. Participants responded to the survey by computer. They were allowed to skip any questions they wished, or to complete only portions of the survey. Data were stored on a password-protected server. A summary of aggregate research results was emailed to all individuals in the original database.

**Table 3** Sample description of family/friend informants and of hoarders as reported by informants

	Hoarder meeting full criteria for compulsive hoarding	<i>N</i>	Hoarder not meeting full criteria for compulsive hoarding	<i>N</i>	FET	<i>t</i>
<i>Family/friend informants</i>						
Female (%)	85.1%	475	81.3%	75	.393	
White (%)	87.1%	482	86.8%	76	1.00	
Age	44.65 (12.25)	468	51.70 (11.72)	73		4.60*
HRS-SR	1.71 (1.77)	482	1.88 (1.62)	76		0.76
<i>Hoarders</i>						
Age	61.29 (12.10)	455	61.80 (13.23)	70		0.26
HRS-SR	6.71 (0.96)	482	4.35 (0.95)	76		19.92*
CIR	5.34 (1.69)	476	4.30 (2.01)	74		4.83*

Note: data are presented as means and (standard deviations) except where noted as percentages. *HRS-SR* Hoarding Rating Scale-Self-Report, *CIR* Clutter Image Rating, *FET* Fisher's exact test. Numbers for gender and race/ethnicity sum to less than the total *N* because some participants did not provide this information

\*  $P < .001$

## Results

### Sample Description

Descriptive information about the family/friend informant sample, as well as the hoarders they described, is found in Table 3. Of the 558 participants who completed the measures of interest about the hoarder, 482 (86.4%) described a hoarder that appeared to meet full criteria for compulsive hoarding. Not surprisingly, HRS-SR and CIR scores for hoarders meeting full criteria were significantly higher (denoting more severe hoarding) than were scores for hoarders not meeting full criteria. It is noted, however, that the hoarders not meeting full criteria were nevertheless described as having moderately severe hoarding. The sample was primarily White and female. Family/friend informants were in their mid-40s to early 50s, and described hoarders around 61 years old on average; those describing a hoarder who met full criteria were significantly younger than were those describing a hoarder who did not meet full criteria. Of the family/friend informants, 20.5% ( $n = 114$ ) indicated that the hoarder was their spouse or partner; 49.4% ( $n = 275$ ) reported on a parent; 2.2% ( $n = 12$ ) described their adult child; 0.9% ( $n = 5$ ) described a grandmother (no participants reported that the family member was their grandfather); 12.4% ( $n = 69$ ) reported on a sibling; 5.2% ( $n = 29$ )

reported on a friend; and 9.5% ( $n = 53$ ) indicated some other relationship. Average severity of hoarding behavior in the family/friend informants was low, as measured by the HRS-SR.

### Insight

Using Y-BOCS item 11, family/friend informants described the hoarder on average as having fair to poor insight ( $M = 2.55$ ,  $SD = 1.04$ ). Hoarders meeting vs. not meeting full diagnostic criteria did not differ on Y-BOCS item 11,  $t(556) = 1.70$ ,  $P = .090$ ; means (SDs) were 2.52 (1.02) and 2.74 (1.18), respectively. Frequencies of specific values were: excellent insight 3.6% ( $n = 20$ ), good insight 12.0% ( $n = 67$ ), fair insight 29.4% ( $n = 164$ ), poor insight 36.0% ( $n = 201$ ), lacks insight/delusional 19.0% ( $n = 106$ ). Thus, over half of the hoarders were described as showing either poor or no insight into the severity of their hoarding condition.

Insight was also measured by calculating difference scores between family/friend informants' ratings of various aspects of hoarding (the extent the living area was cluttered with possessions, the belief clutter was a problem, the extent the person had difficulty throwing things away, the belief difficulty discarding was a problem, and the belief acquisition was a problem) and the hoarder's expected ratings on the same scales. We note again that the hoarders themselves were not queried; rather, these ratings

**Table 4** Family/friend informants' ratings of severity of hoarding and predictions of the hoarders' ratings

	Family/ friend informant	Hoarder (based on Informant's Prediction)	Discrepancy between family/ friend informant and hoarder	Paired <i>t</i>	Correlation between discrepancy rating and Y-BOCS insight item (# 11)
Extent living area was cluttered with possessions	3.71 (0.57)	2.64 (1.12)	1.07 (1.07)	23.68*	0.36*
Belief clutter was a problem	3.88 (0.38)	1.68 (1.11)	2.20 (1.14)	45.49*	0.61*
Extent person had difficulty throwing things away	3.87 (0.40)	2.24 (1.30)	1.62 (1.30)	29.45*	0.43*
Belief difficulty discarding was a problem	3.79 (0.57)	1.54 (1.17)	2.25 (1.29)	41.24*	0.54*
Belief acquisition was a problem	3.57 (0.78)	1.32 (1.08)	2.25 (1.25)	42.45*	0.55*

