Activities of daily living scale in hoarding disorder

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ABSTRACT

Research on hoarding over the last two decades has shown that hoarding disorder appears to be a distinct disorder that burdens the individual, the community and the families of people who hoard. Although hoarding clearly interferes with the daily functioning, especially in the context of extensive clutter, no validated measures of this interference have been developed. The present research examined the psychometric properties of the Activities of Daily Living in Hoarding scale (ADL-H) in two large samples of individuals with significant hoarding problems, one identified through the internet ($n=363$) and a second through clinical diagnostic interviews ($n=202$). The ADL-H scale test–retest (1–12 weeks), interrater and internal reliabilities ranged from .79 to .96. Convergent and discriminant validity were established through analyses of correlational data collected for measures of hoarding severity and non-hoarding psychopathology (obsessive–compulsive disorder [OCD], moodstate, attention deficit, and perfectionism/uncertainty), as well as through comparisons of scores among individuals with hoarding, hoarding plus OCD, OCD without hoarding, and community controls. The ADL-H scale appears to have strong psychometric properties and to be useful in clinical and research settings. Suggestions are made for expansion of the scale, and study limitations are noted.

1. Introduction

1.1. Activities of daily living scale in hoarding disorder

Hoarding disorder, the latest addition to the DSM-5 (Mataix-Cols, Billotti, Fernández de la Cruz, & Nordsletten, 2012), is defined by difficulty discarding possessions because of strong urges to save items; accumulation of clutter (at home, workplace or elsewhere) preventing normal use of the space; and clinically significant distress or impairment in functioning due to hoarding. Hoarding is typically associated with excessive acquiring as well. Prevalence rates range from 2.3% in the UK (Iervolino et al., 2009) to 3.7% (5.3% weighted) in the US (Samuels et al., 2008) and 4.6% in Germany (Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009).

Hoarding interferes with functioning in a variety of ways including loss of job, medical disability, and family dysfunction (Tolin, Frost, Steketee, & Fitch, 2008; Tolin, Frost, Steketee, Gray, & Fitch, 2008), and in severe cases, fires have resulted in death (Frost, Steketee, & Williams, 2000). Health officials report that people with hoarding disorder struggle to keep their home clutter-free even after court-ordered cleaning. Hoarding complaints often involve multiple agencies and a single clean out can cost tens of thousands of dollars (Frost et al., 2000). In addition, family members of people who hoard report experiencing significant childhood distress related to severe clutter, embarrassment about their home and rejection of the hoarding family member (Tolin, Frost, Steketee, & Fitch, 2008). Overall, hoarding disorder affects not only the community and the family of people who hoard, but also the individual's ability to function normally in the home.

Several standardized measures focus on hoarding symptoms (e.g., Saving Inventory-Revised (SI-R) by Frost, Steketee, and Grisham (2004); Hoarding Rating Scale (HRS) by Tolin, Frost, and Steketee (2010)). These instruments provide general ratings of hoarding severity, but do not inquire about the specific nature of the interference in daily living caused by hoarding. For example, the SI-R items include "How much clutter in your home interferes with your social, work or everyday functioning?" and "To what extend does clutter in your home cause you distress?" Similarly, HRS items ask "Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?" The Clutter Image Rating (Frost, Steketee, Tolin, & Renaud, 2008) is a pictorial measure of clutter severity that requires respondents to choose the best matches to their own rooms from among a set of nine photos of an increasingly cluttered living room, bedroom, and kitchen. The CIR provides an index of clutter volume in different areas of the home, but does not address the functional impairment clutter provokes. Thus, these instruments provide general assessments of hoarding

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symptoms, but provide limited information about the impact of hoarding on specific everyday activities (e.g., can you eat at your kitchen table?). Such specific information is valuable for designing treatment (e.g., which locations and activities to prioritize) and monitoring progress.

A related measure, the Home Environment Index (HEI), captures the extent of squalor or unsanitary conditions in the home (Rasmussen, Steketee, Brown, Frost, & Tolin, Submitted for publication). Squalid conditions characterize a relatively small percentage of hoarded homes, but can have very serious consequences (Frost et al., 2000). Although the HEI measures a specific form of impairment, it is not a central feature and characterizes only a small number of hoarding sufferers.