Note: values in family/friend informant, hoarder, and discrepancy between family/friend informant and hoarder columns are *M* (*SD*)

\*\*  $P < .001$

reflect the family/friend informants' expectations for how the hoarder would have rated the items. Larger difference scores reflect greater expected discrepancy of opinion (according to the family/friend informant) between family/friend informant and hoarder. As shown in Table 4, significant discrepancies were found for all items, with family/friend informants' opinions of hoarding severity being greater than their reports of the opinions of the hoarders. Larger discrepancies between family/friend informants' ratings and their expected ratings by the hoarders were significantly correlated with poorer insight (Y-BOCS #11) as rated by the family/friend informant.

#### Relationship Between Hoarding Severity and Insight

Surprisingly, hoarders meeting full diagnostic criteria for compulsive hoarding had *lower* difference scores (i.e., better insight) regarding the belief that clutter was a problem than did those not meeting full diagnostic criteria ( $P < .01$ ); the two groups did not differ on the other measures of insight. When hoarding severity was considered dimensionally, rather than categorically, poorer insight showed differential associations with various aspects of hoarding severity on the HRS-SR. As shown in Table 5, severity of clutter was not significantly associated with any of the measures of insight. Difficulty discarding was associated with poorer insight on Y-BOCS #11 and with 3 of the 5 discrepancy scores (beliefs that clutter, difficult discarding, and acquisition are problems). Acquisition was associated with poorer insight on Y-BOCS #11 and greater discrepancy regarding the belief that

acquisition is a problem. Impairment was associated with less discrepancy on the belief that clutter is a problem, suggesting that more impaired hoarders show greater agreement with the family/friend informants on this item. Notably, distress on the HRS-SR was negatively and significantly associated with all measures of insight; that is, hoarders who were described as less insightful were also described as being less distressed about the hoarding.

#### Relationship Between Sample Characteristics and Insight Ratings

Hoarders' gender, race, and the experience of or threat of eviction were not significantly related to insight on Y-BOCS item #11 or the family/friend informant versus hoarder discrepancy scores on appraisals of hoarding severity (all  $P$ 's  $> .05$ ). Older age of the hoarder was modestly but significantly associated with poorer insight (Y-BOCS #11) ( $r = .18$ ,  $P < .001$ ) and also with greater discrepancy between informants' and hoarders' perceived beliefs about the hoarder's difficulty discarding ( $r = .10$ ,  $P = .017$ ) and extent to which this was a problem ( $r = .11$ ,  $P = .009$ ). Hoarders' age was not significantly correlated with other discrepancy scores ( $P$ 's  $> .05$ ).

A multivariate analysis of covariance was used to examine differences of each of the insight-related measures for different relationships to the hoarder (spouse/partner, parent, sibling, and friend) while controlling for age of the hoarder and the family/friend informant. This yielded an overall significant main effect of the relationship between family/friend informant and hoarder [ $F(3, 446) = 5.34$ ,  $P = .001$ ,

**Table 5** Correlations (Pearson's  $r$ ) among measures of insight with hoarding severity (HRS-SR) rated by family/friend informants

	YBOCS #11 (Insight)	Discrepancy regarding extent living area was cluttered	Discrepancy regarding belief clutter was a problem	Discrepancy regarding extent person had difficulty throwing things away	Discrepancy regarding belief difficulty discarding was a problem	Discrepancy regarding belief acquisition was a problem
<i>Family/friend informants' ratings of hoarder</i>						
HRS-SR item 1 (clutter)	0.06	−0.02	−0.02	0.04	0.04	0.08
HRS-SR item 2 (difficulty discarding)	0.19*	0.11	0.14*	0.02	0.13*	0.15*
HRS-SR item 3 (acquisition)	0.14*	−0.04	0.03	0.07	0.11	0.29*
HRS-SR item 4 (distress)	−0.22*	−0.14*	−0.30*	−0.22*	−0.20*	−0.19*
HRS-SR item 5 (impairment)	−0.10	−0.02	−0.17*	−0.09	−0.11	−0.10

\*\*  $P \leq .002$  (Bonferroni corrected)

**Table 6** Univariate analysis of variance of discrepancy ratings and insight (Y-BOCS #11) for various informants reporting on hoarding family members, controlling for age of informant and of hoarder

	Spouse/partner	Parent	Sibling	Friend	F (3, 445)	$\eta_p^2$
YBOCS #11 (insight)	2.30 (1.32) <sup>a</sup>	2.77 (1.43) <sup>a</sup>	2.42 (1.23) <sup>a</sup>	1.68 (1.08) <sup>b</sup>	6.28**	0.04
<i>Discrepancy scores for</i>						
Extent living area was cluttered	1.31 (1.38)	1.03 (1.50)	1.13 (1.29)	0.81 (1.13)	1.95	0.01
Belief clutter was a problem	2.30 (1.44) <sup>a</sup>	2.28 (1.56) <sup>a</sup>	2.20 (1.35) <sup>a</sup>	1.35 (1.18) <sup>b</sup>	5.33**	0.04
Extent person had difficulty throwing things away	1.57 (1.75)	1.69 (1.90)	1.60 (1.63)	1.64 (1.44)	0.09	0.00
Belief difficulty discarding was a problem	2.33 (1.70)	2.28 (1.83)	2.30 (1.59)	1.84 (1.39)	1.02	0.01
Belief acquisition was a problem	2.13 (1.61)	2.47 (1.74) <sup>a</sup>	2.10 (1.50)	1.46 (1.32) <sup>b</sup>	3.54*	0.02

\*  $P < .05$ ; \*\*  $P < .01$

Note: Within each row, numbers with different superscripts have significant differences from each other,  $P < .05$ . Values in spouse/partner, parent, sibling, and friend columns are estimated marginal  $M$  ( $SD$ )

$\eta_p^2 = 0.04$ ]. As shown in Table 6, follow-up univariate analyses of variance showed significant differences on these measures of insight. Friends rated their identified hoarder to have better insight than did all types of family members as measured by Y-BOCS #11 and the family/friend informant vs. hoarder discrepancy regarding the belief that clutter was a problem. Friends rated their identified hoarder to have better insight than did parents for the belief regarding acquisition as a problem.

## Discussion

The present results are consistent with previous data (De Berardis et al. 2005; Frost et al. 1996; Matsunaga

et al. 2002; Samuels et al. 2007; Steketee et al. 2001; Storch et al. 2007) suggesting that compulsive hoarding is characterized by poor insight into the severity of the problem. On average, family/friend informants rated their hoarders as having fair to poor insight, and the majority were described as having “poor insight” or “lacks insight/delusional.” Although it is not clear how the family/friend informant report on Y-BOCS item #11 compares to the interview version, the difference between the present sample and previous samples of OCD patients is striking: prior studies have shown that 15–36% of OCD outpatients receive this designation (De Berardis et al. 2005; Marazziti et al. 2002; Matsunaga et al. 2002; Okasha et al. 1994); odds ratios comparing the present results with previous OCD studies therefore range from 2.15 to 4.07,

suggesting that individuals who hoard may be 2–4 times more likely than are OCD patients to be described as having poor insight.

As described in the Introduction, insight can be defined in several different ways. The present study does not address the construct of overvalued ideation, as we did not examine the degree to which specific hoarding-related beliefs were thought to be true. Additional research on this topic is needed. The present results are more reflective of anosognosia, the lack of awareness that the problem even exists. Indeed, one of the most common questions posed to the present authors from the community is some variant of: “My parent is a hoarder but doesn’t seem to recognize that there is anything wrong. What can I do?” Such questions point not to the strength of a specific delusional belief, but rather to a more basic lack of self-awareness. One way to operationalize anosognosia is as a discrepancy of opinion between the individual and an observer. The five discrepancies measured in this study all correlated significantly and positively with the YBOCS item #11.

In the present sample, family/friend informants reported that they viewed all aspects of the hoarder’s behavior as more severe than did the hoarders themselves, regardless of whether full diagnostic criteria for hoarding were met. Several limitations to this finding must be taken into account. First, the present study was limited to family/friend informants; we assessed only the family/friend informant’s *perceptions* of the hoarder’s opinions. More accurate assessment might be accomplished by recruiting pairs of individuals (one hoarder and one family/friend informant), and having each participant rate the items separately. It is also worth considering that just as hoarders may underestimate the severity of hoarding, so too might family/friend informants *overestimate* its severity. Family members’ frustration toward the hoarder, lack of frequent contact or visits to the home, or help-seeking response style could all contribute to magnification of the problem on the part of family members. It is also possible that family/friend informants interpreted hoarders’ indifference (i.e., a diminished affective response to hoarding behavior and clutter) or defensiveness (i.e., interpersonal conflicts in which denial of illness is employed as an argumentation strategy) as lack of insight. Corroboration using trained observers and raters would help clarify whether hoarders (a) lack

awareness of their behavior and its consequences (anosognosia), (b) hold inflexible and irrational positive beliefs about their behavior (overvalued ideation), (c) are aware of but unconcerned with their behavior and its consequences (indifference), or (d) deny symptoms as an argumentation strategy (defensiveness).