There have been several attempts to measure specific activity interference in hoarding, particularly in the elderly where such difficulties can have serious consequences. In an interview study of hoarding in the elderly, Kim, Steketee and Frost (2001) asked participants about restriction of movement in the house, access to kitchen utilities (stove, refrigerator, sink) and personal hygiene but provided no formal measure. Frost et al. (2004) asked participants to rate frequency of interference in routine household activities due to the clutter (e.g., "Using the stove," "Eating at a table," "Sitting on a sofa") on a 3-point scale. Internal reliability of the 12-item scale scores was .83 (α), and the scale was moderately correlated with the SI-R total scale as well as with subscales of difficulty discarding and clutter. Grisham, Frost, Steketee, Kim, and Hood (2006) expanded this instrument to 15 items rated on 5-point scales – the Activities of Daily Living in Hoarding (ADL-H) – to determine how much clutter interfered with daily activities for people with hoarding. They calculated a mean of the items to create a single score.

The present study examined the reliability and validity of this scale using a sample of self-identified people with hoarding problems from a large internet study and a sample of carefully diagnosed hoarding participants. We employed standard measures of hoarding severity, as well as measures selected to address impairment in the home (squalor) and comorbid problems and personality features (e.g., attention deficit, OCD symptoms, depressed and anxious moodstate, perfectionism/uncertainty) associated with hoarding (see Pertusa et al. (2010)) that may influence daily activities.

2. Study 1

2.1. Method

2.1.1. Participants
Potential participants who had provided e-mail information following several national media announcements were invited to complete a web survey in September 2009. Of the 852 individuals who logged on and self-identified with hoarding, 535 met study inclusion criteria for serious hoarding and were asked to complete the ADL-H along with other study measures. Inclusion criteria for hoarding status required scores of 4 (moderate) or higher on clutter, difficulty discarding, and distress or interference items from the Hoarding Rating Scale. These criteria are consistent with criteria proposed for DSM-5 (Mataix-Cols et al., 2010) and have been used in previous studies to indicate significant hoarding problems (Frost, Tolin, Steketee, Fitch, & Selbo-Bruns, 2009; Tolin, Frost, Steketee, Gray, et al., 2008). A total of 363 (68% of 535) completed the ADL-H.

Participants ranged in age from 22 to 80, with a mean age of 52.8 (SD=10.3). The sample was predominantly female (94.2%) and white (94.2%); other racial/ethnic groups were African-American (2.2%), Asian (1.9%), Indian (2.2%), and Other (3.2%). The study was approved by the Institutional Review Boards at Smith College, Boston University, and Hartford Hospital. All participants gave informed consent before completing the survey.

2.1.2. Measures
The Activities of Daily Living in Hoarding (ADL-H) contains 15 items (see Appendix) related to activities of daily living such as "Prepare food," "Use bath/shower," "Use refrigerator," etc. Items are rated from 1 ("can do it easily") to 5 ("unable to do"), with higher scores indicating more impairment. A "not applicable" (NA) response is provided for cases where individual items don't apply. Scoring

consists of the mean of items not designated as NA. The ADL-H items were generated from responses of hoarding participants to interviews about the ways in which clutter prevents them from using different parts of their homes (Frost & Gross, 1993). The measure was designed to provide information about the specific activities impaired by hoarding, and not as a measure of saving or discarding behavior.

Three measures of hoarding severity and a measure of squalor were used to assess the convergent validity of the ADL-H. The Hoarding Rating Scale-Self-Report (HRS-SR; Tolin, Frost, Steketee, & Fitch, 2008) is a 5-item self-report measure that rates the dimensions of hoarding (clutter, difficulty discarding, excessive acquisition, distress, and impairment) from 0 ("none") to 8 ("extreme"). It is designed to provide a global index of hoarding severity. Scores on the scale have demonstrated internal consistency (α=.80 in the current study), and test–retest (1–12 weeks) and interrater reliability (Tolin, Frost, Steketee, & Fitch, 2008). The interview version of the HRS scale differentiated hoarding from non-hoarding participants and correlated highly with other measures of hoarding (Tolin et al., 2010).

The Saving Inventory-Revised (SI-R; Frost et al., 2004) is a 23-item measure assessing hoarding severity. Subscale scores corresponding to the three primary features of hoarding (clutter, difficulty discarding, and excessive acquisition) are calculated along with a total score. Items are coded on a scale from 0 to 4. Reliability and validity of all scale scores on the SI-R have been documented, and the measure has become the most widely used self-report measure of hoarding severity (see Frost and Hristova (2011)). Internal consistencies for the present study were: total score (α=.91), Clutter (α=.90), Difficulty Discarding (α=.83), and Excessive Acquisition (α=.84).

The Clutter Image Rating (CIR; Frost et al., 2008) assesses severity of clutter through nine photographs of each of three rooms (living room, kitchen and bedroom). Participants choose the picture that most closely represents the living conditions in their own home. The mean of the ratings for the three rooms constitute the CIR scale score. Reliability and validity of the CIR scale scores have been established (see Frost and Hristova (2011)). Internal reliability in the present study was α=.78.

The Home Environment Index (HEI; Rasmussen et al., Submitted for publication) consists of 15 items assessing symptoms of squalor in hoarding such as "Rotten food," "Dirty sink," and "Odor of house." The items are rated on a scale from 0 ("no presence") to 3 ("severe symptoms") and summed to create a total scale score. The total scale score has shown evidence of reliability and validity (Rasmussen et al., Submitted for publication). Internal consistency in the present study was α=.75.

In addition, measures of attention deficit, depression, obsessive–compulsive symptoms and perfectionism/uncertainty were used to assess the discriminant validity of the ADL-H. These characteristics have been found to be correlated with hoarding symptoms (Pertusa et al., 2010). The Attention Deficit Hyperactivity Disorder Symptom Scale (ADHDSS; Barkley & Murphy, 1998) consists of 18 items measuring inattention and hyperactivity symptoms over the last six months. Items are rated from 0 ("never or rarely") to 3 ("very often"). Often used in clinical practice, this measure has demonstrated reliability and validity (Barkley & Murphy, 1998). In the present sample the Cronbach alpha for the inattention scale items was .88 and for hyperactivity .83.

The Depression Anxiety Stress Scale-21 item version (DASS-21; Lovibond & Lovibond, 1995a, 1995b) measures the level of depression, anxiety, and stress over the past week. The items are scored on a 4-point Likert scales with higher scores indicating more symptoms. In the current study, internal reliabilities were .92 for depression .83 for anxiety, and .88 for stress.

The Obsessional Beliefs Questionnaire-44 (OBQ-44; OCCWG 2005) contains 44 obsessional beliefs rated on 7-point scales from "disagree very much" to "agree very much." Only the 16-item perfectionism/uncertainty scale was completed by study participants (α=.95) since perfectionism and indecisiveness have been hypothesized to be a core deficits of hoarding (Frost & Hartl, 1996).

The Obsessive–Compulsive Inventory-Revised (OCI-R; Foa et al., 2002) consists of 18 items that assess checking, washing, ordering, obsessing, neutralizing, and hoarding. Questions are rated on 5-point scales from "not at all" to "extremely." A 15-item total OCI-R total scale score, excluding the 3-item hoarding subscale, was used in the analyses for this study (α=.89).

2.1.3. Data analyses
Data were analyzed using SPSS 17.0 (SPSS Inc.). Convergent validity was tested by examining Pearson correlations between ADL-H and scores of other measures of hoarding (e.g., SI-R); discriminant validity was tested using correlations between ADL-H and scores of other measures of psychopathology (e.g., DASS). Out of the 535 initial respondents, 172 did not complete the ADL-H. Among the remaining participants, imputations were conducted for 27 participants (5%) who were missing fewer than 15% of ADL-H items in order to retain them in the analyses; missing values were replaced with mean scores using linear interpolation, yielding a final sample of 363.

2.2. Results

2.2.1. Reliability and validity
All 15 items of the ADL-H showed good item total correlations (r's=.44 to .75). The most frequent activity dysfunction was for finding important things (M=3.30, SD=1.05), followed by moving around inside the house (M=2.65, SD=.62).