Level of insight was significantly related to specific aspects of hoarding severity. Although severity of clutter was not related to insight, hoarders with more difficulty discarding and acquisition were rated as having poorer insight. However, correlations were rather small (indeed, in a smaller sample most would not be statistically significant), suggesting that the relationship between symptom severity and insight is not particularly strong. The clearest pattern of relationships was observed not with the hoarding symptoms themselves, but rather with the individual’s distress (as rated by family/friend informants) about the hoarding symptoms, with less distressed hoarders rated as less insightful in all respects. The surprising finding of *lower* discrepancy ratings for hoarders meeting full diagnostic criteria might be attributable to this pattern. As described previously, our diagnostic criteria were an HRS-SR rating of 4 or higher for clutter, difficulty discarding, and acquisition, plus either impairment or distress. Among the 78 hoarders who did not meet the full criteria, the proportion of individuals below the cutoff was 23% for clutter, 13% for difficulty discarding, 24% for acquisition, 82% for impairment, and 81% for distress. Thus, when individuals were classified as not meeting full criteria for hoarding, it was usually not because of the core symptoms but rather because of a lack of reported distress or impairment—and the lack of distress seems to correlate with poor insight.

This is consistent with clinical observations that many hoarding patients exhibit a surprising lack of distress about their condition, and that this lack of distress seems associated with poor insight or awareness (Steketee and Frost 2003). Poorer insight was also modestly but significantly associated with older age of the family hoarding member, underscoring the particular difficulty in treating elderly patients who hoard (Steketee et al. 2001). We also found that friends of individuals who hoard described the person as having significantly better insight than did spouses or children of hoarders; this is perhaps due to the social alienation and interpersonal rejection

experienced by many hoarders (Tolin et al. 2008a): individuals with more severe hoarding behaviors and poorer insight might well be less likely to have friends who would complete the survey.

An important limitation of the present study is the method of participant recruitment. As described previously, recruitment began with emailing individuals who had contacted the investigators in the prior 3 years for information about compulsive hoarding; we also permitted individuals to forward the invitation to other interested parties. This method of recruitment may have biased in favor of family members of individuals with more severe hoarding behaviors or with poorer insight. Such family members might be more motivated to seek information about hoarding and to contact others for discussion (including joining internet bulletin boards on the topic). Additional research on the families of treatment-seeking hoarding patients would help clarify this issue. It is also worth noting, as shown in Fig. 1, that 41% of individuals who logged on to the web site and defined themselves as family or friends of hoarders did not go on to complete the study measures. The reasons for this high rate of discontinuation are not clear, and it is not known whether those who discontinued differed from those who completed the survey.

Patient insight has substantial implications for treatment. In OCD, overvalued ideation has been associated with poorer outcome in some treatment studies (Foa 1979; Hollander et al. 2003; Neziroglu et al. 1999b), but not in others (Foa et al. 1983; Hoogduin and Duivenvoorden 1988). In an open trial of cognitive-behavioral therapy for hoarding patients, adherence to homework assignments was inconsistent, and significantly predicted treatment outcome (Tolin et al. 2007b). Hoarding patients frequently approach treatment with the belief that what they need is help in organizing or simply more time to “process” their possessions so they can organize and discard. In a large survey of individuals who hoard, 84% reported that they probably or definitely would go for treatment for hoarding problems; however, only 45% had actually done so over the past 12 months. Sixteen percent reported that they probably or definitely would not go to treatment (Tolin et al. 2008b). With regard to motivational “stages of change” (Prochaska and DiClemente 1982), many people with hoarding problems are at the precontemplation stage and will

likely refuse treatment (Frost et al. 2000). Those who are forced into treatment prematurely during the contemplation stage are likely to remain ambivalent about giving up their hoarding behavior and either drop out or remain inconsistent in their efforts. Additional research is needed to examine the impact of adding insight-building strategies to cognitive-behavioral therapy for hoarding.

**Acknowledgments** This study was funded by National Institute of Mental Health grants R01 MH074934 (Tolin), R01 MH068008 and MH068007 (Frost and Steketee), and R21 MH068539 (Steketee). Oxford University Press supplied copies of a book to be used in a raffle for participants. Results of this study were presented at the Annual Meeting of the Association of Behavioral and Cognitive Therapies, November 2007, Philadelphia. The authors thank Dr. Nicholas Maltby for his technical assistance.

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